Prepared for Colin's site on December 28, 2019.

# Journal

## The first e-mail - March 18 (prayers please)

*April 27, 2016*

Our son Colin had been acting strange the last few weeks so we had him taken in for an MRI this week. Unfortunately, the news has come up that he has a brain tumor.
We have no idea yet if it’s benign or malignant or what the treatment options are. It’s apparently quite small. He’s fine and, mercifully, unaware of what’s going on. Christina’s parents are coming up today to take care of Emma and Noah. We’re going to be out of touch a lot the next bit of time, but any thoughts you could spare for us would be appreciated.

— Niels

## The March 19 e-mail

*April 27, 2016*

Just to update everyone (and apologies to those who weren’t on the first mail)

He’s going to have a follow-up MRI on Monday that will, hopefully, be more precise and give the doctors more insights. We’ll likely have the first biopsy on Wednesday. But it might still take a few days until they can tell us what they’re dealing with. The kids are most likely going to go to their grandparents for the next two weeks, as we’ve got the Easter recess right now. Once they’re gone, I’m likely to shift my base of operations to a colleague’s home in western Berlin, since it will put me closer to the hospital and, honestly, I think I’ll crack up if I’m in the house by myself.

## The March 22 e-mail (pre-biopsy)

*April 27, 2016*

The latest update (and apologies to those who weren’t on the previous mails)

Colin’s due for his biopsy at 8 a.m. tomorrow. Strictly speaking, they’re just going to take a sample, though the doctor says that, if they see a chance to take out more, they will. It will take into next week before they can tell us exactly what they’re dealing with and what our treatment options are. The doctor’s not giving us any illusions that this will be a fun procedure, but it is a possible one.

We’re holding up as well as can be expected. Keeping a 2-year-old in a hospital for such a stretch - especially one pumped up on cortisone and with a limited vocabulary of, frankly, not particularly useful words - is a nightmare, but we are surviving.

Thanks for all the happy thoughts.

— Niels

## The March 23 e-mail (post-biopsy)

*April 27, 2016*

Apologies again for those who weren’t on previous e-mails. Each time I put one of these together, I realize there are a few people I should have told earlier. It’s hard to keep your head focused in times like these.

So, we had the biopsy today. Colin got through with flying colors. Despite probing near the brain stem, the doctors did their work well and all his functions seem normal. He is, however, in an incredibly bad mood, which is probably his due after the last few days he’s had. The doctor took a sample which will now be analyzed. For fear of doing any further damage, he did not take more than was necessary for testing, so there is still a 1.5-centimeter tumor in Colin’s head.

Until the analysis is done - which could take until the end of next week - there’s no way to know what we’re dealing with. However, the doctor says there are indications that this is a benign tumor. Again, these are only indications and we can’t get our hopes too high until the technicians do their job, but it’s something.

Colin is now in intensive care for a couple of nights, which means our ability to parent him is even more constrained. I’m staying at a colleague’s house tonight. Christina is trying to sleep on a fold out chair. Hopefully this will not last too long and we’ll soon be back to the very relative comfort of a standard hospital room.

## The April 4 e-mail (after the start of chemo)

*April 27, 2016*

I wanted to thank everyone for checking in on us the last few weeks. It’s an incredibly huge weight we’ve been given, and every time we’re reminded people are thinking of us, it does help.

Last week was busy. We finally got the test results on Wednesday, but for me - a layman - they raised more questions than they answered. Colin’s tumor is an embryonic tumor, which is apparently a very rare, fast-growing tumor. And his happens to be in an unusual spot. I have not had the nerve to look up what an embryonic tumor really is or what the success rate is for treatment. If anyone does want to start looking around, please be my guest. But don’t tell me what you find. I really am not up to it at the moment.

He had a series of minor surgeries Friday to prepare him for the chemo and began his chemo treatment around 8 p.m. Saturday. According to the current plan, we’ll be heading to the hospital in three-week intervals eight more times after this treatment, though that can all change depending upon how he responds. If all goes according to plan this week, he’ll be finished with this current round Tuesday or Wednesday. And then, since this is the first time he’s had chemo, they’ll keep him in the hospital for an extra week. Which means he could be home around halfway through the week of April 11.

His condition is not good. He barely moves. Most of his interaction with us is telling us “no” to things we offer him. He mostly enjoys watching Curious George and will let us read to him from time to time. His appetite has held up. There is disagreement among the doctors about why he’s so lethargic. The neurosurgeons and the oncologist say the tumor is likely pressing against the part of the brain stem that controls his limbs (which is why they accelerated treatment). The pediatricians and the nurses say that many children are disinterested in doing anything after so many surgeries. The physical therapist says she sees no reason why he wouldn’t be moving (and he can still move all his limbs). I can’t help but thinking that exhaustion and depression must play a role in all this, since he hates being in the hospital so much. We’re largely stuck in our room all day long because he’s a carrier of some kind of multi resistant bacteria, which doesn’t bother him at all, but means he needs to be separated from other patients to make sure they don’t catch it.

I’m home with the kids this week while Christina takes over the bulk of the hospital duty. We’ll probably switch again at the weekend. Christina’s Mom is also here helping to take care of the kids. After that, we’ve had a very generous offer for two of my nieces from the States to come over here and help us out with the kids, which will probably be all that keeps us above water for the duration. As I said, any silly note or thing you can send us helps. Even if it’s just a link to something stupid. Any unexpected laugh is oddly helpful at this juncture. If you’re in Berlin and want to come by for a visit, just call first. It’ll depend on how things are going, but speaking only for myself, I’m happy for any distraction while I’m on hospital duty.

Thanks everyone,

— Niels

P.S. Several people have asked what Colin’s “strange” behavior was that tipped us off to the tumor. It went like this. On February 26, Colin began vomiting and did so for two weeks. A lot. It wasn’t every day, but we had several days in a row of it. During the second week, he began displaying issues keeping his balance. Until this point, our pediatrician thought he was suffering a stomach bug and weak from it. Then, March 13, Christina noticed that Colin’s pupils weren’t dilating at the same rate. When she told this to our pediatrician, we were sent straight to the MRI, which is how we got to where we are now.

## The April 12 e-mail

*April 27, 2016*

Colin got sent home from the hospital today after what his oncologist termed as “amazing” progress since the start of chemotherapy. The hope is that, if he can spend a few weeks at home away from all the prodding doctors and beeping machines, he might catch up on his sleep, end up a little less grouchy and, literally, get up on his feet. Nonetheless, we are far from being free and clear. The chemotherapy has left him with no immune system to speak of, so anything from the common cold to a sudden surge of growth in the tumor could land us back in the hospital. As it is, we’ll be heading back for checkups every other day. And, if all goes according to plan, he’ll be back for his second round of chemo somewhere between April 23-25.

Whereas a week ago his activity consisted mostly of lying around and flailing his left arm, he’s started moving around quite a bit. He’s got control of all his limbs and he can move his head without a problem. If you help him into a sitting position, he can feed himself and move around a bit in his stroller. But he, his physical therapist and us are going to have to work on getting him pulling himself into a sitting situation and standing up and walking.

Mostly, the whole family feels like we’ve been chased by a bullet for a month now and have been running as fast as we can to keep ahead of it. The events of the last day or so have us feeling as if, miraculously, we’ve gained a bit more of a lead, but the bullet is still there behind us.

Thank you everyone, for the e-mails, for the gifts, for the hand-me-down books, for the holy oil, for the flowers, for the visits, for the illicit beer in the hospital, the link to the Nirvana cover band with an Elvis impersonator as a frontman, for the other jokes, the medical opinions and for the prayers. It has been enormously helpful knowing we’ve got this network behind us.

— Niels

P.S. As always, apologies for the people I'm just adding to the list and who are coming into this cold. I keep remembering people I should have told about this weeks ago. In summary, our youngest, Colin, 2, has been diagnosed with a brain tumor and we are fighting it.

## The April 23 e-mail

*April 27, 2016*

it's been an up and down week for us with Colin this week, without a lot of major news to report. Plus, the daily ebbs and tides have left me without a lot of energy/time to send e-mails. However, in general, it's seen some positive developments for Colin.

Saturday started with the realization that his hair was falling out. We knew it was probably going to happen. We even knew that this was probably about the day it was going to happen. Nonetheless, it threw both Christina and I off our game. It's an odd thing. In some ways, I find it hard to physically recognize my child, what with the loss of the hair and the bloat from the steroids. In some ways, he's beginning to resemble Rutger Hauer from Blade Runner. At the same time, they took him off cortisone this week, so the grouchy (and constantly hungry) personality he's been sporting the last few weeks has faded and we are more routinely seeing our old Colin, the one who actually wants to cuddle, chit-chat and play. His range of motion is still limited, but he's making definite attempts to crawl and Christina even briefly got him to stand yesterday (while leaning against his play kitchen).

The next hurdle came Sunday, when Colin came down with his first cold of the chemo. His temperature rose all through Sunday (though it never, technically, went into fever territory) and at 3 a.m. we made the call that Christina would take him to the emergency room. He ended up in the hospital for three nights (though his temperature was back down within normal ranges by early Monday evening). Indeed, he recovered better than most anyone expected. Monday the doctors and nurses were saying that, given the cold and the slow recovery rate of his blood counts, there was little chance he would start his second round of therapy today as scheduled. By the time he was released, everything was back on track and we were told to report for chemo on Saturday. The only thing that would stop it now would be if it turned out there was no bed in the oncology ward for Colin today. Other than that, the board is green.

Colin’s recovery from the cold is impressive under any circumstances. Even more so when one considers that I caught it from him and have felt, since Wednesday, like road kill. But we persevere, though we are counting the minutes until Christina’s parents return this weekend to help us out and then, beyond that, to April 30 when my nieces show up to keep us afloat. Thanks to everyone for checking in and for keeping an eye on us.

I might try to start migrating these updates to a website like caringbridge in the near future, but I’ll make sure everyone keeps getting the alerts when there’s an update. Thanks.

— Niels

## A few steps

*April 27, 2016*

I didn't get to see Colin today, just because of my work schedule.  But, according to Christina (and I have no reason to not believe her), Colin took a few steps today, his first since the March 23 biopsy.  The oncologist also paid a visit and is very happy with Colin's progress, so we'll take that as good news as well.  Not much else to report.  He's finished with his second round of chemo and should have come home today, but he's caught some bug that's left him with a slight fever.  Christina says he actually doesn't act sick at all, but given that his immune system is once again compromised, they daren't let him out until they've got the fever under control.  So, we're stuck with another extended hospital stay.

-- Niels

## Comments

Thanks for posting this Niels. The pic is precious (and boy, do I miss American donuts!) and I'm really glad to hear about the steps he took. Hoping he gets out soon!

*—Jeremy Cook, April 27, 2016*

Very happy to hear that - hope the progress continues!

*—Sofia Gueorgieva, April 27, 2016*

Keep those donuts coming and hopefully he'll keep walking to get them! Love to see that smile! Sending strong walking thoughts! - Susie

*—Carol Hamilton, April 27, 2016*

I am so happy to hear about the steps! Thank you for posting. My kids will be excited. They are asking about Colin everyday. We will keep all of you, especially Colin, in our prayers.

*—Lana Spangenberg, April 27, 2016*

What a cutie! He resembles Noah in that pic :)

*—Maddie Sheesley, April 27, 2016*

I am so happy to hear that the doctor is pleased and that Colin took steps!!!

*—Cynthia Meyersburg, April 27, 2016*

Am so looking forward, Colin, to you getting well and spilling the entire stock of the Sorrells cereal all over the house. The sooner, the better. So, hurry!
:-)

*—Boris Babic, April 27, 2016*

Great news on the steps. I endorse any donut-for-walking exchange program. Sugar makes for a fine, fine incentive! I hope he's out of the hospital again soon.

*—Jennifer Dlouhy, April 27, 2016*

Hi Colin,

Love that smile. It looks like a champion's smile to me. Keep on fighting. Daddy said that you surprised everyone by taking a few steps today. Enjoy that donut.

*—Phylles Lagarde, April 27, 2016*

## Heading home after Round 2

*April 28, 2016*

Christina reports from the hospital that they've been released, now that the second round of chemo is done. Hopefully we can keep him home and healthy until the next scheduled round, which is set to start on May 14. I'll update this more later tonight when I get to see him and can say more about how he's doing.

### Comments

Go, Colin! (And I absolutely love that smile of his.)

*—Lea Ann Schnakenberg, April 28, 2016*

A dinosaur supports Colin now.

*—Boris Babic, April 28, 2016*

# Energy for all

*April 28, 2016*

Well, we are learning that it's not so easy keeping a running blog about your child with a brain tumor if the patient in question fights sleep until almost 9:30 p.m.  Let the record show that, no matter what else is happening with him health-wise, his energy levels remain high.

Of course, it's also not as if he's up and running sprints.  His mobility remains impaired, but so much better than it was just a week ago.  If we help him into a standing position he'll stand and even walk around by balancing himself against furniture.  He'll also stay in a sitting position if helped into it.  It's learning how to transition from one position to the other that seems to be the problem and, as I remember, was always one of the big stumbling blocks for all the kids as babies and toddlers.  So, our job now is to get him some physical therapy so he can relearn these steps and to keep him healthy so we can minimize the hospital visits until the next round of chemo starts.

Of course, there are no guarantees that he won't hit a fever and necessitate another emergency hospital visit.  That's just the name of the game these days.  I think one of the problems we're going to have to learn to come to terms with is that the rules of the game seem flexible and ever-changing, depending upon the health status of the day. When we left the hospital after the first long stay, we were told that, as soon as his temperature crept towards 38 degrees Celsius, we needed to run to the hospital.  Today, days after chemo, his temperature is slightly above 38 degrees, but now we're told that that's not so serious and to hold off until 38.5 degrees.  We're happy to follow the rules, but it feels like we're told a different set of them every day depending upon changes in Colin's condition we can't see and upon the professional opinions of the doctor or nurse who happens to be talking to us.

It affects every aspect of hospital life.  Some nurses tell us we have to wear a new surgical gown every time we use one.  Others tell us to wear them twice to reduce waste.  During his first round of chemo, no one bothered telling us until the final hours of a 48-hour procedure that we really ought to be wearing gloves when we change his diapers, as fhe toxins from the chemo come through in the diaper and changing them without gloves means we were running the risk of infertility or miscarriage.  In short, every day is an informational adventure, because all the hospital staff is so busy and rushed they can't think to tell you everything, so your job as the parent is to talk to as many people as possible so you can piece together the most complete picture of today's status.  It's maddening, but that's our life now.

## Comments

This weekend, the orthodox world celebrates the resurrection of Jesus Christ and the promise of salvation of all humanity. From the cradle of Christianity in the Holy Sepulchre Church in Jerusalem, we will pray for you and Colin's speedy recovery.

*—Claudia Busch, April 28, 2016*

True, it seems like the rules keep changing, but this journey must seem like being in a foreign country and not quite understanding their language. Parent's instincts are almost always on target. Just don't give up.

*—Phylles Lagarde, April 29, 2016*

Hang in there! Take care of yourself so you can care for Colin. He sounds like a fighter!

*—Barbara Skipper, April 30, 2016*

## The Americans in Berlin

*May 1, 2016*

We've got our backup out of the US.  My nieces Rebekah and Kaela arrived Saturday.  Rebekah is set to stay for a few weeks; Kaela through the end of July.  I'll attribute it jointly to their skill with children as well as to Colin's recuperation, but he's warmed up to them extraordinarily quickly.  In the weeks since the hospital stay, he's been pretty opposed to meeting new people, especially anyone wearing a hospital gown.  But there was even a stretch where he didn't want to see Christina or me.  The fact that he let Rebekah sit with him yesterday (during Curious George, no less) was a huge mark of confidence.  Kaela's arrival might be welcomed most by Noah, who has long relied upon me for answers to all his comic book questions.  He's grown frustrated of late, because I can't really help him with his Marvel inquiries.  And then comes Kaela, who not only showed up wearing an Avengers T-shirt and pendant, but was prepared, despite jet lag, to engage in a lengthy discussion about the indestructible nature of Captain America's shield.

Colin's showing more interest in toys and sitting up a little better every day.  Movement eludes him, though he keeps showing signs of interest. We were a little worried because he vomited a few times during the last days. Bear in mind, this whole awful adventure started with a stretch of vomiting. But Christina took him to one of his regular hospital checkups yesterday and the staff told her that, honestly, the child is on chemo. He's allowed to vomit every now and then. And he took apart a bowl of spaghetti last night, so his stomach isn't a complete mess.

The rest of us are still just trying to get through our days. We do have enough to occupy ourselves, from setting up the guest room for a long-term stay to wondering if German banking laws allow me to electronically pay a 27,000-euro hospital bill (yes, 27,000 euros). I find one of my biggest problems is remembering that Colin is still a little boy who needs playing, not a patient who needs constant care. Well, technically, he's both. But I have to remember to keep treating him as a person, not an object who needs occasional medicine doses and constant supervision. Then again, if he keeps launching his toy cars into the air the way he's doing, it's going to be hard to ignore him.

## Photos

## Comments

Good your help has arrived - hope you will all notice a positive effect! How does the health insurance work in your case?

*—SG, April 30, 2016*

Hooray!!

*—Cynthia Meyersburg, May 1, 2016*

Wow, Niels, I wish you all the best! I hope and pray you guys will get through this as soon as possible!!! Lots of love from Tel Aviv!

*—Ofira Koopmans, May 1, 2016*

Rebekah and Kaela! Blessings for coming to help!

*—Barbara Skipper, May 1, 2016*

I'm so glad you have some more help. Colin looks great, and Noah has grown so much since the last time I saw him. I can't believe it.

*—Lea Ann Schnakenberg, May 1, 2016*

You want the bad news or the good news. Bad news - the local merchants have noted a serious reduction in sales since Saturday. Good news - my water bill is already down by half :)

*—Eric Sorrells, May 3, 2016*

## The 27,000-euro question

*May 2, 2016*

The size of our hospital bill has sparked some, um, concern. Trust me, we feel the same way.

The good news is that it's all manageable. Christina has amazing insurance and the kids are all covered under her plan. But, getting through the bill payment process is another weird trip down the rabbit hole in the exciting bureaucracy that can sometimes be Life in Germany.

To start with, it's actually a 32,000-euro bill. I misread it the first time. The hospital automatically bills the first insurance for its 20-per-cent share of the bill. The rest I submit it to the other insurer. This is how every hospital bill works for us: Everything is 100-per-cent covered, but it has to be submitted to two different insurers. It's just that, usually, we're dealing with far smaller sums. Tonight I get to learn how to temporarily reset my internet banking access so I can pay the hospital, now that I've (hopefully) been reimbursed by the other insurer.

However, this is not the end sum of our bills. I do not pretend to understand the bureaucracy at hospitals. But this bill represents most of the in-room costs for the initial March 17-April 12 stay in the hospital. There will be subsequent bills for all the visits to the outpatient clinic, plus for every run to the hospital for additional chemo or care. And then, other divisions of the hospital send separate bills. Anesthesiology has already sent its own separate bill for several hundred euros. I'm not sure if the MRI department, the oncology department or all of the other stations where he got tests will soon be hitting us with bills. I know that, when Christina broke her foot a few years back, months after we were done, we got some bill for about 10 euros from some random department. Why they didn't include this fee in the main bill? Ask the hospital.

My favorite part? The 32,000 euro bill includes a 1.08-euro charge for "quality assurance." Who knew quality assurance was so cheap?
But this could easily segue into a rant about hospital life. Suffice to say, the staff makes herculean efforts to care for the patient, but there's a lot of crossed wires and plain stupid policy that makes life hard for the parent of a small child in the hospital. An example: Colin gets his meals delivered to the room. The parental minder only gets a coupon, which can be redeemed at the cafeteria, which is two buildings over and four flights down. How does one feed oneself if it means leaving your toddler with a tumor alone in the hospital room? We're still working on a particularly good answer to that one.
On the home front, Colin remains in exceptionally good spirits. He's warming up to Kaela and Rebekah, in fits and starts. Yesterday, he managed to walk about 10 feet, from Noah's room to my bedroom, with the support of one of Emma's old baby strollers. He then napped for three hours, so, let's all be assured that he's giving this his best.
-- Niels

## Comments

Oh wow, so sorry you have to deal with that paperwork mess on top of all this!

*—Jeremy Cook, May 2, 2016*

Are there any hospital volunteers who could bring the food to the room?
(((((Hug)))))

*—Cynthia Meyersburg, May 2, 2016*

They really do try in the oncology ward. Volunteers set up buffets once or twice a week. But those buffets might get missed because you're busy taking the child to another office for a test or because you're tied up with something in your room. And that still leaves a lot of other meals to cover. You cope by running out and grabbing as much food as you can while your spouse (or other visitor) is there and then storing it in the fridge in the common room on the oncology ward. But then you have to start considering the appeal and nutritional value of cafeteria food that's been stowed away for a night or so. It's not our biggest problem, obviously, but it's one more thing that makes the experience a bit less pleasant.

*—Niels Sorrells, May 2, 2016*

## Normalcy

*May 3, 2016*

Today, we're celebrating my daughter Emma's 8th birthday and, my, does it feel strange to be doing something so basic when there's the big elephant of Colin's brain tumor in the room.  But it's something we have to do.

Indeed, the further we get into this, the more I feel the need to keep forcing us all to do normal things, while, all the time, feeling intensely how strange it is to be doing anything normal because, on a certain level, all I want to do is be outside the oncologist's office demanding updates, breakthroughs and miracle cures.  But we have to try to stay normal or we'll go a little nuts. Certainly our lives will fall apart if we don't do normal things like shop for groceries and get the kids to school and pay our bills (made the 27,000-euro payment yesterday, so yay!). But it is odd, suspending this fear for minutes at a time and just going on with our lives.  A few weeks ago I found myself in an IKEA - we realized we needed to get new clothing storage if Kaela was going to spend the summer with us - and just thinking to myself the whole time "What am I doing here?"  It is surreal, having such an intensely normal middle class experience when you know your youngest is back in the hospital getting chemo.

It requires a suspension of disbelief that I didn't know I was capable of.

Yesterday, I got excited because he got into a kneeling position on his own.  But getting excited about that requires forgetting, at least on some level, why it's exciting that he can master this skill that he could do without trouble not two months ago.  Keeping it medical, Noah ended up in the same hospital as Colin yesterday for some routine tests.  He's been complaining about pain in his foot for weeks now and our pediatrician can't figure it out, so we went for an ultrasound and X-ray.  And the whole time, I'm thinking in the back of my head "I hope it's not cancer" (After the tests, it seems to be dermatological in nature).  And when I tell the results to Christina, she confides that she had been looking into possible cancer causes for his foot problems.  So, the whole time, we've been trying to act like this is normal and, down below, we've got the big C on our minds?  Is that our new normal? Pretending on one level that there is no cancer while thinking about it all the time?  You start to wonder how long you can keep up this balancing act of acting normal while knowing everything is not normal.  I returned to work last week, and I think it's good for me.  And it's not hard to get myself worked up about the quality or our stories and the details of writing style. But is it normal to care about that at this point?  I have no idea.

So, we're going to have Emma's birthday.  Today is just going to be family (we've got enough of it here, after all) and two friends.  We'll have a bigger party at the end of the month with more of her friends from school because we simply were not up to planning parties until about a week ago.  She's getting an insane amount of gifts, and I'm sure when she's gotten them all, she'll ask "Is that all?"  But at least it will feel a bit normal.

## Comments

An outsider, I wonder in terror and in awe, how you manage to deal and do these reports.

Again, with all my heart, I wish and will a happy ending upon your story.

And a happy birthday to Emma.

*—Boris Babic, May 3, 2016*

This is a really thoughtful (and enlightening) description of the new normal, punctuated by your and Christina's secret worries about Noah. Thanks for sharing this.

*—Jennifer Dlouhy, May 4, 2016*

I am impressed you are having the party! That is really great □□□□□□. Happy Birthday, Emma!

For a long time after Kniff's aneurysm, I was afraid if anybody I loved got a headache. After a long while, that stopped being my immediate thought every time. Now it happens once in a while. You'll know you are back to normal when you hear foot pain and think "broken toe" or "eczema" or some other boring thing.

((((((Hugs to your family!)))))))

*—Cynthia Meyersburg, May 4, 2016*

Beautiful post, Niels. In one sense I'm sad that it is this ordeal that has reacquainted me with your fabulous writing, but I'm grateful to be a part of sharing in this with your family. Thanks for your honesty and vulnerability.

*—Jeremy Cook, May 4, 2016*

It sounds like trying to figure out what is normal and if you're normal at all anymore is a perfectly normal response to what's going on with your family. I think you are doing amazingly well. You and Christina are strong, you're great parents and great people.And you know I'm quite fond of all three of your cute kids. I'm glad you all are having some fun and doing it together.

*—Lea Ann Schnakenberg, May 4, 2016*

## Motivation

*May 4, 2016*

Apparently, if you want to get someone with Colin's health condition to get up and walk across the living room, the motivation you need is a stack of his sister's newly unwrapped birthday gifts.  I'm happy to say that none of the gifts were injured in the experience and even happier to report that the birthday girl was out of the room when this happened, as it would have probably led to her getting her own trip to the hospital this week, with an epic case of hyperventilation.

We've actually seen a lot of good movement in the last 24 hours.  Pulling himself up on to his knees so he can play with toys on a chair or a bench does not seem to be a big issue for him.  The walking is unsteady, but he's initiating it.  He's also able to pull himself from lying flat on his back to a sitting position without much issue.  Crawling is still kind of slapdash.  If you're sitting on the floor, he can crawl into your lap.  It's not the most elegant maneuver you're going to see in your lifetime, but, at the end of the process, you do have a child in your lap.  He's just lying face down.

### Comments

Keep up the good work, Colin!

*—SG, May 4, 2016*

Atta boy Colin. That is awesome!

*—GFSantos, May 4, 2016*

Hey, It doesn't matter how you get there (in this case, Dad's lap) it just matters that you GOT WHERE YOU WERE HEADING! Way to go, Colin.

*—Phylles Lagarde, May 4, 2016*

It sounds like he is making so many improvements. I'm so happy about it.

*—Lea Ann Schnakenberg, May 4, 2016*

## earlybird

*May 4, 2016*

Of course, you're always excited when your child fighting cancer shows up in a great mood and flexing all kinds of muscles he hasn't been using in weeks. However, the thrill is dimmed when the kid starts doing so at 4:45 a.m.

### Comments

I love to hear you moan about the things we're used to hearing.

*—Boris Babic, May 4, 2016*

I agree with Boris. It really is fantastic. It sounds like he's getting back to his old self.

*—Lea Ann Schnakenberg, May 4, 2016*

Sorry it was at 4:45-- but so happy it happened!

*—Cynthia Meyersburg, May 5, 2016*

I know Rebekah and Kaela are new there, but at my home they often come to us at 10, 11, or later in the evening to talk to us. I can ask them to do that for you - that way you can be kept up late by the endless chatter of teenage girls at night, and Colin can wake you up in the morning. Then your excitement will be complete.

*—Eric Sorrells, May 5, 2016*

# New Medical Jargon Phrase of the Day

*May 6, 2016*

Episodic apnea.

This (also known as a breath-holding spell) is what happens when a small child gets so upset that he or she can't breathe properly. The breathing passages actually shut down, the child turns blue and passes out.

It is incredibly upsetting to watch.

Guess what Colin has started doing?

To be clear, this has absolutely nothing to do with the brain tumor and it is something that is not completely uncommon in young children, especially 2-year-olds. However, given our current states, we really don't need Colin adding exciting medical conditions to his palette. He had his first attack Thursday and two more today. The second, mercifully, came when he was already in the hospital for a routine checkup so the doctor could tell us what was going on. All we knew was that Colin had started, at times - when he expected to find me or Christina, and instead found himself confronted with Kaela and Rebekah (siblings, insert jokes here) - screaming, stopping breathing, turning blue and passing out. None of this improved his mood. Christina said she just looked it up and, actually, this is kind of the way it's supposed to happen. The screaming locks the vocal cords, which stops up the breathing, which causes him to pass out, which relaxes the vocal cords and passages, and returns your child to the bad mood he was experiencing when he found himself dealing with a cousin who just flew 3,000 miles to help take care of him.

As a friend told me a night or two ago, I just need to focus on the good moments - like the fact that he is now crawling, moving from lying to sitting positions to standing positions and taking some steps on his own - because you never know when something else will come along and kick you in your teeth. It's just another shade of fear we get to add to our growing collection.

Fear has, unsurprisingly, become one of the primary ingredients in our lives since March 17.

When I took him for the MRI on March 17, I was positive I was just humoring my wife and the pediatrician, who were clearly, in my mind, overreacting to a stomach bug. It wasn't my turn to feel fear until the technician - who didn't say a word the whole long walk from the MRI chamber to the pediatric ward - told me my son had brain cancer. And then, because this was all done in German, I had to take a moment to convince myself that I hadn't heard him wrong. And then I had to work up the courage to call Christina, who certainly didn't want to hear the news. And then I had to find some way to call in to work and tell them that I had no idea when I would be back.

The fear keeps coming and going in waves. From March 17 to March 23, I could barely function with the fear. I lost about 10 pounds and could barely pull myself out of bed most days. I kept finding myself wondering how one could possibly write a eulogy for a

2-year-old, and then telling myself I really needed to stop doing that.  And then came the biopsy on March 23.  Bear in mind, every medical procedure in the hospital only comes after a parade of doctors and other specialists come to tell you the 35 things that could go wrong with the procedure and leave your child dead or handicapped.  They have to do this, obviously, but it doesn't do much for the nerves. We were told the biopsy would end by noon. Instead, it took until 2 p.m., leaving Christina and me practically in hysterics by the time they called us to say he was out of surgery.  We found a way to feel things were getting almost normal after that, and then came the day they pulled us upstairs to a new ward so the oncologist, the neurosurgeon and the psychologist could tell us what we were facing.  "Is it malignant or benign," I asked. "It's multi-layered," answered the neurosurgeon.  And then we were right back to fearing the worst through the next few days as we got Colin ready for chemo and waited to see if it would work. April 10 was great, when the oncologist praised Colin's recovery, but the next day, as they sent us home, the nurse terrified us again as she sent us home with two bags full of medicine, masks, syringes, etc, telling us all the medicines we had to give to Colin, all the ways he would suffer if we didn't and how fast we had to react if something unexpectedly awful happened.  As she explained the suppository to use in case of seizures, she admitted that she freaked out every time she saw them happen, and she's a trained nurse, and told us to do our best.
And now we've been getting happy about his performance, and suddenly we have him passing out if he gets to upset about things.  It never ends.

## Comments

You summed it all up perfectly...the beaurcratic legal requirements....the idiocy of statements made by technicians and nurses...the abnormal overlaid on the normal...we continue to pray for you and your family! The one "good" thing...our 2-year-old daughter also had the crying jags that resulted in her turning blue...that is "normal"...but certainly you don't need it now. This too shall pass!

*—Barbara Skipper, May 6, 2016*

O dear! You don't need the screaming apnea. Hope he gets over this habit quickly. Bon courage!

*—SG, May 6, 2016*

I have juvenile apnea too., I also have 5 teenagers, 4 of them girls - I bypass the screaming and just pass out.

*—Eric Sorrells, May 6, 2016*

I continue to send healing thoughts toward all of you. I'm sorry I don't have better words and am not in closer proximity to be more helpful. Sometimes you take one day at a time. Sometimes you take one hour at a time. Be glad for the good hours/days when they come. Big hugs to you all.

*—Michelle Lee, May 6, 2016*

I hope this phase passes quickly. Continuing positive thoughts and prayers.

*—Lynda Schmitz, May 7, 2016*

Parents are supposed to be strong and brave and always have the right answers...(but, truth is, sometimes we don't.) Babies don't come with instruction books for their parents, because every situation is different. Every child and every set of parents have to figure this out along the way. You have just been exposed to the very thing that every parent fears. You are doing great. Colin is just letting his two year old self emerge in the middle of this crisis. Just keep loving him and praying daily for "patience - RIGHT NOW!". Love and prayers to all of you.

*—Phylles Lagarde, May 7, 2016*

## Baby Got Goin'

*May 8, 2016*

It was drawn to my attention that Friday's entry was a little too depressing, given the great progress he's made. Here's a video from yesterday. Please bear in mind, he wasn't walking at all from about March 24 until last week, so the fact that he's on his feet is huge. Yes, that is Emma's old pink stroller, but it's still very manly, because he's taking Lightning McQueen and Max Schnell from Cars on a walk.

## Comments

You know what they say about boys who play with dolls and toy strollers--

They grow up to be loving and good uncles, fathers, and grandfathers.

Love this!!

*—Cynthia Meyersburg, May 8, 2016*

Go, Colin, go!

*—Boris Babic, May 8, 2016*

Great that Colin is walking!

*—Christian Karl Hofmann, May 8, 2016*

Indeed, that is good news, but appreciate your sharing about fear!! It is reality!!

*—martha stanley, May 8, 2016*

Love!

*—Tara Sorrells, May 8, 2016*

Man, he looks so much bigger than the last time I saw him.

*—Lea Ann Schnakenberg, May 9, 2016*

## Take Two

*May 9, 2016*

As usual, the moral of the story is not to let me be in charge of any website, because I managed to upload the wrong video yesterday.  The goal was to show everyone a video of him taking an actual walk, not just toddling around the table.  Adding insult to injury, anything you see here is already outdated, because he's in the next room right now walking whole stretches without assistance of any kind.

### Comments

One small step for mankind, but a giant leap...

Nice to see and hear.

*—Stephan Roch, May 9, 2016*

Hooray!!!!!!!

*—Cynthia Meyersburg, May 9, 2016*

He does not waste time!!

*—SG, May 9, 2016*

Precious!

*—Jeremy Cook, May 9, 2016*

Omg he is awesome. (And I was impressed with the earlier video!) I like how he picks up something from the table and drops it on the floor. Haha! And wow your house is so much cleaner than mine.

*—GFSantos, May 9, 2016*

Wonderful to watch!

*—Marco, May 9, 2016*

Looking good!!!!

*—martha stanley, May 9, 2016*

tap-tap-tap-tap...

*—Boris Babic, May 9, 2016*

Go Colin!!

*—Barbara Skipper, May 9, 2016*

Way to go, Colin!

*—Jennifer Covington, May 9, 2016*

He's looking great! Obviously, he doesn't think Daddy has enough to do. He's putting you on clean-up duty.

*—Lea Ann Schnakenberg, May 12, 2016*

## The best of the Wurst

*May 12, 2016*

If by "recovery" you mean being able to toddle from one end of the kitchen table to the other to get a piece of bread and a tub of liverwurst and then bring it to the cousin - the one you've barely tolerated all day - and demand she make you a liverwurst sandwich without being able to say the words "bread," "sandwich" or "liverwurst" in either German or English, then we are enjoying some form of recovery here in Berlin.

### Comments

Lovely! Keep the good news coming!

*—SG, May 12, 2016*

Such great cousins! And wow, how did you get that kid to like liverwurst!?

*—Jeremy Cook, May 12, 2016*

And thought you were going to say give to the cousin who hates liver wurst!!□□ Reminds me of my grandfather!! Thanks for starting my day out with a smile!!

*—martha stanley, May 12, 2016*

Chalk this one up in the Win column. Sounds like the definition of recovery to me □□

*—GFSantos, May 12, 2016*

From one inmate go another, keep sticking Colin!

*—Boris Babic, May 12, 2016*

From one inmate go another, keep sticking Colin!

*—Boris Babic, May 12, 2016*

So very glad that he's wanting to eat... and what he's wanting to eat! I could never get my kids to eat that! I remember eating that myself as a kid, though (mid-west US German background)

*—Lisa M, May 13, 2016*

## Round 3

*May 14, 2016*

Today Colin and Christina headed to the hospital for the third round of chemotherapy. This is not exactly a make-or-break session. However, the doctors will give him an MRI after this one (June 2) and then decide how he's responding, which will decide if we accelerate treatment, keep on track or consider other options.

It's a strange thing that this is no longer strange to me. We call in the morning that the chemotherapy is scheduled. We confirm they actually have a room for Colin. And then we head over at some point to start the drill. You can get into the mechanics of it and not remember for a few minutes that other families aren't taking their sons to chemo for the weekend.

His mood remains good and the doctors are happy he is walking. He wasn't happy when he actually got the first shot (but he didn't have one of his apnea attacks, so that was nice). And he seemed to actually chat with the nurse today (well, he shouted at the nurse and then threw his pacifier at him), which is a nice change from just screaming his head off every time a medical worker enters the room. You can see in the photos how he's 1) enjoying playing in the room and 2) settling into his standard crossed-leg position for the hours of TV he gets to enjoy while he's in the room.

In other fun, we got another bill. This time for a mere 2,300 euros, but, impressively, bulk of the bill was for "Neubildung ein Nervensystems" (Rebuilding a nervous system), which seems to be the hospital's fancy way of saying "chemotherapy." Happily, the 1.08 quality assurance surcharge remains.

## Photos

## Comments

I love his cross-legged, pacifier approach to TV...it looks so normal until you notice the hospital bed. He is so cute! And a great smile! Continued prayers for family strength and comfort from Steve and me. □□

*—Barbara Skipper, May 14, 2016*

<3

*—Boris Babic, May 14, 2016*

Colin has become such a role model for me. He's strong and resilient - and I really want to adopt his strategy for dealing with hospital personnel to my workplace.

*—Lea Ann Schnakenberg, May 15, 2016*

It looks like Colin is adapting to his routine like a little man. He fusses, throws things, then just accepts life as it is at this particular moment in time. God Bless!

*—Phylles Lagarde, May 15, 2016*

## almost there

*May 16, 2016*

It was an uneven day.
When we started chemotherapy with Colin, we were led to believe it would always take 4-5 days. So, when I dropped Christina and Colin off at the hospital on Saturday, I figured it would be Wednesday or Thursday until they were back home. Thus, when the nurse told Christina late Sunday that she and Colin would probably be heading home on Monday ... we didn't believe them. But then the doctor said they would be heading home. So we sort of started believing them. And then it came up on 4 p.m. and they were essentially trying to shove Christina out the door because they needed the room, but she managed to hold on until I could get to the hospital to pick her up.
And then Colin's temperature went up ... so he has to stay in the hospital until they get that sorted out.
Christina says he's not acting sick and his mood is fine, so hopefully this will just be a 1-2

day extension.
I shouldn't let it get me down. These kinds of twists and turns have become a maddeningly normal part of the hospital experience.

**Bad Example 1:**
*Doctor: "We were going to give your son the MRI he absolutely needs before chemo ... but we forgot that he's only 2, so we only had him signed up to get a sedative. Do you think he'll sit still for the MRI?"*
*Christina and I: (Dear Lord are you insane?) No.* (The bits in the parentheses were what we only said in our heads).

**Bad Example 2:**
*Doctor: He was all ready to get his MRI, but then the hospital lost power.*
Horrifyingly, this is not one little bit exaggerated.

**Bad Example 3:**
*Doctor: Your child is running a fever? Get him to the hospital now.*
*Christina: It's 3 a.m.*
*Doctor: Now!*
*Time passes.*
*Doctor: It's now 10 a.m. and we're going to finally get around to doing something for the child.*

I assume there will be more. We'll keep on pushing through.

## Comments

O, dear! Hope not too many new bad examples :( Bon courage!

*—SG, May 16, 2016*

Keep pushing.
<3

*—Boris Babic, May 16, 2016*

WTF??
I don't even know what to say about those aside from I hope there will be a shift to examples of excellent, fabulous, amazing treatment culminating in healing.

(((((Hug!)))))

*—Cynthia Meyersburg, May 16, 2016*

I am impressed you both kept your real thoughts to yourself when asked about Colin's tolerance for a noisy, time-consuming MRI that would require him to stay perfectly still inside a massive machine separated from his parents. "Out of touch" would be a generous observation.

*—Jennifer Dlouhy, May 16, 2016*

Wow! If you know a journalist, (hah) maybe you should write a book about the misadventures of Colin and family at the hospital. A whole chapter could be devoted to the MRI scenario. Might be a best-seller.

*—Phylles Lagarde, May 17, 2016*

The only reassuring thing about reading about the German hospital system is learning that the American one is not the only one with serious problems. I am continually astonished, in my few experiences, how much "hurry up and wait" there is, along with a lack of coordination. Colin is fortunate to have you looking out for him.

*—Liisa Ecola, May 18, 2016*

## all the rage

*May 18, 2016*

Wow, so one day you look up and realize it's your two-month anniversary of dealing with a child with brain cancer. Unsurprisingly, no one makes cards for this occasion.

The anniversary was actually yesterday, but I spent too much of the day in a fugue of rage and exhaustion to even attempt to put together a proper blog entry. The two feelings were linked. Since we don't know when Christina and Colin will get out of the hospital (the latest gossip is Thursday), we figured we would preposition the car at the hospital on Tuesday, so Christina would have it ready to go when she and Colin got sprung. That meant waking up at 5 a.m. and leaving the house a little before 7 a.m. so I could avoid the worst of the rush hour traffic, get the car to the hospital and still make it to work halfway on time. It would have all gone so well, except I left with Colin's car seat in the trunk, not installed in the back seat. By the time I got to the hospital it had shifted its position in the trunk. I opened the trunk, the car seat fell out, a rod that is required to hold it in place got bent and ... voila ... a useless car seat and Niels cursing incoherently in English in a hospital parking garage during the morning rush hour.

I've really wondered in the last few days if I should take up boxing. Mind you, I have no real appreciation for the sport and have never had any interest in it before now. But the longer I deal with this, the more the idea of punching things sounds good. And, apparently, I'm not allowed to use the interns at work for this purpose. So far, my only outlet has been reacting to rude Germans (and I want to be clear, the vast majority of Germans are not one little bit rude, but there is a subset, as in any country, of rude people. Their rudeness is enhanced by - how I shall I put this in a way that will let me stay friends with German friends and spouses? - certain tics in the German language that make it really easy to be rude ... or at least staggeringly passive aggressive) in equally rude tones, which has its satisfying moments, but doesn't quite pack the punch of screaming in a parking garage or, um, boxing.

Anyways, I ended up heading back to the hospital after work, which had the upside of getting to have dinner with Colin and Christina, then getting the car back home so I could borrow a working car seat from some friends (Thank you Jens and Kathrin!) and then waking up at 5 a.m. today to do the whole thing over again.

I suppose the moral of the story will be that we're just going to have to get used to random fits of rage, whether it be prompted by the doctor who told Christina to "just blow" on Colin the next time he has one of his apnea attacks or by a particularly unpleasant ticket counter lady in Potsdam. But, perhaps better to take it out on a punching bag than, say, the oncologist.

## Comments

Fun, fun, fun, fun.

*—Stephan Roch, May 18, 2016*

Ugh-- how frustrating.

One time I was helping a child who was grieving-- I bought a bunch of chipped or otherwise very beat up dishes at a yucky thrift store, and we let him get anger out by finding a place he could throw the dishes at a brick wall. It was tremendously satisfying.

I think punching something makes a lot of sense!!!

*—Cynthia Meyersburg, May 18, 2016*

Hope no more reasons for looking for something to punch!

*—SG, May 18, 2016*

I can personally attest to the cathartic effects of punching things. Just don't hang the heavy bag on anything load-bearing. :)

*—Melissa, May 18, 2016*

I offer my services as an "uglee American" - just point me to the unpleasant counter lady in Potsdam. I'll bring some chewing tobacco, assume they don't do that much there.

*—Eric Sorrells, May 18, 2016*

I took up kickboxing. It was therapeutic. It also has the added benefit that certain people still have their teeth, because I went for workouts, not their throats.

*—Ivonne Marschall, May 18, 2016*

## Guten Appetit!

*May 18, 2016*

We're still on track to have him home tomorrow. And, as you can see, whatever else the chemo is doing to him, it doesn't seem to be affecting his appetite.

## Photos

## Comments

And before anyone gets worried ... that is iodine on his head.

*—Niels Sorrells, May 18, 2016*

:-)

*—Boris Babic, May 18, 2016*

:-)

*—Boris Babic, May 18, 2016*

Wondered what that was on his head! Thanks for clearing that up!!!□□

*—martha stanley, May 18, 2016*

These pics make me happy. So glad to see. This kid also needs another donut!!

*—Jeremy Cook, May 18, 2016*

He is totes adorbs □□

*—GFSantos, May 19, 2016*

Colin, you are one tough little man!

*—Phylles Lagarde, May 20, 2016*

He and Noah will definitely be battling it out for who will be the biggest. They might even outdo you.

*—Lea Ann Schnakenberg, May 20, 2016*

## forwards and backwards

*May 23, 2016*

I'd like to report that we've had several days without blackouts or vomiting, but that would be a fib.

That said, we're still doing well. It's a fool's game trying to figure out the hows and whys or why he appears to be doing better. I continuously catch myself watching him walking, trying to assess whether he's more or less stable than he was before the diagnosis. He no longer falls over for no reason, that's for sure. But he's not the stablest 2-year-old on the streets either. As for the vomiting - bear in mind, it was routine vomiting that was our first indication that something was not right with Colin - it always appears to come just after he's eaten and, as we keep telling ourselves, he **is** on chemo. We just have to start working on what stays down best. I will say this, initial research is probably lending weight to the argument that a meal consisting entirely of sausage is not good for a chemo patient's stomach. I'll leave it to all of you to guess where Colin and Christina fall on the respective sides of this major policy fight.

The hospital continues to keep us on our toes. When we started this, the deal was 4-5 days of inpatient care during the chemo and then regular visits during our 2 1/2 weeks where he was out of the big house, usually every 2-3 days. This time, he got released on Thursday, came back on Sunday and - surprise - they gave him a short burst of chemo and then sent him home. We have no idea if this was always part of the plan, if they've changed the routine or if someone in the clinic on Sunday just decided to blaze their own trail. And now they don't want to see him again until Friday. So, either we've advanced to some stage where they don't need to see him so often or the system has broken down. All I know is I've got two bills amounting to 4,000 euros waiting for me at home, each with the mandatory 1.08-euro quality assurance surcharge, and I'm wondering if I could just throw a little extra their way to see if that buys me a little better quality, or at least some forewarning when they change the system on us. Failing that, if I do give them extra money and they give us the nurse we don't like the next time we show up, we're going to use that as leverage to demand a staffing change.

## Photos

## Comments

This sounds exhausting but hopefully it is all in the right direction! I once came across a site discussing best food type for somebody in Colin's situation but don't remember much. It will certainly be better for you if feeding him is a successful process and not a waste of time and energy :( Hope the service at the hospital gets better too!

*—SG, May 23, 2016*

That sounds really frustrating. I don't hear people here being as frustrated if they have the right Doctor overseeing everything. That said, I had to fire a doctor of mine to finally get a correct diagnosis after ten years of wrong medications. So...we are certainly not perfect here. My way of thinking now...is that even with all we now know in medicine, there are still many unknowns. If you have the right people overseeing everything...but then I don't know how flexible your system is. I augment everything with prayer to the Greatest Physician. Much love and prayer daily from us both. PS ...i vote against the sausage when nauseaous!

*—Barbara Skipper, May 23, 2016*

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*—Barbara Skipper, May 23, 2016*

Ah, little Germans do love sausage! But sometime, it doesn't love them!

*—Phylles Lagarde, May 25, 2016*

## tales of the fall

*May 25, 2016*

He seems to be stumbling a lot these days. It bothers me.

I mean, there's the natural parental reaction to hate it when your child wipes out. We have the added worry that he has this shunt in the top of his head. The doctors swear up and down to us that nothing can go wrong with it, but, at the end of the day, he has this giant lump on the right side of his head and you can't help but think that, if he were to land on that point blank, it would at least set his therapy back a bit.

But no, the real problem is that, back in February/March, the second symptom that eventually sent us to the hospital was his lack of balance. One day, I was getting dressed and he wandered into the room. He came to a stop in front of me, stood for a beat and then fell on his side. I couldn't see anything that would have knocked him over, which is when I started to worry a bit about his health, though I never even entertained the idea of a brain tumor back then. So, now that he's falling again, it's a game of following him around the house and trying to assess how stable he is and what might have caused him to fall and whether this is a sign of deterioration. Have you ever tried to shadow a 2-year-old? It is insane. And trying to figure out what caused him to fall? Pfft. You might as well try to keep the lights on at a major hospital in Germany full-time.

As usual, we don't know. Perhaps this is a real setback. Perhaps, as Christina says, now that he's up and running he's getting more ambitious and coming up against the edge of his capabilities. Perhaps he's just clumsy. He would not be the first Sorrells so disadvantaged.

At least his mood remains good. Just about every time I see him these days, he's a huge smile trailed by whatever disaster he's just caused. There's some nausea. We haven't quite gotten past the fainting fits (last night he passed out on me while I trimmed his fingernails). But, whatever else is going on, he's pretty happy with the universe, and that's something.

## Comments

(((((Hug))))))

*—Cynthia Meyersburg, May 25, 2016*

The greatest burden for a parent is when you cannot immediately fix what is wrong with your child and your mind goes crazy with worry. It immediately grounds you in what is really important and what isn't. Prayers and Love

*—Barbara Skipper, May 25, 2016*

I go cold inside each time I read one of these that isn't all sunny.

And I go even colder thinking how you two must be feeling.
Am with you, as much as I can and for whatever it's worth.
Love, B

*—Boris Babic, May 27, 2016*

No matter what the odds, Colin is a fighter. He is fortunate to have the two of you as parents. I know that the stress is monumental now, but remember that God is also running behind Colin to help catch him when he falls. Love and prayers to all of you.

*—Phylles Lagarde, May 27, 2016*

## The 2s and their terrors

*May 29, 2016*

There's not much to say, especially since I'm wiped out after spending a weekend chasing him around.  He's 2.  Most of his day is spent trying to climb things that are too high, move things that are too heavy for him or get his toys to defy the laws of physics. Really, one must set aside worries about the brain tumor and be amazed he survives a day just in his normal mode.

We take joy in the little things.  He's begun eating gummi bears again, which were a favorite before he went to the hospital but lost favor for a long time.  The medicine that used to send him into shrieking fits now seems to be a favorite too.  He actually sits down with his mouth open when Christina approaches with the medicine.  Indeed, he seems to think all medicine is his.  Noah needed something after an allergy fit today and Colin was pretty put out that he didn't get any.

The fainting spells remain.  Yesterday was one of the hottest days in Berlin so far this year, so I took him on a walk.  I insisted he wear a sun hat.  He insisted he wear a jacket, even though it was far too hot for that.  After five minutes I tried to take it off and ended up with an unconscious child on the sidewalk.  It's a very strange new normal we have here these days.

Otherwise, we keep our focus on Thursday, when the MRI will hopefully give us a little more clarity about what we're facing.

## Comments

You don't seem tube bored! Hope indeed the MRI gives you positive news!

*—SG, May 29, 2016*

I think we're all waiting for Thursday. In the meantime, I think it sounds like he's doing really well and handling the treatments really well. What a kid!

*—Lea Ann Schnakenberg, May 29, 2016*

My prayers that Thursday's MRI will bring good news about your delightful child's health.. God be with you.

*—Phylles Lagarde, May 30, 2016*

There is always a good reason to hope for the best. In Jerusalem, our prayers are with you.

*—Claudia Busch, May 30, 2016*

Here's best wishes for very positive outcome on Thursday!

*—Marc Galmoud, May 31, 2016*

# The next big thing

*June 1, 2016*

So, tomorrow's not quite The Big Day. I can't quite assign it that title when, for all we know, all we're going to hear is "Six more months of the same." Nonetheless, it is going to be a biggish day. I think, right now, we're just going to be happy if it doesn't turn into a ridiculously long day. Christina is with Colin at the hospital right now signing all the consent forms ("Another way your child might die is...") and it is, of course, taking forever. The appointment is at 2 p.m., but I'm already bracing myself for a long day of holding Colin in front of a laptop with Curious George and hoping that distracts him enough from the fact that he's not going to be able to drink all day tomorrow.

We'll know a lot more after that. Short term, it doesn't look like Colin is going to the hospital for chemo this weekend, just because his blood counts haven't recovered enough from the last round and the surprise chemo session on the 22nd. But that's about all the certainty we have.

Otherwise, we do what we can to keep things normal. Emma finally managed to have her 8th birthday party yesterday. Do not be shocked by the picture. Being my daughter, she is a bit obsessed with comics. So, when they did face painting, she asked to be Batgirl. That led to her getting dressed up as a bat. I've seen the pictures and they look lovely. Then she took the costume off and it looked a bit less than PC. I know I did a double take when she got home (someone had to stay home with Colin because his immune system is not up to a crowd full of children). Think about it this way: even if your PC values are offended, the look might have very well prompted Colin's first three-word sentence: "Was ist das?" (What is that?)

Then again, it's hard to tell, what with the pacifier always being in.

He continues to do well. Honestly, if you didn't know about the cancer, you'd think he was just suffering from very thin hair and an odd bump on the top of his head. He hasn't slept through the night in ages, which is getting old, but that seems to be more standard 2-year-old behavior than anything more sinister. And, based on the baby yoga poses he was doing in his bed last night while he was supposed to be going to sleep, I can attest that he's getting a lot of strength back. You don't get your legs over your head like that just by being grouchy. He only had two fainting spells yesterday. The one came when he thought I was leaving him alone in the yard with Kaela (His concerns about her are understandable, seeing as how she likes Marvel comics). The other came when I ... picked up a bag of building blocks. So, no, there's no real clear thread yet as to what set these things off.

The adventure continues.

## Comments

Bon courage!!!

*—SG, June 1, 2016*

Haha, screw PC, it's a cool pic!
You brave people.

*—Boris Babic, June 1, 2016*

Fun curveball: They've pushed his appointment up to 8:30 am. Guess which family is hitting the streets of Berlin at 6:30 am tomorrow?

*—Niels Sorrells, June 1, 2016*

Oh man, lol on that birthday party. I'm totally reporting you to Spike Lee!
https://youtu.be/YC75n_QRTag

*—Jeremy Cook, June 1, 2016*

Thank God for your (warped) sense of humor. Keep smiling!

*—Phylles Lagarde, June 1, 2016*

:)

*—Marc Galmoud, June 1, 2016*

Happy Birthday to Emma!
http://2.bp.blogspot.com/_2kjisMm3M9Y/Svuxc9ndoTI/AAAAAAAAKy0/F3QV2LZXVNg/s1600/batgirl-comic-book-cover.gif

*—Lisa M, June 1, 2016*

## some good news

*June 2, 2016*

It would seem someone is doing the right kind of prayers.  Whoever it was, please keep on doing them.

We got the call right before dinner time.  The MRI results are generally positive.  The tumor has shrunk and, more importantly, the parts of the tumor that remain are absorbing far less of the fluid they use to monitor it, indicating that it's dying and using less blood.  There was a lot of background noise while Christina was taking the information from the doctor (thank you Emma and Noah), so we don't have all the details, but, in general this is A Very Good Thing.  Christina will meet with the doctors by Sunday at the latest to get more concrete details, but the neurosurgeons are apparently already planning a pow-wow tomorrow to decide what our next steps are.

I don't know exactly what this means, no do I believe for a moment that we don't still have a lot of road ahead of us on this one, but I do very much like the idea that we have next steps.

It would be mean-spirited to spend time in this note talking about the usual hospital disorganization surrounding today's MRI. Suffice to say, they kept the power on and, even though we were on time, we still managed to make the doctors wait for us for a change. Revenge!

## Comments

Yay! So happy to hear that. Go Colin!

*—Ivonne Marschall, June 2, 2016*

That is great news! I'm so glad to hear it!

*—Viktoria Johnson, June 2, 2016*

Fab news! Hope things continue in this direction!!!

*—SG, June 2, 2016*

So happy that I am crying!! What happy, wonderful, best possible news!!

*—Cynthia Meyersburg, June 2, 2016*

That's amazing!!! So happy to hear it!

*—Melissa, June 2, 2016*

Great news! Steps toward recovery!

*—Barbara Skipper, June 2, 2016*

Yessss, great news!

*—Claudia Busch, June 2, 2016*

Beautiful!!!! Let's get more of that!

*—Marc Galmoud, June 2, 2016*

Great, great!!!

*—Boris Babic, June 2, 2016*

Good news, glad to hear about that.

*—Jens Brenner, June 2, 2016*

So happy to hear.

*—Jeremy Cook, June 2, 2016*

Impossible to convey how we have been rejoicing and giving thanks to Him for this incredible good news!! Continuing to pray for ya'll!

*—martha stanley, June 2, 2016*

Tremendous news!

*—Jennifer Dlouhy, June 2, 2016*

That sounds pretty great. We will continue praying here.

*—Jennifer Covington, June 3, 2016*

Hooray!

*—Tara Sorrells, June 3, 2016*

This is such happy news, Niels! Am I wrong to think it might have had something to do with the donut?

*—Lea Ann Schnakenberg, June 4, 2016*

## Friends in high places

*June 3, 2016*

This is a picture of Pope Francis praying for Colin's health.

Yes ... that pope.

No one should take this as a sign they should start praying less just because we've added a heavy hitter who can take up the slack. It's just to show we're all in good company.

Background: Our friends Dana and Marc are friends with a priest in Freiburg, Germany. When he said he was going to Rome, they asked if he might pray for Colin. He clearly decided to up the ante.

## Comments

Cool! And you (and Colin) are just 3 handshakes away from the Pope!

*—SG, June 3, 2016*

Wow!

*—Cynthia Meyersburg, June 3, 2016*

Great to hear about the good news with the MRI results. I'm sure the pope's and everyone else's thoughts don't hurt none either. All the best Colin, Niels and family. We're certainly sending our best your way. Steve, Ellie, Abby and Charlotte

*—Steven Patrick, June 4, 2016*

Wow! With Pope Francis and St. Therese of the roses in Colin's corner, combined with all of our prayers, he is truly blessed. Love and prayers,

*—Phylles Lagarde, June 4, 2016*

## pretty status quo

*June 6, 2016*

I suppose it's not surprising, but we know, essentially, nothing more today than we were told on Thursday.

The neurosurgeon's pow-wow didn't happen Friday because the head of the division wasn't in the office. The news from Thursday's tests have to percolate up to the attending oncologist, who then has to decide how to go ahead, in consultation with other doctors. Once that decision is made, it then has to filter back down to the doctors on duty at the regular clinics before we even have a hope of knowing the plan. What stage that is at is anyone's guess.

Anyways, it's all academic, as the bloodwork during Sunday's check-up showed that, while his blood count levels are on the rise, they still fall far short of the levels needed before he can start another round of chemo. All we know now is that, when we started this, we were told we had a 30% chance he'd respond well to the chemo. And, when we had the MRI on Thursday, they said they'd only call us if they had something spectacular to share. So, I'm working on the assumption that, since Thursday's news was spectacular, we're solidly in the 30%. But I don't see any chemo starting before Wednesday or Thursday.

Otherwise, we're fine. For a kid who was flat on his back a month ago, Colin is suddenly a whirling dervish. A clumsy, accident-prone dervish, to be sure, but a happy one. There are also signs that he's starting to learn how to keep his panic attacks under control so as not to pass out. That would also be a welcome development.

## Comments

Here's hoping for continued good news!

*—Marc Galmoud, June 5, 2016*

It is frustrating not to get answers right away, but things look positive, and Colin looks great. What an infectious, handsome smile he has. We'll keep praying and I know you all will keep fighting.

*—Lea Ann Schnakenberg, June 5, 2016*

Hoping you get more details soon. In the meantime, just try keeping up with that whirling dervish.

*—Jennifer Dlouhy, June 6, 2016*

Not getting info and having to wait to hear about details of upcoming treatment is annoying but hopefully you won't be left in the dark for long. May he continue being happy and get even better - the initial control over the fits is encouraging!!

*—SG, June 6, 2016*

I guess the best plan is to enjoy the happy face and watch him whirling around. It's not all about chemo, recovery is also about love, joy and happiness.

*—Claudia Busch, June 6, 2016*

Way to go, Colin, the whirling dervish! I don't think that any one of us tracking his progress could handle his issues quite as well as Colin has at the age of two. He definitely has learned to cope....just hope that Niels has! Love and Prayers....

*—Phylles Lagarde, June 7, 2016*

Fingers crossed for more good news!! (making it tricky to type)
(((((Hug!)))))

*—Cynthia Meyersburg, June 7, 2016*

## The Chemo Cameo

*June 12, 2016*

I was going to post on Tuesday, after the meeting of the doctors, once they shared with us what they'd decided, if anything.  But, somehow, we've not been in the hospital at the same time as the doctors who were at the meeting, and the doctors who have been present when we're there haven't been told what was decided.

Then I was going to post Friday, after Colin started the fourth round of chemo, but they didn't get him into the room until so late I just had no energy to write anything.

Saturday was busy, so I thought I would then post an update from the hospital on Sunday.  And then, unexpectedly, they released him today, just a few hours after the chemo ended and still not quite done with the related therapy (the one that involves injections into his nervous system).  I am choosing not to take this as an insult: That they just wanted us out of the hospital to make space for someone else.  Instead, I'm choosing to believe that they have simply (if somewhat annoyingly) decided that we're such old hands at this that they can send us home halfway through the treatment with the knowledge we'll do just fine returning for the rest of the therapy as outpatients.

In short, it's all status quo. He's doing fine with the treatments and we have no idea what's supposed to happen next.

## Photos

## Comments

Here's hoping!

*—Marc Galmoud, June 12, 2016*

What can I say? I can only offer prayers...for you and Christine as much as Colin. Hang in there!

*—Barbara Skipper, June 12, 2016*

I like your interpretation, and I am delighted he is doing well enough that they decided to send him home a bit early! □□

*—Cynthia Meyersburg, June 12, 2016*

Thinking about you all often. Keep fighting little one and may God keep the treatments working!

*—Erin and Rich, June 12, 2016*

Your choice of explanation is very plausible! But hopefully soon you will also get confirmation from the doctors!

*—SG, June 12, 2016*

So glad to hear he's doing fine with the treatments. Hang in there!

*—Jeremy Cook, June 13, 2016*

I'm grateful for this update; I was about to harass you to find out how Colin and everyone else were doing. Funny to see him playing with the doctor's kit; at this rate, he'll be ready for med school in no time. I assume that's the same kit that led to a cute/questionable pic of Noah in his bed with the needle once up on a time...

*—Jennifer Dlouhy, June 14, 2016*

Hopefully, no news is good news. BUT parents DO LIKE TO KNOW! Praying with you!

*—Phylles Lagarde, June 15, 2016*

## Still more questions than answers

*June 16, 2016*

The only news we have to report today is that breakfast consisted of chocolate milk AND chocolate yoghurt.

Seriously, I e-mailed the oncologist for details about last week's meeting and got the automatic response that he's on vacation. Am going to make a stab at e-mailing the pediatric neurosurgeon today to see if he feels like sharing with me what medical procedures might be in store for my son. It's pretty clear that, despite the success we're having with the chemotherapy, that there will be at least one more serious procedure before we're all done. The only question is what kind of procedure and how serious (and whether the doctors are going to tell us, or if they're just going to surprise us one day).

## Comments

I think chocolate is a lovely breakfast theme.
And I am cheering, cheering, cheering for Colin.

*—Cynthia Meyersburg, June 16, 2016*

Most doctors capable of empathy - which includes taking the time to explain stuff to patients - quickly lose it and joins the cold, detached bunch that is the vast majority in their profession.

*—Boris Babic, June 16, 2016*

He looks like he is a spitfire and ready to challenge the day!! Great seeing that hearty smile!

*—martha stanley, June 16, 2016*

Niels, thanks so much for taking the time to keep us all informed of wonderful Colin. We know time is not something you have a whole lot of. We're all cheering you on, and we all really appreciate knowing the latest about that lovely little guy - and the lovely big guy, you! - and your whole family. I really have to come see all of you again soon. Miss you!

*—Lea Ann Schnakenberg, June 16, 2016*

I love this picture of him!

*—Lynda Schmitz, June 17, 2016*

No chocolate donut!?

*—Jeremy Cook, June 20, 2016*

## incommunicado

*June 18, 2016*

I suppose I ought not have been surprised that the doctors were brewing up all kinds of plans while they were neglecting to call us.

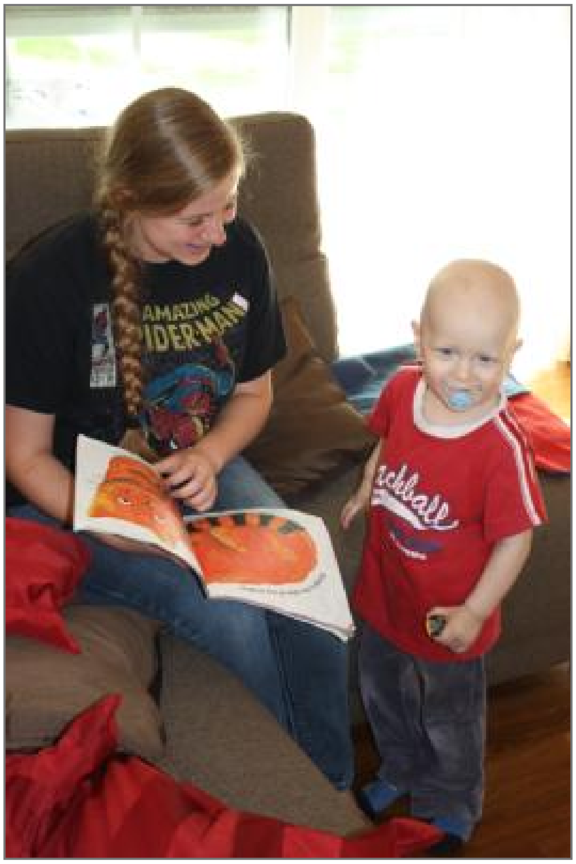
On Thursday, I finally got around to e-mailing the pediatric neurosurgeons, which somehow prompted an e-mail from the oncologist, who is not on vacation, but at a seminar. Neither he nor I are native German speakers, so we've settled upon speaking English, which has its own problems, since it's also a foreign language to him (Demonstrated, adorably, by the fact that he starts e-mails to me with "Dear Sorrells"), so the e-mail mostly created questions, as opposed to generating answers. Turns out he wasn't at the big meeting two weeks ago but, as he sees it, Colin's tumor is now "amenable to surgery," but he also said that another doctor would be getting in touch with us to discuss radiation therapies.

So, imagine Christina's surprise, upon showing up at the outpatient clinic for a regular checkup today, to learn that a follow-up MRI has been scheduled for June 28 and that Colin is slated for surgery the week of July 4. I have to admit, I'm not surprised by the poor communication at this point, though it is still enraging. One wonders at which point they were going to discuss our options and get our approval. We'd also like to know why, in March, the neurosurgeon felt it wasn't safe to remove more than a tiny sample for biopsy, and now they, apparently, feel confident going back in to, we can only assume, remove more, if not all, of the tumor.  I hope answers will be forthcoming.

For me, I suppose the biggest shock stems from my refusal to not research more, since the answers still terrify me.  I had naively assumed that you did chemotherapy and that it either worked or it didn't and, if it did work, that you were then done.  I wasn't really ready for successful chemotherapy simply being the doorway to yet more treatment.

More as we find out.

## Photos



## Comments

Frustrating, Niels. I hope you all can force the docs to sit down and talk about their game plan (including expectations and treatment after surgery). They certainly don't seem used to presenting folks with actual options and choices. I suppose it could be a small comfort that at least things weren't in stasis all this time, though it'd be nice if they saw fit to include the patient and his family in developing the treatment plan.

*—Jennifer Dlouhy, June 18, 2016*

Oh my.....definitely a challenging time for all of you. But Colin looks GOOD and assume no more fainting spells? Now that he is getting used to that stranger!!□□ Hang in there.

*—martha stanley, June 18, 2016*

Already ranted.
:-/

*—Boris Babic, June 18, 2016*

I hear more and more that chemo to reduce size of tumor precedes surgery (or radiation). Surgery on a child would never be scheduled here without involvement and approval of the parents. It will be interesting to hear any radiation option since laser precision is now available in many cases. Hang in there...it sounds like there has been progress despite their despicable communication skills. Much love....prayers every day....and extra ones at church on Sunday when we pray for those who need healing (and parents who need comfort). Barb

*—Barbara Skipper, June 18, 2016*

Supposedly, surgery before stemming the tumor growth entails risks of the tumor spreading to other parts of the body. There is so much in the press about recent cancer cure breakthrough involving drugs boosting the immune system: wonder if those could make the surgery redundant. Hope evth goes smoothly!!!

*—SG, June 18, 2016*

Hang in there! Sometimes docs have to be reminded that they are not just bureaucrats with scalpels. PS. That's a handsome boy you got there!

*—Marc Galmoud, June 18, 2016*

(((Hug)))

*—Cynthia Meyersburg, June 18, 2016*

The fainting spells are growing less frequent. At the very least, they are no longer a daily affair (though we've had days just this past week with multiple spells). But there have been many times when he's been on the verge of blacking out and he catches himself at the last moment, so there's some hope he's figured out a coping mechanism.

*—Niels Sorrells, June 19, 2016*

Stay strong for one another. As always, I am praying for all of you. Just hope the doctors get with the program! Love and prayers,

*—Phylles Lagarde, June 19, 2016*

Oh man, I am so sorry. If the grief of what your little one is going through isn't enough, now to have to deal with terrible communication from those paid to serve you. Ick.

*—Jeremy Cook, June 19, 2016*

The doctors' lack of communication is upsetting and I'm sorry it's a continuing problem. But I'm glad Colin is responding well to the treatment and has decided to make friends with Kaela. He has a beautiful smile.

*—L Smith, June 20, 2016*

# Spectacular

*June 20, 2016*

No real news today, though it is nice to hear that the oncologist on duty today considers Colin's progress under chemotherapy so far to be "spectacular."

## Comments

Spectacular is our favorite!!! So glad to hear it. I hope they include you in a status meeting soon. Love, love, love you guys. Many blessings from Hamburg.

*—Lana Spangenberg, June 20, 2016*

Keep it up!

*—SG, June 20, 2016*

Spectacular sounds very promising, indeed.

*—Liisa Ecola, June 20, 2016*

Will celebrate that!!

*—martha stanley, June 20, 2016*

:)

*—Marc Galmoud, June 20, 2016*

Wow, good news!

*—Jens Brenner, June 20, 2016*

Hooray!

*—Lea Ann Schnakenberg, June 20, 2016*

You know, I've never heard a German use the word spectacular. This is serious!

*—Lea Ann Schnakenberg, June 20, 2016*

Well, if this is 'no real news today', I would like to hear more of the same everyday ☺

*—Claudia Busch, June 21, 2016*

I like "spectacular"! Happy Dance!

*—Barbara Skipper, June 21, 2016*

## The meeting that wasn't

*June 24, 2016*

We spent about six hours in the hospital yesterday ... and didn't really learn anything we didn't know already.

It seems that the meeting two weeks ago was not officially a meeting, since the lead neurosurgeon and oncologist on Colin's case couldn't be present. So, anything that was discussed there was more of a suggestion than anything else. The plan is to now have a meeting on Tuesday, and - most importantly - for them to tell us what they've decided by Wednesday.

Nonetheless, it's pretty obvious that the doctors are leaning towards surgery. Now that the tumor has shrunk, it puts less pressure on the brain and the stem, giving the surgeons more wiggle room. There's the hope the tumor has been degraded, which could make it easier to remove. And, if they get the bulk of it out with surgery, that leaves less work for future rounds of chemo to do. The other big takeaway is that they don't want to do radiation, because it's a tricky treatment for a person Colin's age, to say nothing of the fact that we're talking about something in his brain.

The neurosurgeon was a little less upbeat than the oncologists. The fact that the tumor has shrunk and takes up less of the contrast solution during the MRIs are all good signs, he told us, but they won't know anything until they actually look at it. So, that's less nice than "This is undoubtedly good." On the other hand, the oncologists told us the tumor had only shrunk a bit. He measured the images and said it was more like a 30% reduction, which is kind of huge from where I stand.

More as we learn it.

## Comments

It's definitely good news! 30% reduction is huge!

*—Lana Spangenberg, June 24, 2016*

Hope you soon know more about what will be taking place

*—SG, June 24, 2016*

They've been Pavloved into not being optimistic.
Not you, not us.

*—Boris Babic, June 24, 2016*

I love the word operable. I think shrinking the tumor by 30% sounds like reason for optimism.

(((Hug!)))

*—Cynthia Meyersburg, June 24, 2016*

This is good news! You knew it would be hard, but the tumor shrunk, they believe that surgery is an option - things are developing in the right direction.

So yes, this is good news! And I am very happy for Colin and you!

*—Sabine Kahl, June 24, 2016*

Yes, again! Things are going in the right direction. Beats the heck out of the other way around. We live in hope and we pray!

*—Marc Galmoud, June 24, 2016*

I'm really glad to hear that things are moving in a positive direction, even if the communication is still frustrating. I'll look forward to hearing the news next week.

*—Jeremy Cook, June 24, 2016*

## Brexits and birthdays and burning fevers, oh my

*June 28, 2016*

It turned into a hectic few days.

After we had the talk with the neurosurgeon on Thursday, Colin's fever began yo-yoing up and down.  It kept creeping up into the danger zone and then returning to an acceptable level, keeping us on edge Thursday and Friday.  Friday turned into an epic long day, as I had to be at work at  6 a.m. to cope with the Brexit fallout and then get home so we could have the family celebration for Noah's 6th birthday.  It all left us pretty exhausted, so you can imagine our dismay when Colin woke us up at 5 a.m. Saturday with a 39.3 Celsius (102.7 Fahrenheit temperature).  Christina rushed him to the hospital, where his fever promptly dropped to 37 (98.6) before any doctor had even looked at him.  But the doctors knew about the fever, so they kept him for a round of antibiotics.  He and Christina got checked into a non-air conditioned, fourth-floor room on the hottest day of the year so far, and I was left to host Noah's birthday party with friends with the help of Kaela.  Does it sound bad?  Well, actually, pity poor Kaela, who somehow ended up on the bottom of a pile of 6-year-olds at one point and almost got herself a black eye in the process.

Anyways, he's done with his course of antiobiotics and he's had the MRI the doctors say he needs so they can decide the next step for him.  Theoretically, they're going to meet tonight and get back to us by tomorrow at the latest.  Christina was under the impression today at midday that she and Colin would be sent home today, but ever since they got back from the MRI no one's said anything to them.  It's almost 6 p.m. and it's getting to the point where we ought to be thinking about feeding Colin and getting him ready for bed, not transporting him across Berlin.  We'll just have to see.

## Comments

Eeek!!!

(((((Hug)))))

I do not even know what to say aside from I am cheering for him, for you, for Christina, for more good news, and then for great news. I wish there were some way I could help.

*—Cynthia Meyersburg, June 28, 2016*

Poor Colin, poor all of you, (hopefully Noah had a good time at his birthday party) and hopefully things will improve soon!

*—SG, June 28, 2016*

Happy Birthday Noah! Hugs!
Prayers for Niels & Christina & Colin & Karla! Puts Brexit in perspective....

*—Barbara Skipper, June 28, 2016*

I have learned that boy birthday parties are ALL about running like crazy and the pile up is part of the process. Hope that Colin will soon be the one running like crazy and doing silly boy things.

*—Erin and Rich, June 28, 2016*

They finally got home around 9 p.m. last night. Astoundingly, Colin was still wide awake and managed to spend one more hour romping through the living room.

*—Niels Sorrells, June 28, 2016*

Happy Birthday Noah! Glad to hear Colin is back home after that fever. Continued prayers for his continued recovery and love to you all.

*—GFSantos, June 29, 2016*

Oh, no, it sounds like the birthday party took an anti-American turn.

*—Lea Ann Schnakenberg, June 30, 2016*

## pick your superlative

*June 30, 2016*

After the weeks of meetings and not-meetings and calls to the doctor to get information (My favorite bit, after getting doctor on the phone - Doctor: How did you get this number; Me: Um, you gave it to me), our oncologist called us last night and asked us to come in this morning. Obviously, it got us a little nervous. Even though we were pretty sure the news would be good, you never know if they'll suddenly find something awful.

Happily, the news is pretty much all good.

Colin is responding wonderfully to the chemotherapy. It's about a third smaller than when it was discovered and all the MRI data indicates that it has degenerated to, essentially, a cyst full of necrotic tissue. Of course, there is no way to know for sure what we're fighting until they go in and take a look at it, but this is still all good. The doctor said it was "excellent," that this is turning into an especially chemosensitive tumor and then, grimly, that we're doing quite well, because he's had many much less pleasant conversations with parents in this room. I think it's important to remember that. We're dodging a lot of bullets here.

The plan now is to have two more rounds of chemo, which will take us through the end of July. After that, we'll have another MRI and an assessment. The main question is whether they will then have another surgery. The main question being whether the risks are acceptable for another invasive procedure like that. Regardless of that, they are already booking us a place at a children's clinic in western Germany, where we will go for about six weeks some time in the autumn for radiation therapy. The only question there is whether we go to the clinic in Essen or the one in Heidelberg. And, assuming all this goes well, we'll have a round of oral chemo treatments.

I sincerely doubt that we'll be done even at this point in the game, but I'm starting to hope maybe we'll at least have the worst past us by then.

More as we know it.

## Comments

How does "chemo sensitive" translate in German? What a great, great thing to hear.

> *—Jennifer Dlouhy, June 30, 2016*

Happy to hear about that!

> *—Jens Brenner, June 30, 2016*

Booyah!! Wonderful news. And the bit about the doctor having less pleasant conversations with parents is insightful! Keep your head up! You live in the 21st century in a country that not only provides often ingenious medical technology and has a system in place to provide it to those who need it. You have family and friends rooting for you. And at the end of the day, miracles happen too! Not a bad way to look at things.

*—Marc Galmoud, June 30, 2016*

So pleased to hear this - hope all subsequent news will be good as well!

*—SG, June 30, 2016*

I hopehopehope the worst is behind the Sorrells clan.

*—Boris Babic, June 30, 2016*

This is such fantastic news! It makes me so happy! (And the photo of the two handsome guys you posted doesn't hurt either.)

*—Lea Ann Schnakenberg, June 30, 2016*

So happy to hear this!

*—Jeremy Cook, June 30, 2016*

Great news - they can't do the radiation somewhere in Berlin?? Surprising. Anyway, this is good news.

*—Don Summers, June 30, 2016*

So glad to hear this bit of good news.

*—Lynda Schmitz, June 30, 2016*

Great news - when have you ever heard a German doctor using the word "EXCELLENT" ...? This deserves the largest candle I may find in Jerusalem, specially blessed at the Tomb of the Lord for the Sorrells clan and personally delivered to you 1st of August!

*—Claudia Busch, June 30, 2016*

Heidelberg? Funny!

*—Stephan Roch, June 30, 2016*

Answered prayers!

*—Barbara Skipper, June 30, 2016*

I am so happy to hear! It's so much smaller! Way to go, little guy! It sounds like you guys are doing everything right and that he is being a trooper! I am interested to hear if you can all go to the clinic or if the siblings have to stay in Berlin. I am thinking of all you and so proud of how well you are managing the whole program!!!

*—Lana Spangenberg, June 30, 2016*

## We haven't the faintest

*July 2, 2016*

Nothing really new to report today, though it's exciting to be able to say that we've gone a full week without a fainting spell now.

### Comments

Cool! Hope there are more weeks like this one!

*—SG, July 2, 2016*

:)

*—Marc Galmoud, July 2, 2016*

Yea!

*—Barbara Skipper, July 2, 2016*

Yea!

*—Barbara Skipper, July 2, 2016*

Yeah, Colin...sounds like you had a RED, WHITE and BLUE WEEK of INDEPENDENCE from fainting!
Way to go!

*—Phylles Lagarde, July 4, 2016*

# the waiting game

*July 6, 2016*

We seem to be on permanent standby for Colin's next round of chemo.

First we thought he'd go in on the weekend. Then we thought it would be Tuesday. Then Thursday. Now we're looking at, possibly, Saturday.

The problem seems to be that his neutrophil numbers are not rebounding quickly enough. Indeed, at the level they're at right now, he's at risk of going into sepsis should he get sick right now. That said, the doctors don't seem one little bit worried. They point out that his body is producing tons of the things (they're the primary component of one's white blood cell stockpile), though they haven't quite explained how he's cranking them out without actually accumulating any. My working theory is that he's selling them on the black market.

Nonetheless, I refuse to freak out so long as the doctors aren't acting worried. That said, if anyone who has more of a background in science (qualifications: You took more than two science credits in college) can explain to me how he can produce more without accumulating them, I'm fairly curious at this point.

## Comments

My theory is that he's using them as soon as they're produced, hence no accumulation. [Qualifications: former (1yr) bio major] □□

*—GFSantos, July 6, 2016*

Our cousin Susie or her husband could answer that question, or any others, since they are both medical doctors. I have her email if you need it.

*—Barbara Skipper, July 6, 2016*

A suspicion and a guess: after chemo the blood producing organs (marrow, and thymus and appendix in very young kids), are temporarily damaged, and although working overtime after the chemo assault, are producing many immature white blood cells (neutrophils), so the immature ones are destroyed by the spleen and kidneys and hence the acumulation of healthy, functional ones is limited for a time. However, the blood producing organs usually recover fairly quickly, and will product better ones the longer in between chemo treatments.

*—Don Summers, July 6, 2016*

The obvious answer is that he's a superhero, and he's giving them away to people who don't have the superhuman strength he does.

*—Lea Ann Schnakenberg, July 6, 2016*

## Moo, you say?

*July 7, 2016*

We might not have an appointment for the next round of therapy yet, but we're getting our Knock, Knock jokes down.

### Comments

This video improved my mooooooo d. :)

*—Cynthia Meyersburg, July 7, 2016*

That is pretty darned adorable. Also, one of my favorite knock knock jokes.

*—Melissa, July 7, 2016*

You would appreciate the shirt I got Todd a while back.
https://shirt.woot.com/offers/knock-knock

*—Erika Dickstein, July 7, 2016*

□□□□□□□□

*—Boris Babic, July 7, 2016*

That one's a popular joke in our house as well. Your kids are waaaaaaaay more into it, though! :-D

*—Lisa M, July 7, 2016*

I don't get it! But I'm a bit slow on the uptake these days.

*—Marc Galmoud, July 7, 2016*

love it!

*—Barbara Skipper, July 8, 2016*

OK, that was seriously funny. And seriously adorable.

*—Lea Ann Schnakenberg, July 9, 2016*

## Lucky 13

*July 12, 2016*

We've had a hectic few days.

First off, many thanks to everyone who jumped in with answers to the neutrophil question. We are wiser now.

The neutrophils in question took their sweet time getting back up to an acceptable threshold. Anything below 500 means he's in danger of sepsis if he gets an infection. He needs about 1,000 before he can begin therapy. His numbers lingered at just above 500 for most of last week before finally inching above 800 on Friday. Then, Sunday, we thought we had a setback when the hospital told us that the numbers had dropped down to around 400 again. It was not a good feeling, but at least we learned our problem was not so much Colin's health, rather a clerical/laboratory error. His numbers on Sunday were actually around 800 again, slightly higher than Friday's figures, but not bounding upwards as we would like to see them do.

I started Monday figuring he would not be starting chemo before Wednesday at the earliest. Instead, Christina got a call around noon that the 800 figure was "good enough" (this is the moment when you begin to realize that chemo is more of an art than a science) and that he should be at the hospital by 7 p.m. to start round 5 of chemotherapy.

I will not pretend it wasn't a little jarring. It certainly threw me off kilter for the better part of Monday evening/Tuesday morning. However, a few hours in the hospital with him this morning playing with his fleet of cars took care of that.

Christina and Colin are now set to be in the hospital through Friday. Spare a thought for them. They scored the triple trifecta this time - a room without air conditioning, blackout blinds or its own toilet (they have to share one out in the hallway with another room). Only marginally making up for that, Christina says she has an excellent wi-fi signal, so you can commiserate with her live on Facebook and Whatsapp for the next few days. Of course, it is room #13.

## Comments

Will be thinking about you all on Friday - and take the car fleet, too !

*—Don Summers, July 12, 2016*

It IS all about having good wifi ;-) Sheesh; will be thinking good thoughts.

*—Liisa Ecola, July 12, 2016*

Hope it all goes very well!!! Bon courage!

*—SG, July 12, 2016*

This is WHY GOD (IN HIS INFINITE WISDOM) GAVE US MOTHERS!
Hang in there, Christina. Show the world that HIS decision was right! Love and prayers to all.
Phylles

*—Phylles Lagarde, July 12, 2016*

## the late shift

*July 16, 2016*

And then there are the days the hospital finishes up your kid's chemotherapy at 7:30 p.m., meaning he gets home by 8:30 p.m.  So, you let him run around a little bit and then try to force him to bed around 9:30 p.m., meaning you fall asleep with him and emerge half-asleep from the bedroom around 10:30 p.m. to realize that there's been an attempted coup in Turkey and, since you're in the news business, you probably ought to get to the office ... and work until 3:30 a.m.

Other than that, everything is fine.  As usual, you wouldn't know he's on chemo, the way he eats and never stops moving.  We've got one more round of chemo to go before we start thinking about the next stage in our treatment plan.  If we stick to the plan, that round would start August 2.  However, given that his blood counts were on the low side when we started round 5, the doctors have already warned us to expect the start date for round 6 to slide a little bit, so he gets time to build his counts back up.

## Comments

□□

*—Boris Babic, July 16, 2016*

□□

*—Boris Babic, July 16, 2016*

One step at a time...hang in there!

*—Barbara Skipper, July 16, 2016*

Glad to hear that he's eating and in constant motion as a 2 1/2 year old should. So sorry, though, that sleep is still a rough go for you! Hang in there... praying every day for you all!

*—Lisa M, July 17, 2016*

You really make a great team! Colin brings energy and Niels brings fortitude and gratitude.
Love and prayers,

*—Phylles Lagarde, July 17, 2016*

Your kids are just keeping you lean and mean. You should try out for the Olympics - if you had the time

*—Lea Ann Schnakenberg, July 17, 2016*

I was very impressed with you that night! Thanks for being a news junkie ;-)

*—Marco, July 17, 2016*

## liverwurst and chocolate

*July 23, 2016*

I continually feel as if I should post regular updates when, truth be told, very little is happening. We're in a strange little "normal" now of chemo every couple of weeks, waiting for him to recover until he's up for another round (and by recover, I just mean getting his blood counts back up: He's a whirlwind), and then repeat.  It's probably going to be the end of August before we start having to make some serious decisions about the path ahead.  Until then, the only thing truly out of the ordinary for us is Colin's recent decision to, apparently, live off of liverwurst and chocolate yoghurt ... and nothing else.

### Comments

He can have my liverwurst!!□□

*—martha stanley, July 23, 2016*

Chocolate and liverwurst-- why not? I love that he is doing so well!!!

*—Cynthia Meyersburg, July 23, 2016*

Has he tried them in the same mouthful yet?

*—Jennifer Dlouhy, July 23, 2016*

Agree with the liverwurst, but would have chocolate and (plain) yoghurt separate :) Hope everything continues well!

*—SG, July 23, 2016*

Hey, whatever works and keeps him happy!

*—Liisa Ecola, July 25, 2016*

## to be clear...

*August 3, 2016*

He eats the liverwurst sandwich and the chocolate yogurt separately.  Perhaps in the same meal, but definitely, two separate dishes.

Now that we've got that cleared up...

Things are moving along fairly well.  We're waiting for the sixth round of chemo to start. So far, we're doing better than in our waiting period for the fifth round, where he started before his neutrophils had actually hit the magic number of 1,000.  We thought that would mean his numbers would take forever to recover this time as well.  But last week he was already over 100.  On Sunday, when I thought we'd be lucky to hit 300, he was over 500. He's at the hospital now for a checkup and his numbers are already at 980, so it looks like we're starting Friday, putting us somewhat back on schedule.

After that, it's all still a mystery.  We have the MRI at the end of the month and then they'll tell us whether they want to perform surgery or whether they want to go straight to radiation, and in which facility.

In other news, we sent au pair extraordinaire (and niece/cousin) Kaela back to the States this morning after three months of hard labor (we're high maintenance, OK?)  We managed to take her to Stralsund, on the Baltic Sea, for a two-day trip before she left just so she could see one other part of Germany, which was nice, even if Emma and Noah will tell you that we nearly walked them to death.  We're now on our own to a degree for the rest of the month.  Christina's parents will take Emma and Noah down to Bavaria for about two weeks.  I'll then take Emma and Noah on a short side trip/vacation and then we'll have a week or so of the two of us juggling the kids (and hospital visits) on our own before our next helper, Ricardo, arrives at the end of the month.

## Photos

## Comments

It's great that you guys have willing helpers..... it's a busy and stressful time, and I'm sure that the help is appreciated. And very considerate that you took Kaela on a vacation.

*—Don Summers, August 3, 2016*

Your program seems very intense - hope you all manage to have a good time this August! Take good care

*—SG, August 3, 2016*

Go Colin!

*—Boris Babic, August 3, 2016*

I am so happy he is bouncing back so quickly. If it is radiation, will it be targeted radiation?
(((Hug)))

*—Cynthia Meyersburg, August 3, 2016*

It makes me happy that you have help (and, of course, that the chocolate yogurt and liverwurst are separate treats!). Glad Emma and Noah are getting their own vacation too. Where?

*—Jennifer Dlouhy, August 3, 2016*

Glad the numbers are looking good. Hang in there!

*—Barbara Skipper, August 3, 2016*

Sorry, can't help but think of baseball. Kid's about to bat 1,000! Yea!

*—Jeremy Cook, August 3, 2016*

## into the unknown

*August 8, 2016*

Colin got home yesterday from his sixth round of chemo, which could, theoretically, be his last round of chemotherapy for the time being.

It's odd how I feel about this. On the one hand, it's nice to think that, in about three or four weeks his blood counts will normalize and we won't have to worry about every errant germ that might pass his way.  But, once he reaches that point, the doctors are going to decide whether they want to attempt another surgery to remove what's left of the tumor and then, regardless of what they decide, he'll be heading for radiation therapy at some point in the autumn.  When looking at the path ahead, and realizing I have no idea what to expect, I realize that I've grown very comfortable with chemotherapy.  Yes, it's frustrating and scary, but we've at least gotten this drill down. You take his temperature a lot, you get him to the hospital at the first sign of fever, you make sure everything he eats is fresh and you take him to the hospital every couple of days to get his blood counts checked.  It's exhausting, but it's at least familiar.

However, it would seem we don't have a lot of other options ... so onward.

And, for all of those who are keeping watch on the food front, chocolate yogurt has fallen out of favor ... to be replaced by a strong desire for vanilla pudding and mashed potatoes.

## Comments

Hope everything goes smoothly no matter how exactly the doctors decide to proceed!

*—SG, August 8, 2016*

You are in my thoughts (((hug)))

*—Cynthia Meyersburg, August 8, 2016*

Colin's taste in food is great.
We're with him and you as much as we can be.
Go Colin, yet again!

*—Boris Babic, August 8, 2016*

Bet Kaela got him into the mashed potatoes phase!!!□□

*—martha stanley, August 8, 2016*

Prayers, love and hugs...

*—Barbara Skipper, August 8, 2016*

What I'm thinking is that Colin has come through this phase of his recovery and is soon to go on to the next phase so you can soon put all this behind you. And then you can go back to normal worries, like what frightening uses nail polish and glue sticks are being put to in your house.

*—Lea Ann Schnakenberg, August 8, 2016*

You think you're tired now, wait till he hits puberty! ... Keep plugging on!

*—Marc Galmoud, August 8, 2016*

If only his parents could take this thing in stride, like Colin is doing! Isn't he wonderful? Love and prayers to all of y'all. (Spoken with a southern drawl!)

*—Phylles Lagarde, August 10, 2016*

## spoke too soon

*August 12, 2016*

When I posted last time that we were done with chemo, I had forgotten that, after every third round of chemo, there's a follow-up "surprise" round of chemo about a week later. We got hit by this in May on a day when we hadn't expected chemo.  And, I guess, in all fairness, I shouldn't call it the "surprise" chemo so much as "the doctors neglected to tell us about it" chemo.  Further, I should be grateful I suppose, because this time Christina and I remembered that the extra chemo was on the schedule, while the doctor almost forgot to schedule it.

Anyways, that's over now.  He had his 20-minute burst of chemo yesterday and doesn't seem particularly fussed by it.  So, now we start looking forward to our August 25 MRI and hopefully a game plan for the autumn.

## Comments

Good job remembering! Hope things continue well!

*—SG, August 12, 2016*

Small victories!

*—Jeremy Cook, August 12, 2016*

Surprise chemo. Ugh-- I want your family's next 264 surprises to be fun, happy surprises!!!
Or how about all surprises starting now!!
But glad it went well, and hoping it was very effective.
(((Hug)))

*—Cynthia Meyersburg, August 13, 2016*

:)

*—Marc Galmoud, August 13, 2016*

## the vacationing kind

*August 18, 2016*

We're supposed to be on vacation in the States right now, but that plan was put to rest back in March when we got Colin's diagnosis (typically, we bought our plane tickets about three days beforehand).

We can't really do anything about it, but we're going to see if we can salvage Emma and Noah's summer a little bit.  They've been at their grandparents for about two weeks now.  I'm heading down today to get them and then I'm going to take them to a kids resort for a few days, so at least they have a few fun summer memories.

Christina will remain here with Colin.  Once again, she gets the short end of the stick. However, Colin's doing pretty well so, hopefully, all she'll have to do is a run or two to the hospital for checkups.  And do the usual work of keeping a 2-year-old busy, which is a full-time job all on its own.

The extra round of chemo on Friday seemed to weigh on him a bit over the weekend. His appetite more or less evaporated (unless you offered him vanilla pudding ... there's always room for vanilla pudding), but he started eating again yesterday, so hopefully that was just a short-lived development.

## Comments

I actually wrote this before I left, but a technical glitch kept it from getting posted (OK, let's be honest and admit that, when I write "technical glitch" I mean "human error"). I have since collected them, spent a day with the in-laws and been whisked away to our Bavarian retreat with around-the-clock self-serve beer stations (I'm not making this up). We've done the bumper cars and the pool so far (both children can now say they've gone down the water slide without me, though Noah will only go if Emma is with him). Tomorrow they've got a raft of activities they're looking at, so I might just nap. Either way, it's a nice break from everything.

We also got confirmation that our next au pair (and de facto nephew) Ricardo got his visa, so he'll be with us from August 30, learning all our dirty secrets and enjoying the integration into German society.

*—Niels Sorrells, August 18, 2016*

Were you able to arrange a credit for the airfare? If not, call and ask for a manager-- it may be that given the reason why, they may be willing to help.
(((Hugs)))

*—Cynthia Meyersburg, August 18, 2016*

I'm glad he started eating and that you get a break. Give Christina a hug for us when you get back and I would love to see a picture of you in one of the bumper cars.

*—L Smith, August 18, 2016*

Hope you can get some money back from your tickets and that the rest of August goes as pleasantly as possible for all of you!

*—SG, August 18, 2016*

Stay-cations can be the best! Have fun!

*—Marc Galmoud, August 19, 2016*

Sounds like Christina should get the round the clock self-serve beer station!

*—Erin and Rich, August 22, 2016*

## into the unknown

*August 23, 2016*

Assuming there are no technical problems, we're about two days from the next MRI, the one that's going to let the doctors decide how to proceed.  It is very strange to think that, in a few days, this strange sense of normal - which isn't normal at all - is going to be disrupted.  I could not tell you what I want out of this.  Logically, I know that, if the doctors say "surgery" that that is the best way to get what remains of the tumor out of him.  And I also know he's in a better state than he was in March.  The tumor isn't causing any side effects that we see and, since it's now smaller, it gives the doctors more maneuverability.

But I also remember the biopsy surgery he had in March and how he was flat on his back for about two months after that.  And I also know that, no matter how good the doctors are, this is brain surgery we're talking about.  So, I'm a little apprehensive.

And, there's no escaping the fact, that this just isn't fair.  He's two and a half.  All he wants to do is run around, get into his sister's stuff, watch Curious George and, when given the chance, empty all the backyard toys out of the shed and spread them liberally around the yard.  There's no way he wants to go under the knife again.

That said, we have no idea if the doctors are going to say surgery.  They might very well opt to go straight for radiation therapy, which sounds like it's own mix of unpleasantness.  No one has yet been able to say if they'd be sending us to Essen or to Heidelberg or when.  We don't know if we'll have to stay there with him for weeks on end or if we'll be shuttling back and forth (neither is particularly near to Berlin).  I'm trying to brace people at work for the fact that I might be MIA for large parts of the autumn, but it's kind of hard to impress upon people that, after weeks of a seemingly normal life, we're about to go off the cliff again.

I guess I'm just trying to say, it's probably going to get a little intense for us.

That said, I'm pretty optimistic.  I think everything will turn out all right in the end.  I just kind of wish we could skip to the end part.

## Comments

We who follow Colin's hard journey also became lulled. I wish I could find good words to make it better or easier. Even more I wish it to, well, end well. With you as much as I can be. <3

*—Boris Babic, August 23, 2016*

Like Boris said, it's hard to know what to say, except I feel what you're going thru. A little at least. I can imagine somewhat of what you're going thru and know that I don't want to go thru it. I suppose it's good to get it off your chest though and know in the end people around you understand and sympathise. That's something. And as lame as it may sound, I and I'm sure all your friends and extended family are rooting for a happy outcome you and your little guy.

*—Marc Galmoud, August 23, 2016*

I wish you could skip ahead, or at least get an encouraging text from your future self. Cheering for him and for you all (((hug)))

*—Cynthia Meyersburg, August 23, 2016*

It must be really hard to live with that uncertainty. Even a "new normal" is one that it's easy to get used to. I love the idea of getting an encouraging text from your future self - surely somebody at some start-up is working on that capability now ;-)

*—Liisa Ecola, August 23, 2016*

"New normals"....I use that term all the time as I age...trying to make an abnormality sound ok. The progression is such that when I look back to where I started, it is frightening to think that I have accepted it....but what choice do I, you, Colin, have? You are right...we expect it as we get older but never in a 2 year-old. I have come to learn that it is most difficult for a parent, even more so than for the child...children are so resilient. It is unfair. Prayers for strength and courage during these difficult times are sent your way and know that we care. Love, Barbara and Steve and Family

*—Barbara Skipper, August 23, 2016*

Uncertainty is not fun so hopefully soon you will at least have a good idea which treatment path Colin will be on. And hopefully, it will all go smoothly in the end, though as you describe it, neither choice appears to be non-disruptive for either him or you as parents :( Bon courage!!!

*—SG, August 23, 2016*

Keeping it real, they just rescheduled us from 2 p.m. to 7:30 a.m. for the MRI. That would be the Sorrells family in the corner hectically replanning its Thursday.

*—Niels Sorrells, August 24, 2016*

We're with ya, Niels and Christina! Thanks for the update.

*—Jeremy Cook, August 24, 2016*

This is a terrifying ordeal and my heart goes out to you and Christina and the kids. All we can do is trust that Colin will be safe and at the end of it all, healthy. Stay strong for your beautiful boy and know that we are all with you throughout this.

*—GFSantos, August 25, 2016*

## Another round of the waiting game

*August 25, 2016*

The MRI is done. We're old pros at this now, so no problems to report.

Christina was told that Colin's case will be discussed at the Tuesday meeting of the different hospital departments, so we don't expect anyone to be offering us options until Wednesday, at the earliest. More then.

## Comments

A pity you've had to get used to this procedure. Hope the news you hear on Wed or so is all good.

*—SG, August 25, 2016*

Till then!

*—Marc Galmoud, August 26, 2016*

## maybe, maybe

*August 30, 2016*

Tomorrow, we might get to hear if all the doctors working on Colin's case have agreed on a treatment plan.  Then again, I e-mailed the oncologist on Monday to remind him that we'd love to, you know, hear his thoughts if he might have time to meet with us on Wednesday.  I got the response that he's on vacation until the end of June ... 2016.  So, I'm going to assume he doesn't read his e-mail that regularly.  Christina told the hospital-appointed psychiatrist that we'd really like to hear from the experts, and she has in the past been able to round up the usual suspects.  But there are no guarantees.

So, tomorrow might be the day we get a lot of answers.  Or it might just be a normal visit to get his bandages changes and his blood count tested.

At some point the doctors will have to share their thoughts with us.  Here's hoping they manage to do it before they book a surgical theater for Colin.

In brighter news, Ricardo - who for reasons of simplicity, we'll call my nephew - arrived today to spend the next year with us as an au pair.  First indications are good.  Yes, Colin did try to lock him outside the house early on in the afternoon, but an hour later Colin was playing ball with him and even let Ricardo pick him up.  Of course, the two hours before all that happened, Colin would not stay in the same room with Ricardo unless Ricardo sat quietly and avoided eye contact, so we'll just take things one step at a time.

## Comments

Promising start with the au pair already, hopefully Colin will quickly warm up even more. It will be enough better if tomorrow brings other positive news!

*—SG, August 30, 2016*

Hoping for good positive news for you tomorrow. That is good about Ricardo.

*—Lynda Schmitz, August 30, 2016*

Glad to hear the au pair is beginning well. We have found that you know pretty well if the au pair will work in the first week.

*—Erika Dickstein, August 30, 2016*

# a holding pattern

*August 31, 2016*

So, today was kind of demoralizing.

Understand, we started the day with the understanding that we were done with chemotherapy and were just waiting now for the doctors to make the decision on whether we were going to go straight to radiation therapy or have surgery followed by radiation.  Colin's started getting his hair back.  We were even thinking about making social plans the next two weeks (we haven't been able to socialize with most of our friends the last few months because Colin can't be around other kids, at risk of picking up germs and what-not).

After a very long wait we managed to get a meeting with the most senior doctor who doesn't seem to be on vacation. And it turns out no decisions have been made yet because most of the relevant doctors have been away on vacation. Which isn't great. But, what's worse is that, after supposedly wrapping up the chemotherapy and then scheduling the MRI, no one seems to have set a timeline for a time by when Colin should be moved on to the next stage of therapy. Essentially, we've just been treading water without a plan. And now that we've reached the point where we really need to make a decision about what should be done, we can't, because no one is around.

Don't get me wrong. The doctors deserve a vacation. They have hundreds of cases to worry about. But, if you're going away, you need to have someone keeping an eye on things and making sure balls aren't dropped. Right now, Christina and I feel that, if we weren't in their faces regularly asking to make sure there's a plan of some kind, we would just kind of keep randomly doddering on without any direction. And that's not a good way to feel, because you expect the experts to be on this.

In the end, the MRI showed little change over the last two months, which was kind of expected. We had been told that the last MRI showed that most of the blood vessels serving the tumor had been shriveled away, meaning that there's no way to get the chemo to the remaining tumor cells. So, staying the same size is neither good nor bad. It's just expected. However, since we're not coming up on three weeks since Colin's last chemotherapy - and we have no further plan in sight - we run the risk of having the last months of chemotherapy work undone. So, lacking a plan, we're going to have him back in chemotherapy this weekend, meaning the hair is going to fall out, we're going to cancel our plans and his blood counts are going to plummet once more.

It's not good news. It's not bad news. It's just a holding pattern until we knock enough heads together at the hospital for them to come up with some plan.

## Comments

How is that possible, leaving a kid - or any patient with a dangerous condition - without oversight and therapy?
It really sounds like slaparound time.
Damn.

*—Boris Babic, August 31, 2016*

□□

*—martha stanley, August 31, 2016*

Argh!!!!!!!!!!
□□

*—Cynthia Meyersburg, August 31, 2016*

Wow this is unbelievable. You are handling it way better than I would; it must be so utterly frustrating -- so defeating -- to be going back into chemo as essentially a necessary placeholder while you wait for doctors to get back and make a decision, rather then moving on to the next step right away. Hopefully this time will prove constructive and helpful in other ways. Life's plans may be on hold again, but hopefully this extra time will allow the doctors to really huddle together and figure out the best strategy for him going forward.

*—Jennifer Dlouhy, August 31, 2016*

I am sure they will prepare an excellent plan right after their vacation, just remain optimistic. This is not a setback, it's just a small pause on your way.

*—Claudia Busch, August 31, 2016*

:( Sounds very frustrating. So sorry to hear the treatment is not managed well at this stage :(

*—SG, August 31, 2016*

## Some clarity

*September 1, 2016*

Something we did on Wednesday seems to have sparked activity at the hospital today. When Christina tracked down one of the other main oncologists, she learned that a bunch of the doctors had held a hurried e-mail conference about Colin's treatment in the last 24 hours, apparently having realized that they, maybe, ought to have done such a thing a few weeks ago.

In the most logical order:

Colin will go in for chemotherapy, most likely on Friday. This is needed to keep the tumor from starting to grow again.

He will not have surgery for now. The tumor's location is too dangerous.

Radiation therapy will begin on September 25 in Essen. He will have to go there for a few days around Sept. 12-13 so the doctors can do some setup work. Once radiation therapy begins, he is looking at a short radiation treatment Monday through Friday for six weeks, under full anaesthesia each time. That's 30 times this poor child will be put under.

We're still trying to sort it all out. Who goes to Essen with Colin? Who stays here in Berlin with Emma and Noah? What family help do we call in (on top of that which is already here, thank you very much Ricardo!)?

Speaking for myself, I'm relieved there will be no surgery. The risks of paralysis seemed far too great to me. At the same time, surgery had the benefit that the doctors can see what they're doing; they can be relatively sure they've removed a tumor because they're looking right at it. Working with chemotherapy and radiation means relying upon an MRI, which means a lot of guesswork and inferences as you try to interpret the images in front of you. The odds are good that they'll get it all out, but it's harder to be certain.

There is concern, of course, that radiation is bad for a child Colin's age. It is true: This is far from ideal. However, our choices are possible damage from radiation and near certain death from the tumor, so we have to make the best choice we can. The doctors hope to apply techniques that affect the surrounding tissue as little as possible. Of course, then they also point out that being so precise raises the possibility that you miss tumor tissue if it's migrated to a nearby location.

We're shifting gears and in a big way. We'll take any prayers you know.

## Comments

Showing disappointment has helped you - good! A pity he will need the extra chemo though :( Another pity is that the radiation cannot be performed in Berlin - 6 weeks for one of you in Essence.is long. May everything turn out very well in the end!

*—SG, September 1, 2016*

It has never been easy for all of you in the last weeks and months. But please recall the positive news you had, the surprisingly good results of chemotherapies and the speedy recoveries after each round of therapy. We remain optimistic that the treatment will continue in the same manner. You will find additional prayers tomorrow in your inbox.

*—Claudia Busch, September 1, 2016*

Keep ploughing.
:-/

*—Boris Babic, September 1, 2016*

Thanks for letting us know. I wish there was something I could say or do that would offer some relief, but I know there isn't. We are praying for you and hope things go well.

*—L Smith, September 1, 2016*

You got it, will do.

*—Jeremy Cook, September 1, 2016*

You got ours for sure!

*—D. Mebus, September 2, 2016*

You get to your knees then get knocked back down. The yoyo life of your family for the last six months must be so exhausting. Hopefully, GOD will give all of you the strength and courage to keep fighting. It is so worth it. My love and prayers, as always.

*—Phylles Lagarde, September 2, 2016*

Sending lots of prayers.

*—Erin and Rich, September 6, 2016*

## Kafka would be proud

*September 4, 2016*

Let's start with a game of "Bad Combinations."  I'll start: a) a 2-year-old who has recently discovered that it's fun to spin around until he's too dizzy to stand connected to b) an IV drip. Oh, the fun we've had this weekend.

As we started this weekend I call "The Unnecessary Seventh Round of Chemo," we were told to call the hospital Friday morning to figure out when we should show up (the hospital never knows until the day of how much space it will have available).  Christina called at 9 a.m. and was told to call at 10 a.m.  She called at 10 a.m. and was told to call at 11 a.m.  When she called at 11 a.m., she was told to show up at 8 p.m. so she and Colin could bed down for the night and start the therapy Saturday morning.

At 6 p.m., the hospital called to say that, if we showed up in the next hour and a half, we could start the therapy that night.  Given that Christina was in the middle of preparing dinner for Colin in anticipation of leaving with him at 7 p.m., that was not feasible.  After a lot of tense negotiation, it was agreed that we would show up at 8 p.m., as originally scheduled, but that the therapy would still start Friday night.  Bizarrely, the hospital also began talking about having them out by Sunday night, even though it's a four-day therapy.

On Saturday morning, they said Christina would be in until Monday, though she would have to come back to get the final injection for Colin at the outpatient clinic on Tuesday.

On Sunday, the doctor said it might make most sense after all for Christina and Colin to leave Sunday night, coming back for outpatient treatment on Monday and Tuesday. Then they realized that the only appointment they could get for Colin at the outpatient clinic on Monday was on the standby list, so we all agreed he would stay in the hospital after all until Monday, since it at least increases our chances of seeing a doctor on time.

So, current plan is to spring him from the hospital this afternoon. He'll be back into the sepsis danger zone in a matter of days, but the preparation for the radiation therapy in Essen (which is clear across the country) will start with a preparatory visit on September 13 with plans for the therapy to start on September 25/26.  Apparently he's going to get some kind of chemo while he's on radiation, which sounds like hell.

Colin is, at least, fine. As usual, he's walking off the chemo. I swear he eats more when he's getting the chemotherapy.

## Comments

Sounds very exhausting! A pity you have to go through this horrible logistics!

> *—SG, September 4, 2016*

Wow, this kid is amazing. Now may his parents keep their sanity in the midst of hospital craziness!

> *—Jeremy Cook, September 4, 2016*

Here's to keeping your heads up through it all!

> *—Marc Galmoud, September 4, 2016*

I am so frustrated for your family. I used to take one of my aunts to her chemo appointments (she is well now, but she had breast cancer), so I saw how hard chemo was for her. I am sorry he is going through additional chemo instead of moving to radiation immediately.

> *—Cynthia Meyersburg, September 5, 2016*

Makes me tired just thinking about your schedules! Praying for peace and comfort and stamina during these trying times. Love you all!

> *—Barbara Skipper, September 5, 2016*

Sounds like you all are spinning. Yikes! Best wishes.

> *—Lynda Schmitz, September 12, 2016*

# If the cancer doesn't kill you...

*September 14, 2016*

Then the bureaucracy just might.

Christina and Colin are in Essen for the preparatory work ahead of the radiation therapy. One glitch as they headed to the appointment was that the government office that handles Colin's health care had not yet signed off on the costs linked to the treatment plan. Yesterday, things came to a head. The hospital said they needed a signature right now, otherwise the preparations could not go ahead and Colin's treatment plan timetable would slip. But the insurance office said they had yet to receive critical information from the hospital, so could not grant approval. That created the risk that we were going to sign up for a therapy and then find ourselves stuck with about 40,000 euros in costs that the insurance was not sure it could carry.

"Unpleasant" doesn't quite cover it. We were both having meltdowns, Christina in Essen, me in Berlin. There was very little Christina could do in Colin. I could only try to make some calls, all the while with my brain stuck on two topics 1) How do you say "second mortgage" in German and 2) It might be a good time to figure out how Kickstarter works.

After a half hour of misery, it all turned out fine. The hospital provided the data. The insurance confirmed it will cover all the costs. Colin will start therapy on Sept. 26. Interestingly, he will also receive a round or two of chemotherapy in Essen in between bouts of radiation therapy. Like I keep saying, he continues to walk off all the chemo, but you do get the impression that we're really testing this kid's outer limits with all this.

Anyways, they're back in Berlin tonight and then, hopefully, we get a week or so of normal life before we jump back in to the adventure.

## Photos

## Comments

Glad it all worked out! There's another saying, whatever doesn't kill you, makes you stronger. You and the family I guess are going to be pretty bulked up for life after this episode!

*—Marc Galmoud, September 13, 2016*

A pity you had to go through all the stress of additional insecurity wrt cost coverage. But very good that has been resolved now. Bon courage for what's ahead!

*—SG, September 13, 2016*

I can try to, but I already know I can't find adequate words...
Sorry. I just hope all turns out fine very soon.

*—Boris Babic, September 14, 2016*

You are all stronger than I can imagine. Sending hugs, positive thoughts, and all the emotional strength I can gather.

*—Jennifer Covington, September 14, 2016*

## Six months in

*September 18, 2016*

I was too busy yesterday chasing the kids, but we had a minor anniversary yesterday: Six months since we first got Colin's diagnosis.

It's hard to really draw up a list of what we've gained and what we've lost in that time period. Colin's lost his hair, but also about a third of his tumor. He's lost and regained his ability to walk. He's kept his good spirits, love of Cars and Curious George through the whole thing. He's also greatly expanded his vocabulary, but that's mostly been in just the last few weeks.

Only speaking for myself, I think I've weathered this better than I could have ever expected six months ago. That said, I still find traces of depression in my mood. I would love to hit something many days. I find myself dead tired, even on the days where I get plenty of sleep. I find myself looking to get to work for a chance to clear my head and then, once I'm at work, I feel bad for not being with my family. There is still a lot to work through.

The medical care has been excellent. The medical bureaucracy continues to cost us our sanity, though we seem to have that under control for now.

Our next step begins in a week, when I take Colin and Christina to Essen for the radiation therapy. They'll be there 6-8 weeks, during which Ricardo and I will be trying to keep the homefront up and running. Ricardo has to figure out the German trash separation system (I've counted nine different kinds of trash we separate). I've got to figure out how to read and properly assess the homework the kids bring home. I'm not sure which of us will have the tougher job.

I remain hopeful that the therapy will do its job, but there are still questions. This week, he returned from his pre-therapy meeting in Essen with a black line drawn in magic marker down the back of his neck. This is apparently the tracking line the hospital's high-tech system will use to align itself with Colin, the tumor and the mask he has to wear during the therapy. And all I can think is: *It's a line in magic marker*. More troubling, the line wears away, so we have to redraw it - by hand on a squirming 2-year-old - every three days or so. There is no way the line he returns to the hospital with next week will be the same line they sent him away with, so we'll see how many monkeywrenches that throws into the therapy. Again, I continue to have faith in the therapy, but I have so many questions about the details.

## Comments

May you soon have better anniversaries to celebrate! Bon courage in the meantime, hope everything goes smoothly!

*—SG, September 18, 2016*

Keep up the good work and keep your head up! We're rooting for you all!

*—Marc Galmoud, September 18, 2016*

Considering the way Colin has been doing and how well he's been handling everything, I think the person with the hardest task ahead is Ricardo figuring out Germany's trash/recycling operations. You all have been incredibly strong through this, and I know you'll keep on fighting. Colin has a great team in his corner.

*—Lea Ann Schnakenberg, September 18, 2016*

# arms behind backs

*September 23, 2016*

We're not exactly on an easy glide in our final week before radiation therapy.

Colin came down with a cold over the weekend and, when you're on chemotherapy, you never have "just a cold." His white blood count is negligible, meaning he barely has any resources with which to fight off the cold. It hasn't landed us in the hospital this week, but it has kept us on edge.

Essentially, when we're in this situation, his temperature readings come in three varieties: fine; get ready to go to the hospital; and you should have left for the hospital by now. His temperature keeps yo-yoing between those three. Every time we think he's good, it will spark up for a minute or two into the danger zone, and then settle back. But you never know at that moment if this is a spurt or the next half day. As I told Christina yesterday, he's not so much a child as a climate zone right now.

It's maddening, because Christina wanted to get some things done before she spends the next two months in Essen. Instead, she's been in a perpetual state of getting ready to go to the hospital in Berlin. It's maddening because it would have been nice to have one halfway normal week before the big separation, instead it's a lot of shooing Emma and Noah out of the room while we try to figure out how worried we should be about Colin. It's maddening, because we keep thinking we shouldn't have to be putting up with this, and yet we are.

Essen isn't helping, since they seem to have a similar communications policy to Berlin. Today they told Christina that they might not be able to start radiation therapy on Tuesday if his blood counts are still weakened by chemotherapy. But this is the same hospital (indeed, the same doctor) who told us they planned to have him continue his chemotherapy while he was getting radiation. So, which is it? They've changed the start of therapy and they've given us different opinions at different times. Expect several more rants about hospital communications, that's all I'm saying.

That said, we're doing OK today. Colin's temperature is in the safe zone and his spirits are high, as could be seen by his unspooling an entire roll of toilet paper in the bathroom this morning. We'll get to Essen, we just might have a shot of something strong once we get there.

## Comments

It is effing maddening.
:-/

*—Boris Babic, September 23, 2016*

Good your sense of humour has not abandoned you but sad to hear it has been put to the test!!! Bon courage

*—SG, September 23, 2016*

Maybe a couple of shots! Prayers, love, and hugs....for all of you!

*—Barbara Skipper, September 23, 2016*

I am wishing you a temperate zone toddler.
Hang in there, hang in there, hang in there!!!!!!

*—Cynthia Meyersburg, September 23, 2016*

Well, as of today, the doctors say he's out of sepsis, so things are looking up!

*—Niels Sorrells, September 23, 2016*

Have the whole bottle.

*—Liisa Ecola, September 23, 2016*

Wishing you all well!

*—Marc Galmoud, September 23, 2016*

GOD must really LOVE Y'ALL, because HE sure is testing you! With the combined German determination in y'all, you are up to the challenges being thrown at you. (A combination of a strong drink and a loud prayer might help, though!)

*—Phylles Lagarde, September 26, 2016*

# 3 down (27 to go)

*September 29, 2016*

Colin is, as I type, undergoing his third round of radiation therapy. Better put, he is going through photon therapy.  So far, it is going well. None of the horrible symptoms that we were told might develop have cropped up yet. Then again, we are three days into this adventure.

So far, the staff here at the clinic in Essen are giving the appearance of paying a little more attention to detail than their colleagues in Berlin. We have a case manager here in Essen, ie, a single contact person for all of our questions.  Yesterday, when Colin's therapy was delayed by an hour (apparently, this is a common occurrence with such precise technology) they called us on Christina's mobile to tell us we could show up later.  Let me repeat that: They called us.  In Berlin, we would have shown up and gotten put into a waiting room for a day and a half until they got around to telling us the deal.

Which is not to say that everything is running perfectly. On the first day, they gave us an ID badge for Colin and told us to never, never lose it. The anesthesiology team took it with them when Colin was wheeled to his first appointment ... and then promptly lost it. Also, he seems to be registered at the radiation department and the children's clinic under two different spellings of his name, which is causing a lot of bureaucratic mishaps.  But, in general, it's working well.

As I said, he's reacting fine to all this. He's grouchy in the morning because he can't eat or drink before the therapy, so he's usually getting his first sip of water/meal around 1 p.m., as he has, so far, segued straight from the anesthesia straight into his midday nap.  It makes the mornings a little rough.  Also, he hasn't quite gotten over his cough, which is not helped by the fact that he can't drink for the first half of the day.  But, once he gets some food in him, he's his usual self. The biggest side effect happens if he has to stay in the radiation cell for a long time. He has to wear a tight-fitting mask while he's in there and it will leave a series of marks from the fabric cutting into his skin. They go away in a few hours, but there is a spell there where he looks as if he's spontaneously contracted a very symmetrical case of chicken pox.

The doctors have now confirmed that they will give him chemotherapy while he's here and it won't interfere with his radiation therapy, so those worries we had last week were just a big misunderstanding.  Because he's getting so much therapy now, he's back on a lot of the medication with which we thought we were done months ago. It feels like a step backwards, going back to about seven doses of medicine a day, but it's for the greater good. Mostly, we're worried about the reintroduction of cortisone to his system, as it turned him into a grouchy eating machine. But, reducing the swelling will help with targeting the tumor, and that's that.

Pictured somewhere in this post you'll see the Westdeutsches Protonentherapiezentrum Essen, Christina and Colin's home away from home through early to mid November.  The apartment they're using is right across the street, so that's helpful.  In Berlin, we need 45 minutes to get to the hospital.  Here, it's one minute.  The room itself is nice. The university clinic campus ... takes a little while to get used to. The architectural concept is a mix of "Love Affair with Concrete" and "We need more exterior stone staircases. No ... more."  But one can get used to that. The main problem will be that, although shopping is nearby (we even found a really pretty neighborhood in Essen, which is something I hadn't really expected a week ago), the clinic is in a valley, meaning every time Christina takes Colin on a food run, she's going to have a very steep uphill to conquer first.  But we'll figure it out.

I return to Berlin tomorrow (we decided to extend my stay here by one day so Christina could do as much shopping as possible while the car is still here) and then we'll see how this plays out.

## Photos

## Comments

<3

*—Boris Babic, September 28, 2016*

Hope there are only positive developments in store for you!

*—SG, September 29, 2016*

We so appreciate the updates. It does sound like a better medical/patient relationship there. All the right things appear to be happening. Prayers of healing and comfort for the entire family. Love you all!

*—Barbara Skipper, September 29, 2016*

We so appreciate the updates. It does sound like a better medical/patient relationship there. All the right things appear to be happening. Prayers of healing and comfort for the entire family. Love you all!

*—Barbara Skipper, September 29, 2016*

Hope Essen keeps up the good work! Hugs!

*—Ivonne Marschall, September 29, 2016*

Wow, Colin continues to amaze. And so do you. glad Essen is proving to be more considerate and organized.

*—Lea Ann Schnakenberg, September 29, 2016*

Eeek! But just saw the architecture. Pretty hideous

*—Lea Ann Schnakenberg, September 29, 2016*

I love the mama-son and lion picture.
You are going through so much, all of you, and so many people who care are far away.

Is there any grocery delivery service? My local grocery store delivers (for customers who are ill or need help for some other reason). Would any of the local grocers or pharmacies deliver?

*—Cynthia Meyersburg, September 29, 2016*

Glad things are working out! Best wishes for the nerves of mom, dad and baby!

*—Marc Galmoud, September 29, 2016*

Re: the love affair with concrete: It's an actual architectural style called "brutalism." I am not making this up.

*—Liisa Ecola, September 29, 2016*

Looks a lot like the medicare HQ campus in Baltimore, which is notorious among policy wonks as the ugliest buildings around here.
Colin looks pretty amazing despite going through all of this. Incredible kid.
Love you guys.

*—Rich Daly, October 3, 2016*

# joining the party

*October 4, 2016*

I had meant to blog some more about Essen and Colin fairly immediately upon my return to Berlin on Friday, but that was not in the cards.  The Thursday before I drove Christina and Colin to Essen I'd biked a little faster than normal, probably tearing a muscle slightly.  Then I was in the car for eight hours on the drive to Essen and seven hours back. Somewhere in there, a clot formed in my left leg and, Saturday morning, on my way to work, cut loose and laid me low with a lung embolism.

So, I've just emerged from the hospital after three days.  I'm fine.  I'll have to take blood thinners the rest of my life, but I'm fine.  We managed to get my mother-in-law to stay in Berlin, so she was around to help Ricardo with the kids.  I'm back home now and off sick for the rest of the week.  We'll keep on coping.  Mostly, I'm just annoyed with myself because I've had problems with blood clots before and should have known to go to my physician before I left to get some anti-clot medication before taking off on the drive.  I should have definitely thought about seeing a doctor (especially given that we were living on the grounds of a university hospital) when my leg hurt the whole week.  And yes, I know I'm distracted with Colin's health these days and I've got a lot to juggle, and yes, I know this isn't 'my fault,' but it's still annoying.  The goal of everything we're going through is not just for Colin to survive, but for the whole family to survive ... and that's not going to happen if we're not all taking basic steps to watch our health.

Enough about me. Colin continues to do well in Essen.  I forgot, in my praise of Essen, to point out that they've greeted us at the start (or end, depending upon how you look at it) of every week with a weekly plan. It includes all of our appointments for the upcoming seven days. Of course, some of the appointments slip - and I hate to continue knocking Berlin - but it is so nice to get an idea of what's ahead after months of generally not knowing things more than a minute or two ahead of their occurrence.

They do go a little overboard on their safety wear, as you can see from the picture.  Bear in mind, it takes a minute to get from the apartment to the clinic.  Then Colin and everyone with him have to get into the safety garb (though I must note, the hunter's green at this clinic is our favorite shade of safety garb so far) so we can walk 45 seconds to the safe room where we wait for treatment to start.  We probably wouldn't mind, but there's little logic to it.  Nothing is supposed to come out of the safe room without being thoroughly sterilized.  But the doctors come and go with their files.  On my way out Friday, they asked me to carry Colin's bloodwork upstairs.  Hell, as they wheel Colin from the room to the laser therapy area, he's not decked out in green. So, you really wonder if we're protecting the world from Colin's bacteria or just wasting the environment, but rules are rules.

## Comments

:) Amen on everybody surviving! Take care of yourself!

*—Marc Galmoud, October 4, 2016*

Take good care all of you!!!

*—SG, October 4, 2016*

Yes. You have to take care of yourself, too.
Please do.

*—Boris Babic, October 4, 2016*

Oh my gosh. I cannot believe you landed in the hospital in Berlin. Poor Christina, poor you, poor kids. Bless you all! Sounds like Emma and Noah are being real troopers about all of this. Colin looks lovely in that shade of green, by the way. I love that the new hospital includes you in on the plan. It would kill me not to know what to expect each session. Big hugs to you from Hamburg, my friend. I am thinking of you!

*—Lana Spangenberg, October 4, 2016*

Wow! Prayers and more prayers!

*—Barbara Skipper, October 4, 2016*

I am relieved that you are recovering well from the embolism.
(((hug)))

*—Cynthia Meyersburg, October 5, 2016*

Boy, life sure keeps kicking you! Stay well - your family needs YOU! Love and prayers...

*—Phylles Lagarde, October 6, 2016*

Stay strong!

*—Lynda Schmitz, October 9, 2016*

## halfway there

*October 18, 2016*

Colin's halfway through his radiation therapy treatments as of today. With his usual aplomb, he's walking off the treatments. None of the side effects they've warned us about have manifested themselves so far. Indeed, they've decided to dial back the medicine they've given him to counter the side effects (which had side effects of their own). We just have to hope that they keep up at the pace they've been going, with the radiation cannon not breaking down on them or anything.

It's still not easy. Spare a thought for Christina, who still has 3-4 more weeks of a 2-year-old as her roommate in a one-room apartment. He can be an awesome roommate. But, let me repeat: He's 2.

Otherwise, there's nothing else to report which, given the pace we've been keeping of late, is no bad thing.

## Comments

Always thinking of you guys since Chuck Bukowski shared the news with me. You are in my thoughts daily.

*—Jeanne Clayton, October 18, 2016*

Good to hear - hope thongs continue this way!

*—SG, October 18, 2016*

You can make it, Christina! You're an amazing mom.

*—Jeremy Cook, October 18, 2016*

Hurray! Keep up the good work, and best wishes to Christina!

*—Marc Galmoud, October 21, 2016*

# jinx

*October 25, 2016*

Well, I didn't quite jinx us, but the day after I posted how the machine hasn't broken down on us once, it almost broke down.  Poor Christina and Colin were stuck in the hospital for about six hours waiting for the machine to get back up and running.  Bear in mind, Colin can't eat during this whole time and Christina thinks it would be kind of rude to eat in front of him.  It can get unpleasant.  The whole situation repeated itself again yesterday.  So far, we remain on track to be done on November 8, but it's easy to see how that schedule could get derailed.

The hospital is throwing up a lot of mysteries for us as well. He's still doing chemo while he's getting radiation. This time, they decided to give him a hormone treatment so his neutrophil count would rebound more quickly.  It did, big time.  At one point he was up to 11,000.  Then, this week, it's back down to 150.  No idea what that means (other than that it's not looking good for chemotherapy to continue as planned on Saturday).  They are also talking about giving him an MRI next week and, depending on what it shows, accelerating or increasing his treatments, or maybe even giving him fewer.  So, as usual, all of our plans are right up in the air.

## Comments

Thanks for the update. And continue to wish you all a quick recovery!

*—Marc Galmoud, October 25, 2016*

Hope the machine behaves better and the MRI brings good news! Take good care all of you!

*—SG, October 25, 2016*

Sending you prayers from Holy Jerusalem.

*—Claudia Busch, October 25, 2016*

All of you are in my thoughts and prayers. Stay strong. God Bless!

*—Phylles Lagarde, October 26, 2016*

## nothing to see here

*November 3, 2016*

I would like to update everyone with information, developments, etc, but they are sadly lacking.

On Tuesday, Colin had his first MRI since radiation therapy began, but we haven't been given the results yet.  Depending on how they turn out, he could be finished with therapy as early as Thursday, Nov. 10 (the original hoped-for completion date of Nov. 8 slipped by a day because everyone forgot there was a holiday in the state where Essen is located on Nov. 1, meaning no therapy that day. Then the date slipped one more day, because the technicians couldn't give him his full treatment on one of the days that the machine almost broke down).  However, there's also the possibility they might keep him two extra days to give him an extra blast of radiation, which would mean he's staying put until Nov. 14.

So, as usual, our plans are right up in the air.  I'm taking a "no news is good news" policy for now.

## Comments

I'm grateful for the update. I have been thinking of all of you and wondering how the radiation was going. Will Christina and Colin return right after radiation treatment ends, whether Nov. 10 or 14?

*—Jennifer Dlouhy, November 3, 2016*

(((((Hug)))))

*—Cynthia Meyersburg, November 3, 2016*

Think how far you have come from where you started! Prayers the family can soon get back to being a family and Colin a kid!

*—Barbara Skipper, November 3, 2016*

Think how far you have come from where you started! Prayers the family can soon get back to being a family and Colin a kid!

*—Barbara Skipper, November 3, 2016*

Hope you will hear (positive news) soon and Colin won't have to stay there longer than planned!

*—SG, November 3, 2016*

My superficial thought writing this from Kenya: really, stuff breaks down in Germany? It's not just Africa? Ugh, sorry about that, man!

*—Jeremy Cook, November 3, 2016*

## known unknowns

*November 4, 2016*

Christina got a quick, five-minute breakdown of the MRI results this morning. We'll get more details Thursday when we get a chance to talk to the doctor.

The short version: The doctors are happy. Looking at the images, they say they no longer see a tumor, rather what appears to be a cyst-like structure. If that is the case, the hope would be that his body would eventually absorb the cyst and that would be that.

We're not quite popping champagne corks yet. It is good news, don't get us wrong. But, right now, the doctors are looking at an image, and there's no way to look at the actual mass. A lot of this is inference and educated guessing. It also raises questions: What if the cyst isn't reabsorbed? Is that a problem? Or just a thing he'll live with? And, no matter what, so long as there is something in his brain stem, I think we'll always be living in terror of a recurrence.

Nonetheless, Colin is doing fine and has displayed none of the feared side effects they warned us about when this started (another thing that made the doctors happy). Assuming no other glitches, he'll have his last round of radiation therapy for this session on Thursday and we'll get him and Christina back to Berlin sometime between then and Sunday. Of course, soon after that, he'll probably have to begin his final round (for this session) of IV chemotherapy, so it's still going to be a little while until we're fully back to our new normal.

In short, mostly good news. I just don't think we dare get too excited just yet.

## Comments

It sounds hopeful - may the good conjectures cone true!

*—SG, November 4, 2016*

Maybe no champagne yet, but definitely a whole lot of hope. (((Hug!)))

*—Cynthia Meyersburg, November 4, 2016*

This is fantastic news. Yahoo!

*—Lea Ann Schnakenberg, November 4, 2016*

Sounds really good.

*—Jens Brenner, November 4, 2016*

This is so good to hear. Hoping for more positive news.

*—Lynda Schmitz, November 4, 2016*

Answered prayers! Prayers continue for a final resolution, comfort, and peace. Love you all!

*—Barbara Skipper, November 4, 2016*

Answered prayers! Prayers continue for a final resolution, comfort, and peace. Love you all!

*—Barbara Skipper, November 4, 2016*

So good to hear, *sigh*, we are all praying for you guys!

*—Jeanne Clayton, November 4, 2016*

Still very good news!
Keep whuppin' ass, Colin!

*—Boris Babic, November 4, 2016*

Yay!

*—Jeremy Cook, November 4, 2016*

Cautious optimism is a good thing! Continued prayers for you all.

*—Erin and Rich, November 4, 2016*

Focus on the positive news and ditch the what ifs. You have so many people praying for your family and God is listening.
Love and prayers,

*—Phylles Lagarde, November 4, 2016*

:) !!!

*—Marc Galmoud, November 4, 2016*

# the long haul

*November 9, 2016*

I'm leaving in a few minutes to pick Christina and Colin up in Essen.  Last time I took this trip, I ended up in the hospital with a pulmonary embolism, so hopes are high that this time will go better. That said, they're predicting snow along most of my trip so, here's hoping for low doses of unnecessary inconvenience.

We meet with the doctors at 3:30 pm (9:30 am EST) to get more details. My primary question will be if, after seven rounds of chemo, the MRI in August showed that the tumor looked like a dead cyst, what have we accomplished with radiation, if it still just looks like a dead cyst?  I don't know when I'll be able to post what we learn, as we don't have any good internet connections on the hospital campus, but I will keep everyone updated.

## Comments

Drive safely!

*—SG, November 9, 2016*

Have a safe trip!

*—Claudia Busch, November 9, 2016*

Take care! Good wishes for all the best!

*—Marc Galmoud, November 9, 2016*

Continued love and prayers. I appreciate the updates. We care. Steve and Barbara

*—Barbara Skipper, November 9, 2016*

Continued love and prayers. I appreciate the updates. We care. Steve and Barbara

*—Barbara Skipper, November 9, 2016*

Continued love and prayers. I appreciate the updates. We care. Steve and Barbara

*—Barbara Skipper, November 9, 2016*

(((((Hug)))))

*—Cynthia Meyersburg, November 10, 2016*

## Always something there to remind me

*November 10, 2016*

Not much new to report, but it's good so far. Radiation seems to have destroyed the tumor. There is still something showing up on the MRI, but it's not active. Might be a cyst. A scar. Or just a fluid-filled cavity. I suppose I had expected there would be nothing left when all was done, but the doctor pointed out something like this doesn't happen to a person without leaving a mark.

Sent from CaringBridge iPhone app

### Comments

That is great news! Love and prayers to all of you.

*—Jeanne Clayton, November 10, 2016*

What wonderful news!

*—Cynthia Meyersburg, November 10, 2016*

Hooray!

*—Tara Sorrells, November 10, 2016*

Yeah!

*—Boris Babic, November 10, 2016*

Wunderbar! Das ist so, so gut!

*—Sabine Kahl, November 10, 2016*

That's great news! So glad to hear!

*—Viktoria Johnson, November 10, 2016*

Such a splendid piece of news!!!

*—SG, November 10, 2016*

Glad there is some good news this week!

*—Liisa Ecola, November 10, 2016*

Great to hear, Niels. Take care of yourself, as well.

*—Rich Daly, November 10, 2016*

This is heartening news and worth celebrating even if there are still lingering worries. Thinking of you all.

*—Michelle Lee, November 10, 2016*

Glad you made it to Essen OK. I know you've been cautious as Colin has undergone his treatment, but this sounds like more good news. And since you used an '80s song reference, I'm taking that as a good sign.

*—Lea Ann Schnakenberg, November 10, 2016*

This is really good to hear, Niels.

*—L Smith, November 11, 2016*

That sounds like pretty wonderful news!

*—Jennifer Covington, November 12, 2016*

Sounds good! Keep up the 80s music. It seems to be helping.

*—Marc Galmoud, November 12, 2016*

Good news!

*—Barbara Skipper, November 12, 2016*

## the long haul

*November 13, 2016*

Well, we're back in Berlin, meaning I have wi-fi and a proper keyboard, so I can be a bit more thorough.

To answer everyone's questions: Yes, this is good news.  It is, however, not the final word.  And, given the last half year we've had, I'm not sure what it's going to take to get me and Christina to believe that this is really, truly over.

That said, we did have a glass of champagne with dinner on Friday night.

So, after eight rounds of chemotherapy and 30.5 rounds of radiation, the doctors see nothing in the spot where the tumor was that indicates an active tumor.  They can't tell us what is there, but they don't see anything tumor-like. Now, if this tumor was placed anywhere else in the body, the procedure at some point would have been to go in surgically, make sure everything is clear and really have a good look at the spot in question. Given that he didn't walk for two months after the biopsy, no one is willing to risk that again.  So, it means we're relying on images and inferences, meaning the doctors have to keep reminding us that they can't promise us anything 100%.  But yes, it looks like they got the thing.

Which is not to say that we're done. Not by a long stretch.

The name of the game now is making sure they got it and making sure that no parts of the tumor managed to break away and metastasize. That means, even though we just got back to Berlin tonight, Christina and Colin are probably headed to the hospital here in Berlin on Tuesday for three to four nights of IV chemotherapy, because the doctors want to do all nine rounds, as planned. When we're done with that, he'll probably have months of oral chemotherapy ahead of him.

We have no idea what most of this means.  We're old hands at IV chemo now, but we've never done it during cold season. Just about everyone in the household is sniffing and Colin is going to have no immune system to speak of about a week after he returns from chemo. Any cold can become a fever with him when he's in that state, so I don't know that we won't be back in the emergency room before this is all over, fighting a fever.

When we move beyond that, we'll have a lot to figure out about oral chemo. He's currently taking a battery of pills daily to help him deal with the radiation side effects, and he's sick of taking them all. Those pills are going to go away soon, but are we going to be able to get a chemo pill in him on a daily basis once that therapy starts? Given how much he's spit out in the last few days, one wonders. And what happens to the therapy is the patient refuses to participate?  I've no idea.

We also have to figure out if we'll be able to take any kind of family vacation in 2017 and whether we'll ever be able to get our family back to normal in terms of the groceries we buy (Colin can't eat food that's been open more than a day or so, because of the compromised immune system) or when we'll all get back to school/work.  When do we get the heart catheter out?  Would doing so mean he can swim again?  Take a bath? We've got a long way to go before we're at all close to normal.

So yes, good news. But it's hard to jump for joy when you realize you've got to save your energy for the marathon ahead.

## Comments

All this and an election too! G_d does send his trials. What the reasons are, better not think about that! Just know you have friends who care, and as much support as you need! But glad the over all news is positive. Let's think on that!!

*—Marc Galmoud, November 13, 2016*

A damned hard, long campaign. No other way, though. A salute to all you Sorrellses. <3

*—Boris Babic, November 13, 2016*

Well explained and said, Niels! Thanks for sharing the good and the bad, and whatever lies in between. We just have to take one day at a time and rejoice at the progress that has been made since March!! Hugs to all....

*—martha stanley, November 13, 2016*

This sounds like wonderful news, even if there are some outlying issues. Colin and you have had to endure so much already. Let's hope better days are ahead.

*—Dan Wooldridge, November 13, 2016*

Really glad to hear this, despite the challenges ahead.

*—Jeremy Cook, November 13, 2016*

Hope these unexpected challenges will pass as smoothly as possible but it is still annoying that the end to this experience remains so elusive. Take good care all of you!

*—SG, November 13, 2016*

Thank you for all the news. You are all so strong, hang in there, prayers to you.

*—Jeanne Clayton, November 14, 2016*

But look how far you have come! Look at how much you will love the everyday things when you get there. You now know what is important and what is not. So sorry you had to have this experience. So happy Colin is so much improved! Prayers and love! ❤

*—Barbara Skipper, November 14, 2016*

I am sorry Colin's treatment is not yet completely finished. I can only guess at how exhausting this has been and continues to be for each of you. It sounds like Colin is doing as well as possible-- and there is a lot of reason to feel hopeful-- and that is because you, Christina, the medical professionals, and family worked so hard for that to be a possibility for him. (((Hug)))

*—Cynthia Meyersburg, November 15, 2016*

You are all amazing, Colin foremost. The body and spirit have surprising and unknown capacities and it sounds like you all have tapped into those and then some. Sending big, big hugs and wishes for continued good news.

*—Michelle Lee, November 15, 2016*

## out, patience

*November 16, 2016*

We're stumbling towards our final round of IV chemo. The good news is that Colin is, apparently, no longer considered to be in such a critical state that they rush him in every time a bed is open. The bad news is that this means we routinely slip to the bottom of the list when they're deciding if they have space in the ward or not.

He was supposed to start the 9th round of chemo on Tuesday. Now we'll see if he gets in tomorrow. Christina calls each morning and gets an update on the likelihood of them admitting him and then we proceed from there. It's limbo. It's become an annoyingly familiar state for us.

### Comments

Bon courage!

*—SG, November 16, 2016*

Scheduling notwithstanding, no longer considered to be in such a critical state is absolutely wonderful news. I am thrilled for him and you all □□

*—GFSantos, November 16, 2016*

## stay a while

*November 17, 2016*

It was very weird returning to the oncology ward today, the first time I've been there since September. There was this sense of homecoming, followed by this rebuke inside my head of "How on Earth can you be sentimental for this place?"

Nevertheless, Colin is now safely ensconced there and getting his final round of chemo. In a fun twist, they've told us that he'll be there through Monday, which we had not expected. All this week, Christina had been expecting a three-night stay. There have been several times in the last half year where they've bent rules to get us out after one or two nights - when we should have been there for three or four - so they could clear up some bed space. And now we're long-term guests? Go figure.

Oh well, we'll readjust our lives, figure out who is going to buy the groceries and juggle things to get the important stuff done (Ricardo's visa needs renewing, for example). Perhaps when this is all done, we'll be officially qualified as crisis managers.

### Comments

Thoughts are with you guys, you are a crisis manager! Prayers!

*—Jeanne Clayton, November 17, 2016*

You will be valuable resources to future unwilling participants on similar journeys. It sounds like the end is near. Knot the rope and hang on. Barbara

*—Barbara Skipper, November 17, 2016*

## An era ends

*November 19, 2016*

Christina reports from the hospital: Aaaaaannnnnd...... That was it. Last med of last round of chemo.

We're far from done with this, but we've put one big hurdle behind us. Here's hoping we get a chance to meet with a doctor Monday to find out what our next steps are and how we're going to cope with them.

## Comments

Thumbs up!

*—SG, November 19, 2016*

Hat off to all the Sorrellses!

*—Boris Babic, November 19, 2016*

Here's to a calm Christmas Season!!

*—Barbara Skipper, November 19, 2016*

Wow!

*—Stephan Roch, November 19, 2016*

Hooray!!!

*—Cynthia Meyersburg, November 19, 2016*

Great news. Hope this means you can relax (a little), approach some sense of normalcy again and enjoy the holidays, even if the journey isn't completely over.

*—Jennifer Dlouhy, November 19, 2016*

Whew!! What a relief! Good for you!

*—Marc Galmoud, November 19, 2016*

Great news! He's a brave boy for going through all this. Celebrate this milestone.

*—Dan Wooldridge, November 19, 2016*

Fantastic!

*—L Smith, November 19, 2016*

Good to hear this.

*—Lynda Schmitz, November 19, 2016*

Wonderful news!! Happy Thanksgiving!!

*—Jeanne Clayton, November 21, 2016*

## The night we finished a bottle of champagne

*November 22, 2016*

Colin came home last night, the first time since April he hasn't had a long-term hospital stay planned for the near future.

He finished his chemo on Saturday, but the cocktail he received was so toxic that they had to flush the IV tubes leading to his heart catheter for 48 hours before they could release him. It's standard procedure.

Now we figure out the way ahead. Short term, we've got the problem that he's very closely bonded with Christina after nearly two months with her and no one else in Essen. He'll play with me, but if I try to put him to bed it turns into a bit of a hostage situation. I managed to get him to sleep last night and even put him down in his own bed. But then he found his way into ours at some time around midnight, prompting a night of no sleep for anyone, mostly because Colin kept waking up and screaming Christina awake with his version of "There's a strange man in bed with us."

"It's Daddy," she would tell him.

"Not much better," was the gist of his response.

So, we have to work on that.

His oncologist had a good long sitdown with us before we left. I find the more good news they have to share, the more willing they are to sit and chat. The upshot is that he will start oral chemo, probably after Christmas, and do that for six months. During that time his immune system will continue to be suppressed, though not as significantly as with the IV chemo. We still can't start day care again (we had not considered that as an option), but we can be a little more relaxed about inviting friends with kids over again. He'll see the doctor weekly and get MRIs every few months. If all goes well, maybe we'll be done with this phase by the summer.

I do have a lot of hope we've beaten this. I believe the tumor will not come back. However, despite hearing the positive assessments (and sharing the bottle of champagne), hope is not quite enough to buoy our spirits just yet. You don't spend half a year in terror and then, suddenly, act as if everything is all right. Maybe we'll relax after we've gotten one or two 'all clears' with the MRI. For now, we'll just move on.

One good thing: The doctor said this tumor was not linked to any genetic predisposition, which is a relief. It means we don't have to worry about the other kids as much. It also means the odds are much higher that this tumor is not going to come back. Again, it's great news to hear, but we're still waiting and watching.

Even longer term, there's a lot of our lives to pick back up. During the last half year, we've put so much aside for Colin. We have to wean him off a pacifier. We have to think about potty training. We really have to get him used to sleeping in his own bed. There are just all these traumatic little building blocks to raising a 2-year-old that we had to put on hold the last year because, thank you, we've had quite enough trauma to go around of late.

## Comments

Hope there will really be no setbacks in this respect any more. And don't fret about potty training and pacifiers - that can be resolved quickly a bit later. Take good care all of you!

*—SG, November 22, 2016*

Potty training can wait.
What wonderful , spectacular news.
(Aside from the whole strange man bit.)
I am guessing it will take a while to stop feeling terrified.
(((Love to all of you)))

*—Cynthia Meyersburg, November 22, 2016*

Pop, fizzzz!Am happy with you.

*—Boris Babic, November 22, 2016*

I'm sure there is a growing sense of relief to all of this. It's great that Colin can be back home without your having to anticipate another long hospital stay. Sounds like things will get back to a routine of normal in due time. Best wishes for the future!!

*—Dan Wooldridge, November 22, 2016*

Strange man in the bed--it is amazing how much kids dislike change. Our guys still freak out over the slightest change in routine and they are much older. So glad to hear the good news and celebrating with you all.

*—Rich Daly, November 22, 2016*

Prayers. Not to worry about the pacifier....our little Meri had one in her mouth the day we picked her up at the adoption agency. She was 4 months old, and the pacifier comforted her greatly during the transition. So...who was I to take that bit of comfort away? So I didn't, and she nearly took it in her lunch box to kindergarten. Lol. So happy for where you are today compared to where you have been. Much love comes your way!

*—Barbara Skipper, November 22, 2016*

A pacifier is much better than a finger! You can hopefully discard a pacifier after a decent length of time. Our Laurie sucked on her "pointer" finger long after she was in kindergarten (along with her constant companion - her baby pillow - that was recovered too many times to count.) The only encouragement was from the dentist, who said that the finger was much better than her thumb! Potty training was no walk in the park, either. I'm glad that you have your family back together. It will take some adjustment for all concerned (especially Daddy.) Prayers,

*—Phylles Lagarde, November 28, 2016*

# keep 'em guessing

*December 4, 2016*

We brought Colin home from his last chemotherapy about two weeks ago and then, because we're a little dumb, unpacked the emergency hospital bags we've been keeping for him and Christina the last few months.  Days later, Colin began flirting with a fever and we've been on standby to take him to the hospital ever since.  He's never gone full on into fever territory (though he's come close) and we haven't had anything but normal check-ups at the hospital since, but it's just another sign that we're not quite done with this yet.

Keeping it interesting, when Christina took him for his check-up on Wednesday, his neutrophil count was about 100. This means he, essentially, has no immune system, but it's normal at this point in the chemotherapy.  During his check-up on Saturday, his count was suddenly up to 1,600.  No one's saying this is medically unprecedented, but it's very odd.  Based on past experience, his count would, maybe, have gone up to 500 or so in that period of time ... and that would have been when he wasn't fighting a fever.  How he got up to 1,600 is a mystery.  They even took blood twice and rechecked it at the clinic, because no one quite believed it.  Perhaps he's found a black market somewhere.

It, of course, puts us in an odd place.  The whole reason we have to rush him to the hospital when he has a fever is because his immune system is compromised.  If he's got 1,600, he's got an intact immune system (on the low end of possible neutrophil counts, but still within parameters), raising the question of whether he needs to be hospitalized in such a case.  But then, no one understands why his numbers are the way they are and it's not like we can ignore a patient recovering from chemo who suddenly develops a fever.  Whatever this is, it's not boring.

Also, Emma's apparently sick.  Just to keep us on our toes.

In other medical news:

Christina learned yesterday that his multiresistant rectal bacteria has apparently gone away, probably the victim of the flood of antibiotics he's received since March. Apparently this finding came out in September, but they only told us now.  In general, this worked out for us, because it made sure we got a private room in the hospital every time we went in.  On the downside, it's hard not to think of all the surgical scrubs we went through in Essen because of this bacteria that was, apparently, no longer present.

And they've scheduled his heart catheter for removal on Dec. 20. We would have liked to wait until after the holidays. It's a fairly straightforward procedure, with little risk of complication. But there's always that small danger, and we'd prefer not to end up in the hospital over the holidays over something so minor at this point. What can I say? One worries. But, once it's out, he can get baths again (you try hanging out with a 2-year-old who hasn't had a proper bath since March) and he can go in the pool when we go on vacation at the end of January, which will be nice. Indeed, the very fact that we've been cleared for vacation by the doctors is a pretty nice thing.

## Comments

It's getting better

*—Boris Babic, December 3, 2016*

:)

*—Marc Galmoud, December 3, 2016*

Life is indeed not boring for you - but it is marvellous that Colin is showing this magical skill of reverting to healthier levels so quickly! May everybody be in good shape during the holidays, without any need for medical attention, and afterwards!

*—SG, December 3, 2016*

This all sounds like good news. Good luck to you all. Enjoy the holidays and the upcoming vacation!

*—Dan Wooldridge, December 4, 2016*

Hi Niels, Christina, meant to rely to your last entry but I'll do it here. Ellie and I and the girls are SO happy that Colin overall is doing so well and is out of the hospital. What a long difficult road you all have had. We think of Colin and you all often and wish you all our best for the holidays and coming year. 2017 we know will be much better. Steve

*—Steven Patrick, December 4, 2016*

Yay, vacation! Swimming!

*—Jeremy Cook, December 4, 2016*

Continued prayers for Colin and the entire family....praying for an amazing vacation! Hugs!

*—Barbara Skipper, December 4, 2016*

Glad to hear he's doing better. I hope you all have a great vacation and he continues to get better!

*—Jennifer Covington, December 4, 2016*

Keep focusing on the upcoming vacation. ..AND Christmas miracles! God Bless Everyone!!!

*—Phylles Lagarde, December 7, 2016*

Good thoughts!

*—Lynda Schmitz, December 10, 2016*

## Some steps forward, small steps backward

*December 19, 2016*

If all goes well, tomorrow at this time, Colin will be a bit less of a cyborg: His heart catheter is coming out.

Of course, the final approach to this moment first required a six-hour stint at the hospital, so we could sign all the consent forms.  Yes, we understand that there are legal reasons for this. But, given that Colin was put under 31 times this autumn alone during the radiation therapy, it feels a bit silly to have to listen again to the talk they need to give you before they administer anesthesia one more time.  But it's what we did.

And, just to make sure we're on our toes, the oncology and anesthesia departments told us two different times for the start of the surgery, so we have no idea when we're supposed to be at the hospital tomorrow.

But we did have our final talk with our main oncologist as we are now officially done with this round of chemotherapy. He continues to be positively giddy about Colin's chances. Yes, there's a 30% chance of recurrence, but it's hard to focus too much on that when the oncologist is telling us to get Colin into music lessons as possible. This guy is clearly thinking long term.  Nevertheless, we have to be realistic. This was a nasty tumor and, between the fact that it developed at all, combined with Colin's young age, we have to be on the lookout going ahead.

We'll start oral chemo soon enough.  That will be 25 weeks of getting some kind of medicine in him once a day, preferably at about the same time every day.  Oh, the fun. And we get to keep giving him his antibiotics on the weekends (it's part of the therapy). We shall not be lacking for hobbies here in Berlin, I can tell you that.

And, in our main setback, it turns out that he still has the rectal bacteria. You need three negative tests to be declared free, and Colin failed test #3. So, demerits to that nurse for getting up our hopes prematurely.  But, the fact that there were two negative tests is a step in the right direction.

## Comments

I'm so happy things are looking up for you guys and you seemed to have turned the corner. We are thinking of you every day and thank you for the posts. Hugs and love to your family for the holidays and beyond!

*—Jeanne Clayton, December 19, 2016*

Bon courage for tomorrow and sign up for those music lessons!!! Take good care, the entire family!

*—SG, December 19, 2016*

I think music lessons sound wonderful (even if they are out of key!!) (((Hug!)))

*—Cynthia Meyersburg, December 19, 2016*

Bravissimo, Colin!

*—Boris Babic, December 19, 2016*

Prayers that tomorrow goes well. Then: On to those music lessons!

*—Jennifer Dlouhy, December 19, 2016*

Hope you guys have a happy Christmas!

*—Rich Daly, December 20, 2016*

Do you remember an OLD SAGA "The Perils of Pauline"? You could write a sequel, called "The Perils of Colin Sorrells" or "The Misadventures of the German Medical System as it Relates to Colin Sorrells". Do you happen to know someone who could write this sequel? Hmmmm. Thank Goodness, this part is over and you can await the next adventure in your lives. Hope that your Christmas was a blessed family event and that 2017 will bring only good things to all of you. Prayers,

*—Phylles Lagarde, December 29, 2016*

## the time warp

*December 20, 2016*

The heart catheter is out and, true to form, the hospital managed to turn a 20-minute medical procedure into a seven-hour hospital stay. I suppose we should award them points for consistency.

The appointment was not at 10:30 a.m. It was not at 11:30 a.m. It only started at about 1:45 p.m., and that's because they magically found some space in the gynecology operating ward. Now, I get it. I really do. You've all heard about the terrible incident with the truck and the Christmas market yesterday (none of us were anywhere near it, and thanks to everyone who asked how we were), and a lot of the hospital staff got called in for second or third shifts yesterday to help care for the wounded. I understand that's going to weigh on the staffing situation the day after. But we had a 2-year-old who hadn't eaten or drunk anything since about 7 p.m. the night before (no food or drink allowed before the surgery). Had we known the procedure wasn't until 2 p.m., we could have given him some food at 6 a.m. and made everyone's day a little less miserable. Had we known we were being pushed so far back, we could have shown up at the hospital later. And so on and so on.

It didn't help that my watch stopped and the two clocks in the waiting area were both 35 minutes behind. We had no idea what time it was the whole time we were there.

And then, since it took so long, Colin fell asleep. Which was actually a blessing, because it meant he could have been asleep when they administered the anesthesia. Except, we wheeled him into the room and told everyone *to speak very softly because of the sleeping baby*. And then walked in the doctor and asked SO WE'RE WORKING ON COLIN SORRELLS TODAY? And we all said *shoosh*. And he said WHY? And then Colin woke up and it didn't matter any more.

And, when the procedure was done, the gynecology ward wouldn't let him wake up in their recovery room, because of his rectal bacteria.  And the children's ward wouldn't take him, because they had children recovering in there with compromised immune systems. And the oncology clinic was actually looking for him to let him recover there, but couldn't find him, because neither of the other wards could figure out where he was. And that's why we were in the hospital until past 5 p.m.

OK. I think that will be it for now ... happy holidays.

## Comments

Happy holidays, Sorrellses

*—Boris Babic, December 20, 2016*

Oh my....want to laugh as I read these mishaps one after the other, but yet know it was not funny!! Thank you for all these updates, and know you will have a Merry Christmas!!

*—martha stanley, December 20, 2016*

Merry Christmas to you guys. After stories like this, mulled wine, anyone?

*—Jeremy Cook, December 20, 2016*

Your day has been unnecessarily eventful. Poor Colin and poor parents. Hope you can get some good rest today! Happy holidays!

*—SG, December 20, 2016*

I think you need some eggnog!

*—L Smith, December 20, 2016*

Having been on both sides, it sucks being the patient (or the family). Having said that (and watching way too much news from Aleppo) one can also imagine much worst. This does NOT help when your baby only knows that everyone is suddenly and inexplicably being mean and not letting him eat or drink after constantly insisting that he eats and drinks on every other day!

But major progress getting the catheter out!! YAY Colin!

*—Carol Hamilton, December 22, 2016*

## a lot to swallow

*December 31, 2016*

Given how I worried this year might play out at some points in the spring, I think it's more important than usual to wish everyone a happy new year this year. Our 2017 looks pretty bright, but I'm sure there will be a storm cloud or two along the way.

We continue in a holding pattern for now. During the two days of 17 hours in the hospital for a 20-minute procedure (can you tell I'm still bitter?) right before Christmas, we had a long talk with our oncologist about the transition to oral chemo and all agreed that Colin would need his medicine in liquid format, because there's no way we can ever get anything bigger than a mini Smartie (think a really small M&M) down his throat ... and he actually *wants* to eat those. I doubt we'll be so lucky with his medicine.

So, on Wednesday, Christina took him to the hospital where we ascertained that his blood levels were great and he'd be able to start on oral chemo, at which point they presented her with a tray full of pills. After a grouchy few minutes, we established that the doctor had misplaced his notes and forgotten all about Colin's stance against pills. So, now we are due to start the oral chemo on Tuesday, with a firm promise that it will be in liquid form this time.

The incision from the heart catheter continues to heal just fine. Had we stuck to the rule that he could have had his first bath five days after removal, he would have had his first bath on Christmas Day. But the nurses advised us against rushing that moment, because, really, did we want to have something go wrong with the bathing process and then end up at the hospital on Christmas Day? We then thought we'd try January 1, but when Christina was at the hospital this week, she was not given the all-clear for the bath (though it's not clear if they explicitly didn't give us the all-clear or if the topic just didn't come up), so we will wait again. But, at some point in the next week or so, you will feel a disturbance of the force, and that will be a little boy getting his first real bath in nine months.

## Comments

I think he needs a fleet of boats for this auspicious moment!

*—L Smith, December 31, 2016*

Be bright - you're emerging from it!
Great job, guys.

*—Boris Babic, December 31, 2016*

Glad to hear it is going well despite the several "hiccups" on the part of the medical staff! Einen guten Rutsch ins neue Jahr!

*—SG, December 31, 2016*

Wishing you and your family the brightest happiest New Year! Love you all!

*—Barbara Skipper, December 31, 2016*

Happy New Year and lots of bath-time fun for all!

*—Marc Galmoud, January 2, 2017*

Happy New Year to all of you! What wonderful news!

*—Jeanne Clayton, January 3, 2017*

He may be the first little boy to actually want a bath! It's a great step forward--hope it happens soon.

*—Erin and Rich, January 3, 2017*

More good wishes!

*—Lynda Schmitz, January 7, 2017*

# a spoonful of chemo does not help make the medicine go down

*January 9, 2017*

It turns out that giving oral chemotherapy to a 2-year-old is about exactly as fun as it sounds...

Yes, we're on Day 7 and we're still trying to figure out our options here. The short version is that Colin doesn't want to take the medicine. I mean, he really doesn't want to take it, meaning every dose is a two-person operation of holding him down and hoping we get more in him than he spits out.

Christina doesn't think it's the taste. In a clear bid for "Mother of the Year" she even tasted the chemo solution and dubbed it "better tasting than his antibiotics." (I said 'mother of the year,' not 'marketer of the year). More likely, Colin just objects to having his day interrupted to take what is, for someone his size, a Big Gulp of chemotherapy. It's 12.5 milliliters, which isn't that much for an adult, but requires 2-3 baby-sized oral syringes. It's a nightmare.

The hospital, of course, is giving us no useful information about how to get the stuff into him. They can't even tell us if it's important that he gets every drop, or how bad it is if he misses some. We've been hesitant to put it into food. What happens if we put it in a tub of pudding and then he eats only half of it? If we run out of all options, some nurses have suggested a feeding tube, which would somehow run up his nose and stay in place for six months. My immediate worry was that he would rip it out. Christina said she was more worried that one of his siblings might. Between those two fears, I think we have the likeliest problems covered.

So, we'll keep on plugging along.

In good news, the one pill they couldn't get into liquid form only has to be delivered intravenously about once every week or so. Considering we'd been fearing 3-4 times a week, that is good news. Also, he only gets the chemo in 10-day bursts, followed by 10 days without. Given that I'd worried about six months straight of chemo, this seems like some relief.

We also have a new MRI appointment and a new scheduled visit to Essen, this time with a schedule that has been approved by a doctor, so that's something. Last week, they had him scheduled for an MRI for Thursday, even though we could find no doctor who wanted one then and even though having it then would have been far too early for the team in Essen to use when they assess his status at the end of February. It's nice to know that, if we dig our heels in long enough and say "Explain to us why this is necessary," they'll eventually change their planning. It would just be nicer if we could skip the step and have them make plans that make sense in the first place.

## Comments

Will Colin respond to "rewards" if he takes the medicine ? I agree that this is a form or bribery, but at his age and current condition it is justified.

*—Don Summers, January 9, 2017*

Oh, dear! Christine's and your work seems to be far from over regarding this ordeal. Hope you get an answer to your questions from the doctors and a way to solve successfully the intake problem!

*—SG, January 9, 2017*

I think you both deserve the Mother and Father of the Year Award. Poor Colin. His struggle for independence - the terrible twos and all that - works against your efforts. It's almost as if you told him not to drink it, then in an act of defiance, he would drink it. I'm trying to think of a small liquid treat that he really likes that you could mix it with, but I don't know what that would be. Maybe even one he could drink in stages during the day when he's thirsty. Best of luck to all of you in figuring this out!

*—Dan Wooldridge, January 9, 2017*

What about mixing it with flavored yogurt and letting him snack on it throughout the day? I just remember how much my guys loved Gogurt (a US brand) at that age. And maybe yogurt would hide it better from him than juice?

*—Rich Daly, January 9, 2017*

I am hoping bribery will work, and I agree that you and Christina both merit parentnof the year awards.
(((Hug)))

*—Cynthia Meyersburg, January 9, 2017*

## babies and bathwater

*January 16, 2017*

So, after they took out the heart catheter, they said to wait a few days before bathing, like until Christma.

Then there was still a stitch, so they said to wait a few more days, like until New Year's.

And then they said to wait a few more days, just to be safe.

Finally, all the stitches were out and all the bandages gone, so we drew a bath last night.

And then Colin said "Oh dear God, no" and acted like we had a bathtub full of acid, so we're no closer to a clean child than we were when we started.  Oh well.

## Comments

Oh dear! And you are planning on taking him to a swimming pool... Hope he changes his mind!

*—SG, January 16, 2017*

:-)

*—Boris Babic, January 16, 2017*

An indoor swim party sounds like an awesome (if potentially messy) solution. Maybe Noah and Emma could throw him one?

*—Jennifer Dlouhy, January 16, 2017*

□□

*—martha stanley, January 16, 2017*

Kids are predictably unpredictable! Lol

*—Barbara Skipper, January 16, 2017*

Wow! No excuses - Just NO! Best one yet - simple and to the point! GOOD LUCK (and buy some interesting bath toys!)

*—Phylles Lagarde, January 17, 2017*

Tell him it's a bath or you'll hose him down in the backyard

*—Lea Ann Schnakenberg, January 18, 2017*

Tell him it's a bath or you'll hose him down in the backyard

*—Lea Ann Schnakenberg, January 18, 2017*

Coming to this late, but thanks for sharing! The dirt will come off eventually.

*—Marc Galmoud, January 29, 2017*

# the count of three

*February 3, 2017*

Colin turned 3 today, which is kind of an achievement given that, 10 months ago, I wasn't sure he'd live to see two and a half.

So far, he's had a nice family birthday today (plus a visit to the hospital - just a routine one). Tomorrow he'll have two guests (and their extended families) over, as we start trying to slowly integrate him back into the world of playing with other children. And he's just come off a nice vacation to this family-focused resort we go to every year.

Big news of that trip? We got him into the pool! The first attempt ended before it began, because they were having a pool party with loud music that drove him right back up to our room (and maybe we're just being rewarded for our loyalty to this place, but I still choose to believe someone intervened and let the hotel know about the year we have, because we got upgraded to a room that was about twice as large as we had requested). But, on the second try, and after a lot of coaxing, we got him into the pool and then four more times after that. It's not a bath, but he hasn't been this clean in ages! And yes, I know it's not exactly cool to let months of grime (some of it quite visible) wash off in a hotel swimming pool, but it's a resort that caters to small children. I'm sure turning the pool into a Colin soup is one of the less objectionable things that happens in those waters each year. Also, we kept him out of the hot tub, so the soup-making was kept to a minimum.

The oral chemo continues to be a disaster.  They moved the second round up a bit and shortened it to seven days so we wouldn't have to do it while we were on vacation and each day was like waterboarding him.  He's figured out the score when we show up with the oral syringes and start holding him down and, let me tell you, that child can clamp his mouth shut tight.  Never, ever believe one of these spy movies where they shove drugs into a person's mouth, especially if the victim is under the age of 5.  So, while it feels like we're giving up, it will help us save our sanity and, starting with the third round, we're going to go to a feeding tube.

That means, starting on the 10th (and about every three weeks after that), they'll insert a tube up his nose and down his throat - hopefully securing it so tightly that neither he nor any siblings can remove it - so we can just shoot the medicine down his throat, hopefully without him ever having to taste the stuff.  It will get removed at the end of every 10-day cycle and then put back on, etc, etc, until about June.  I'm not happy with the solution, but it can't be worse than the last two sessions of putting him into a wrestling hold and trying to pry his mouth open.

Back to happier things.  Included is a picture of today's small birthday party, with him enjoying a gift from the hospital (a Fireman Sam set!).  Who knows what thrills await him tomorrow?

## Comments

Happy Birthday Colin!! You are so cute in your fireman outfit!

> *—Jeanne Clayton, February 3, 2017*

Happy happy birthday, and wishing you many more vacations during which you make the pool into Colin soup. □□

> *—Cynthia Meyersburg, February 3, 2017*

Happy Birthday, Colin!

> *—Dan Wooldridge, February 3, 2017*

Srećan rođendan, dragi Koline, ovaj i narednih 100!!!

> *—Boris Babic, February 3, 2017*

Happy birthday sweet Colin! Great stuff about the pool - may the swimming fun continue! Take good care all of you!

*—SG, February 3, 2017*

Happy Birthday. Colin.
Niels and Christina, you guys are nominated for sainthood !

*—Don Summers, February 3, 2017*

Happy Bday, Colin!

*—Jens Brenner, February 3, 2017*

No way what he put in that pool was worse than what the adults put in the indoor pool where I take our kids. OK that sounded even grosser than I meant. Happy birthday, Colin!

*—Rich Daly, February 3, 2017*

Tell Colin Happy Birthday from us!! I'm glad he's getting to play with friends and that things are starting to normalize. Good luck with the chemo delivery. It really is shocking how well those little ones can lock their jaw.

*—L Smith, February 4, 2017*

Happy third birthday to your little fireman! Prayers continue for him and the family as you complete the treatments!

*—Barbara Skipper, February 4, 2017*

Happy Birthday Colin!!!

*—Lynda Schmitz, February 4, 2017*

Happy Birthday to Colin, belatedly. And yuck! "Also, we kept him out of the hot tub, so the soup-making was kept to a minimum." Remind me not to go swimming with little kids.

*—Marc Galmoud, February 5, 2017*

## soup's on!

*February 5, 2017*

Today, he took his first bath since March. And, when it was done, he tried to climb back into the tub.

### Comments

Hooray for Colin!!!

*—martha stanley, February 5, 2017*

:)

*—Marc Galmoud, February 5, 2017*

Hooray for Colin (and his bath)! Just takes a while to get back to normal.

*—Dan Wooldridge, February 5, 2017*

This is very good news for the entire family!

*—Lea Ann Schnakenberg, February 6, 2017*

Wonderful!

*—Jeanne Clayton, February 6, 2017*

Rub-a-Dub-Dub! Colin's in the tub! YEAH!!! Isn't it odd that something so basic can also be so exciting? Another big step for your little man. He's a tough one that you can be extremely proud of. Thanks for sharing.

*—Phylles Lagarde, February 6, 2017*

Yay!!

*—Jeremy Cook, February 15, 2017*

## the 11th hour

*February 11, 2017*

In case you were wondering: Watching a nurse insert a feeding tube into your son's nose is about as much fun as it sounds like.

That said, after an initial 20 minutes of "what the hell did you people just do to me?", he seems to be pretty calm about the whole thing. And he's received two doses of his oral chemo through the tube now, with 100% less drama than we had to endure with the other method.

However, that said, getting to this point required an 11-hour marathon in the hospital on Friday.

Understand, Christina and I are quite naive.

Our tasks yesterday were as follow:

1) We had to sign the medical waivers for his MRI on Monday: one with the MRI department, the other with anesthesiology. Yes, you are absolutely right. After a year of doing this, you'd think we'd just be able to sign a general waiver for these things. But no, we can't. Each MRI requires it's own set of waivers;

2) We had to get him hooked up to an IV for the one chemo medication they have not been able to convert into oral form; and

3) We had to get the feeding tube inserted.

Gleefully, we thought we could get this all done in 4-5 hours. There was even talk of getting home and having a nap before Emma and Noah got home.

We arrived at the hospital around 9 a.m. and got the waivers taken care of fairly quickly, in the sense that everything was signed by noon (in hospital world, this is like running a 3-minute mile). We then headed to the clinic, agreed we would put some anesthetic patches on Colin's hands so he'd be numbed for the injection for the IV, and told the doctors we'd be back around 1 p.m., after some lunch.

This is when things started going badly. Upon returning to the clinic, the doctor realized that the pharmacy had prepared the right solution, but had put it into the wrong delivery device. It is important that this chemo be delivered by a drip bag, as it has to be introduced slowly. Quick introduction risks serious tissue damage at the point of entry. He called the pharmacy and they agreed they could get the medicine back to the clinic in the proper packaging by 3 p.m. The clinic told us not to bother coming back until about 3:30 p.m. Christina said that it meant nothing was going to happen before 4 p.m.

So, we went out and had coffee. Colin fell asleep on the way back, meaning it was that much easier to insert the IV when we got back. Let the record show, it was past 4 p.m. when this happened.

This is when the nurse came in and suggested we put the feeding tube in Colin while he was asleep. Despite the obvious question - won't that wake him up? - she insisted we go ahead. Colin did indeed wake up and was justifiably angry at finding someone shoving multiple centimeters of tubing up his nose. But we more or less got it in and Colin stabilized.

Then the team noticed that, amid all the fuss, the IV drip had more or less stopped. Bear in mind, there is no real technology to this. It is a plastic bag, hanging from a high hook, attached to Colin by a tube. All that is required is gravity and more pressure in the bag than inside Colin for this process to work. But the medicine wasn't flowing. Indeed, a bit of blood was backing up into the tube.

They messed with the bag and the tube. Nothing. They tried to set the bag even higher. Nothing. They put an IV into Colin's other hand (which was no longer numbed). Nothing.

At some point, one of the nurses wondered out loud why we didn't just use the version of this chemo that could be introduced via feeding tube. That's the point when everyone in the room stopped and experienced a moment of despondency, I'd say.

Anyways, it was getting on towards 6 p.m., which is when the clinic closes. So, they arranged for us to go across the road to the oncology ward, which we had kind of hoped we would never have to see again after our last stretch there in December. Magically, gravity began to work over here and the drip was done in about an hour. On the plus side, we also know that we might be able to avoid IV drips for the remaining six rounds (including this current one) of the oral chemo.

Colin got to bed around 10 p.m. and slept until almost 7 a.m. The tube still doesn't seem to bother him, though we're going to have to figure out how best to hide the trailing end beneath his clothing, as we're going to live in terror that either he or one of the other children will accidentally rip it out. He'll keep it in until Monday, February 20, then live about 10 days without one, and then get another re-inserted for the next 10-day stretch of chemo. Hopefully this will ease our lives.

Like I said, the MRI is on Monday. This is just a control that we need, now that the heavy duty chemo is over (and the team in Essen needs something to look at when they give him a checkup in a few weeks). God willing, the results will show that the mass has done nothing but deteriorate since the last MRI.

## Comments

Oh, the torture.
:-(

*—Boris Babic, February 10, 2017*

I feel your pain; however, with the progress Colin has shown thus far (medical professionals notwithstanding!),I got think it's worth it, oder ?

*—Don Summers, February 11, 2017*

No one should have to go through such torture! Prayers for all.

*—Barbara Skipper, February 11, 2017*

No one should have to go through such torture! Prayers for all.

*—Barbara Skipper, February 11, 2017*

No one should have to go through such torture! Prayers for all.

*—Barbara Skipper, February 11, 2017*

Poor mom, dad and baby! Here's to a swift end to the ordeal!

*—Marc Galmoud, February 11, 2017*

He's handling everything so well. IVs are a horror show, I agree. Nothing like seeing it not dripping and red inside. So awful. I can only hope, in addition to his getting well, that he remembers as little of this as possible when he's older. Amazing job to you and Christina. What an agonizing ordeal.

*—GFSantos, February 11, 2017*

Sad that you had to go thru all these problems! You three are heros but may you not have to demonstrate it any more!

*—SG, February 11, 2017*

I have to admit, your writing skill makes this event even more profound!! Feel like I am living this myself!!□□ Thanks for sharing!!

*—martha stanley, February 11, 2017*

He is never going to have to wonder if he is loved. I am sorry you all are still going through this ordeal, and I am cheering for him, for all of you. (((Hug)))

*—Cynthia Meyersburg, February 11, 2017*

Huge hugs from Nairobi. You guys are loved, and more importantly, it is so clear how much Colin is.

*—Jeremy Cook, February 11, 2017*

That answers my question on the mail note. Sorryl

*—Eric Sorrells, February 12, 2017*

## no news

*February 15, 2017*

The MRI results are back and we're happy to say the doctors saw nothing unusual (for our situation).

Yes, we'd be happier with "It all magically disappeared," but that would be extremely unusual after the last year. For now, nothing looks active, nothing looks like it's growing and everything looks like the therapy is continuing to do its job.

## Comments

thank you

*—Boris Babic, February 15, 2017*

Excellent news!

*—SG, February 15, 2017*

Wonderful news!

*—Marc Galmoud, February 15, 2017*

Great news!

*—Barbara Skipper, February 15, 2017*

Excellent!

*—Jeanne Clayton, February 17, 2017*

Yay!

*—Jeremy Cook, February 20, 2017*

# The 60% cure

*February 18, 2017*

Fun with chemo continues in the Sorrells household...

To recap, after two rounds of chemo where we couldn't guarantee that Colin had ingested more than about half of the medicine, we went for the nasal feeding tube.  It looked awful, but it worked great.  We sat him down in front of the TV, pushed the medicine in and, most times, he didn't even notice.  Since we're worried about his liquid intake, we even introduced a little extra water that way. By Day 6 of this 10-day cycle, we were cautiously optimistic that we might get a whole round into him.

And then he got a fever.  Sigh.

The fever, in and of itself, isn't that big a deal (trust me, he's playing right next to me and you would have no idea he was feverish based on his current behavior).  It certainly wouldn't be a problem if he was in between oral chemo cycles.  But, right in the middle of one, where his neutorphil counts are dropping, not such a good plan.  Christina was briefly worried they were going to hospitalize him so they could put him on an antibiotics regimen.  Instead, they ended the chemo after six of 10 days and gave us four days' worth of amoxicillin to get into him.

On an good note, aesthetically, they pulled out the feeding tube, so he looks less sickly. On a sad note, medically, they pulled out the feeding tube, so we now have to get three doses of amoxicillin in him a day until Monday. The brief respite from oral chemo did not lessen his ability to spit out the vast majority of medicine given to him in oral form, I'm sad to say.

We're rolling with it.  The doctors continue to be happy, so we're happy.  However, one questions, given how ineffective the first two rounds were, and now that we've got a third round aborted, can we even pretend to say we're following this particular regimen? I suspect the doctors have a lot of flexibility built into the plan: I think that's just the way oncology rolls.  Most likely the biggest problem is my obsessive-compulsive nature: I want a plan presented and then I want it followed to the letter. This constant improvisation keeps me nervous that we're straying too far from the plan.  Then I have to remind myself, this is a 3-year-old.  Plans are rarely followed through when dealing with this demographic.

## Comments

Oh, dear! Hope he manages to ingest all the antibiotics he needs and get over this fever quickly!

*—SG, February 18, 2017*

Thinking positive thoughts for Colin.

*—Lynda Schmitz, February 18, 2017*

I am guessing I would feel the same way. And I say this despite being a much less organized kind of person. Uncertainty is profoundly frightening. I would want a plan of action I could just follow to get the child to safety.

But I think you are right: I think that oncology treatment is part science, part art. The plan has to be evolving-- especially because he is three. It sounds like his team is very committed to healing him, and I think that they will adapt and find a way to make it work for your child. You are doing your part, and despite the bureaucracy, I really think they are working hard to get him through this and healthy.

I wish there were something I could do that is more than pray and sympathize and care. (((Hug)))

*—Cynthia Meyersburg, February 18, 2017*

I'm like you...give me a plan! But the medical community...not so much. Prayers for comfort and much love for all!

*—Barbara Skipper, February 18, 2017*

I'm like you...give me a plan! But the medical community...not so much. Prayers for comfort and much love for all!

*—Barbara Skipper, February 18, 2017*

Ditto for the previous comments. Thinking of you and Colin. With three year olds, there just has to be some leeway built into the system!

*—Marc Galmoud, February 18, 2017*

Niels, you and Christina are doing great !! And maybe this experience with "deviation from the plan" will moderate your obsessive compulsive nature :) And a note: the human body deviates from the plan all the time/

*—Don Summers, February 18, 2017*

As a fellow, fairly OCD person myself, I feel for you! Can't even imagine. Bless you guys.

*—Jeremy Cook, February 18, 2017*

It's always good to have A plan - and plan B and plan C .... As long as the doctors are relaxed, don't worry - everything will be just alright!

*—Claudia Busch, February 18, 2017*

Remember - there are no guarantees in life. Most of life is like an experiment - trial and error until you find something that works.
Also remember that God is there with all of you - and He is seeing that "trial and error" is working for Colin.

*—Phylles Lagarde, February 19, 2017*

## sea change

*February 21, 2017*

I cannot tell you what has happened, but as of yesterday, Colin willingly takes his antibiotics.

He stands there and swallows them without a fuss.  He even asks for seconds.

We don't understand. We don't question it.  We're just grateful.

Also, he's letting us brush his teeth too. It's all a mystery.

### Comments

*—Jeanne Clayton, February 21, 2017*

A good mystery too. You are right, don't question it, just go with it! Thinking of you.

*—Jeanne Clayton, February 21, 2017*

Accept the mystery!

*—Liisa Ecola, February 21, 2017*

Don't look a gift kid in the mouth :)

*—Don Summers, February 21, 2017*

Love, love, love!!

*—martha stanley, February 21, 2017*

This calls for champagne!!

*—L Smith, February 21, 2017*

Kids are an enigma! Lol

*—Barbara Skipper, February 21, 2017*

Sweet, beautiful mysteries!

*—Jeremy Cook, February 21, 2017*

Wow! Don't try to understand it - he may have just had a dream! May it last, especially brushing the teeth...

*—SG, February 21, 2017*

It's called growing up. One day it just clicks. I remember once when it happened to me as a kid. One day, I just thought 'things would be simpler if I just do what mom asks.' Go figure!

*—Marc Galmoud, February 22, 2017*

Maybe 3 is the magic number (age)! Colin is a big boy now! I had forgotten that his birthday was the day before mine. Happy Birthday, little guy!

*—Phylles Lagarde, February 23, 2017*

# status quo

*March 3, 2017*

We went to Essen this week. We had a devil of a time finding decent restaurants (which is ironic, given the name of the town). We had a pretty good trip there and back. We learned that the doctors in Essen pretty much think the same thing as the doctors in Berlin, so odds are that we will be doing all of our communications with Essen by telephone in the future, because it's a long way to travel to hear "What he said."

Nonetheless, we still felt it was good to let the team in Essen have one look at Colin, seeing as how they did spend the autumn irradiating him. And, since it was two days where we were in Essen and not getting Emma and Noah ready for school, it was like a mini vacation, so that was nice.

The upshot remains: It looks like they got the tumor. The tissue remaining where the tumor was looks the way one would expect the remains of a tumor to look. There will always be something there, because no amount of chemotherapy and radiation will return him to his original settings. But, as they've told us before, the best way to think of it is as scar tissue. And, right now it's inactive, which is what we want. Now the long haul begins because, since he's had one tumor, he has a higher chance of getting another. Not astronomically higher, but high enough that he gets to have at least one MRI a year for the near future.

So, good news all around.

The only things on the downside. Once again, he got two tests showing his rectal bacteria had disappeared, only to have the third one find traces of it again. He needs three clean tests in a row to be declared free (and then we'll never let him be tested again).

And, our one insurer has installed a new system that means repayments now take more than a month. Given the rate at which we get bills, this could turn into a problem at some point. But we'll overcome.

## Comments

Yea! "We shall overcome!"...your family motto.

*—Barbara Skipper, March 3, 2017*

Yea!

*—Barbara Skipper, March 3, 2017*

Excellent news! Hope thongs stay good and may the new insurance setup cause you no trouble.! Yes, I've always wondered about eatery options in Essen. A pity the town does not leave up to its name :)

*—SG, March 3, 2017*

Great news!

*—Jeanne Clayton, March 3, 2017*

Wrong tense at the end.
You DID overcome.
Great stuff, after all that torment.

*—Boris Babic, March 3, 2017*

Sounds like the best news possible!

*—Liisa Ecola, March 3, 2017*

Celebrating your good news!!

*—martha stanley, March 3, 2017*

Yay! BTW, coming to Bavaria in May before a swing over to France for T's 10th B-school reunion. Wish we could see you guys, but obviously a big country.

*—Jeremy Cook, March 3, 2017*

Congratulations! Glad to hear the good news. And thanks for sharing about the rectal bacteria. I should have finished breakfast before I started reading.

*—Marc Galmoud, March 3, 2017*

That is good to hear. A victory for sure.

*—Lynda Schmitz, March 4, 2017*

## gloom and doom

*March 7, 2017*

We do appreciate all the "attaboy" and "great news" posts we're getting in response to the blog. They really do buoy our spirits.

And my goal is not to bring down anyone else's spirits. But, after getting the rush of congratulations, we kind of tried to figure out why we don't feel as thrilled as all our friends seem to think we should be. After all, it's hardly as if we have a "Sorrells: 1, Cancer: 0" scoreboard on our wall. Things are no longer as grim as they were in March/April 2016, but there are still moments when we're gripped with the fear that this is not over.

To wit, in the recent round of MRIs, the doctors did notice one dot in the tumor site that is responding to the dye. There are multiple explanations for what it could be. There is no reason to assume it is the tumor regrouping. However, there is no way to rule out that those are active tumor cells. Time, and further MRIs will tell. Until then, we have to keep up our spirits the best we can, hoping for the best but preparing for the worst. As one of the doctors recently told Christina: They've more or less thrown everything they have at this tumor. If it regroups, it's not clear what we can do about it.

So yes, we'll be doing things like finishing our taxes and making another attempt at getting grass to grow in our garden in the coming weeks. But we've got an eagle eye on Colin to make sure we don't see a return of the behavior that heralded the start of the tumor last time.

And we focus on the positives. For example: Colin discovered croissants while we were in Essen.

## Comments

(((((Hug)))))
If the dot turns ominous, is surgery the next step? If so, would it be in Germany, or would

they refer you elsewhere?
In the meantime, I hate that dot. I am hoping it is any innocuous things it wishes to be. But for now, I hate that dot for being scary. Love to your family!

*—Cynthia Meyersburg, March 7, 2017*

Here's hoping for the best. And best advice I have: Enjoy all the good that is now, and don't think too much about the what ifs of the future. And have another croissant!

*—Marc Galmoud, March 7, 2017*

A pity it is not possible to be more definite about what is to expect - but enjoying everyday pleasures is good! Take good care!

*—SG, March 7, 2017*

Don't think too much about the dot - it might be gone on the next MRI - but enjoy spring in Berlin and the huge variety of French pastry here!

*—Claudia Busch, March 7, 2017*

## fourth time lucky

*March 10, 2017*

It took us four tries, but we finally managed to complete an oral chemo cycle without interrupting it due to illness or not being sure he was getting sufficient medicine because of toddler resistance.

As a bonus - and an additional step towards Christina earning a de facto nursing degree - she then removed Colin's feeding tube at home, with minor assistance from me and Ricardo. Trust me, after the year we've had, if you're ever in a medical emergency, you want this woman looking after your well-being.

## Comments

Go Christina!!

*—Barbara Skipper, March 10, 2017*

Go Christina!!

*—Barbara Skipper, March 10, 2017*

She also knows how to treat someone who has sprained an ankle!!□□ Go .hristina!!!□□□□❤

*—martha stanley, March 10, 2017*

# One year on

*March 17, 2017*

Today marks one year since we got the diagnosis.

I felt I should note the moment. Beyond that, there's nothing much to report. We're in between oral chemo cycles. It seems most of our drama surrounding Colin these days revolves around hunting down his die-cast Lightning McQueen car, which he insists be with him at all times, but which, annoyingly, he also tends to throw around, hide away and, pretty much, lose about three times an hour.

But, obviously, the tumor and the prospect of it returning are never far from our minds.

Other than that, it's been a year. We've learned that the German medical bureaucracy is just about as maddening as you'd expect. We've learned that you take your life in your own hands if you order anything but the mac and cheese at the hospital cafeteria. We've learned that we've got a lot of friends and family who are willing to rearrange their lives at the drop of a hat to help us with the mess that was ours during the last 12 months. We've learned that our employers and colleagues will pick up a lot of slack to help us get through this. And we've learned that we could probably spend the next 12 years saying thank you to everyone and it still probably wouldn't be enough.

Which is not to say we won't keep trying. Thanks everyone for your support. The next update will be shortly after our next medical mishap.

## Comments

:)

*—Marc Galmoud, March 17, 2017*

One year ago you must have been afraid of thinking a year ahead - good that things turned out better than you feared, and you are marking this anniversary with Colin next to you and in an energy-full mode, as playful as a child his age is expected to be. May all next anniversaries be as positive!

*—SG, March 17, 2017*

Such a long, scary year.
Such a tough, good family.

*—Boris Babic, March 17, 2017*

That's what friends are for - just keep going.

*—Claudia Busch, March 17, 2017*

You guys are doing great. Of course I'm thousands of miles away and no help so you better be doing great. Colin looked great in the croissant pic.
BTW, did I understand right that you are trying to get grass to grow in the middle of winter? Are your winters really mild?

*—Rich Daly, March 17, 2017*

Thanks for inviting us along!

*—Jeremy Cook, March 19, 2017*

It's been the longest year of your lives! But you are all still standing thanks to love and determination. Just keep on putting one foot in front of the other, with faith and hope.

*—Phylles Lagarde, March 22, 2017*

## search and rescue

*April 21, 2017*

I'd just been thinking that I should really write another update, but kept running into a wall - the fact that little has happened.

And then today came along and Colin was supposed to start his sixth round of oral chemo, but couldn't, because the hospital lost his chemo.

Let me repeat that: THE. HOSPITAL. LOST. HIS. CHEMO.

I'm just saying, this sounds like the start of a plot to a movie that might involve, say, Christian Slater and John Travolta and end with a zombie apocalypse. I'm not so much mad as befuddled. I mean, how do you lose chemo? Does this happen regularly? Are hospital staff alerted when it happens? If they ever find it, can they still use it? Is there a risk that someone wandered off with it? Should people be extra cautious about drinks served in the hospital cafeteria during the next few days?

Whatever. They've promised it will be available tomorrow. We breathe in. We breathe out.

Colin takes it all with aplomb. As I tell everyone, he's pretty much a typical 3-year-old. True, he has the odd scar or bump that you might not expect someone his age to have, but he's generally healthy and happy. He just got to take his first trip down to Oma and Opa's for Easter and had a blast with his cousins. His next MRI is in a few weeks and all we can do is hope for the best.

The rest of us soldier on. You can tell we remain brittle. I didn't post at the time because it was just too much, but we had an incident a few weeks ago where he vomited at breakfast. I have to emphasize: It was nothing. He's 3 and throwing up is part of his job description. Also, he was trying to cough while eating breakfast. But it threw Christina and I off of our game for the better part of the day, since we couldn't shake the memory that unexplained vomiting was our first hint of this tumor.

So, that's where we stand. More news as events unfold.

## Comments

Keep the faith! Breathe in, breathe out! :)

*—Marc Galmoud, April 24, 2017*

## a certain chemistry

*May 2, 2017*

In the end, Colin got his chemo. I don't know if this makes me feel better or worse, but it wasn't just his chemo that disappeared. Christina was told all the chemo went missing that day. It's not clear if that means the chemo for the pediatric outpatient clinic, the pediatric inpatient oncology ward or just all chemo for all patients at the hospital (or some combination of those), but that's clearly a lot of missing chemo. Just one more of those things that probably would have horrified me two years ago but, today, leaves me with a sense of "Well, these things happen at the hospital."

Otherwise, no real news to report. We have an MRI scheduled for May 15 now, which will be our next big status update.

## Comments

I am thrilled to hear there is no news to report! Keep breathing and thanks for keeping us in the loop. Love you!

*—L Smith, May 2, 2017*

I, too, am a fan of no news!!

*—Cynthia Meyersburg, May 2, 2017*

## They don't ask and we won't tell

*May 10, 2017*

And then there are the days you're happy the clinic calls and interrupts dinner time.

After months and months of testing and hoping and always falling just short, Colin has finally gotten three negative tests in a row for his multiresistant rectal bacteria.  The nurse in the clinic was so excited when the results came in that she called us straight away, instead of waiting for us to show up on Friday for our next round of visits.

The timing is very good.  As annoying as they were, those bacteria had the advantage that we were in a single room every time we were in the hospital with Colin last year, so it might have been a small blessing to have them active during 2016.  But now that we're done with overnight stays, it is a nuisance.  Because he can't come into contact with other children when he's carrying such bacteria, it means we've been barred from the common rooms at the clinic.  He spends most of his visits strapped into his stroller. Because they have to disinfect every room he goes into, it means they usually schedule us for late in the day, so that they don't have to scrub the room down between patients. And let's not forget how annoying it was to have to put on the scrubs and masks and everything associated every time we left his room while in the ward (and let's not get me started on how Berlin and Essen had different rules for what had to be covered and when, even though we were talking about the same bacteria the whole time).

Of course, it's all a little riiculous.  He's had negative test after negative test over the last few months, but the third always came up positive.  The fact that he had three negative tests in a row might mean they're gone.  It just might mean we got lucky and the swab didn't find any.  The point is, the hospital seems to have agreed to a conspiracy of silence, whereby they won't ask any more about the bacteria, and we're certainly not going to say anything.  Perhaps they're gone, perhaps they're coming back: We're all just going to pretend they're not there.  Aside from making clinic visits a little more pleasant, it also means we don't have to ask for special quarters (or get stuck with special restrictions) should we make it to this medical family retreat in the autumn.  Because, at the end of the day, it was a rectal bacteria and he still wears a diaper, so the odds of him spreading the stuff to any other patient was always pretty minute.  Now we just get to live without the safety restrictions whenever we're in the hospital.

We're going to have a celebratory drink now.

Monday is the next MRI.  All prayers and good thoughts welcome.  Extra prayers that the MRI machine doesn't break down on Monday would be good too!

## Comments

Excellent news! Keep them coming!

*—SG, May 10, 2017*

Great! <3

*—Boris Babic, May 10, 2017*

Yay!! Sending prayers and good thoughts for good results from Colin's MRI.

*—Dan Wooldridge, May 10, 2017*

Hooray!!!!!!

*—Cynthia Meyersburg, May 10, 2017*

Prayers and good thoughts coming your way!!

*—Jeanne Clayton, May 10, 2017*

Good to hear!! May the good news keep coming!

*—Marc Galmoud, May 10, 2017*

Prayers!

*—Barbara Skipper, May 10, 2017*

Prayers!

*—Barbara Skipper, May 10, 2017*

We all just need to get T-shirts made that say, "Go, Colin!" Your kid is so tough, he doesn't need a cheering section, but he definitely deserves one.

*—Lea Ann Schnakenberg, May 10, 2017*

*—Jeremy Cook, May 10, 2017*

Lots of prayers and good thoughts to Colin for Monday!

*—Lynda Schmitz, May 13, 2017*

# The Early Bird

*May 14, 2017*

Fun side effect of no longer being labelled as a carrier of multi-resistant bacteria: Since the hospital no longer has to intensively scrub down rooms after we're in them, they can schedule our appointments earlier in the day.  To wit, tomorrow's MRI has now been pushed forward to 7:10 a.m.  It's at least a 45-minute drive to the hospital. to say nothing of the fact we have to get ourselves up and ready before we even try to shove him out the door.

And, just like that, I'm missing the days of the bacteria.

## Comments

There's always an upside...lol

*—Barbara Skipper, May 14, 2017*

Bon courage!!!

*—SG, May 14, 2017*

well, at least less traffic at this early hour - always look on the bright side of life!

*—Claudia Busch, May 14, 2017*

So funny, and yet it is not!!

*—martha stanley, May 14, 2017*

Ahh, the joys of unintended consequences

*—Markus Sorrells, May 14, 2017*

□□□□□□

*—Boris Babic, May 14, 2017*

## Wanna Cry?

*May 16, 2017*

Given all the news during the weekend about the cyberattack that seemed to be hitting hospitals more than other institutions, none of you will be surprised to know that I went into Monday's day at the hospital for an MRI and the start of the seventh round of chemo with more than a little trepidation.

Silly me.  I should have known that the hospital could turn everything into a mess without the help of any silly old ransomware.

The MRI went OK.  We were there 20 minutes early for our 7:10 a.m. appointment which, as far as I'm concerned, means we're up for a Parenting Lifetime Achievement award.  By the time they got the happy juice in him (which, in theory, makes him goofy enough that he won't pitch a fit when they try to put an IV in) and let that do its job, etc., an hour had passed, meaning it was 8:10 a.m. before the people in the MRI team even got a look at him.  But I had never imagined they were actually going to start at 7:10 a.m., so that was fine.

The MRI went off without a hitch.  We had him in the wake-up room by 9 a.m.  He woke up a little early, so we spent the better part of the next hour and a half trying to keep calm a toddler who was awake, but understandably perplexed about why he was so groggy as he fought off the effects of the anesthetic, but that was OK.

Our first signs of trouble came when we tried to call over to the oncology outpatient clinic to request a nurse escort us over.  No one picked up.  At 11 a.m., the nurse in charge of the wake-up room said we could walk over by ourselves because, as far as she was concerned, we're outpatients, and she never keeps her outpatients for more than two hours.  We marched over and discovered the clinic in a bit of disarray.

Let me rephrase that: More disarray than usual.

One of the rooms was being painted, so they were short of space.  I don't know if they were shorthanded by plan or if someone called in sick, but there were not enough nurses.  And one of them is brand new, so she had a lot to figure out.  There were about six families just waiting to get into a room when we got there, to say nothing of the ones already receiving treatment.

This is about the time we were told that the IV component of this session's chemo (Of the eight sessions of oral chemo he's doing, a few require him to come to the clinic 2-3 times for an additional dose of a kind of chemo that can only be administered through an IV) had not arrived from the pharmacy yet.  Hey, at least it wasn't missing this time.  It's just no one had made sure it would be at the clinic, even though Christina worked out with them on Friday that we might be there very early on Monday.

So, we waited two hours.  They hooked him up and that part went fine.  Somewhere in there, we met our lead oncologist (this is not a matter of course, he works in several different stations) who was unbelievably upbeat about Colin's diagnosis, without even having seen the MRI results, so we're going to assume he knows something the rest of us don't.

And then we found out that we still had to wait a little while for the arrival of the oral chemo from the pharmacy.  At least they managed to bring it to us before we were done with the drip.

We packed up quickly, as we were all hungry.  Christina said she thought it was strange that the outside of the bottle was a little wet, but, seriously, it was three hours past lunchtime at this point.  I shoved it into my bag and we left.

When we got home, I realized a little had leaked out, but it was inside a bag in my bag, so I didn't think much of it.  Then Christina went to administer the first dose and realized that they'd given us the chemo in a bottle that didn't seal properly.  Meaning a fair amount had leaked out.  And, since this is a custom-made suspension that needs to be shaken before every administration, we had no way of knowing if the fluid that had leaked out was the actual medicine or just the liquid in which it was suspended.  We called the hospital: Their only advice was not to touch the bottle (which led to me spending the rest of the day trying to remember how quickly I had washed my hands after pulling the leaky bottle out of the bag) and to come back Tuesday for a new batch.

So, chemo delayed by one day.  And this time they want to give it to him over 10 days, not seven.  And he has to show up at least twice more during this period for IV chemo. So much more potential for disaster.

We discuss the MRI results with the optimistic oncologist on Monday.  I'll try to update as soon as we know something, though I wouldn't rule out another entry before then with me railing against the hospital for yet another administrative goof.

## Comments

:( Sorry to hear things have been so messed-up! Hoe it all works out fine in the end!

*—SG, May 16, 2017*

Argh!!!!!!!!!

*—Cynthia Meyersburg, May 16, 2017*

Your writing/description makes me think I am reading a novel! You do such a great job letting us know what is going on in the ongoing saga of Colin's treatments. Thanks!!

*—martha stanley, May 16, 2017*

I'm not sure about taking care of stress myself - but closing your eyes and breathing in and out concentrating on nothing but the breathing helps, I think. Keep on keeping on!

*—Marc Galmoud, May 16, 2017*

## A numbers game

*May 23, 2017*

We came, we chatted with the oncologist, we left confused.

In general, the news is good.  The tumor continues to show no significant activity.  It certainly isn’t growing or getting bigger, so the appearance of being a mass of dead tissue is still there.  But, since they can’t safely look at it surgically, the doubt about his diagnosis is also still there.

Because we had a little time (not counting the hour past the scheduled appointment time we had to wait, but we’re used to that now), the oncologist took us through a lot of facts and figures and images and options.  He skimmed through a lot of MRI images and told us how this or that could clearly be seen.  I’m the guy who never was able to make out a single thing on the kids ultrasounds when they were in utero, so a bunch of MRI images might as well just be a series of color bursts for me.  It also didn’t help that,whereas white was always the bad color in previous MRIs, something flopped in the contrast and this time, even though there were big splashes of white on the images, now they’re good.

We learned for the first time that the tumor is definitely on one side of his brain stem, which is good for Colin.  Were it in the middle, he’d be paralyzed. By virtue of being off to one side, enough of the brain stem is still functioning to let vital signals through.  It means we always need to keep an eye on him, make sure that both sides of his body are developing normally, and that he has fine motor skills.

Also, for the first time, the figure of a 45% five-year survival rate was thrown out … and I’m really glad that one never came out earlier in the process.  It’s an overall number, not specific to Colin.  And a lot of the people who don’t make it five years have all kinds of setbacks that Colin hasn’t experienced, so we shall continue to be optimistic.  Also,the five-year-clock starts with diagnosis, so we’ve already put a year and change of that five years behind us.

I suspect that all of the meetings with the doctors will continue to confuse us. It's so obvious that both of us, at all of our various meetings with doctors, at some point get overwhelmed and have to flee to a happy place. Christina remembers one set of numbers and survival rates presented to her. I remember different numbers. Sometimes we agree. She has the advantage that we're doing all of this in her native language. The point is, a lot of these numbers seem new to one or both of us a lot of the time. We've probably heard them all before, we're just able to process them better now. Of course, being able to process them, means we spend a day teetering on the edge as we take in all the new information. But it's stuff we need to know.

Ultimately, all we can say is that we’re not out of the woods yet, but that the doctor is generally happy with everything.  There’s still a lot in store for us.  Already they’re considering new tests and therapies,some of which might be with Colin for the rest of his life.  In the end,all we really have is that Colin is acting more and more like a normal, happy 3-year-old these days.

****

I wrote this on Monday, but didn't have time to post it until Tuesday. One other bright spot: We might have found a day care spot for him at a new facility, since we've kind of been turned off on the old one. He might not be able to start until December, but we can work on it. It would mean he's not returning to day care until he's almost 4. That sounds perfectly fine to my American mind, but having lived in Germany this long, I realize that's really late for a kid to be jumping into the world of day care. We'll make it work.

## Comments

I find it confusing and overwhelming myself too - what matters is for everything to turn out very well and hope it goes very smoothly with the nursery!

*—SG, May 23, 2017*

The strength of you and Christina is amazing. Your unity is key to get Colin through this. It may not always be clear that unity is there while youre in the midst of this maelstorm but from the outside I gotta tell you, that bond you guys have maintained is the impressive.

*—Rich Daly, June 1, 2017*

# The nose knows

*May 24, 2017*

And today is the day that we learned that, if Colin and Noah play-wrestle, it is possible for his feeding tube to get yanked right out.

He's fine, if rather unhappy with the universe. You pull a tube out of your nose at high velocity and see what that does for your day...

## Comments

□□

*—martha stanley, May 24, 2017*

Owwah! :(

*—Marc Galmoud, May 24, 2017*

damn, damn, damn and blasted!

*—Boris Babic, May 24, 2017*

Oy!!!

*—Cynthia Meyersburg, May 24, 2017*

Ouchie!!! Colin's a tough little guy - he's been through a lot tougher situations! Yea, Colin!

*—Phylles Lagarde, May 24, 2017*

## the final countdown

*June 8, 2017*

Colin began his final round of oral chemo today, which seems as good an occasion for a journal entry as any.  Seven days this time and then we'll be on to our next stage of this process.  We're still exploring our options.  The one proposal on the table is to start him on a kind of anti-epileptic that, apparently, has the side effect of discouraging immature cells, like tumor cells, from maturing into proper tumors.  But the side effects of those medicines can, in themselves, be pretty rough for the patient, so we're thinking.

The final round of chemo has not been without its misadventures.  It's a cocktail of two kinds of medicines and, apparently, the doctor got the numbers mixed up between the two of them when he wrote out the dosage protocol for Christina.  It would have meant that he was getting way too little of the one kind of medicine, which, I guess, in the short term, is the better scenario.  But you still kind of wonder what would be happening if Christina wasn't, well, paranoid, and triple checking everything the doctor says.

Otherwise, things are going OK.  We think we might have found a day care spot for him starting in December, which would be a nice return to normalcy for us.  We've also gotten the initial approval from the health care company for us to go on our family medical retreat in the autumn.  It's not without its hiccups.  The approval was only for three weeks of a four-week retreat, but Christina insists that's just a typo.  And we still have to get at least one other insurer to sign off on the plan.  But it's a start.  As for me, we've decided I probably need a little psychotherapy after all this (I'm having a very hard time decompressing).  It turns out, finding an English-speaking psychotherapist who takes my insurance is, essentially, a full-time job here in Germany.  Hey, it's something to take my mind off things.

Also, the kids and I are all on vacation this week, so we've been taking some day trips. If I manage to upload it, you'll see here a photo of Colin actively disagreeing with Christina at the palace gardens in Oranienburg.

## Comments

Decompressing is not always easy. Prayers of joy to your family!

*—Barbara Skipper, June 8, 2017*

Decompressing is not always easy. Prayers of joy to your family!

*—Barbara Skipper, June 8, 2017*

You have been in emergency mode for a long time-- it is terrifying, exhausting, and so terribly hard. I imagine that it would be very tough to decompress. I think a therapist is a good idea-- and maybe some fun/relaxing activities. I think it is important to restore all of the reserves you have depleted.

Love and best wishes to you, to Christina, and to your children.

*—Cynthia Meyersburg, June 8, 2017*

Therapy, stiff drinks - whatever works.

*—Liisa Ecola, June 8, 2017*

Tell her, Colin!
□□

*—Boris Babic, June 8, 2017*

Oh my! Colin's gotten so big!

*—Lea Ann Schnakenberg, June 8, 2017*

Thanks for sharing! And remember a disagreeable child is a typical normal healthy child! You're headed in the right direction. May you find the decompression you surely need! Take care.

*—Marc Galmoud, June 8, 2017*

He is cute even in defiance. So glad that he is almost through the chemo. Talking with someone to help with decompression is a good thing. Best to you in finding that as well as progressing with the fall plans. Very glad to hear that you should have normalcy back for all the family. Thank you for posting. I still continue to pray for all of you.

*—Lisa M, June 9, 2017*

Big fan of counseling. Do whatever it takes, man!!

*—Jeremy Cook, June 10, 2017*

## the last drop

*June 14, 2017*

Today was the last day of chemo for the foreseeable future.

We had a glass (or several) of sparkling wine when I got home to mark the occasion. I won't lie: It's hard to feel like it's a party when we have no idea what's coming next or whether any of what has happened already has been the beginning, middle or end of this trip. But, still, it's nice to have some closure on this stage, even if it's frightening because we don't know what the next stage is.

Then again, that's life, isn't it?

We'll get another appointment with the oncologist to find out more about this anti-epileptic medicine he thinks might work. We're going to keep an eagle eye on Colin in case any symptoms show themselves again. And we're going to familiarize ourselves with every experimental therapy there is, just in case. The next MRI is on August 16 (the 40th anniversary of Elvis Death Day - a good sign, at least in my world). Before then, we're going to take the kids on a nice vacation to Denmark. More news as warranted.

## Comments

WOOT! Enjoy your well-deserved vacation. I'm heartened to hear this news and hope this is truly the end of this particular journey for all of you. Some things really are about the destination and not the journey. Hugs to you all from Ohio.

*—Michelle Lee, June 14, 2017*

Have a glass on me! Enjoy a worry-free vacation!

*—Marc Galmoud, June 14, 2017*

# Breaking Bad: Berlin

*June 17, 2017*

A lighter moment:

We're still pondering this anti-epileptic medicine theory the oncologist has suggested. One of its guaranteed side effects is to put children straight to sleep. Bearing in mind that we live in a neighborhood where just about everyone has children aged 2-10, a neighbor has pointed out that, should we start on this therapy, we could make a tidy sum on the side selling doses of this stuff on the black market to desperate parents, turning me into the Walter White of Berlin.

## Comments

:) Smart neighbour!

*—SG, June 17, 2017*

Funny.......

*—martha stanley, June 17, 2017*

□□□□□□

*—Boris Babic, June 17, 2017*

:)

*—Marc Galmoud, June 19, 2017*

Humor always helps in a pinch!

*—Phylles Lagarde, June 30, 2017*

## treading water

*July 18, 2017*

There's been mercifully little to report. Plus - in a weird positive signal - I've been too busy with everyday life to sit down and write here for a while. Yes, it means I'm exhausted, but I'll take it as a positive that we're allowing other matters to dominate our attention for the time being.

Had I been more focused, I would have udpated after our latest meeting with the oncologist, which was on July 10. We are feeling more comfortable about the anti-epileptics after he filled in more detail. It also helped that our friend Melissa did a ton of research and managed not to mention the word "death" once as a possible side effect. We're not 100% on board, but it's looking more likely that he will start this therapy in August, which would then last for three years.

There were also a lot of facts and figures thrown around. You can tell it is starting to get overwhelming on this front when Christina and I both remember that something about "40%" was mentioned, but neither of us can remember to what, specifically, this pertained or if it's a figure we should be happy or sad about. The one new detail (to us) is that, if the tumor were to recur, it would most likely do so within two years of the last dose of chemo. The last does of chemo was on June 14, which means the clock starts then. Here's looking at June 15, 2019.

Other than that, we've got two more weekends of antibiotics to give him. They're simply a precaution: He gets them during chemo and for six weeks after. It's gotten tricky because the only way we can get them in him is to hide them in his soy vanilla milk, with which he is obsessed. Except, as of Sunday, he's now randomly boycotting the milk. If this keeps up, I have no idea how we'll ever get the anti-epileptics in his system.

He's also going to start physical therapy. I don't see it - but I believe the doctor and Christina - that he favors one foot over the other. He also does have a habit of cocking his head oddly. Most likely, this is lingering pressure/damage from the mass in his brain stem. It should all be manageable. The tricky part will be finding a physical therapist that Colin will let near him. Right now, the list of people he lets near him is short: Christina, me, Emma, Noah, Ricardo (grudgingly), and our friend Stephan. Though he did cozy up to our neighbor Corinna yesterday, so there's hope that he's willing to consider a broader circle of friends. That said, we had a school event on Friday where Colin spent the day stalking some poor child wearing a Fireman Sam T-shirt, so maybe we just need to find medical professionals willing to wear the right cartoon character wear.

There's also a plan to let him start swimming, though I think it's going to be a long time before he lets someone not on the approved list take him into a body of water.

Otherwise, we head off on vacation next week. And I've begun my therapy, which has been a slightly odd experience, with extra doses of bureaucracy, because this is, after all, Germany. The status of our family retreat in the autumn is still not 100%, but we think it's going to happen. And we're still waiting on a final word about whether Colin will be accepted to the new day care facility, with a tentative starting date in December.

## Comments

Hope you will soon find a good solution to the antibiotics and the physio and may the holidays be as enjoyable as possible!

*—SG, July 18, 2017*

Prayers....I have several friends that have these timelines hanging over them...never fun. Love you all!

*—Barbara Skipper, July 18, 2017*

Prayers....I have several friends that have these timelines hanging over them...never fun. Love you all!

*—Barbara Skipper, July 18, 2017*

Always love reading your posts! Thanks for sharing and blessings to all□□

*—martha stanley, July 18, 2017*

Good to the backhanded good news. Enjoy your holiday!

*—Marc Galmoud, July 24, 2017*

## notes from Denmark

*August 6, 2017*

We're on a long-awaited vacation to Denmark. We've been here about a week and have about a week to go. Tomorrow is Legoland, so getting the children to bed tonight (and getting them to stay in bed) has been a combination of the horrors of Christmas Eve and night before your birthday bedtimes.

Almost exclusively, it's been great. Colin has been having a blast. One of his continuing problems is mild panic if he doesn't know where Christina is. If he can't find her, he'll make do with me, but it's grudging. This house is small enough that he can always tell where we are, so we've had rainy days where he just plays and plays for hours with his cars and his animals. I've sat down and read entire magazines undisturbed by him while his brother and sister do things in their room I'm probably happier not knowing about.

We've also had a few outings. We went to a Hans Christian Andersen themed playhouse this week where he got to wander around sets based on the stories. One, set up like an old kitchen, occupied him for hours as he ... apparently made onion soup (with play food!). Hey, if it makes him happy and keeps him occupied, I'm not going to judge. There's also been vikings and Copenhagen and a 16th century village.

That said, he has his first fainting attack in months today, when he thought Christina was leaving the beach without him. It's been so long since the last one that I didn't believe it at first when Christina said it was happening. It was doubly maddening, since I was holding him at the time. I was supporting his weight with my hands under his arms, because I was trying to keep him from lurching towards Christina. Or so I thought. Turns out that he was actually passed out. In my defense, the transition from the one state to the other is subtle in kids of this size: They often go all "sack of potatoes" when they're not getting what they want. So, that's not great. I mean, it is his first one of the year, but that's like saying "Hey, it was only your first stroke of the year." It leaves one feeling kind of defeated and drives the point home that we have a big decision in just a few weeks to make about this valporoic acid. We'll probably let him have it, but you keep trying to forget you've got this long road to go, and then there comes a point where you realize you have no choice but to pay very close attention to it.

Oh well.  As I said, tomorrow is Legoland.  Hopefully that will let us ignore our problems for at least one day.

## Comments

Legoland: were three children can be lost ;-)

*—Stephan Roch, August 6, 2017*

(((Hug)))

*—Cynthia Meyersburg, August 6, 2017*

Fainting attack aside, it sounds like a well-deserved vacation. I'm sure the kids will have a blast tomorrow.

*—Dan Wooldridge, August 6, 2017*

So poignant. Prayers for all as normalcy becomes more normal.

*—Barbara Skipper, August 6, 2017*

A pity there is this fainting to ruin the otherwise pleasant stay, as you so wwll describe it. Hope no more bad surprises any more and you all have a splendid day in Legoland!

*—SG, August 6, 2017*

# the spoils of Legoland

*August 8, 2017*

We survived Legoland.

I'm told Colin had a fabulous day. I was assigned to Emma/Noah duty, which meant I spent most of the day running to one attraction after another, only to begin wondering what the next attraction would be the second we began lining up for the one we'd just arrived at. I'm not saying it wasn't fun, I'm just saying I slept until almost 9 a.m. this morning.

And now they each have their bounty. He picked out his Cars Duplo playset by himself and has been playing with it for hours now. You are expected to sit next to him while he plays with it. You may read a magazine while he does so. If you attempt to introduce other toys to the new playset, they will be firmly and efficiently removed. If you try to play with him, you will be semi-politely ejected. If you try to leave the field of play, you will be escorted back to the sofa, where your magazine will be waiting for you.

## Comments

Prayers!

*—Barbara Skipper, August 8, 2017*

So cute! He lets you read the magazine at least :)

*—SG, August 8, 2017*

## the waiting game

*August 24, 2017*

We got Colin's latest MRI results today. Everything has stayed stable, which is the best we could hope for (barring a sudden disappearance of all tumor material).

Of course, it all took far longer than you'd expect to get this information and, when the doctor showed up, he told us he was one of the people on staff not so familiar with Colin's case, so he couldn't really tell us anything about the steps ahead. In short, the hospital is functioning efficiently as ever.

So, we have a new appointment for when Colin's prime oncologist is back from vacation. Hopefully he'll show up that day and finally we'll figure out how we're supposed to start him on this new medicine, the valproic acid. On the one hand, we haven't had to give Colin any medicine of any kind for weeks now. On the other hand, he's supposed to get this new medicine during the two years after chemo when the chances for a recurrence are highest. If they don't get their act together, the two years are going to pass before they even start him on the medicine.All in all though, good news.

## Party of Five

*September 1, 2017*

For the first time in ages, we are a five-person household again.

Our au pair, Ricardo - who showed up from the States at the end of August 2016 with only a basic knowledge of German, no experience of Germany and no real idea who we were as a family - finished his contract Thursday and pretty immediately headed off into the distance.  He's found love here in Berlin and has two weeks to enjoy it until his visa tells him he has to leave Germany on September 15.  He's taking his chance to pursue it, which I can't find fault with. Had I not pursued my German in 2003/04, despite having known her less than a year, I wouldn't be where I am today and in this glorious mess you call a family, loving many (if not every last) minute of it.

It is going to be a strange return to normal for us.  Until Tuesday, we had expected Ricardo to stay with us until his visa expired, so this is a bit like having a long-lasting bandage pulled off in one go.  School starts Monday and let's not even pretend that we're looking forward to getting Emma and Noah out the door by 7:15 a.m. without an extra pair of hands.  But we were going to have to start doing this sooner or later, so now's as good a time as any.

Plus, we probably need it.  As we talked to Ricardo in his final weeks - he was exploring some options that would have kept him in Berlin past Sept. 15 - we'd told him that he couldn't stay with us forever because, quite frankly, having him in the house isn't "normal."  Which is not a judgement on him.  We had simply never ever planned to have an in-house helper, and having this extra person is a change to the family dynamic.  I mean, introducing a new child to a household will disrupt it.  Multiply that by the difficulty of integrating a fully formed young adult with his own history, background, opinions and justifiable questions about why we put the mugs on *that* shelf or why we allow the kids to do this instead of that.

So, as difficult as it will be without him - and my niece Kaela, who took care of us for three months before that, as well as Rebekah, yet another niece, who had our back for three other weeks - but I think, in general, it's better for us to return to a five-person unit and find our own footing again.  Let's check back in a week and see if I still feel that strongly about living without extra support.

In the meantime, we're already meeting our old babysitter again tonight, because Christina and I hope to get out of the house every now and then, even in this new, post-Ricardo age.  On Monday, we'll meet with Colin's doctor (at least, that's what his calendar says), to hopefully get a more detailed analysis of the last MRI and to figure out how we're finally going to get him started on this valproic acid.  And, sometime next week, Christina is going to sign the forms that will enroll Colin in day care again, with a start date envisioned for December.  As exciting as this is, it will start the traditional avalanche of German paperwork, forcing us to figure out where we ever mislaid the 2015 tax statement, among other things.

I'll try to update next week after the meeting with the doctor - or after we get Colin's first post-cancer haircut - we'll see which yields more material.

## Comments

It will be a change not having the live-in help, but with the kids back to school it might indeed be less needed. Also hopefully it will not be too tough to hire hourly help in case you need it from time to time! Bon courage! (We are sure you'll manage just because not managing is not an option!)

*—SG, September 1, 2017*

As always, enjoy your posts!! Interestingly enough, just yesterday I asked Donna about Ricardo's status! You answered that one!! But have faith you two will handle this JUST FINE!

*—martha stanley, September 2, 2017*

## Dropping Acid

*September 4, 2017*

We met with Colin's doctor today.  It was only an hour after the time we were scheduled and he was under the impression we had long since started the valproic acid therapy, the very same therapy which we had planned to get the final details from him today so we could start the therapy.

Nonetheless, that's done.  We'll start in the next day or so.  The amounts involved are small, so hopefully we'll be able to sneak it into his milk.  We're also told that he won't pass right out after ingestion, so there should be time between the milk and unconsciousness to brush teeth, get him into pyjamas, etc.

Today's doctor had also had a closer look at the MRI, though there wasn't much more than to say it's stable.  A structure of some kind remains, but there's no way to say what it's nature is.  We'll all keep an eye on things.  In the meantime, Colin is now set to start physical/behavioral therapy, which is a step in the right direction too.

### Comments

I will give you my favorite quote (one which my then teen-aged children learned to despise!)
DIFFICULTIES ARE GIVEN TO YOU TO OVERCOME! (Supposedly it makes you stronger, like a butterfly struggling to get out of its cocoon makes its wings strong enough for it to

fly. But definitely is not popular with most people) Anyway, that is my contribution for now.

*—Phylles Lagarde, November 3, 2017*

## The German health insurance industry strikes back

*October 11, 2017*

I really need to remember to update this journal every now and then when things are fine. When there are no real problems. When all I have to say is "All the doctors are happy. Colin is healthy."

Perhaps next time.

The good news is that Colin's health is, as near as we can tell, fine. The valproic acid is a bit of a nightmare, because he's supposed to drink a lot of it at about the same time every day. We hide it in his vanilla soy milk, which he loves, every day around 4 p.m. Some days he knocks back 2-4 glasses of the stuff and gets his full dose without a blink. Other days we're stalking him around the house until 7 p.m., going "just one more sip. Please!"

No, today's issues are bureaucratic.

There is a plan whereby we will head off to our family therapy retreat next Friday. In the preferred version of that plan, all the proper papers will be filed beforehand and everything that needs to be approved will be signed, sealed and delivered.

But there is, unfortunately, also a possibility where that will not be the case.

As is so often the case, our problems stem from German bureaucracy. The short version is that, because I'm a regular employee at a private company, I am insured by the public health care system. As a civil servant, Christina gets to take private insurance, which is actually a mix of coverage by two different insurers. The kids are covered under Christina's plan (though, just to add to the confusion, the mix of coverage provided by the two insurers is set at different percentages for them).

Since Colin's health problem is what is necessitating this therapy, the guiding principle by the organizers of the retreat has been to saddle his insurers with all the costs of the care. There has, of course, been resistance, since the private insurers question why they should have to pay for my costs, as I have my own insurance. It has led to an impressive amount of back and forth between the different groups involved.

It has also led to a state of tension, because, weeks ahead of the departure, we knew for sure that we should bring extra towels for the swimming pool (not the ones provided for in-room use) and what kind of shoes to wear in the athletic facilities, but not how much, if any, costs we would have to pick up.

We thought we just about had this sorted out, when my human resources department asked what the German pension system (Deutsche Rentenversicherung) had to say about all this. As Christina learned yesterday, it's truly unfortunate that none of the administrators - who are allegedly the experts on these kinds of things - talked to this group. Because even though Colin's situation is what is prompting all this, I remain insured by the public system. And, while costs associated with my attendance at the facility can be picked up by Colin's care, the certification that I'm eligible to attend this program has to come from the pension system. That, in turn, is important because, without that certification, I might not be able to claim leave during my absence, meaning I might not get paid for the time I'm away.

Everyone is hopefully dealing with this now, but it raises the unpleasant possibility that this new group of bureaucrats might not make up their minds before we leave, or, even worse, reject the application. So, we might be heading into this therapy under the threat of having to forgo a month's salary. Which is not an intolerable situation, but a bit of a blow after all the non-medical financial outlays we've had since Colin's diagnosis.

Adding to the nuisance, I've decided to switch therapists amid all this. I was never sure that I had a great relationship with her, but a series of scheduling problems over the last week led me to the realization that I should not have settled for the first therapist available when I really, truly wanted to conduct my therapy in English. Of course, resuming the hunt for a therapist means I'm once again, essentially, speed dating my way through the Berlin psychotherapeutic scene, calling up doctors, getting told they have no time for new patients, and then looking for the next one. It is truly astounding. I have lived in Berlin 13 years this time around and, in my time here, everyone - from the Aldi checkout guy to my kid's oncologist to the lady at the Vodafone help desk to most Germans in my office to just about every waiter/waitress I've ever had in Berlin - wants to speak English to me as soon as I hear my accent. I've spent days of my life insisting that I be allowed to conduct business in German with people convinced (often wrongly) that their English is better than my German. And now, now when I really need a German to speak English to me, I can't find a single taker.

Back to the battle with bureaucracy...

## Comments

Sounds nightmarishly complicated - hope you will be able to sort it out in good time!

*—SG, October 10, 2017*

The German bureaucracy looks amazingly worse than the American bureaucracy that on January 1 kicks Steve and I off of the retirement health insurance plan that we have been on since 2001 at our own expense and promised to have throughout our retirement. Don't get me started on our countries lack of sane leadership dismantling the only other other health care system available. Don't get me started. Prayers for us all. Like you and your family need this type of uncertainty and confusion. So happy about Colin's progress. Prayers. Love you all!

*—Barbara Skipper, October 11, 2017*

You may already know about this website:

http://www.actberlin.info/

From their website: "ACT is an organization of International multi-lingual Therapists, Counselors, and Social Service Providers working in Berlin."

*—Dan Wooldridge, October 11, 2017*

Ugh! So sorry, Niels. Such annoying annoyances!!

*—Jeremy Cook, October 12, 2017*

I'm sorry you have to go through all this, on top of everything else. I hope it's all sorted soon with the best outcome. Also I didn't get a chance to wish you Happy Birthday, but I was thinking of you! Hope it was great and that the retreat was fun for everyone, despite the bureaucracy involved □□

*—GFSantos, October 13, 2017*

Since you already blew the chance to use "speed dating my way through the Berlin psychotherapeutic scene" as the headline for this entry, I'm hoping you at least find ways to randomly tuck it randomly into conversation, because that is a gem.
It need not be appropriate at the time for full effect. IE, if you're dealing with German bureaucracy challenges again, you could absolutely contextualize it by observing: "Well,

at least I'm not speed dating my way through the Berlin psychotherapeutic scene."

*—Jennifer Dlouhy, November 7, 2017*

## Debt relief

*October 13, 2017*

I have not mentioned enough on this blog how wonderful my company, dpa, has been through all this.  Within hours of Colin's diagnosis, I had a text message from the company's chief editor - someone with whom I normally have little contact, just because our jobs are so different - expressing sympathy and offering his full support. Since then, every time I've had to disappear for a health care concern, the rest of the staff has simply shouldered the burden created by losing one staff member.  It's truly been great.

Today, it happened again.  Since we're running out of options on organizing this therapy retreat, we called human resources and they made it as simple as possible.  I'm going to go on paid medical leave, and that's that.

Yes, I know, that seems like a simple solution, but there's a lot of bureaucracy in the background.  Had the application been turned in properly, one of the health insurance providers would have covered my salary during the therapy, freeing up money for dpa to hire a replacement in my time away.  This way, dpa eats all the costs.  And I'm not sure they have to do this, as I'm not technically "sick," I'm received therapy, which is, bureaucratically, different.

So, yay dpa.

We are going to make one last stab at getting Christina's health insurance to provide salary coverage.  The odds don't look good.  Apparently the law does not allow a civil servant to take their private sector-employed spouse with them on these retreats.  Trust me, I also find it odd that my disqualifying factor is that I'm not a government employee.  And, by virtue of that, we're being treated as if we're some kind of exotic mix of family, like we'd filed in our application "Oh, by the way, we're polygamous, so we'll need to bring along our six sister-wives. Also, we follow a cannibalistic diet, so make sure the staff in the kitchen is ready for that."

Anyway, for now, it looks like all systems are once again on go.  The trick will be to make sure we keep things that way for one more week.

## Comments

I'll bet you could get an insurance bureaucrat's head to explode by asking to bring your six sister wives...

*—Liisa Ecola, October 13, 2017*

Yay indeed for your employer!!!

*—SG, October 13, 2017*

Yea!

*—Barbara Skipper, October 13, 2017*

Yea!

*—Barbara Skipper, October 13, 2017*

Yea!

*—Barbara Skipper, October 13, 2017*

Wow.....Go God!!! How long is this Retreat? And is this for the whol-e family?

*—martha stanley, October 13, 2017*

Where there's a will, there's a way... even through German bureaucracy! Yeah!

*—Claudia Busch, October 13, 2017*

Oh, love that German healthcare, attitude by industry to healthcare and families, and, despite bureaucracy the Germans usually come through, in ways that we Americans in the USA can only imagine, and in some cases, doubt. And hopefully there will be some fun on the retreat.

*—Don Summers, October 13, 2017*

Enjoy the retreat! A break will do you good!

*—Marc Galmoud, October 21, 2017*

## Payday

*October 18, 2017*

Apparently the hidden cost of living in a social democratic paradise with free health care handed out like candy is that you have to spend every second of every day before you enjoy the health care dealing with bureaucracy.

In good news, Christina's insurer - after telling us last week that there was no way they could ever be responsible for covering my forgone salary because Christina was silly enough to marry someone who worked at a private company - decided within 12 hours of receiving the application we sent in for the hell of it that, look and behold, yes they can. Well, they can cover 80%. Heaven knows who will cover the remaining 20% or if it even will be compensated. At this point, I've just detached myself from the proceedings, viewing it as an absurdist comedy that I only directly interact with when someone needs my signature.

Otherwise, packing has begun. Plans are being made. We leave Friday.

Oh, and a psychotherapist whom I had contacted back in the spring - the rarest of gems, one who speaks English and is in my network - suddenly has an opening, so I'll be starting with him when we return from the therapy.

The only stumbling block was our receipt of the official doctor's letter from the hospital. None of this was necessarily news to us. None of this was unexpected. But it's still tough - after sitting down with a doctor who sounds relatively optimistic about Colin's chances - to then see him write it all down in black and white where, due to the choice of words they have to choose from, it doesn't sound particularly optimistic, especially the part where they write about his "unfortunate" chances.

So, that set us back a bit this week (and me with no therapist at hand), but we're recovering and moving on. Maybe his chances aren't the best, but he's beaten a lot of bad odds in the last year and a half and, from where I stand, he's still giving it his best.

## Comments

Hey, absurdist comedy worth 80% of salary - I'd take that comedy any day. BTW, the Dr. has to give all the possible outcomes, in case the worst one were to happen (note subjunctive here...) just to cover himself. Have a great retreat, and fantastic that you have found a therapist - is he American, or a German with good English skills? Guess you'll find out.

*—Don Summers, October 18, 2017*

Happy to hear about the positive developments! Enjoy your trip

*—SG, October 18, 2017*

Based on his accent, I'm going to say a German. However, his CV shows a lot of study in Britain/Ireland. And his name is also Colin, so that might indicate an English-speaking parent.

*—Niels Sorrells, October 18, 2017*

Don is right. Unfortunately, in this day and age, doctors have to cover themselves. If he is giving you positive feedback in person, things are looking pretty good. It's unlikely he would say positive things to you, if he didn't believe them. Hugs.

*—L Smith, October 18, 2017*

Colin will continue to be the poster child for miracles just as you have become the master of bureaucracies. Prayers and Happy Thoughts your way!

*—Barbara Skipper, October 18, 2017*

Colin will continue to be the poster child for miracles just as you have become the master of bureaucracies. Prayers and Happy Thoughts your way!

*—Barbara Skipper, October 18, 2017*

Usually, doctors are never optimistic when it comes to official paper work. I am glad that your trip will start soon. Enjoy it! On my way to Jerusalem soon, I will send you some prayers and good vibrations from the Holy City.

*—Claudia Busch, October 18, 2017*

Take the good where you can find it. Your friends are right: the doc's spoken words are probably closest to what he feels. Enjoy your trip and congrats on finding a therapist! A good one is always a help.

*—Marc Galmoud, October 18, 2017*

## exhaustion therapy

*October 23, 2017*

We've been at the retreat for a little more than 48 hours and I'm going to have to break it to my boss soon that I am going to need a vacation to recover from the retreat.

It's a very regimented program here (insert German joke at this point). Off the top of my head, we have so far been enrolled in: individual therapy for Christina and myself; couples therapy for Christina and myself; group therapy with other parents of children with brain tumors; massages (this one is not exhausting, I admit) and aqua-fitness.  Colin has physical therapy; aqua therapy; sports with his children's group; parent-child sports; and aqua therapy with a parent.  Emma and Noah have school; individual therapy; group therapy and sports class.  Thank God Colin doesn't really speak yet, otherwise they'd probably have him in psychotherapy as well.  They keep telling us to use our free time to relax or take a hike, and it's all I can do to not stand up and shout "Seriously?"

That said, the facility is nice.  I've stayed in crummier three-star hotels.  It has its quirks.  The original building is probably a century or so old, but the additional structures were all either built or remodeled in the 1980s.  Having grown up in Germany in the 80s, it's quite the blast of nostalgia for me, wandering the halls, trying to imagine how modern everyone thought the place looked in 1985.  But it gets the job done.

The room is an apartment with three rooms. Because they want to test our limits, apparently, you can only reach the third room with a ladder, meaning we get to spend about 30% of our time in the room keeping Colin from climbing and falling to his death.  Good thing we never have time to be here, I guess.  Also, oddly, when we got here we found the apartment only had single beds, none of them next to each other, giving more the impression of a middle school class trip than a home for the family.  We stuck it out for two nights and then got the psychiatrist's permission today to shove the beds together for Christina and me, so if housekeeping comes after us we can send them to her.  Now I just have to find a way to keep Noah in his bed.  He's invaded my space each night so far.  Imagine sleeping next to a cement mixer.  Now imagine sleeping next to one that talks in its sleep and hasn't bathed for a week.  Yep.

Mealtime is absolute hell. There is about an hour set aside each day for breakfast, lunch and dinner, meaning all 30-40 families descend on the cafeteria at the same time. The food is fine. The portions are a little small, but I think that's part of the general concept of healthy living. The problem is, we get to the table and then Christina runs off to fight her way through the crowd to get food for the kids. But Noah's food is already at the table, because they set out a special plate of food that won't set off his allergies. Which means I have a thrilling 10 minutes of keeping Colin from lunging into Noah's plate. Then Christina feeds the kids, I get up to get a plate and find that the horde has already picked the place clean. It's magic.

That said, there is a bar (I had just assumed that a cancer therapy center wouldn't have alcohol - silly me, it's Germany!) where they sell my favorite beer for 2.10 euros, so about half the price as in a Berlin bar. That takes away a lot of the sting.

Anyways, they all seem very nice. The place is a labyrinth, so I imagine I'll spend the entire four weeks learning my way around. Mostly, I'm excited to have found the "parent's oasis," which is just a room where the kids can't go. The decor looks like my aunt's living room, again from 1985, but it's got some damned comfortable chairs where one might happen to fall asleep after one's first massage therapy.

The kids are warming up to their teachers and, amazingly, Colin is going into the day care without much of a fuss, which gives us hope that he'll go without a fight when we start taking him to his real day care in December. Other than that, we've got to get to know the other families. It's a lot to take in, especially when you look at a family of five, trying to figure out which one of their kids had cancer, and then realize that they're probably looking at you with the exact same question in mind.

Anyways, they've promised us that the first three days are the worst, as we go through all the assessments and check-ins and scheduling. From here on out, we should just have to keep to the schedule, which will probably be an undertaking in and of itself.

## Comments

Go easy on the beer!
:-)

*—Boris Babic, October 23, 2017*

(((Hug!)))
Which beer?

*—Cynthia Meyersburg, October 23, 2017*

At least there is good German Beer and messages. Just don't have too many beers and get lost in the labyrinth, although, I'm sure that could be its own adventure unto itself.

*—Lisa M, October 23, 2017*

Sounds like a proper adventure! Good your sense of humour is still going strong, so there is chance you will have good memories from the experience. And now you understand why they keep paying you a salary where you are not at your real work... :) Bon courage for the remaining 20+ days!

*—SG, October 23, 2017*

I cannot even imagine even with my 66% German brain (according to Ancestry.com)...cannot even imagine!

*—Barbara Skipper, October 23, 2017*

How I love reading your posts, but had no idea this Retreat was four weeks long!! Think you just MIGHT be ready for your own home by then!!

*—martha stanley, October 23, 2017*

Sounds like a blast, really! How are normal vacations with kids any different? Just asking.

*—Marc Galmoud, October 24, 2017*

## a week in

*October 27, 2017*

We're still trying to figure out how we're supposed to be reacting to all the new therapies and stimuli being thrown at us in this therapy setting.  In some ways, I feel like I've been throw into an extremely deranged episode of "The Love Boat,"  ... and I have yet to figure out which one of the series regulars is Isaac.  Yes, there is a bar here.  I want a bartender with Isaac's vim and verve, is all I'm saying.

Otherwise, we're trying to figure out how we'll negotiate Friday, when I am scheduled for couple's therapy at 9 a.m., but Christina is down for an aqua aerobics class at the same time.  Questions have been raised about which spouse I would plan to bring to this therapy, and if I think it's likely that I'll have the spouse I began with if I bring the new Mrs. Sorrells with me to the psychiatrist.

On a serious note, we cope.  it's not fun and games being here.  Given the five different schedules we keep, I feel I've barely seen Christina since Saturday.  Noah is acting up. Colin is less enamored with day care than he was at the start of the week.   Group therapy with other parents has been both good and bad.  It's been good in the sense that we get to talk to other parents who have had similar experiences to us.  It's been bad in that we've been horrified to hear all the stories of the brain tumor patient families that were so much worse off  than ours ... and it's not like our story was a fun-filled jaunt.

## working at relaxing

*November 1, 2017*

In general, I'd say things have grown more relaxing.  Emma and Noah are growing more self-sufficient, even if "self-sufficient" sometimes is just code for sneaking back into the room so they can read books or listen to their CDs.  Nonetheless, it is easier with them finding their own way from event to event.  Emma has even made a few friends, though one suspects the quality of the friendship is heavily reliant upon the willingness of the friend to let Emma play Minecraft on their tablet/computer/phone.

Colin still is skeptical of the whole affair.  After initially loving physical therapy, he's turned pretty solidly against it.  Balancing that out, he loves going to his educational therapist, though that love is heavily purchased by the fact that she has a ridiculous assortment of Playmobil figures - including fire company ones - for him to use while there. I generally sit and read outside her office while he's in there and, so far, it sounds like a lot more play than therapy. But I'll take it if it helps him learn to warm up to other people.

That said, he has been showing surprising flashes of being outgoing. After the year in which most new adults turned out to be doctors or nurses (the worst version thereof being a nurse prepared to insert a nasal feeding tube up a nostril), he was understandably frightened of any new adult. But, about a month ago, he wandered over and started chatting up one of our distant neighbors - a guy neither Christina or i know all that well - at a block party. True, the "chatting" was limited since he only has a vocabulary of about 40 words spread between English and German, but it was a start. Last week, while waiting for his physical therapy - which means waiting in the tiny fitness room here - he watched one of the other Dads doing a workout and started mimicking the guy as he stretched, etc.  The Dad - who turns out to be a cop from western Germany whose job contract must stipulate he spend about half his day in the gym - was great about it and talked Colin through a tiny stretch. Perhaps he made it up on the spot, but it was still great to see Colin being so friendly.

A side note. The cop is always in the fitness room.  I'm trying to make use of it while I'm here.  Yesterday, the cop announced that he was going to do the "best stomach workout ever" and was willing to show anyone there how it's done. The guy is clearly in shape, so I figured I'd take any pointers I could get.  The lesson being: if you want to be able to walk without pain, don't agree to take fitness lessons from cops who are clearly in better shape than you.  Breathing hurts right now.

There are, of course, downers.  We all take our meals together and I find it impossible to not try to figure out which kid is sick in each family.  With some, it's obvious.  With others, I still have no idea.  With those, it's almost worse when you find out which child is the sick one, because you kind of hope none of them are sick.  And it keeps sneaking up on you.  Like the moment I realized the one girl was wearing a wig or the moment of clarity I had when I stupidly wondered why there were so many girls here with extremely short hair.  And then there's our neighbor, a 10-year-old boy who had significant muscle and bone removed from one leg because of a tumor, offhandedly referring to the time "when he could walk."  I'm not saying it's too much to take in, but it is a lot.

Then again, I think that's part of the therapy, just realizing that so many people are in the same boat as you are and they are all, somehow, surviving.  Several families here have been dealing with the results of cancer for five, 10, 15 years.  Just learning how they've coped - everything from personal mental health to tips on medications - is good to hear.  It's astounding to watch the children younger than Colin dealing with their trauma - one boy had a brain tumor and is having to relearn to crawl; another girl, maybe 2, had a leg removed - and they're just pushing through, because kids just want to move on, not dwell on their problems.  Perhaps it's not quite uplifting, but it emboldening to see that we're not in this alone.

So, tomorrow we'll get up and do it all again.  I won't share our schedule for the day, because it will traumatize you, but it is becoming manageable.  We've lost parts of two days because Colin keeps getting feverish - as all the young kids do when families from all over Germany gather to share germs - but I am still thinking that maybe we might get something out of all this.  If nothing else, I'm averaging 7-9 hours of sleep a night, which is at least two more a night than I'm used to getting.

And when all else fails, there's this to hold on to. The city of Triberg is about 15 minutes away by car and it's claim to fame is being host to the world's biggest cuckoo clock. Christina has promised (with witnesses present) that we can go and see it.  This could be even more life-altering than regular sleep.

## Comments

How I love reading your posts! Yes, there are serious moments, but there are also moments when a smile comes to my face! Just glad you are all together!! Enjoy the trip to Triberg! Our cuckoo is still going strong after 53 years!!

*—martha stanley, November 1, 2017*

So insightful. There is a lot to be said for a lot of sleep!

*—Barbara Skipper, November 1, 2017*

I think about you guys all the time. And am in awe.

*—Boris Babic, November 2, 2017*

Wow!

*—Lynda Schmitz, November 15, 2017*

# a life of leisure

*November 2, 2017*

Today we discovered that the athletic activities they incorporate into this therapy are good at engaging me, but bring out a competitive spirit that is dangerous for my fellow therapy recipients.  In aquafitness, we played a basketball game that saw me attempting to body slam women half my size and, at one point (perhaps unsurprisingly) turning into quite a bossy teammate. Then we warmed up for our class where we learn exercises to help our back. It was also a basketball-style game where I ended up swatting a woman in the face while reaching for the ball and sending her upstairs to the doctor.  Worse, she was on my team.  Look, I didn't see her, and, as penance, I must have done something to a finger on my other hand at one point and am now thinking about getting one of the cheap beers downstairs just so I can hold something cold in my left hand for a few minutes.

As further penance, the back exercises were torturous.  Charmingly, the class was led by a Ms. Ohnmacht, whose name translates, appropriately, into "unconscious" in English.

My only other problem is today's realization that I'm here with only one pair of sweat pants, one pair of gym shorts and a few T-shirts.  Every other Dad here seems to have a new tracksuit per day.  I'm trying to figure out if this is a comment on my fashion sense, an indication that I don't go to the gym enough or some combination of the two.

Colin continues to hate his physical therapist, though, if you give him his pacifier, he can be tempted to go into her room and then ignore every instruction she gives him.  Sadly, his educational therapist was out sick today, though we did stop by her door for a moment today to pine for her Playmobil collection.

In his cutest moment of the therapy so far, we were taking the elevator, which has a seat in it for the disabled. It's always falling open (it's supposed to stay latched in an upright position), so I fixed it, which earned me a "Sehr gut gemacht Papa" (Very well done Papa) from Colin.

## Comments

It's always reassuring to get the occasional pat on the back from a 3 year old! ... And you don't go to the gym enough!

*—Marc Galmoud, November 2, 2017*

## rehab renegade

*November 3, 2017*

Today I learned that the lady I hit in the face is named Nadine. This is good, because it means Christina and I can stop having awkward conversations that being with "I just had coffee with the lady you hit in the face" or "The lady you hit in the face says she doesn't think it's even going to turn into a black eye."

Also, we had couple's therapy today.  My main takeaway from that event came before we even started, when Christina forbade me from wearing sweat pants to the therapist session, because that's apparently breaking the dress code of a place where everyone else seems to have a separate tracksuit for every day.  And this on a morning in which the rest of my appointments consisted of massage and relaxation therapy.  It's good to know where your spouse draws the line, I suppose.

## Comments

I suppose....lol

*—Barbara Skipper, November 3, 2017*

I suppose....lol

*—Barbara Skipper, November 3, 2017*

I suppose....lol

*—Barbara Skipper, November 3, 2017*

:)

*—Marc Galmoud, November 3, 2017*

# The Black Forest Clinic

*November 7, 2017*

On some levels, I never want to leave this place again.  It feels safe here, like we're in a cocoon where nothing bad could get at us.  Of course, that's absurd.  I spend a few minutes every day wondering how, with so many children recovering from cancer, how we haven't had to airlift someone to an urgent care facility.  And, as sweet as everyone is here, it is not home.  The food is good, but the furnishings are utilitarian, the workout room is tiny and I miss sitting on my comfortable sofa in Berlin.

Also, every time we leave the place, disaster strikes.  The first weekend, we went to Freiburg to visit our friends Marc and Dana.  On the way home, our GPS tried to mislead us home by way of a footpath, which would have only worked had we been prepared to abandon the minivan for the last 4 kilometers of the journey.  Undeterred, we returned to Freiburg the next weekend, where Marc and Dana gave us a tour of the city (the first weekend, we didn't really leave their house, which I can highly recommend, especially if you want to get a glimpse of the kind of bathroom furnishings that were considered the cat's pyjamas back in the 1980s; act on this tip quickly, they're planning to redecorate soon in a scheme that involves significantly less brown and yellow).  The tour was great.  After two weeks of having every minute scheduled for us up here, it was wonderful just following people around a town having the sights pointed out.  It's also a very pretty town.

The GPS got us back from the second trip to Freiburg without a problem.  But then, on Sunday, we drove to Salem, Germany, to visit the washing machine of Christina's sister (and also the sister and her husband and their kids).  In yet another example of irony having its way with us, we got most of our laundry clean, but then we left the house too late and all got the pleasure of Noah vomiting explosively in the backseat about halfway home.  So, clothes clean, car covered with half-digested spaghetti.  Noah felt fine after the eruption (and Colin was mercifully asleep), but we then had to contend with Emma, who could have been empathetic about her brother's gutbuster, but instead chose to complain loudly that a) the car smells, b) she didn't want to stand outside in the rain while we cleaned the car and c) she could not imagine how she could have been left in a situation where her choices were smelling vomit or being wet.  We got started again, even later than we had hoped to be under way, only for the snow to start when we were about halfway up the mountain back to the therapy center.  We're at 1,000+ meters and all I'm saying is that thank heavens we had the foresight to get the winter tires on our car before we left.

That said, it's beautiful up here now, as the pictures (which I not only though to take, but managed to upload) will hopefully show. They're not the view from our room (that involves a whole lot more parking lot, but it's also still a nice view), but it's only a short walk from the facility to the spot where I did take them.  That's Emma and Noah sledding the hell out of the mountains in the second and third photos (Colin wiped out while being pulled on his sled and refused to even think about a downhill ascent).  And the final picture shows a view of the clinic, with the clinical areas in the foreground, obscuring the living quarters.

All the snow makes it prettier than it usually is, but it also means tonight's bonfire is cancelled.  That's tremendously disappointing to the kids, but kind of an upper to the parents, who feel this weather gives us a perfect excuse to sit inside and drink mulled wine.

## Photos

## Comments

It has been adventurous indeed - hope the good aspects continue to be more than any negativities and you all get an overall pleasant experience! The Snow so early is magical!!!

*—SG, November 7, 2017*

The ordeal with Emma could have been worse. You could have had three girls instead of one. Enjoy the snow and the adventures!

*—Marc Galmoud, November 7, 2017*

Glad you enjoyed Freiburg - hope you got to see the old part of the University - I did my junior year of college at the Uni there in 1964-1965. Was a great place to visit and live in those days, and not so touristy as I hear it is today. Sounds like your retreat has been excellent!

*—Don Summers, November 7, 2017*

Beautiful pics!

*—Barbara Skipper, November 7, 2017*

Beautiful pics!

*—Barbara Skipper, November 7, 2017*

Say hello to Prof. Dr. Brinkmann and his Schwarzwaldklinik!

*—Stephan Roch, November 7, 2017*

## another way to die

*November 8, 2017*

So, one of the things I'd been missing up here was talking to other Dads about how they've coped.  There are group therapy sessions, but most of the other guys seem to avoid those (and some who do show up, do so grudgingly).  I have started talking to the cop (Andy) in the gym, which was a start.  Yesterday I decided to take advantage of it being men's night in the sauna, figuring that might be a place where people go and chat.  It did, and we talked, essentially all agreeing that cancer does indeed suck.

It also played a role in how I almost died today.

A week ago, they announced that the climbing platform would be open to the parents today.  I had decided on my own last week that I wanted to do this.  But, this sentiment was, of course, reinforced by several guys speaking over post-sauna beers about how they were totally going to scale the platform.  I mean, if a guy with military and police training can do it, why can't a copy editor who's really good with semicolons?  I defy you to come up with a good counterargument.

Today dawned and the rumor quickly spread through the clinic that the climbing adventure would be scrapped.  There was a light snow when we woke up.  Even when that stopped, it remained cold and damp.  Visibility can't be much more than about 20 meters with all the fog.  But, during lunch, they announced that the climbing would happen.  So I wandered over, secure in the knowledge that my ability to explain gerunds would translate into climbing prowess.

We were divided into two groups. Each had to climb an 8 meter ladder to a platform. My group then had to walk across a wooden log, probably, about 4 meters long, reach an opposite platform, turn around, get halfway back, then allow oneself to be lowered to the ground. Three guys went ahead of me. Two made it. One froze when he got to the top of the first platform. The woman who was helping us is tiny, so she always made sure one of the other men was standing behind her, providing her with ballast so she could lower us to the ground safely.

When I got to the top, I could see that the guy who was supposed to be providing me with ballast - I've taken to calling him Joe-Bob - was attempting to provide the ballast, but his wife was trying to take the reins from him because she didn't think he would do it right. I did think for a moment "Well, that would be a crummy way to die," but I figured I was secured and let's not forget the power of the guy talk the night before. I got across the beam, slowly but confidently. When I turned around to start my way back, I slipped a bit, because my shoes and the log were both wet, and there was probably a little bit of ice. Also, I'm a klutz.

Don't worry. This was the least of my worries. The tether worked. I wobbled around a bit up top and then managed to negotiate myself into a sitting position on the log, perhaps closer to the platform than my minder would have liked, but still manageable. She reminded me what to do - lean backwards and stretch out my legs - and it worked fine, for about 2 seconds. Then I suddenly dropped about 4 meters in a second. Bystanders tell me that Michaela, the organizer, went about 3 meters into the air. Apparently Joe-Bob, who is presently low in my esteem, couldn't understand the simple instruction of "hold my belt and push down when we let the 100-kilogram guy dangling from the rope down" IN HIS NATIVE LANGUAGE and was just sort of standing there when she started trying to lower me. They caught me about a half meter before I hit bottom and I suspect the only lasting damage will stem from the fact that I probably managed to pull every muscle in my body as I tensed up waiting for impact. I'll be lucky if I manage a dead man's float in aqua fitness tomorrow.

I hung around for a while and even attempted the second exercise, which was a whole lot harder, because it involved stepping across a series of hanging logs when you are 8 meters up. I even made it halfway across when my muscles suddenly reminded me that doing all of this is a far cry from correcting prepositions in a text about Thai politics and it was time to get back to the ground.

During all of this, Christina and Colin stayed safely at the baby climbing wall, which was indoors and which didn't interest Colin at all, even though he spends all of his free time in the room trying to scale the ladder to our extra room. Emma and Noah also seemed to escape the nonsense. So, we all survive for yet another day. Tomorrow an oom-pah band visits the facility, so I can't promise no fatalities tomorrow. But, for today, we're fine.

Otherwise, we keep moving on.  I find it shocking how easily I'll just start talking to people I don't know that well, asking things like "And where was your kids tumor?"  I guess we're all battle-hardened.  Our neighbor works in a hospital and told us the horrible story today of how they removed the stitches from the surgery incisions on her son's legs after removing substantial amounts of tissue to get at his tumor.  "Do you want to see the pictures?" she asked.  "I'm good," I said.  "They're not so bad," I said, forgetting that she had, not three minutes ago, told me she works in a hospital and probably has a higher tolerance for gore than I do.  Dear God, had you told me this was a wound with gangrene I would have believed you.  But she wanted to share.  Indeed, I think she needed to share.  So, I looked and noted that, indeed, the pictures from today were better than the pictures from a few months ago, but there's still no erasing the fact that there's no way to explain a universe where something like this can happen to a 10-year-old.

## Comments

:-)

*—Boris Babic, November 8, 2017*

How easy will it be trying to reintegrate into normal life back in Berlin?

*—Don Summers, November 8, 2017*

# winding down

*November 15, 2017*

We're winding down our stay here at the Katharinenhöhe therapy clinic.  One more load of laundry to do.  Some things to mail back, because our car was at capacity on the way here and arts and crafts have been committed on the premises, meaning our car would pop if we tried to pack it all in there.  This week is a few random activities, but mostly final meetings with the therapists and getting progress reports on how they think the kids did here.  It's starting to feel as busy as it did the first few days when we were trying to get all of our appointments down.  However, I imagine the most stress will come Saturday, when 40 families simultaneously try to check out of their rooms and get their cars loaded by 9 a.m.  I expect fistfights.

Things have been calm since I last posted.  We planned to take it easy our last weekend here and maybe do some very local sightseeing.  Instead, we got weather.  I don't know if it was a particularly bad storm or if things just feel that way when you're on top of a mountain, but the entire weekend felt how I imagine being trapped in a squall at sea would be.  Christina made a shopping run downtown and then announced that no one really wanted to leave the building all weekend.

Of course, it meant we were all trapped together for a weekend.  I think, if you consider that these last four weeks has been about each of us getting our individual heads straightened out, then you have to work under the assumption that our next step will be to learn how to function as a family again, and we've got a lot to figure out there.  After a year and a half of Christina and I leaving the older two kids in the care of various babysitters and relatives who often gave them electronic entertainment, while we took Colin to the hospital (where he often ended up with a tablet in his hand to pass the hours), it's a bit of a challenge being all together and going "Oh, we could play Clue" or "Oh, we could kick a ball around" mostly because the kids default to electronics. And I realize that's hardly specific to our family, but it feels a bit like a self-inflicted wound, albeit one we had to incur to deal with the larger health problem staring us in the face.

So, we're working on that. We marched them out into the snow today, which went mostly well for Emma and Noah. Colin seemed to think he had been kidnapped by the Viet Cong (in the Black Forest, of all places) and mostly screamed every time he saw snow (which was everywhere), so that was draining. But it's a start. And, if all else fails, we can always get them to agree on the pool. We'll just have to figure out what to do back in Berlin when there are not so many distractions within 500 feet of us.

Otherwise, the activities have continued. I pretty much hurt everywhere. There is another cop here, a policewoman from a small northern German town. I keep ending up in dodgeball scenarios with her and the other cop, which makes one wonder how one is supposed to relax when you're spending all your down time being pursued by individuals trained to catch people, but I've survived. And have managed not to injure anyone else in recent days.

The highlight was Monday, when we had the traditional St. Martin's parade. If you don't know what these are, I have one word for you: Wikipedia. But they're nice, with kids marching around with lanterns. In Berlin, we usually have a band of some kind leading us through the streets. There was no band here, but we had a guy with a guitar and the older kids carrying actual torches as they led us into the forest. The only downside came when someone, perhaps inadvisably, gave one of the older kids, who is a bit mentally impaired, a torch, leading to a lot of people suddenly moving very quickly to give this one kid a very wide berth. Otherwise, we survived. I would have more pictures, but I had to carry Colin on my shoulders. Not only does it mean that I have to hold him at all times, because he also tends to treat these moments as another Viet Cong hostage situation, but he also insisted on holding his lantern directly in front of my eyes most of the time.

Tonight there's an accordion concert, which should be revealing. Tomorrow, there is karaoke, which has a lot of people worried that there's no way any of us can get drunk enough quickly enough to participate fully ... and, finally, we understand why the alcohol is subsidized up here.

And then it's back to Berlin, where reality awaits. Thanks to the superior house sitting of my buddy Jens, I already know that a decent stack of bills is waiting for us, including, charmingly, about 3,000 euros of bills from Colin's treatment in **April 2016**, which really gets you worrying about how much longer we're going to be paying for the first round of care he received.  It also gets me worried about how long it's going to take to reclaim the costs of this medical adventure.  But I can worry about that on Monday.

## Photos

## Comments

I am going to miss these amusing descriptions of your Retreat together and all the adventures that you have had the last four weeks. Always bring smiles to my face! And simply can not believe how much your two eldest have grown and changed!! Hopefully Berlin will be a tad warmer? And no snow! Going back to work will be fun□□

*—martha stanley, November 15, 2017*

I love your writing! So descriptive and illustrative that some experiences, challenges, and human interactions transcend all cultures. Thank you for sharing your experiences! I will miss them...perhaps you could start a blog in your new found spare time. Lol

*—Barbara Skipper, November 15, 2017*

# Accordion discordia

*November 15, 2017*

Had you told me a year and a half ago, when Colin first got his diagnosis, that a side effect of all this misery would be that, one day, I would find myself in a dining room in the Black Forest listening to a 20-person strong accordion band performing hits of yesterday and today, I probably would have backhanded you.  And yet, here I am.  In this photo, they are performing "The Lion Sleeps Tonight."  When I one again have a connection that is not designed to break either me or the internet, I will upload the videos I took of them performing Bryan Adams' "Summer of '69'" and Whitney Houston's "One Moment in Time."

## Comments

Must... see... video.

*—Lisa M, November 15, 2017*

Can't wait!

*—Lynda Schmitz, November 15, 2017*

I hope it's soon. Little did I know that I've waited my whole life to see amd hear that

*—Lea Ann Schnakenberg, November 15, 2017*

I wonder long it takes to find 20 accordion players?

*—Liisa Ecola, November 16, 2017*

## The Gym Nerd's Revenge

*November 16, 2017*

We're sitting in the room on our next to last night of the retreat, wondering how long it will take for the kids to go to sleep and wondering, if they do, if we ought to go to the karaoke evening.  If there isn't a specific word that describes dread of karaoke - especially when 50% of the song book is most likely to be German pop ('Krautrock,' as I call it) - then there ought to be.

We're doing a lot of final evaluations.  Everyone seems to think Colin made some progress.  Christina is still a little on the fence about whether this was all worth it, mostly since it feels to us as if we spent most of our time shepherding kids from event to event - i.e., exactly what we do back at home.  As for myself, I'm still pretty happy with the whole experience.  I lost a whole pound, which is quite impressive when you consider the access I had to cheap beer.  Also, during the final sports class, I was told I was doing push-ups perfectly.  That moment all by itself probably erased decades of repressed trauma from all my poor performances in gym class in high school.  The trick apparently was to stay about the same weight into my 40s while many of my peers, um, didn't.  All I'm saying is that, when we play team sports, no one groans and says "Oh no" when I'm put on their team.  Kind of the opposite, actually.  And that's a far cry from my gym class experiences back at Heidelberg High School.  Indeed, I kind of want to track down all my gym teachers now so I can write letters to them and point out that it turned out I wasn't hopeless after all.

Also, I'm happy to report that there was one final injury during sports class today and I had nothing to do with it. (Less happily, the poor woman is on crutches and has to escort a hyperactive 4-year-old home by train by herself on Saturday).

We're half packed.  We wised up and just mailed some stuff home.  We're dreading sorting through our finances upon our return (I don't draw a salary this month, but will get reimbursed at least partially by the insurance.  I shudder to think how long it will take for that bill to get paid), but I think the kids might appreciate Christina's cooking more after a month of the cafeteria here (which was actually quite good) and I'm really ready to ditch the bed here.  Also, I think my liver would like a little more distance between me and the closest bar.

And finally, one more beautiful Black Forest photo, courtesy of Christina.

## Comments

Amazing picture! I always skip the Karaoke in ANY language. Lol

*—Barbara Skipper, November 16, 2017*

Great photo! And thank you for your tales of wonder and woe! Looking forward to seeing you back in Berlin.

*—Marc Galmoud, November 16, 2017*

## We are Berliners again

*November 20, 2017*

After what seemed like a never-ending drive across Germany, which stretched across two days, three McDonald's and one drum set, we got back to Berlin late Sunday. We then pulled ourselves together and headed off to school/work on Monday. I don't know how the kids are doing, but I certainly could have done without a German political crisis on Day One back at work.

But still, it is odd to be back. It was odd to be driving back. It was odd to get up at 5:30 a.m. and shove kids out the door. The train felt strange. I steeled myself for work with Guns 'n' Roses, which is not my usual method.

I'm finding that I miss a lot of little things about the sanatorium. Like, walking past the toast stand at the breakfast bar, where the toaster seemed to regularly steal the toast. Every time I walked by that toaster, someone was primed to shove a fork in it and pull their toast out, and every time I wondered if this would be the moment someone electrocuted themselves. It's an odd thing to miss, but it was a nice ritual.

The fights about the laundry room were also a highlight. There were only four washer/dryer combinations in the whole facility, which is not a lot to share among 34 families. The system only worked in that people had to sign up for one-hour slots in which to use the machines. As predicted, things got a little grouchy in the last few days, since everyone wanted to do their laundry before departure. I joked with Amina one day, who was going to try to slip in and do laundry without an appointment. When I ran into her later, I asked if she'd been successful, prompting a small tirade.

"She's signed in for two machines at 3 p.m. Two machines. And now it's 3:20 p.m. and only one of them is in use. What do you do in this situation?" she fumed.

I said it sounded a lot like a question I'd expect on a German citizenship test, prompting her to roll her eyes and leave. I'm used to that reaction in Germany though.

I'm going to miss the Tower of Babel aspect of the place. Most people were from southern Germany, but there were families from as far away as Bremen and Cologne (and Berlin!). And you have to understand, even though most people can speak high German, they like to revert to their native dialect when they're relaxed. Which works fine if one dialect is dominant. Here, you'd have evenings over beer with about six different dialects going at once. I spent many nights having no idea what was being said. But, I also picked up a few new words. To my German-speaking friends, do not be surprised if I start using "daheim" in regular conversation. I've decided I like the word.

I think we all benefited a little. Noah learned a little bit about dealing with others. Colin learned that not all adults are scary. I learned that I like sports more than I thought. Emma made a lot of new friends. Christina probably enjoyed the experience the least of all of us (basically, she just transferred parenting duties from Berlin to the Black Forest), but even she says she feels she got something, even if she can't tell you exactly what.

I'm not saying it was all fun. Hearing some of the stories of the parents with blind, disabled, etc. children were murder. Before this, I had to worry about Colin. Now I know that I'm going to worry about these 33 other children as well, because I spent so much time hearing about them and watching them. Statistically, this is not going to end well for some of the families. On some level, it means we share the burden. On another, it means there's more to worry about. But I have new friends now. We got some ideas from others. Hopefully we're all a little stronger. Hopefully we all have a few more people we can lean on when times turn tough. I suppose that's all you can ask for in a situation like this.

And yes, to everyone out there demanding it, the accordion videos are coming. These things take time...

## Comments

Bon courage getting acclimatised back to your usual routine!

> *—SG, November 20, 2017*

Welcome "daheim".

> *—Stephan Roch, November 20, 2017*

Amen!

> *—Barbara Skipper, November 21, 2017*

# Are you ready for some accordion?

*November 22, 2017*

As promised.  You'll never listen to Bryan Adams the same way again.

Enjoy the Noah cameo (and all of his attempts to block the camera with random objects on the table.)

## Comments

Glorious!

*—Lisa M, November 22, 2017*

OMG... is there an English word for "fremdschämen"?

*—Claudia Busch, November 22, 2017*

# Yet more for the accordion lovers out there

*November 22, 2017*

This one's harder to recognize, but I'm told on good authority that it's Whitney Houston's "One Moment in Time."

## Comments

Wow... just wow!

*—Lisa M, November 22, 2017*

# Add it up

*November 24, 2017*

Day after day, I will scramble and I will pay. But the day after today...

I'll probably just have more bills to pay.

This is the frustration of the return from therapy talking. Ignore it.  But only a little bit.

So, we got back late Sunday.  The kids went back to school Monday.  I went back to work.  Christina has to keep everyone's head above water.  Monday we got a babysitter and went to a concert.  Tuesday we planned for Thanksgiving (and, by planning, I mean we tried to tell our friend Jens, who volunteered to cook Thanksgiving, what to expect and how to cook around Noah's allergies.  It turned out amazingly well and I'm going to nominate him to appear on a reality cooking show when I have a free moment).

And Wednesday? Wednesday was my first crack at trying to figure out our finances again.  Beyond the usual mess we've been in ever since Colin's diagnosis, I drew no salary while we were away for therapy (the insurance will compensate us for some, if not all, of it).  The therapy center very efficiently had our bills waiting in our mailbox when we got home (14,000 euros), and then we incurred another 4,000 euros of bills in our absence, including the curious bills from April 2016. And, this morning, I saw a new 1,200-euro bill in the living room I'd never seen before.

Of course, even if I scrape together a 20,000-euro insurance claim tonight (it will also include the mileage for the drive to the clinic), this will still be far from the biggest claim I've filed since all this began.  But still, it makes you think.  We're making this work, but we're getting most of our bills recompensated.  It's still hard.  And then you think back to the retreat and realize how much harder it is for the others.  One of the mothers told me towards the end that their initial claim to the pension system was rejected because her child, who has Down's Syndrome, would never theoretically have a job and pay into the system, meaning they were under no obligation to support her therapy.  The regular health insurance provider then stepped in, but it is mind boggling to hear stories like this. Ultimately, I think it boils down to little more than I'm tired of "bill paying" being one of the main ways I spend my off-work hours these days. Ditto "stretching our finances until the next insurance check arrives."

## Comments

*—Barbara Skipper, November 24, 2017*

This does sound very frustrating and stressful. I'm sorry you have to go through this, on top of everything else. Hearing others' stories does put it all into perspective. Colin is doing well, your family is healthy and happy, and those are the most important things. Stay strong, friend. Happy Thanksgiving and I hope it's a great day for you all □□

*—GFSantos, November 24, 2017*

Stay strong, stay positive. It'll get done and be behind you.

*—Marc Galmoud, November 24, 2017*

Happy Thanksgiving to all of you!

*—Stephan Roch, November 24, 2017*

## care package

*December 4, 2017*

I like to call this photo "Portrait of a Little Boy Unaware He's About to Return to Day Care."

He had his first day of care, though it was only an hour.  And Christina and I were there the whole time.  Germans introduce children to day care *very* slowly.  It will probably be weeks before he's staying there more than a couple of hours by himself.  It seems very nice and it's small and there are a few children we know there.  That said, I'd say Colin's prevailing attitude towards the whole thing was skepticism.

And then we took him with us Christmas shopping at Toys R Us, where he personally tried to heist a Lightning McQueen car big enough for him to sit in.  'Tis the season.

## Comments

Treasure every minute, every second, even the frustrating ones...life is too precious not to be treasured!
It sounds like small progressive steps are being made. Congratulations!

*—Phylles Lagarde, December 7, 2017*

I love this picture!

*—Lynda Schmitz, December 10, 2017*

## Undiscovered territory

*December 17, 2017*

The sentence I think I've grown to most dislike in the last two years - with the obvious exception of "Your son has a brain tumor" - is "No one's ever asked for that before."

I don't know if it's a feature of the kinds of insurance we have or the rarity of Colin's tumor, but at every step of the path, there seems to be a disconnect between the caregivers and the insurers that requires some step or piece of paper that one side or the other has never, ever, in the history of health care had to require before.

So, here we are, two weeks after filing the insurance claims for the medical retreat and the private insurer Christina and the kids use - which provides about 20-30% of the coverage - says they need a medical report from the therapy center before they can pay out.  The therapy center, of course, has never, ever had to provide this kind of document - and this place pre-exists World War II.  It will all work out, but again, one more annoying bureaucratic step.

At least the government insurer, which provides the bulk of the coverage, paid out without a fuss, so we have money to cover most of our bills. Annoyingly - I see it as kind of a "screw you" to me from the health care system - each of us received a separate bill and, because of the limits to how much I can transfer a day, I have to pay one bill a day for the next five days.  Just kind of a constant drip-drop of bureaucratic fuss to see me through the first days of my Christmas holidays.

That said, we're fine.  The kids have three more days of school and then we're headed down to Bavaria for the holidays.  The holiday stress seems to be weighing on us a bit more this year, but I think that's just a function of going straight from therapy to the Christmas rush.  Colin is integrating well into his day care, though I guess we'll have to see if a two-week break for Christmas sets him back to the starting point.

And, finally, this is a bit delayed, but a photo from the St. Nicholas festivities, when good little boys and girls (allegedly, that's the only kind we have in this house) get treats in their shoes.  Colin scored this Playmobil emergency services helicopter.  It actually belonged to one of his therapists at our retreat.  After every session, he's boost it from her room and, in the end, she decided to just let him have it, since she was getting a new one for her room with a Christmas order.  It's good to see him reunited with one of the great loves of his life.

## Comments

Mulled wine, anyone?
Where are you going in Bavaria? I fell in love with that place.

*—Jeremy Cook, December 17, 2017*

I love reading your posts and I'm so glad Colin is doing so well. Merry Christmas to you and your family.

*—Jeanne Clayton, December 18, 2017*

Sounds like "normal as you know it" is actually getting back to normal"! Hope your Bavarian Christmas was wonderful! Jim got a new aortic heart valve and a pacemaker for Christmas! So Santa was good to us, too!
Prayers,

*—Phylles Lagarde, December 30, 2017*

## Season's end

*January 8, 2018*

We mark the end of the festive season today.  For some families, that's when New Year's comes. More faithful families mark if on Three King's Day.  It's not officially over in our household until today, Elvis' birthday (He's 82 and doing fine, if you must know).

Anyways, we've made quite a bit of progress the last few weeks.

On the insurance front: After our secondary insurer initially told us that they would need the Form That No One Has Ever Before Requested before they could reimburse us for the family retreat, Christina drafted a harsh letter to them. But, before she could send it, the full payments for her and the kids showed up, so one wonders how important that letter really was.  They also said they would need more time to process my claim, because - and let me walk you through this - before we left, they agreed they would pay something like 9 euros a day towards my costs.  And we were there for 28 days.  So they need time to figure it all out.  28X9 is apparently a tricky proposition for them.  I just came up with 252 euros in about 10 seconds, but I'm not a highly paid insurance adjudicator, so I imagine it takes them longer.

That said, we have the money, all of our bills are paid, we're expecting a few more payments and we actually have cash in hand.  I don't remember the last time this happened, so I'm just assuming there's some giant bill waiting out there with our name on it.

On the day care front: Colin was warming up to the group nicely before we went to Bavaria for the holidays.  I figured a two-week pause for Christmas would leave us with a lot of ground to cover, but by the end of the first week back, he was eating lunch with the group (indeed, he was eating peas, which he has never eaten at home) and taking naps there, etc.  As I write this, I'm in a house bereft of children, because we've shipped them all off to professionals.  It's kind of liberating.

On the holidays front: We all scored.  I think the pictures I'm attaching of Colin lounging on a sofa at his grandparents' house with the bulk of his loot strewn before him is all we need to attest to that.

On the health front: No complaints.  The next MRI is at the end of the month.  Think of us then.

## Photos

## Comments

That's great news! Glad the holidays went (mostly) smoothly :)

*—Maddie Sheesley, January 7, 2018*

Happy New Year! Lovely to hear things are good and may they continue like this!

*—SG, January 7, 2018*

Am thinking of you always.

*—Boris Babic, January 8, 2018*

## overshare

*January 8, 2018*

One thing I forgot to say - perhaps because I didn't want to be a downer - but the whole situation still has a way of sneaking up on you.

On Saturday, I took Colin to a friend's fourth birthday party. Indeed, I'm pretty sure this was the first birthday Colin ever attended (not counting siblings'). Because of scheduling fun, Noah tagged along.

I was tired (my own fault), perhaps a little hung over (definitely my own fault) and I'm never keen on jumping into a room of people I barely know and chit-chatting in German (my therapist and I are still working on who gets the blame for this one), so I spent most of the time hanging out with the kids. However, I did wander over to see what the adults were doing every now and then. I did end up chatting with one of the Moms a little bit.

So, picture this: I wander back to the kids room after yet another brief foray to the adult side and find this Mom sitting on the floor playing with her kid. Noah and Colin are both mucking about in the room and I hear the tail end of a conversation between Noah and the Mom, in which he says (in German) "And that's why Colin's a little strange, because of the brain tumor."

Now, I don't know if the Mom believes Noah or thinks he's just making things up or thinks I'm an awful person for standing there and not disciplining Noah for making up health lies about his brother. I certainly don't have the energy to say "Yeah, brain tumor. Right here." But it seems unfair to just leave her hanging there with this tidbit of information (which is what I did). And I don't want to tell Noah to NOT talk about his brother, but I don't have the words to say in a way a 7-year-old will understand that "Maybe not everyone is ready for this information."

So, there's always something to do.

It's not the end of the world. But it's the kind of thing that always sneaks up on you when you're not paying attention.

In other news, Colin briefly refused a diaper today, and all of our furniture apparently lived to tell the tale.

## Comments

Don't worry about other parents. They will be fine. And I think it is great that Noah speaks so freely about it. He is not ashamed and he doesn't make up excuses or lies about his little brother but protects him and explains, why Colin may behave a little different than the other kids.
And I don't think that any parent will believe that a seven year old kid can make up anything like that.

By the way, Colin was definitely the only kid that was invited to all of Simons Birthday Parties! He was here last year for Simons third Birthday with only one other friend and he was the only friend invited for the second birthday. (I don't remember what we did for his first birthday ...)

*—Sabine Kahl, January 8, 2018*

Hey! That's the FUN part of being a parent...there is ALWAYS the UNEXPECTED when going anywhere with your children (kids)!
You just have to live with it and learn to laugh instead of crying. You have now joined the "EMBARRASSED PARENT CLUB".

*—Phylles Lagarde, January 17, 2018*

## MRI Monday

*January 29, 2018*

As I type, Colin should be either in the MRI or getting prepped for it (though, let's not underestimate the hospital's ability to throw a curveball at us in terms of delays or systems outages).  We have no particular reason to be apprehensive about this one.  He's displayed none of the signs you'd expect to see if the tumor was coming back.  But still, but still, but still...

It's a warped world we live in.  I told my therapist recently that one of my bigger problems is that I don't feel I can be sad, because we seem to have survived this thing, but I can't feel happy, because I have no guarantee that this is a permanent situation.  So, what are we?  Apprehensive might be the best word for it.  We watch Colin obsessively.  If he were to begin vomiting, that would be a clear (and obvious) sign.  What trips up, literally, is his predisposition to tripping and falling.  That was also one of the signs two years ago when this happened.

Now, back then, he fell down a couple of times for absolutely no reason.  Today, he's days from turning 4 (it's on Saturday!), so being clumsy is part of the job description.  He also does still have the disability from the tumor remnants in his neck, which throw him off and will probably require years of therapy until he learns to compensate for the balance problems.  But, lord, he falls a lot.  And, more often than not, there's a reason.  He tripped over his own feet.  He tripped over our feet.  He tripped over some furniture.  He moved too fast and slipped.  A sibling was involved (this is, perhaps, the most common one).  But it means every time he slips, we essentially have a special episode of CSI in the household to figure out his trajectory and what might have laid in his path, because you can't see every time he falls.  Seriously, he's a blur of motion, so there's always an air of mystery.

I think the worry I have is that neither of us wants to come up with the conclusion that there was no reason for the fall, because that leads to a truly awful conclusion.  So, are we fooling ourselves?  I don't think so, but, lord knows, I don't want to be the one to see a fall for no reason.  I certainly don't want to have to tell Christina I saw one.  But then I start worrying that we'll ignore evidence just to protect our psyches, when we're ignoring something vital to Colin's health.  Cue the vicious cycle.

That said, there's very little we can do for it, so we just move on.  Christina and Colin will be back later in the day (I had to stick home to shove the older two siblings out the door to school) and then we'll see.  Results won't be available for a few days.  Indeed, I don't think we're sitting down with the doctor to discuss them for almost two weeks. Nonetheless, any thoughts are always welcome.

## Comments

Waiting for information does cause a lot of anxiety but hopefully you will only hear encouraging news! I very well understand the reasoning behind looking for a reason for his tripping - may there always be an innocuous explanation and may he (and you) have a great time on his 4th birthday!

*—SG, January 28, 2018*

I figure the worry/fear you live with, after the ordeal Colin and you have had to endure, is as real as the shock we feel that one time we touched a live wire.
Every time he get's an okay and each day he does well, it weakens. Every time he trips and tumbles, it recharges some.
We all hope for more and more of the first and less of the second and for that numbing worry to go away.
You guys did so well in the face of terror and continue to do well.
In the end you will that fear in the ass just as you got Colin better and as he continues to get better
<3

*—Boris Babic, January 28, 2018*

Our oldest used to knock himself down by repeatedly running his forehead into the underside of the kitchen table. Just never saw it because i guess he was always looking down. Because of all the bruising we tried to make him wear a bike helmet.
A bike helmet.
No insights. Just sharing our ridiculousness.

*—Rich Daly, January 30, 2018*

# Between 3 and 5

*February 3, 2018*

We've got a 4-year-old this morning. And, while it's always nice when your child has a birthday, there's this added bonus with Colin, given that I was sure several times less than two years ago that he wouldn't make it to 3.

It's been 120 hours since his MRI and no one from the hospital has called us yet. Christina told them they had until today to let us know if there was anything urgent, so I'm going to hope that their silence means that everything was standard for the MRI (if standard means having the remains of a tumor pressing upon your brain stem) and we'll get the results when we're back from our vacation in a week.

## Comments

Happy birthday to Colin! All the best to him and may he continue bringing all of you lots of pride and joy for years on end!

*—SG, February 2, 2018*

Wishing him a happy fourth birthday, and wishing you the joy of sharing many, many, many birthdays with him.

*—Cynthia Meyersburg, February 3, 2018*

Happy Birthday to Colin! Celebrate, celebrate!

*—Jeanne Clayton, February 5, 2018*

# Party of 4

*February 13, 2018*

Colin had his real birthday on February 3 and then he had three of his friends over for a belated party on Sunday.  He was very much into the part of the party where he received gifts.  After that, he became one of those people who sulks upstairs while his guests have a good time below.  In the attached picture, you'll see the first time in Colin's life where he has not wanted to blow out a candle.  Normally, you light a candle anywhere in the house and, three minutes later, Colin is there trying to blow it out.  Put it on a cake for his birthday and he needs half the family to help him blow it out.

Anyways, it was very nice.  And he scored well.  We're not any better to cope with a fire than we were before the party.  However, in case we need to pretend to put out a fire, we are much better equipped with fireman-themed toys.

Tomorrow we meet Colin's oncologist for the results of the MRI two weeks ago.  I am working under the "no news is good news" concept: I figure someone must have looked at the MRI by now and a call would have been put through to us had anyone seen anything untoward.  That said, the hospital has surprised us in the past with its - whimsical, shall we say - approach to organization and management, so we can't entirely rule out the possibility of hearing bad news tomorrow.  We're both a little on the edge, wondering if this will be the last day of our current normal, or the first day of a new awful normal.  We keep telling ourselves that he's displaying no abnormal behavior and that his therapist and his day care minder keep telling us how well he's integrating.  I really do believe that, were the tumor returning, we would see something in the way he carried himself.  But still...

Here's hoping for the best case scenario, where the oncologist shows up halfway on time (a big if), we get good news and we don't spend all of this Valentine's Day waiting around the ward for him to make an appearance.  If we really luck out, maybe I'll even get lunch with my wife and son before heading into a Valentine's Day evening shift at work.

## Comments

So sweet! Happy birthday Colin! Nd hope only positive news!

*—SG, February 12, 2018*

Happy Birthday to Colin from Dan and Don!! And wishing you good reports tomorrow!

*—Dan Wooldridge, February 13, 2018*

Hoping for a good-news-only Valentine's Day!

*—Liisa Ecola, February 13, 2018*

# Status quo

*February 14, 2018*

Traffic kept us from getting to our 10 a.m. appointment until 10:20 a.m.  Then the doctor kept us sitting around until 11:50 a.m. to tell us that there's been no change to the tumor site.  While we were waiting, Christina nosed through Colin's file and saw they came to this conclusion on January 30, so you can see we're clearly no longer on the priority call list.

That said, we did get unexpected time with the physical therapist, so we have some more insights into how the tumor remains are affecting him physically and what we need to do to mitigate that. Plus we have paperwork and prescriptions to keep us busy for months.

So, if you're going to spend Valentine's Day with the oncologist, this is probably the best outcome.

## Comments

Wonderful news! So happy to hear it. Late Happy Birthday to Colin and Happy Valentine's Day to all. ❤

*—GFSantos, February 14, 2018*

Congratulations on the great news!!!

*—Dan Wooldridge, February 14, 2018*

Marvellous news!!!

*—SG, February 14, 2018*

!!!

*—Boris Babic, February 14, 2018*

A belated congratulations!!!

*—Marc Galmoud, February 16, 2018*

# a loss

*February 18, 2018*

We just got the news tonight that one of the kids from our rehab getaway died.

We didn't know him particularly well: He was in the pre-teen/teen group, so we had next to no contact to him.  Nor did we know his Mom well, though we were all together in the bar at one point or another during that month, talking about the hell of cancer.

Still, a kid we met during that time when we were all hoping to put cancer behind us is dead, not even three months since we all said goodbye.  The killer is that, we all knew one of us would be the first to send the note that we lost.  I just didn't think it would be within six months of departure.  And there's this guilt of being glad that you're not the one sending the note.

In the end, there were 34 families at this thing.  There was no way there was ever going to be 34 happy endings.  But still, it's a miserable feeling being faced with that reality, when you were hoping that maybe this would be the group to break all the odds.  Because if the group could break the odds, then you would break the odds.  And it's just another bitter reminder of how the odds are still not overwhelmingly on our side.

## Comments

Thanks for sharing that, Niels. I can imagine that was not easy to write. Despite the strange, sad commonality among that community, I'm glad you got to share it with them.

*—Jeremy Cook, February 18, 2018*

# 730 days and counting

*March 17, 2018*

It's been two years, as of today, since we went down this particular rabbit hole.  Which means that, it's been 722 days since we were first told Colin only had a 30% chance of survival.  He's still here and surviving (though, based on his current obsession with kitchen appliances, I'm not sure I can say the outlook it quite as good for our Sodastream machine), so that's something.

I don't want to be depressing.  Overall, I think we're happy.  And he's a joy to have around, if you ignore his current obsession with taking the kitchen apart.  His return to day care has been about as easy as we could have ever hoped for.  As of Monday, Christina is no longer on sick leave: She'll start burning some of the vacation that she's been sitting on since 2016, with an eye towards returning to work in the second half of April.  Emma and Noah both have good days and bad days, though I'd say more good than bad.  I've started to get into a healthier lifestyle (as in, I've made it to the gym).

And yet, and yet, and yet...

I can't stop thinking about the kid from the therapy center who didn't make it.  I can't stop thinking about whether everyone in my family is acting normal, or if the moments of irritability we show are some lingering stress from the last two years.  I hate the fact that every time someone tells me about their problems, I have to almost stop myself from firing back "At least your kid doesn't have cancer," because, on some level, I just don't have the capacity to think about anyone else's issues.  I don't feel normal.  I don't think any of us do yet.  There's this brittleness that always feels like it's right there waiting to get us.  But we catch ourselves and move on, because the kids need us.  I hate to say it, but this might be the closest to normal we'll be for a long time.

So, that was thoroughly depressing, but it's been my background setting for most of this week, as I remember that it's been two years since we were thrust into the hospital and all the nightmares of bureaucracy and inefficiency that come with it.  It is getting a bit better each day, but it's a pretty deep hole out of which we're climbing.

## Comments

As difficult as it has been and continues...you are a light to us all. Our journey began last Friday. You give us faith and hope. The genuiness of your journey sugar coats nothing about the illness or the beauracracies that exist. Keep fighting through it, and I believe that your thoughts and feelings are shared by all who unfortunately are required to tred this path. It is all about trying to successfully establish “new normals” at every stage even if you never expected, wanted, or liked them. Barbara

*—Barbara Skipper, March 18, 2018*

I can only imagine, but I expect I would feel similarly.

I knew I finally was doing better when I started being interested in hearing about other people’s problems. (Prior to that I was terribly angry whenever I saw couples being unkind to each other— I was angry they got to squander that time— I was missing Kniff. Don’t get me wrong— I still miss him, even though I am happily married. And yes, my husband and I squabble.)
So, eventually maybe that brittle feeling will pass, and the aguish and terror recede, and he urge to punch idiots will reduce. (((Hug)))

*—Cynthia Meyersburg, March 18, 2018*

HOPE!!! We all live with our demons and our HOPE! Yet in the background, in that little deep dark place inside of us, there remains that feeling of dread; the fear that this can happen all over again. Don't give in to that feeling. Hang onto that HOPE WITH ALL OF YOUR BEING. It will give you the strength to face each day. Prayers,

*—Phylles Lagarde, March 30, 2018*

It seems like the Sorrells relatives have the cancer gene. Colin, Zack, Susie, Harold, Gilbert,Edith, and myself. If there are others, I am unaware of them. But to have two juvenile cancer patients is not the norm. After a biopsy March 19, I was told that I have breast cancer (DCIS) in the right breast. Tuesday, April 10th, I elected to have a bilateral mastectomy. This occurred 40 years after my melanoma. At age 80, and with an ailing husband, I thought this was the best option for me. I am home, sore and stapled, but at this point will not have to have radiation, but will have some interaction with the cancer center here. I am SO glad that Colin is doing well. Your journey has not been easy, but hopefully, you are through the worst part. My prayers are always with you.

*—Phylles Lagarde, April 13, 2018*

## ice cream/social

*April 18, 2018*

First I wanted to post something because I got a picture of Colin enjoying his first-ever ice cream cone.  Then I wanted to post because we were getting a little nervous about his balance issues.  Then I got another nice picture, so it seemed I should post.

I think the back-and-forth is pretty illustrative of our lives right now. We've got good days.  We've got bad days.  Christina saw a study a few days ago noting far higher survival rates for Colin's tumor than we'd ever seen before: It's nice to see, but it's not like we're taking him off his medicine any time soon.  For a change, I was the one worrying obsessively about his posture and the way he carries himself (which could be indicative of a returning tumor) and Christina was the one who told me to not worry so much, until the day she called me in tears because she was worrying about it.  Just about every day I discover a new song or video that triggers emotions in me about my role as a father and husband. Often they're songs to which I never knew I had a connection.

I find I'm obsessed with our house's security.  Indeed, I find that I'm becoming manic about a lot of things.  Those of you who have known me for years will probably think "You've always been that way Niels." The difference is that, before, I thought it was a perfectly normal level of mania.  Nowadays, I catch myself going "Dear Lord, you're coming unhinged."

Colin remains, blissfully unaware of it all.  He's tasted ice cream (and needs to learn to eat it before it melts in his hands).  His obsession with Lightning McQueen and Curious George only grows.  He continues to thrive at day care and doesn't seem to mind his multiple therapy appointments a week. Christina got a haircut for him right before Easter, so we can once again clearly see his biopsy scar from 2016, which always throws me for a loop, but doesn't bother him at all.  He is not the most coordinated child you'll meet in your life, but that's an understandable leftover from having a growth lodged in your brain stem.  That said, it seems half or more of the time when he collapses on the ground, he's done it for fun because, somehow, he thinks that's enjoyable.  In most respects, he's a perfectly normal 4-year-old.  It's weird to put it like this, but if we're lucky, we're going to be the ones who need to get ourselves right after all this, not him.

## Photos

## Comments

❤

*—Boris Babic, April 18, 2018*

As a parent, it's your job to do the worrying. Colin's job is to be a kid and enjoy himself. He seems to be doing his job very well. Love all of you!

*—Phylles Lagarde, April 20, 2018*

Beautiful pictures of Colin being a kid! Very sweet.

*—Lynda Schmitz, April 22, 2018*

## Whatever you call 'normal'

*May 14, 2018*

We had a small reality check this week.  It's not like we've ever forgotten that the risks loom, but, speaking for myself, I'd say I might have allowed myself to think that our new normal was something we could take for granted.

Don't panic.  Nothing bad has happened.  We just had a bad day.

This weekend was Emma's first communion. We had about a dozen relatives visit for the event.  Colin got a lot of movement, a lot of commotion and probably not enough sleep.  Adding to the problems, he might have gotten a slight bug at day care.  And we're trying to potty train.

So, you put it all together and, by midday on Sunday, he was very unstable on his legs.  That's, of course, always the case.  His left leg works more or less normally, but his right leg acts like he's got weights in his shoes.  On Sunday this was more extreme.  And then, once or twice, his right leg just gave out under him.  I noticed it first and debated whether to tell Christina, because she normally notices these things without me telling her and we did have a lot going on.  But I did.  And then, not five minutes later, he wiped out right in front of us.  She got nervous.  I got more nervous.  She got moreso.  We couldn't really talk about it because we had a house full of visitors.  It turned into a bit of a feedback loop.  I felt all the same sensations I had back in March 2016.  The bottom of my stomach dropped out.  I couldn't sleep.  Everything started going through my head, from "How do we prepare for the worst?" to "Does this mean I can't get my hair cut on Thursday."  The dread of going back to the hospital consumed me.

It was an awful night.  I woke up this morning in the same mode I was in back in 2016.

Every step was just a matter of "Get this done and then move on to the next step. Shower.  Then make lunch for the kids.  Then get them dressed, etc. etc. etc."  I remembered my prayers, that's for sure.

As luck would have it, we had to go to the hospital today for the MRI prep (the MRI is on Wednesday).  We also ran into Colin's oncologist, who told us we can't freak out over these things.  If he's tired or has a slight bug, he might have a bad day.  Let's not forget the potty training.  He's in that awkward phase where he no longer wants to use a diaper, but he's not ready to commit to a toilet. So there's a lot of time spent trying to fight nature's call.  You try to walk normally when you're fighting constipation.

He was also in great shape today.  He spent all the time chasing me around the lobby while we got his paperwork and was all about chasing when we waited for the talk with the anesthesiologist.  His footing was as stable as usual and he was fine.  Even after a long day, he got home and then spent a fulfilling afternoon stuffing his older brother into my closet (don't ask).

When we went to bed last night, Christina said she hoped we could just wake up and have Colin back to normal.  It's a nice sentiment.  We just forgot this is our normal.

## Comments

Sorry to hear things were nerve wracking yesterday! You all have had an exhausting day (but hopefully Emma enjoyed it!). Good that things are back to ok and let's hope your oncologist is right and Colin was just overwhelmed. Take good care

*—Sofia Gueorgieva, May 14, 2018*

Prayers and love your way!

*—Barbara Skipper, May 14, 2018*

# the early bird

*May 15, 2018*

Clearly, the hospital can tell we're nervous about this next MRI and want to get it done as quickly as possible, because the ~~fasci~~, I mean administrators at the hospital have scheduled the procedure for 7 a.m. tomorrow.

On the good side, there's very little traffic at that time of morning, so we don't have to worry about blindsiding anyone on the way to the hospital when we fall asleep at the wheel and accidentally drift across six lanes of highway traffic.

## Comments

Nightie night!

*—Marc Galmoud, May 15, 2018*

Are you sure, medical staff will be already around at the early hour? Maybe they will need a lift... :-)

*—Claudia Busch, May 15, 2018*

Good thoughts!

*—Lynda Schmitz, May 15, 2018*

Hoping for the best for all of you today.

*—Dan Wooldridge, May 15, 2018*

# chemo at dawn

*May 16, 2018*

In one of those "Situations That Would Have Been Bad Before 2016," we seem to have a stomach bug going through the family.  I had it the first few days this week.  It looks like Christina might have gotten it too.  It's not too bad, just kind of makes you want to lie around and moan.  The important thing is that the day care called Monday to say they were asking kids not to come if possible precisely because of a bug going through their ranks.  And Colin might have conceivably had this bug at the weekend before passing it on to us.  Heaven knows, it's an altogether better explanation for his clumsiness on

Sunday than a return of the tumor.  And my stomach is telling me, even as I type, that it's a plausible theory.

Anyways, as for our Dawn Patrol adventure today, it went as well as a hospital run can go.  Christina, Colin and I were in the car by 6:05 a.m., which is already kind of miraculous.  We got to the hospital by 6:55 a.m., picked up Colin's records and were at the anesthesiology station by 7:10 a.m., latest ... where they had no idea we were coming.  They sorted themselves out, but it was 8:15 before they took him down to get fully sedated.  Then they told us, it would take half an hour, tops, to get everything done.  I totally knew that was a lie and, indeed, they didn't come out with him until about 9:30 a.m.  He slept it off for two hours and we were home by 1 p.m., where we immediately parked all children present in front of the TV and slept because, come on, we were awake at 4:45 a.m.

We meet the oncologist Wednesday (May 23) to get the results.  I'll just assume that, if no one calls us before then, that there's been no change to his status.

## Comments

You experiences with the health system are making me seriously reevaluate my impression of deutchhe Ordnung. Although my own experience in a German hospital indicated that estimations of timeliness were equally as inaccurate.

*—Don Summers, May 16, 2018*

Hope you get over the bug quickly (a vicious thing even if nothing too dramatic), catch up on sleep and only get good (or no) news!

*—Sofia Gueorgieva, May 16, 2018*

Wow! I would never have made it through your day!

*—Barbara Skipper, May 16, 2018*

Navigating through the medical system takes the patience of a saint and the stamina of a Saint Bernard! Good luck!

*—Phylles Lagarde, May 22, 2018*

# the middle child

*May 23, 2018*

As if the universe heard all the advice and urgings from our friends and therapists to find some way to take our mind off Colin's tumor, yesterday at breakfast we had a massive allergy attack that landed Noah (and Christina, as accompanying parent) in the hospital for a night.

I'll say this to you, universe, I certainly didn't think about the tumor for a whole half hour or so.

We have no idea what happened. He didn't have anything for breakfast that he hadn't already eaten a dozen times. He had already left the table and I had to go to the bathroom. But, when I got there, I found the hand towel streaked in chocolate spread, so I went off to find him for our weekly conversation about washing hands AND then using the towel. He was up in the kids room and when he turned to look at me, hand washing etiquette was no longer the hot topic. Think of whatever stereotypical Aunt Jemima-style black person you would have seen in advertising or film back in the 30s or 40s. Then make the lips about twice as big. I have no idea how he was still breathing.

I rushed him downstairs to Christina and her emergency pack, where we gave him the first two stages of anti-allergy treatment. We hemmed and hawed, but eventually called emergency services, where Christina got them to lose their professional cool by telling them that Noah looked "like Mick Jagger." The emergency worker apologized for snickering and then got two crews to our door by 10 a.m. I had to take over Colin duty, because Colin has become astoundingly social of late and was trying to explain his Lightning McQueen collection to the ambulance guy who was trying to figure out Noah's status. But, apparently, things went downhill as soon as Noah got wind of the fact that he might get a shot. He started screaming, so I actually had to press Emma into Colin duty so I could carry Noah into the ambulance where we then had to strap him down and let the ambulance crew give him some kind of sedative, Noah screaming loudly enough the whole time you could hear him through the closed ambulance door. I have not done it yet, but I still think I should go around to all our neighbors and assure them we're all still alive after that.

Fun fact: the sedative they use on him is the same one they give Colin before his MRIs. What we do is take Colin to the hospital, where he gets the sedative in the prep room, which theoretically will have him relaxed enough by the time we get to the MRI room that he won't resist the proper anesthesia. It's wonderful in theory, but Colin never willingly drinks the sedative and usually ends up at the MRI more tense than beforehand. Last week, as we showed up in the MRI room, the technician mentioned that we should think about using the nasal version of the sedative, if Colin won't drink it. Christina and I waited a beat, looked at each other, and then Christina asked the technician why, after we've been fighting our way through this for two years, no one had ever mentioned to us that the sedative came in nasal form.  He just shrugged.

Arghh!

Anyways, after yesterday, we now know that the nasal version does indeed calm a kid right down.  Christina and Noah got to spend a night at the hospital.  He's stabilized and should come home soon.  We have no idea what hit him, so it's just back to being careful as usual with him.  Also, he probably gets to skip school for the rest of the week, so that will upend our schedule nicely.

Meanwhile, I wrangled Emma and Colin for the rest of the day, which has its own set of problems: Colin runs around aimlessly from one moment to the next, because he's 4. Emma listens to all of m plans and then tries to come up with better plans, often acting on them even when I tell her to quit it.  But I got them all fed and to bed and even got the laundry done.

Colin and I will now head off to our post-MRI meeting with the oncologist.  Given that no one has called us in a panic since last week, I'm assuming this meeting will be unsensational.

Oh, and to keep everything in perspective, Emma, who busted her finger on April 30, is due to get her cast off tomorrow.  That's three kids in three clinics in three weeks, for those keeping count.  Yes, Colin's visit was planned months in advance, but I'd submit there's nothing routine about his situation.  Who's keeping the German health care bureaucracy busy 24-7?  That's us: Team Sorrells.

## Comments

Too hectic and nerve-wracking by any standards! Hope all kids feel better soon and you with Christina manage to get some deserved rest!!!

> *—Sofia Gueorgieva, May 23, 2018*

I remember when ours were little wondering how many doctors fancy cars we were helping make the payments on. Our son loved the emergency room doctor and the orthopedic surgeon (he broke both elbows the same year)! Hang in there...this too shall pass! Love you all!

> *—Barbara Skipper, May 23, 2018*

Honestly: I began sweating. :-(

*—Boris Babic, May 23, 2018*

You need to write a book! Your posts are so captivating.....can not break away from reading them!!□□ Seriously, hope your days become more routine!!!

*—martha stanley, May 23, 2018*

## lightning (mcqueen) strikes

*May 23, 2018*

After arriving at the hospital an hour late for our appointment, I was chasing Colin around because he had seen another child wearing a Lightning McQueen shirt, which always prompts him to stalk the other child in a way that pretty quickly makes everyone feel uncomfortable, when we happened to run into our oncologist, who chose not to keep us on eggshells until he actually got time to see us: everything was fine with the MRI. Our diagnosis remains: disease stable.  It's odd how good that sounds, considering the unfortunate wording.

It was an hour until we had our proper meeting, but that was all pretty non-spectacular. Next MRI is in September.  Noah is back from the hospital and Emma gets her cast off tomorrow.  I expect to spend the rest of this month getting an exciting range of bills from various health care providers.

### Comments

Stable is underrated! Glad to hear it.

*—Liisa Ecola, May 23, 2018*

You and Christina deserve the Nobel prizes for patience and perseverance! Kudos!

*—Don Summers, May 23, 2018*

## a downer

*May 29, 2018*

I remain surprised by how it all continues to sneak up on me.

I'm at work.  The BBC has a report on about a breakthrough in treating brain cancer. It seems to be a vaccine (we have to keep the sound off, so I can only read what they use as captions). The upshot seems to be that it increases the average length of survival from 15 to 23 months. The longest-surviving patient lasted seven years.

I imagine most anyone seeing that would think it's a positive. I start doing math: 26 months since his diagnosis, 11 months since his last chemo treatment, nine months since he started his current medication.

Suddenly, 15-23 looks pretty grim.

Now, I know, I need to keep perspective. It seems to be a completely different kind of tumor in a completely different part of the brain. But still, I'm supposed to be at work (if you're my boss, you didn't read this, OK?) worrying about Italy's political crisis and the North Korea talks and ... I'm doing morbid math in my head.

## Comments

Don't do math at work! And keep positive.

*—Stephan Roch, May 29, 2018*

HIV and cancer sores both are caused by viruses. One is life changing, requiring a cocktail of medications to prevent HIV from progressing to AIDS, and the other means that one’s mouth is intermittently uncomfortable.

As you know, cancers also differ from one another.

(((Hug)))

*—Cynthia Meyersburg, May 29, 2018*

I think Cynthia means cold sores, but you get the point. Don't let your imagination run away with you! Take care.

*—Marc Galmoud, May 31, 2018*

As a parent of a child with cancer, how can you not anxiously read every new article on the subject with elation, then
doubt sets in as you process your particular situation BUT...never lose FAITH and HOPE. They are your best friends, dear cousin. Prayers,

*—Phylles Lagarde, June 6, 2018*

## getting closer

*June 9, 2018*

Given our recent stretch of rough days, I suppose yesterday barely registered, but still...

Another kid from the rehab died.  This boy was about a year younger than Colin.  He had a brain tumor as well, though, of course, a completely different kind in a completely different part of the brain.  I didn't interact a lot with the boy, but his parents and I hung out a lot.  His Dad was the one who taught me the word "daheim."  His Mom was in our support group, and was one of the first to tell a story that made me think "Dear God, we don't have it so bad."  Fabian could barely walk because of his tumor, which meant, being 2, that's all he wanted to do.  They had a time with him.

Also, they seem to have just had a little girl, who was born just weeks before her brother's death.  I can't even wrap my mind around how the two of them must be coping.  I also don't know how I'm going to send any kind of useful message to them because, no matter how carefully I pick my words, everyone knows that there's going to be a "Thank God it wasn't my kid" floating in the background.

I just never thought that six months after this rehab that the death toll would be so high.

The only news on our health front is that Colin brought head lice home from day care, so we had a fun Friday of dipping everyone's hair in special shampoo.  After that was done, Colin either rolled around the floor enough to leave a house-sized greasy smear - or the cleaning lady used something new on our floors - and now no one can walk through the house without slipping.  Poor Colin, who has balance troubles on the best of days, is having a time of it.  But, at least it's not a run to the emergency room.

## Comments

Maybe reassure them that it was clear how very louche they love their son? And that they all are in your heart?
I don’t know— they must be in such pain.
(((Hug)))

*—Cynthia Meyersburg, June 9, 2018*

<3

*—Boris Babic, June 10, 2018*

I am sure, you will find the right words of love and support for these parents to reassure them that they are not alone during these dark hours.

*—Claudia Busch, June 10, 2018*

That is so sad. You write so beautifully, I know anything you say will be comforting.

*—Jeanne Clayton, June 12, 2018*

# another milestone

*June 15, 2018*

Yesterday marked a year since Colin had chemo of any kind.  There's nothing else remarkable to report, other than mild progress on potty training and giving up the pacifier.  I would have marked the date here yesterday, but since we're a family with young children, about 40% of the population was laid up with the flu yesterday.

Still, every time I think about survival rates and such, it's nice to see a milestone marked.  I think I have to hold on to these things.  After the news that Fabian, the boy from the rehab clinic, had died, two more parents logged on to say that they didn't think they have much more than a few more days with their children.  That could mean four of 34 kids dead within half a year of the clinic session ending, which might be the most depressing thing I've ever personally countenanced.

## Comments

It would be tremendously upsetting if it were one child; four is completely heartbreaking. I don’t know any of these people, yet I feel sad for their families.

And at the other end of the emotional spectrum is the relief and hope I feel reading that your son is a full year out from chemo. That is great news, and the further out he gets, the more you can breathe and look forward...

*—Cynthia Meyersburg, June 15, 2018*

One year milestone! Wow! Now focus on two, three, four, five and more years without chemo....way to go, Colin.

*—Phylles Lagarde, June 16, 2018*

# Forget Me Not

*July 26, 2018*

Colin's last MRI was in May, which means the next one is expected sometime in September. Demand is so tight for these procedures (and I suppose they have to leave buffer time for emergencies and those days when the power goes out) that they essentially have to schedule the next one as soon as the old one is finished.  Usually, if everything goes well, we'll get a letter in the mail telling us when to show up.

So, when it got to be mid-July and we hadn't gotten the notification letter, we began to get suspicious.  And then the possibility of a work trip in September/October came up, so it became important to know when I'd be around and whether that would clash with the MRI.  Which led me to email the hospital last week to get the not entirely surprising response that they had totally forgotten to schedule the MRI and could we just hang tight until they got back to us with a response?  Except, after a week passed, the possible business trip became a definite business trip and it became necessary to set precise dates for it.  So, I emailed again, and this time got an email back from the oncologist's assistant informing me that he was on a well-deserved vacation and wouldn't we please let them know when I'm around so they can schedule the MRI accordingly?

I refrained from responding that, yes, the oncologist most definitely deserved a vacation, which sounds like an awesome thing that we can't do while, even though the MRI scheduling department can't get a thing done, the billing department at the hospital is working just fine, meaning we're swimming in debt and staycationing in Berlin this year. I'm also not going to get into the fact that while it's great that we get to schedule the MRI this time, had they done their job we wouldn't be lounging in such luxury.

In short, it's simultaneously heartening and annoying as hell that we've fallen off the priority list, because they sure as heck didn't forget his MRI appointments when his chance of survival was down around 30%.  I'm trying to view this as a glass half full situation, but it's difficult at times.

Colin's doing well.  He started his physical therapy this week, so that's another step towards getting his sea legs back.  His vocabulary grows all the time.  We've gotten some five- or six-word sentences out of him, often in an interesting mix of German and English.  A lot of what he says seems to be recitations of things he's heard on TV.  And, because he's learning, not everything comes out quite right.  He's prone to saying "Kann ich helfen" (Can I help you?) when he means to say "Kannst du mich helfen?" (Can you help me?)  But he gets through his day.  We're seeing less pacifier time every day and the potty training is making progress.  He knows to go to the bathroom to pee, but often doesn't think to do so until the dam is about to burst.  This is when he starts his Riverdance, which is entertaining, but stressful for all involved.  That said, if he has to do more than pee, he is still not ready to trust his fate to the potty, so we're not done with diapers yet.  He sleeps well and, during our Berlin staycation, we've gotten him to sit on his bicycle every now and then, even if it takes me, Emma and Noah to then get him moving.  It's a start.  One day we'll have him biking to day care (or school) under his own power.

## Comments

Thanks for the delightful and interesting update. We (it’s a family deal) just finished 5 rounds of 9 hour chemo sessions. Steve has been released for surgery by his oncologist. Our appt with the surgeon is on Aug 6. Steve may even be considered for robotic surgery , which has a faster recovery time. Glad your ordeal is “stable”. I understand the mountains of debt, but we are good and thankful. Prayers continue for Colin. Love you all.

*—Barbara Skipper, July 26, 2018*

Sorry to hear all that German efficiency is just a myth...

*—Liisa Ecola, July 27, 2018*

## MRI madness

*August 3, 2018*

To recap:

Colin's last MRI was in May. Everything turned up fine.  At the time, the oncologist repeated the warning that the next MRI has to be rescheduled almost immediately, because spaces can be taken up months in the future.  Why he warned us, when it's his job to schedule these things, is only now becoming clear.

I'm currently on the final day of a three-week stay-at-home vacation with the kids that would have been a lot more fun if the temperatures had been about 5 degrees cooler. The day before I went on vacation, the possibility arose that work would send me to Sydney, Australia, for a few weeks in the autumn (or spring, depending on your perspective) to help out with a manpower shortage there.  I said I couldn't sign on until Christina agreed.  She didn't quite say "Are you an idiot, say 'yes,' but there was little hesitation about me taking what could be a once-in-a-lifetime opportunity.  That means part of my vacation has been tied up with visa applications and tracking down a place to stay in Sydney.

Early on, we realized that one stumbling block could be the next MRI, which was due in September, when I would likely be on the other side of the planet.  I emailed the hospital to ask if a date had been set.

There was no reply.

I emailed again.  This time they replied that they would look into it.

A week passed.  I emailed again.  This time I got the response that the doctor was on his "well-deserved" vacation and would it be OK if his assistant went about scheduling it?  I responded with an emphatic "Yes," it would be nice is someone took care of this.

Two days ago came the answer, which read essentially like, "You sillies, of course we can get a date for you in September.  But, if that doesn't work for your schedule, we can push it back to October 9, but not a day later because that would be medically unsound."

I know these people are trying to help.  I know they're stressed.  But, honestly, why have we been told for months that these things have to be scheduled 3-4 months in advance only to find that when, oops, they totally forgot to do their jobs, it's possible to schedule one with six weeks warning?  And why are we being made to feel like annoying helicopter parents when we're just asking people to do their jobs?  I don't even know where to start with the advice that we not wait past October, since we were the ones pushing for them to get us an appointment for the last three weeks.  Christina says there is a decent chance the email is meant nicely and it is all in German, my second language, so maybe I'm missing a nuance, but it all sounds pretty condescending to me.

Anyway, as luck would have it, the day before the October 9 date came up, i had suggested flight dates for Sydney that would have had me back two days too late.  I've since asked for an altered flight plan and not heard back from work, so I'm just going to assume everything is trundling along fine.  But man, these people at the hospital, while being great about saving people's lives, certainly find other ways to tax your health.

## Comments

Bon courage! They are indeed testing how patient the patients are and if patients are good at taking a deep breath!

*—Sofia Gueorgieva, August 3, 2018*

I've recently had my own share of, "Gee, I wish some people would just do their bleeping job!" so frustrating. Sorry, Niels! I do hope you get to enjoy Australia.

*—Jeremy Cook, August 8, 2018*

Remember my mantra: DIFFICULTIES ARE GIVEN TO US TO OVERCOME! You WILL survive this latest snarl in your life. Take a deep breath and SMILE. Enjoy your trip. Your Cuz

*—Phylles Lagarde, August 11, 2018*

*August 16, 2018*

Excitingly, we went the first two months of August without receiving a single bill. When the first one did arrive, it wasn't even for one of the children! Darn that wife and her medical needs.

If the trend continues, there feels like there might be a chance we'll get our finances in order one of these days, though a lot depends on the insurance companies starting to speed up their claim processing and us ever getting our German tax return. The fact that we're constantly shifting money this way and that way to keep the kitty full and the bills paid these days feels like a lingering insult from everything that's happened the last few years.  Like life is going: "Fine, you don't have to spend every minute worrying about Colin's health any more, but we'll hit you in the wallet instead."  I suppose if I didn't have this problem, I'd find some other way to worry about everything that is happening, but this is the one that gets my attention.

The bills come in (I'm currently sitting on about 2,000 euros of unpaid medical bills, all of which I have to pay, though we do get compensated by the insurance companies).  The last claim went in on August 6, and they've been taking an average of six weeks to repay.  Payday isn't for another week or so.  One finds ways to get creative with the finances, though I haven't resorted to outright theft yet.

In good news, Colin keeps making progress.  We have him in all kinds of therapy.  He's slowly embracing potty training.  He goes hours and hours without a pacifier.  This week I got a full sentence out of him.  It was in German and it wasn't grammatically correct, but he clearly asked for a glass of water, which is a nice change after so many years of grunting and pointing.

Off to work.  Maybe today is the day our tax return will come back.  One can hope.

## Comments

Keep up the good fight!

*—Marc Galmoud, August 17, 2018*

This, too, shall pass!!

*—martha stanley, August 17, 2018*

We got your back!

*—Keena Graham, September 2, 2018*

## Sydney so far

*September 7, 2018*

I'm a little more than 24 hours into the Sydney adventure. So far, my big takeaway is that their public transit system is challenging.

So, aside from some really annoying seat mates - who spent the whole flight getting in and out of their seats and returning their drinks to the stewardesses because they had the wrong amount of ice in their whiskey - the flight was painless.  The special neck pillow I purchased was very comfortable, but did not help put me to sleep at all.  In exchange, I've now seen all the Avengers movies and am available for venting about the terrible ending of the most recent movie with anyone who cares to do so.  Shockingly, I'm not feeling the jet lag very much, so perhaps 10 years of not getting a solid night's sleep thanks to the kids was all just training up to this moment.

My apartment is, literally, a converted garage.  It is very nice, but it's just a garage where they added a kitchen area and a bathroom and a loft for the bed.  My front door opens right into an alley, which is a sobering way to start the day.  Nonetheless, the only complaints I have are that it's a little cold here and the building is really only insulated for cars, not people.  Also, I'm right in the Sydney Airport's flight path, so I get some terrifyingly low overflights about five times an hour.

The neighborhood has ... its charms.  The main drag, a block away, is called Parramatta Road.  I'm told it has seen better days.  It reminds me of Main Street near the Bradley University campus more than anything else I've ever seen (except that it's about 20 times longer than the little drag outside the university).  When I started at Bradley, it was a very depressing block or two of crummy stores. By the time I graduated, a coffee shop and a comic shop had moved in, so it was less depressing.  But it was still not much to brag about.  That said, I've got two flamenco dance schools within a 10-minute walk of my garage/apartment, so how bad can the neighborhood be?

I did have dinner at a colleague's house last night and saw a good deal of Sydney from the bus in transit, but it was dark and raining, so I don't know how much that counts. Plus, I was busily trying to figure out when to get off the bus, so I couldn't really take it all in.  Sydney buses seem to operate on a "Oh, wouldn't you like to know" system regarding information about where you are and where you are going.  The bus stops are labelled and give you an idea of which direction the buses are going in, but once you get into a bus, you're in an informational black hole.  There is no display anywhere in the bus telling you which stop is coming up next.  You can't expect to memorize how many stops it takes to your destination, as the bus doesn't stop everywhere. And, when it stops, it usually doesn't stop right in front of the bus stop, so you don't have a chance to read the label of which stop you're at.  Even if the bus did stop perfectly in front of the stop, the label is in a ridiculously small font, and high up, so you only have a chance of seeing it if you're standing right at the door.

The first part of the trip went OK, because I knew I had to ride until the end station. After I figured out which bus would take me the rest of the way, I asked the driver how I would know when i had to get off.  He told me he'd shout out if he "remembered to."  I did not ask what would happen if he forgot and he got me where I needed to be.

That said, the bus drivers here are insanely nice.  I mean, if you took the nicest bus driver I've ever met in Berlin, he's still a couple of leagues down in the friendly tables compared to the three Sydney bus drivers I've met so far.  Also, amazingly, everyone in Sydney says "thank you" to the bus driver as they get off.  I thought he was making special stops for people, like between marked bus stops.  But, no, he was just doing his job and people are just calling out thank you - even from the back of the bus - because he did nothing but take them from one designated stop to the next.  I wonder if this would improve the morale of Berlin's drivers.  I also am trying to remember when I got thanked at work for just doing my job.

Otherwise, I've done nothing touristy, but will get to it.  Just walking around this neighborhood is an eye opener though.  Granted, I know nothing about animals and plants, but I swear I'm seeing trees and birds here I've never seen anywhere else.  That said, I'm about to take my first walk to the water and then hit a grocery store, where I'm told everything will cost about four times what it would cost in Germany or America.

I'll share the excitement as it comes.

## Comments

Good to know you have had a good start to your Land of Oz adventure - hope it continues even better and you will have fun exploring not just the city but also the flora, fauna, and maybe lovely beaches too (and everything in Berlin will go smoothly). It is a very English habit to thank the bus driver when leaving the bus - maybe this is the connection to the Aussie custom. Looking forward to your next travelogue instalment

*—Sofia Gueorgieva, September 8, 2018*

Haha loved this! Glad flight and first day went okay. What an adventure! Do you miss the kids? How does it feel to travel solo without them? You wouldn't like NYC buses here, which operate exactly the same as what you described. In fact, until this Sydney entry and Greg's mentioning to me that public buses in Canada announce stops, I thought all public bus transportation was this way. I thank the bus driver if I exit in front and must pass right by him. If I exit from back, he gets no thanks from me because I find it hard to shout in public.

*—G Santos, September 8, 2018*

Fascinating travelog of first impressions of Aussie Land....Your humble garage abode that opens to an alley would have me the most concerned. Who arranged for your lodging? Looking forward to the next chapter!

*—Barbara Skipper, September 8, 2018*

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*—Barbara Skipper, September 8, 2018*

## endless manners

*September 10, 2018*

You know what else says thank you in Australia?  The vending machines.  Honestly, this is the most polite country ever created. Their public transit system is going to drive me to distraction, but man, they've got manners.

To address Barbara's concern, yes, it is weird that my door opens up onto an alley. Every time I step out and there's someone walking through the alley, I have a brief flash of shame and a need to pull them inside to show them that, look, I live in a semi-normal dwelling, not a dumpster.  But, as the owner noted in her description, there are other residences that open straight out onto the alley (though I don't think they're garages), so it's not as if I'm the odd man out here.

I am getting settled.  I found the office, which might as well be in New Zealand, it's so far away, where our Sydney crew works in a room with a bunch of other teams from other European agencies that have decided they don't want to pay for night shifts back home when they can keep a team working in Syndey, where they'll slowly be bankrupted (today I learned that a postcard to the States requires $3 of postage, so everyone should stop holding their breath before they start thinking they're getting any of those from here: $3 buys me a whole pack of tangerines which are, excitingly, in season here).

Anyways, it's kind of funny, because I'm surrounded by people happily speaking French or Swedish or whatever.  And they can all talk at the top of their lungs, because they know no one else in the room has a clue what they're saying.  Meanwhile, we have to watch what we say, because everyone can understand English.  Though I don't know how they could hear us, as we sit right next to the Finns and they never stop talking at the top of their lungs, which is bursting several of my stereotypes about Finns.

I've had beer with my boss and learned much gossip and I've learned that I can get shirts dry cleaned and pressed for $3 which a) removes my need to track down my landlord to find out why this place has an iron, but no ironing board and b) is the price of a postcard to America (or Germany, for that matter).

We'll see what the trip does for me on a personal level. Ever since I started therapy, my counselor has suggested it would be a good idea for me to get away to get my head together, the idea being that I might just calm down around the kids if I could just decompress a bit.  We killed that idea when it became clear that going away would cost money and inconvenience work and probably not do much long-term good, since I'd just come back and have to jump into my routine.  But this trip to Australia has offered the chance to give his theory a try while putting a lot of the expenses onto my employer (love you dpa!).  I am certainly trying to keep it low-key.  The fact that I'm still too jet lagged to do much more than drag myself into the office certainly helps.  But I'm trying to read and exercise.  The plan is to attempt a bike ride to the office for the first time on Friday, a mission the cab driver who got me here from the airport told me is asking for death, but which my colleagues say will be just fine.  I've got Wednesday and Thursday off, so I'm going to be a tourist.  And I just learned from my colleagues that the zoo, which usually costs $40 (this is equivalent to about $28 US dollars; I expect to be able to take an animal home for that price), lets you in for $1 on your birthday, so I'm going to go and see some duck bill platypuses for cheap when I turn 47.

So yes, I'm having a good time.  On the other hand, I spent parts of Saturday being racked by anxiety on account of being separated from my wife and children. Every time I see a kid on the street, my first response is "Oh, I miss mine." So, if the therapist's master plan was to make me be better around them by missing them insanely, then his plan is working.

## Comments

Hey, careful what you say about us Finns! My dad is one of the chattiest people I know. But happily not at the top of his lungs.

*—Liisa Ecola, September 10, 2018*

<3

Don't let Sash know you are going to see platypuses....

*—PJ Smith, September 10, 2018*

Platypodes (FFF: Anm. d. Red.)

*—Lynda Schmitz, September 14, 2018*

## the milky way

*September 11, 2018*

I'd had a lot on my mind recently, what with the trip to Australia, but I had really thought our year anniversary of Colin starting his valproic acid was a few days away. But I just checked and saw I posted on September 4 last year that we were going to start it in a few days. So, yay, we're a year into a two-year regime and everything seems to be going well. I don't know what happens when we're done with this or what the official odds will be for his long-term prognosis once he finishes, but it's good that we're getting through this relatively painlessly.

That said, getting him the medicine is becoming ever harder. He's wise to the fact that we slip it into his milk every afternoon, but he'll still condescend to drink it if he gets to watch TV while drinking. Even then, it's only 15 ml of medicine mixed into a small cup of milk.  Theoretically, he could knock this back in five minutes: We usually end up watching two TV shows before he gets the last drop down.  There's a lot of physically holding him in place and cajoling and threatening to turn the TV off to get that medicine/milk combo in him.

One more year. That's where we are.

As for me in Australia, no major news.  I was really excited about getting some down time while I was here.  Now all I do is go to work and come home to miss my kids. There's no pleasing me.

## Comments

How long are you going to be in Australia? How's the weather down under?
MS

*—Markus Sorrells, September 11, 2018*

## Sydneyside

*September 23, 2018*

Oof. I've been unsure of what to do with my Australia experiences. I dislike putting too much of my life on display in Facebook and, honestly, I look like I'm in distress in all the selfies I've posted there. But this blog is supposed to be about Colin and his health, not my travels through Sydney.

On the homefront, my sources tell me that it's been more good than bad. Colin continues to fight this cold that he's had since before I left. I stress, it's just a cold, but man, can that child produce mucus. It's kept him home once or twice. More troublingly, his seizures have come back.  We had next to none from August 2016 through August 2018.  Then they started reoccurring right before I left to Australia. Christina says there was even one day with multiples.

Her theory is that he's overtired because he can't get a good night's sleep, on account of all the mucus. That leaves him prone to reacting to stressful situations, which, for him, is when Christina tries to get him to wash his hands or brush his teeth. Who knew hygiene was such a trigger? I wonder if it has something to do with the fact that he's getting older, and he's learning that we have slightly higher expectations of him. We ask him to set the table sometimes (never dull) and we keep bringing up the idea of finally doing away with the pacifier. Also, we're sticklers for hygiene. Perhaps the added responsibility is weighing on him? It's hard to say. He speaks a lot more than he did even a few weeks ago, but it remains very stream of conscious, with a lot of repeating of advertising slogans he's happened to see on TV.

All I know is that it's hard for Christina to deal with all of this on her own (her parents were there for two weeks, but they headed back this weekend), and it's miserable for me to be here in Sydney unable to do much more than offer moral support. Saturday when I Facetimed back to Germany, I found Christina and Colin in the hospital, because the one seizure got everyone worried enough that it seemed a good idea to look at his vitals. That's not what you expect when you drop a line to say 'Hi.'

I briefly though about burning up any and all goodwill I have left at dpa and upping sticks back to Germany, but Christina said he was fine and, honestly, he looked a lot livelier in Sunday's call. There's also the reality that, even if I decided right this second to hop in a plane back to Berlin, the earliest I'd likely be back in Berlin is Wednesday. Let's not even think what costs that would entail.

Instead, I'll work my last 10 shifts here in Sydney and get on the plane on October 5 as scheduled. The work here seems to come at a slower pace than in Berlin, but there's also the challenge of the days when I have to be here at 6 a.m. and then try to stay awake while very little comes in. Even worse is when I'm here bleary eyed at the crack of dawn having to deal with sports, which is not my natural element.

I've got one last "weekend," which will be on Thursday-Friday. i plan to make one more stab at watching whales - this part of the trip is not working for me at all; they seem to hate me. Then I'm going to head to Katoomba so I can hike in the Blue Mountains on Friday. For everyone who says "Why don't you get in a car and drive to the Outback?" please realize that Australia is big. That would be like suggesting I take a quick drive to Spain from my home in Berlin for my two days off.

Mostly I hike around. Sydney does have museums, but few of them interest me. And, honestly, it seems dumb to stay inside when there's such scenery. I've done two big coastal hikes and one through a fun little suburb, including down a spit of land that was exactly wide enough for a street and houses on either side, which is exactly what they did. People in this place use every inch of land available to build upon. Aside from the scenery, the other highlight has been briefly walking with this Australian woman giving me tips on how to get to Balmain, before she started telling me how she'd just seen "The Book of Mormon," stopping half a beat later to ask "You're not Mormon, are you?"

Once I return to Katoomba, it will be seven straight days of work (five of them 6 a.m. shifts :( ), while I spend my last nights trying to finally see if I can find a comic book shop (one must take advantage of these things while in an English-speaking country) and maybe going to see the Maritime Museum. My colleague is also obsessed with getting me into the ocean. I'm not fundamentally against the idea, despite a recent rash of shark attacks, it's just not been particularly warm since I've gotten here.

Twelve more days and then back to normal. I could tel you the exact number of hours, but let's just say I miss my kids.

## Comments

Have you done the Finding Nemo tour yet? □□

*—Jeremy Cook, September 24, 2018*

## Walkabout

*October 5, 2018*

I think most people who read this also see my shenanigans on Facebook, but for the few who don't, the Sydney adventure is drawing to a close.  I'm in an airport bar drinking a $12 beer as I type this.  My gate is behind me and the flight leaves in an hour.  I wrangled a seat in an exit row, so here's hoping I can stretch out and pass out for a good chunk of this flight.  Heaven knows, I haven't slept so great in Sydney.  I've gotten a lot of rest and time to myself, but I always sleep better when I have my wife and my kids under my roof, not on another continent.

I entered this month primarily to help out work, but also because I thought I needed a bit of time to get my head on.  To figure out if there's a way to get closer to the me that was before Colin got sick.  I don't know what I found out other than that I get intensely homesick when I don't have my family with me, no matter how excited I was before departure at the prospect of controlling the remote by myself and not having to force children to school in the morning and so on and so on.  I'm better with my wife and kids.

It was fun.  Because Sydney is so huge and because I never had more than two days off at a time, I stuck close to Sydney, but Sydney is a sprawl and a lot of that sprawl is along beautiful beaches, so you can hike all day long.  Between all the walking and having to eat my own cooking, I can tell you one thing: My pants fit better than they did a month ago.

I've talked to Christina almost every day (talking to the kids is harder because as soon as they get the phone they start talking over one another and goofing off with Facetime filters).  Colin's cold keeps coming and going.  The fainting spells also keep coming and going (though, knock on wood, they seem to be staying away a little bit right now).  The next MRI is on Wednesday and there's always the apprehension before that, but we really don't feel worried.  His health problems are a cold and his penchant to pass out when stressed (and randomly high fevers).  None of those are fun, but they're all independent of his tumor.

So, I'll be en route for the next 25 hours or so.  But I'll be seeing everyone in Germany soon.  Well, those of you who live in Germany, that is.

## Comments

It is great when you are centered by family. We are never exactly the same person after we have endured a family member’s failed health...but maybe the trade-off is that we will never ever not appreciate and fully enjoy the healthy days. Godspeed.

*—Barbara Skipper, October 5, 2018*

# a series of firsts

*October 8, 2018*

Today was MRI prep day, which is always a frustrating and stressful time in the Sorrells household. At least this time there was some novelty, not all of it necessarily good.

It usually involves being at the hospital on the early side. First you have to run to the pediatric clinic to register (We're back for more treatment. Looking forward to the giant bill! Hugs!), then to the cancer clinic to pick up Colin's file, which they've mercifully edited down so it's been reduced in thickness by about a quarter, meaning you can pick it up without cracking a vertebrate.

Then we go the MRI office, which takes no time at all. You fill out a questionnaire, confirming once again that your 4-year-old does not smoke and is not pregnant, and then the doctor comes out and says "You again." And we say "Yes."

Then the annoying part starts. We head across the courtyard to the anesthesiology clinic.  Your job is to take a number, which gets called relatively quickly. But that's just a trick. Because the first time you're called, you just get the questionnaire. Then they usually let you wait 2-3 hours before you get to meet a doctor.  The normal breakdown is that you get in, they're working with ticket number 20, you've pulled 28, but then you realize that number 20 is only up to get the questionnaire, the doctor is actually seeing number 12, for example.

Today we got there, and number 12 was up. And we pulled number 13.  And the doctor was already at 5.  People, we were in within an hour and had finished the whole thing - from registering to seeing the anesthesiologist - within two hours.  This has never been done.

Of course, we achieved nothing.  Colin developed a cold shortly before I flew to Australia and, as near as we can tell, segued rapidly from that one into two other colds.  He did have very short-lived high fevers on three nights at the end of September, but always bounced back from them within hours. His lungs have stayed clear the whole time.  But he is horribly congested and sounds like a defective vaporizer when breathing (though, oddly, breathes clearly when asleep).

In the end, it was enough to make the anesthesiologist nervous.  Colin has to be put under for the MRI, because he's 4 and would never hold still in the noisy confines of an MRI machine. And if he's congested, it makes it harder to keep him breathing properly, etc.

So, now that we've planned our next two weeks around a Wednesday MRI and a meeting with the doctor a week later, we have everything pushed back about two weeks. Unfortunately, this falls during the school's autumn recess, when we had hoped to finally take Emma and Noah on a little trip somewhere, since our dire financial situation kept us home for the summer vacation.  The good news is that we're so unorganized that we hadn't planned a thing, so there's nothing to cancel.  The bad news is: Well, we're not straying far from Berlin this holiday.

As a colleague pointed out, if you look at this from a glass-half-full perspective, we've gone from worrying about Colin's health to being disappointed about vacation plans. It's true, but it still wears on a person.

In other news, Christina learned that our primary oncologist is going to be gone for a year, I assume on research or a sabbatical. Christina is kind of upset about it.  I have to say, I always found him a little cold and distant (and I know this is all stereotypes, but this is a Spanish guy working in Germany - you'd expect him to be the bubbliest person for miles).  Also, maybe the new doctor will remember to make the MRI appointments on time and then not try to blame my business trips as the reason that we're behind schedule on MRIs.

## Comments

Not good that all the rush and getting in quickly (and you must be jetlagged) did not help you tick this task off your list. May be you can still have a trip organised!

*—Sofia Gueorgieva, October 8, 2018*

## The dealer wins

*October 11, 2018*

Well, just because the MRI got delayed, it doesn't mean we couldn't have a hospital run this week.

Colin's episodic apnea has returned with a vengeance. It started up right before I went to Australia, picked up speed while I was there and has gone into a bit of overdrive this week.  It remains horrible, mostly because it's so unpredictable.  If he doesn't get what he wants; if he can't find Christina; if he gets Scotch tape stuck to his back ... any of this is enough to prompt an attack.  He feels it coming, gets scared, makes a scared face and then gets stuck in this position while his lips turn blue and he seems to be locked in until he passes out.  Then his muscles relax and he breathes again, usually understandably unhappy about the whole experience.

It is a miserable situation for us all.  It also makes parenting nearly impossible.  Colin doesn't like our decision?  He passes out, more or less winning the argument each time. I say he should walk to day care.  Down he goes.  He gets to ride on my bike.  Christina says he should play a little.  A moment later, he's out cold.  And then he gets TV.  How do you establish any order like this?

This morning he came downstairs with me and wanted to play on the tablet.  When he didn't get it fast enough, he went under.  When he went under, he wet himself, so when he woke up, he was upset that he was wet, and went back under.  Furthermore, he's been congested for weeks, so when he came to the third time, he was having problems breathing, and down he went.  He was out (or close to it) for so long that we called an ambulance and gave him a suppository to help.  And the ambulance doctor said he should go to the hospital, so that was our morning.

Worse, I don't see any way to avoid it. It all started because he wanted to play tablet, and I wasn't even trying to keep the tablet from him. I simply hadn't found it before he went under.  It's like playing with a stacked deck.

I have no idea why this has come back.  We went nearly two years with hardly an attack.  Now we're having one to three a day.  They started before I left.  They started well after he started physical therapy (which he enjoys) and returned to day care after the summer break.  I see no specific event which would have sparked this.  Then again, in 2016, he didn't develop them until we'd already gotten one or two chemo treatments behind us.  And then they went on for about four months.

All I know is, it's dis-spiriting.  The doctor asked me this morning if he had anything else besides the brain tumor and the apnea.  I asked if she didn't think that was quite enough.  We can occasionally get our hopes up that the tumor is behind us, but now there's this.  It's like we brought on world peace, but the price we pay is that everyone gets hemmorhoids.  We'll get through it, but it wears you down.

He's staying home from day care.  I'm staying home to keep an eye on him.  We're trying to get him an EKG appointment just to check on things.  As the curse goes: May you live in interesting times.

## Comments

So sorry to hear you have had this to make your everyday life more "interesting"! It is indeed a major source of bargaining power for him and an ordeal for you :( May you or the doctors or even Colin come up with an acceptable suction soon!

*—Sofia Gueorgieva, October 11, 2018*

Niels - is this like a seizure, with arm and leg movements while he is "under", or is it more like fainting? I just wonder if it is solely a behavioral problem, as it seems to occur after an emotional reaction, per your description. I'm sure it is frustrating to you. Have you mentioned it to your therapist?

*—Don Summers, October 13, 2018*

# Carpe Colin

*October 15, 2018*

The question came up: Does he faint or have a seizure?

I can only answer as a layman, but I would say it's more of a seizure. It goes like this: Something upsets him - it can be anything from his sister forcibly removing him from a room to me not finding a pacifier for him quickly enough to him getting wound up in Scotch tape. He seems to feel them coming, as he will tend to make sure he's near Christina or me, or he'll try to find a seat.

As he's 4, he'll tend to over-react to multiple things a day (or, if you want to use the technical term, have a tantrum). Often we won't notice until we're already well into the process of comforting him over whatever perceived injustice has happened. His body will become rigid. His extremities will stiffen slightly. He'll slump, because he's losing consciousness. At this point, we'll usually roll him away from us to find his lips are gone blue and his face is frozen in a panicked expression.

If we're lucky, this only lasts a few seconds. He then loses consciousness, begins breathing, and then comes back to consciousness. However, there can be extenuating circumstances. He's got this cold he can't shake and, if he notices he's having breathing problems due to the congestion, that can send him back under. Because he loses consciousness, he'll often wet himself. If he's not wearing a diaper, that will usually send him into a new panic attack. When we took him to the hospital on Thursday, it was most likely because he had about two or three back to back.

Not everything leads to unconsciousness. Yesterday he clearly had some conflict with Noah and marched to where I was to yell at me about it (details were unclear), but stayed conscious despite there clearly having been a major injustice. At one point yesterday he clearly went under, because he wet himself (and me) while I was trying to comfort him about a lack of a pacifier, but it happened so quickly I didn't notice that he'd been out until I realized we were both soaked.

Today he had his first attack with the minders at the day care. Details are unclear. Apparently he was brushing his teeth (Inquiring minds would like to know why he won't brush his teeth at home), and he was not happy with the way Max (the minder) got him the toothpaste. They know about his situation, but it's one thing to have us tell him about it and another thing to see his face blue and panic-stricken and his knees buckling. They ended up calling an ambulance and Christina had to get him from the hospital.

We're sorting it out.  We have no idea why the seizures began in 2016 and why they mostly stopped in August of that year.  We don't know why they came back this August. Nothing really changed then.  It was before I went to Australia and well after he'd returned to day care following summer break. It's a mystery.  Until we sort it out, he's going to have to wear pull-ups to prevent that trigger and Christina and I are probably going to have to be more permissive about him getting a pacifier and tablet time.  When an indignant sibling asked me this morning why Colin got to play tablet while he had to get ready for school, I could only answer "It's better than having Colin pass out."

That said, this is no recipe for effective long-term parenting, so something has to change.

We are trying to get an EKG just so we can confirm whether there is any physiological cause for this.  Frustratingly, with our primary oncologist going away for a year-long sabbatical, we've lost one of our best direct contacts.  His assistant isn't responding to our messages and no one is picking up the phone at any of the clinics.  Nor is our pediatrician getting through.  And we'd all really like to get this looked at sooner than later.

I do honestly believe this will pass, as it did before.  But it feels like one more punch in the gut, to which I can only point out to the universe: I feel we've had our share.  His cold is at least getting better, and hopefully his October 29 MRI will happens as scheduled. But even that - and I realize this is a small thing after all that has happened - means we're stuck pretty close to Berlin for the two-week fall break that starts in a week, meaning we can't take the family on a vacation. And Emma and Noah haven't really been anywhere on vacation for more than a year at this point.  Again, I get it's not the topic of greatest concern to us these days, but you can't help but think sometimes about how screwed over Emma and Noah are getting in all this, and how well they're dealing with it, all things considered.

## Comments

I wish so bad we could fly Emma and Noah down here for a classic African safari! What troopers.

*—Jeremy Cook, October 15, 2018*

Our daughter at that age , when mad, would hold her breath, turn blue, pass out, start breathing again, and be ok. But this sounds different with the loss of bladder control, etc.

Many prayers!

*—Barbara Skipper, October 15, 2018*

Our daughter at that age , when mad, would hold her breath, turn blue, pass out, start breathing again, and be ok. But this sounds different with the loss of bladder control, etc. Many prayers!

*—Barbara Skipper, October 15, 2018*

If you ever need a safe and friend uncle to help entertain the other two kids, I'm available.

*—Marc Galmoud, October 18, 2018*

## Playing Possum

*October 16, 2018*

We seem to have gone a full day without an attack. It's not a record, but it's something.

That said, we've also rearranged our and Colin's lives to minimize his stress levels as much as possible. I know it's good for him, but it feels like a series of small defeats as a parent.  You want your child to grow and progress.  Instead, we're putting him back into diapers, giving him the pacifier more and letting him zone in front of his screens for longer and longer to get him calm. It feels like we're letting him down on a long-term level right now.

Mostly, I think I've developed some small appreciation for the lives of the people who handle celebrities like Madonna and Beyonce, spending all their time keeping a person in a bubble, away from the smallest irritant. It is exhausting.  I see a lot of showing up late to work in my near future, as well as dashing away early.  I see a lot of putting our lives on hold until we get him to a calmer place.  It's going to be a lot of half days at day care - so he stays used to the place, but doesn't get stressed out by it - with Christina and I doing a lot of flying handovers so one of us can work an early shift and the other a late one and keep all of our plates spinning.

All is not lost.  I know we'll reverse all this at some point. He was making excellent progress on potty training. Less so with the pacifier.  And his vocabulary is growing by leaps and bounds. There's even been progress on playing with others (although, too often this devolves into him kicking strange children to get their attention).

We also finally made contact with the new doctor, who apparently has met me at some point in the recent past, but I've met a lot of doctors in the last two years.  We'll see how our relationship with this one goes.  She agrees he needs an EEG (not an EKG as I noted earlier) as soon as possible, so we'll see when that happens.

## Comments

Prayers. Anti-Anxiety meds may help....just for a short time to get him back on track. Just a thought...one of our grandchildren is a highly anxious individual.

*—Barbara Skipper, October 17, 2018*

We've thought about it, but the medicine he's on now is an anti-epileptic, so we'd have to see what potential interactions there could be before we head down that road.

*—Niels Sorrells, October 17, 2018*

Prayers. Anti-Anxiety meds may help....just for a short time to get him back on track. Just a thought...one of our grandchildren is a highly anxious individual.

*—Barbara Skipper, October 17, 2018*

# A breathing machine

*October 20, 2018*

We are not done with these breathing attacks yet, though it does seems that all of us, Colin included, are getting better at calming him down before he goes into a full panic and passes out. We've had several periods of 24, 36 or even almost 48 hours between attacks. I think, as I write this, we're going on 28 hours.

In one phase this week I almost had him go under twice in one day. The first was when I picked him up at day care.  I stopped to chat with the minders and I guess he thought I was going to leave him there, but I talked him down.  A little later I asked if he wanted to watch Curious George.  He said yes, but then violently objected when I put that show on.  Turned out he wanted Ninjago, but kept saying Miyago, so it took me a while to figure out what he wanted.  Again, it got close, but I pulled him back from the brink.

The same day I caught him licking margarine straight from the tub and told him to stop.  He did and didn't even seem fazed.  Which is good news, as it means I'm still capable of drawing some lines in the sand without risking him going under.

He loves physical therapy and the therapist's husband works in the same office, doing some Chinese medicine.  He told me that he can feel that Colin's kidneys and liver are stressed by placing his hands on Colin.

"Look," he said, hands on Colin.  "There's stress."

Then he put one hand on Colin's back and tapped Colin's skull with the other.  Colin seemed kind of entertained.  After a few beats of this, he put his hands back on Colin's torso and said "See, much better."

Honestly, I don't believe in this stuff at all, but I'm figuring at this point, what the hell.  So later, after I get the tablet out of Colin's hands, I'll be tapping his head and seeing what happens.

## Comments

Pleased to hear there is good news! Hope there is more to come! And don't laugh too much at Chinese practice - I have my personal example where Chinese massage helped successfully resolve a blood circulation problem I had that Western medicine and pharma couldn't :-)

*—Sofia Gueorgieva, October 20, 2018*

Whatever works, go for it. After all, you and Christina are his primary, and most important therapists. By the way, do Emma and Noah ever get helpfully involved in dealing Colin, talking him down, etc
.?

*—Don Summers, October 20, 2018*

Hey, Niels, I hadn’t read the journal this month so catching up. Whew, an exhausting place you and Christina are in. And Colin and Emma and Noah. But seems to me you are thinking about it just right and doing as well as possible balancing his comfort and security with your need to parent and guide. But what a tough row to hoe. One foot in front of the other...stay with it cuz!

*—Carol Hamilton, October 21, 2018*

## Deep Breaths

*October 25, 2018*

We are not entirely out of the woods yet, but we are routinely going 48 hours between attacks right now.  The last one was Tuesday, when he realized I was going to bring him to bed, not Christina.  This is not to say there aren't a series of mini-attacks in between.  He won't lose consciousness during those, but he holds his breath and goes rigid, clearly upset by the experience.  But we consider it a success if we keep him from going under.  After one a few days ago, Christina said "Das ist ja genial," which roughly translates to "That's pretty good," which only shows you how warped our perspective of what is acceptable have become. The main difficulty remains in figuring out what will set him off.  He almost went under one morning this week, not because I wouldn't give him the tablet, nor because it took me too long to get him the tablet, but because I suggested we take the tablet upstairs so I could fold laundry while he played.

That said, Christina and I are no longer viewing these as panic attacks.  He's not typically scared when they start.  He's mad.  Mad because he's not getting his tablet or because things aren't going the way he wants.  These are temper tantrums going bad.  Nor are we worried that this is some kind of epileptic seizure as the medicine he's on - the semi-experimental medicine designed to keep his tumor from reoccurring - was originally an anti-epileptic, so we were taking measures against that before the possibility of seizures even came up.

Again, we're not doctors, so what do we know.  We just know that when it comes to tablet time, TV time, pacifier access, bedtime negotiations or questions of walking anywhere, thinks can get ugly.  I find the last the saddest, because, as recently as August, he loved walking, heading to physical therapy and day care by foot without a complaint.

Although he still coughs a little, most of that is cleared up.  We head to the hospital for MRI prep tomorrow and are hoping that we will then be cleared to finally get the MRI on Monday.  As for the EEG, they originally scheduled it for November 2 - which would have been a challenge, as Christina is going to be away with her mother and sisters that day - but then decided they actually want him to come and stay overnight for two days for a 48-hour EEG.  They're still working on scheduling that, but hopefully it won't be too far into the future.  Again, we're not terribly worried about them finding something physically wrong with him, but it will still be good to know he's been tested.

## Comments

Things are indeed relative, and you are gaining a lot of experience, but it would have certainly been better if you did not have to become experienced in this field.. .Good luck with all forthcoming challenges!

*—Sofia Gueorgieva, October 25, 2018*

Yes, for peace of mind. Prayers

*—Barbara Skipper, October 25, 2018*

# And on the fifth day...

*October 27, 2018*

My earlier count was wrong.  Colin's last major attack was Monday night, not Tuesday. So that means, as of this morning (Saturday) we were at four and a half days without a major incident.

And then came the fight about the alarm clocks. For those of you without children, prepare for a march through some of the daily drama you have even without a cancer patient.  A few years ago, I got a Superman Lego alarm clock.  It was much coveted by the younger members of the family, so, for Easter this year, Emma and Noah got Batgirl and Batman Lego alarm clocks, so they could have their very own alarms to sleep through on school days.

Colin loves these clocks.  He will routinely gather them all into a central point and then play out games with them.  The older two, who routinely ignore the clocks (especially when they're sounding the alarm to go to school), only show an interest in them when Colin is already playing with them.  Today, Noah had to have his Batman clock back from Colin's play world.  Christina was in the shower.  I was downstairs trying to get things together for an outing.  I came upstairs and found Colin complaining to Emma and Noah in a defensive huddle with Batman.  I tried to get Batman away from Noah, figuring this would calm Colin down.  Then we heard the thunk and the bang.

Colin had stopped breathing while Emma was hugging him. Either she wasn't prepared for this or couldn't physically hold him up, but he essentially planked and then tilted backward, knocking the back of his head against a pretty hard floor. We got him up and moving (he suffered a series of mini-attacks after the bump to his head) but eventually got him down in front of the TV. The lump went down, he got active again, Batman was liberated from Noah's clutches. Life moved on.

In retrospect, we probably should have let him have a nap then, but I thought it would be better to keep him moving around after such a knock to the head. So, we drove about 45 minutes out of town to a place where we could pick apples from an orchard. Upon our return, Christina had to head out grocery shopping. Colin was none too pleased about her departure, so I took him upstairs to distract him as Christina left the house. I had to resort to using the tablet. And then I couldn't get him off of it. As it became clear that the tablet was soon going to power down anyways due to lack of battery life, I gently removed it. But then he said he wanted to go to bed. It was 6:30 p.m. and he hadn't eaten dinner. Also, we gain an hour tonight, so if I'd put him to bed at 6:30 p.m., he would have bounced through our door around 3:30 a.m. Sunday. I tried to get him downstairs to dinner, he went under again. And each time he came up, the realization that I was trying to get him downstairs to dinner put him right back under. It wasn't until we pulled out the tablet again that we got him awake and happy (if refusing to leave the bed).

I called Christina to ask if I should just put him to bed, which only panicked her. It didn't help that Emma was in the background saying that Colin had gone down eight times (I could not verify that myself, I routinely forget to count when he goes under) and that once he was out for 26 seconds. I'm trying to keep Christina calm on her end of the phone, but I don't want to make Emma feel bad by saying to Christina that I question her counts, so there's general guilt and panic throughout the family. Christina is also supposed to leave on a trip with her mother and sisters on Thursday - one they've been planning since before Colin's diagnosis - and now I've got to convince her all over again that we can cope with this and that she really does deserve the time away.

I will say this, Emma is a huge help. Perhaps almost too much, as she pushed me aside once or twice because she was sure she could care for Colin better than I. We have to work on Noah. I get sibling rivalry and how the Batman clock is only interesting when someone else is into it, but I can't have him provoking his brother when Colin is always treading the edge of a temper tantrum that can result in unconsciousness. His therapist told me a while back, that, when asked to rank the scariest events in his life, Colin's illness didn't even make the cut. It reminds me of Emma, when she was 8 (Noah's current age) saying that she didn't think Colin's brain tumor was as big a deal as the concussion she'd recently had when she took a big fall. I guess 8 is not an empathetic age. Noah said as much today, that he finds it annoying that Colin gets all the attention and always gets his way. I get it, but I can't have it.

Colin at least seems to be be coping.  I don't want to imply that we had no incidents since Monday night, just that, every time he held his breath for a very long time, we always saw him pull himself together before losing consciousness.  So, we remain on edge.  He was cleared to get his MRI on Monday (we feel good about that) and will have to see when the doctors schedule the EEG.  They now want him to come and spend 48 hours in the hospital, so we'll have to figure out when we can schedule that.

That said, we'll just reset the clocks and hope that we can go five or more days this time between events.

## Comments

Great news that Emma and Noah are at times expressing resentment that Colin gets so much attention and at other times are helping to care for him. In a difficult situation sounds like they are coping pretty well. As are you and Christina, even though it’s tough a lot of the time. You are all saints.

*—Don Summers, October 27, 2018*

## treats, no tricks

*October 31, 2018*

I was out trick-or-treating with the kids when Christina texted me that the new oncologist had called to report that this week's MRI showed that everything was stable.

First, yay!

Second, given that our original oncologist never called us within 48 hours of the MRI to give us the results, because it's much more satisfying to schedule an appointment with us 10 days later - for which you'll show up late and then spend half the time on the phone with your wife trying to explain to her where you hid the spare pair of house keys. Perhaps this new oncologist will still show up with some new, awful fault, but, so far, it's looking like she has a bedside manner of sorts, whereas our first oncologist might be better suited to research work. We'll have to see if we aren't going to try to keep our new doctor (whose name I must learn) when next year rolls around.

Third, they are keeping an eye on this small dot that's been there since Colin's been taking MRIs and are beginning to wonder if this small site might have something to do with his fainting spells. But, given that the fainting spells disappeared for two years and that dot hasn't budged, it seems unlikely. Besides, the spells are so clearly linked to moments when he's upset about something, it's hard to not think they must be behavioral, not physiological. Then again, we're not doctors and we're a bit emotionally invested in this, so maybe we're not the best people to ask. Anyways, the oncologist said not to think about it too much. They wouldn't be calling us to give us the all clear if they were particularly worried about it. It looks like the EEG will now be November 12-13. Until then, we'll see.  At the moment, we're 36 hours without a fainting spell, so that's something to hold on to.

And finally, you'll see from the photo that we upgraded Colin's Superman suit for this year's Halloween. Not only does it look like he's been hitting the gym, but Colin managed to time it so that he's resumed an interested in pastries and sweets just in time for Halloween.  For about two years, he's showed almost no interest in any of it.  Yesterday, he ate his first cookies in our recent memory.  And today, he not only passionately got into trick or treating, but he cut a respectable swath through his take, which will not make his dentist happy, but seemed like good deal to us, because, heaven knows, this is one kid who deserves a little sugar.

## Comments

Yea!

*—Barbara Skipper, October 31, 2018*

Yea!

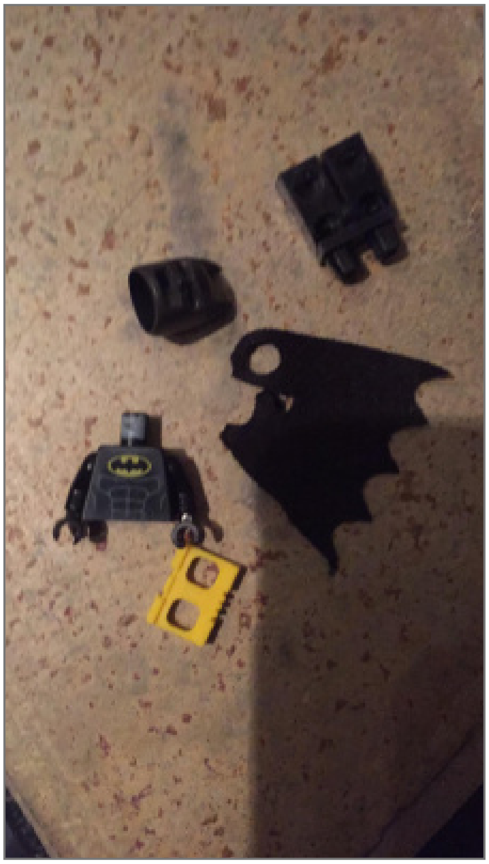
*—Barbara Skipper, October 31, 2018*

Great news! And don't minimize your and Christina's observations of the circumstances surrounding Colin's "episodes". It could be that his emotional state triggers some unusual seizure activity, which might show up on an EEG.. There are several types of seizures besides and unrelated to the well-known grande mal seizure, which doesn't sound like what you describe. Hopefully the EEG will shed some light on these events - would be interesting if he had one of these episodes while undergoing the EEG.
Happy Halloween, and All Saints' Day too.

*—Don Summers, October 31, 2018*

# Bring me the head of Batman

*November 3, 2018*



To fully understand this story, it is important to know that there are at least two versions of Lego Batman figures.  For all I know, there are 45 different ones.  The important thing is that we have two of them in our household.

Colin's favorite toys go in cycles.  Some of them make it into his "security bag" and stay there for months.  Some barely last a day.  Of late, he's been into Lego figures.  Batman has particularly smitten him.  For a while, we had both Batmen figures, complete with capes and utility belts and what-not.

The one toy trend that does not go out of style, however, is Colin's love for taking the toys apart and throwing them around.  You can see how this does not end well with a Lego figure that can be broken down into about five different parts.  We lost the head of one of the Batmen a week or so ago, but it didn't seem like that big a loss, since Colin had all the parts to make the Batman that he clearly considered the superior of the two. (A side note: He's also obsessed with a Lego Batplane Noah got for Christmas a few years back. Because children play with it, one wing came off ages ago, but Colin is fine with a one-wing plane. Indeed, when I took a few minutes last week to reattach the second wing, he got mad and forced me to tear it off)

And then came today. Earlier, I caught him lying halfway up the stairs, taking Batman apart and then dropping the pieces individually from a height of about eight feet, so he could come downstairs and complain loudly that I didn't know where all the pieces were. It's like "This is the most precious thing in the universe to me right now, so I'm going to destroy it and make it your fault. Welcome to parenthood."

Miraculously, I did recover all the pieces (it was a near thing with the cowl) and got him through the rest of the day.  We went to the playground and returned home in the middle of a near bathroom emergency.  I did get him to the bathroom in time, but not before he grabbed Batman and, as near as I can tell, dismembered him in his anguish about needing to relieve himself.  When I realized it, I pulled the pieces together, but could not find the head.

However, earlier in the day, while tidying the boys' room, I had found the long-missing other Batman head.  So, when it came time to put on pyjamas and Colin wanted to know where his Batman was, I got him upstairs and attached the alternate head and it seemed good enough.

Now, Christina is off in the Czech Republic with her sisters and mother, so I'm juggling the balls by myself in Berlin for a few days.  The panic/fainting spells haven't disappeared, but they're at least not coming quite so fast and furious.  We had three on Friday, at least one because a comic book wasn't shared.  By the time bedtime rolled around today, I was feeling pretty good, because we hadn't had one at all.  Then Colin wandered into Emma's room looking for a "dragon."  None of us knew what he was after, and next thing we knew he was out.  We got him back on his feet and took him downstairs so he could watch TV with the other two (I didn't want him to go straight from being unconscious to being asleep; I wanted to watch him and make sure he was reacting normally) and that was fine. And then came bedtime.  And he was fine with that.  And then he wanted Batman.  And I told him Batman was upstairs and I'd take him to him and all that, and I almost got him to the room, but he passed out again on the upstairs landing.  So, again I pulled him together and got him to bed and pulled out the tablet so he could have a period of wakefulness between being unconscious and asleep. All of this is, of course, making bedtime take forever.  But then the tablet time ends and he wants Batman, so I hand him the figure.

And then he takes off the cowl.

Let me tell you.  Maybe if you put these two Batman heads next to one another I'd be able to tell the difference.  The one I found upstairs certainly looked enough like the one downstairs to fool me.  But Colin - who has all the tracking and finding skills of a normal 4-year-old - could tell immediately that this was the replacement Batman.  Another fit was had.  He didn't go under this time, but definitely held his breath for a little while.  I managed to calm him down and then get him to sleep.

And now it's 9:55 p.m. and I'm going to use the rest of my Saturday night looking for a Lego Batman head that, by this point, could have been kicked anywhere in the downstairs part of the house. Sweet dreams everyone!

### Comments

Oh, no. Good you still have your sense of humour. Bon courage with the search!

*—Sofia Gueorgieva, November 3, 2018*

## Rejoice!

*November 4, 2018*

Emma found the missing Batman head! Now, if we can find the missing cape to the unpopular Batman, we'll have two complete figures.

## Something like a setback

*November 8, 2018*

In the hierarchy of bad days since Colin got his tumor diagnosis, yesterday was not the worst, but I think it clearly ranks in our top 10.

To recap, he had his last MRI on October 29.  On October 31, the new oncologist called us to say that everything was stable. There was one spot that indicated some fresh bloodflow, but she said they wouldn't casually mention this on the phone if it was something they were terribly worried about.  There was the chance it had something to do with the fainting spells.

As usual, we ran into traffic on the way to the hospital on Wednesday.  We were headed there for our usual post-MRI chat.  We called to let them know that traffic was a problem.  The nurse said not to worry and, by the way, we'd be meeting with our normal oncologist, not the new one.  This set off alarm bells.  Why bring in the old guy, especially since he's off on sabbatical (turns out he's not leaving Berlin, just teaching classes here and lightening his diagnostic workload).  I attributed it to standard hospital disorganization.

The upshot is that they are a little concerned about this site showing new bloodflow.  The tumor mass itself has not changed size, but they don't know what the new bloodflow means.  One theory is that it's a delayed reaction to the radiation therapy from two years ago.  Our neurosurgeon said they frequently have odd results on MRIs that show up one test and disappear on another.  The oncologist said that it is not the kind of change normally associated with the return of a tumor.

But they don't know.  So, Colin is going to have his EEG Nov. 16-18 to see if they can figure out anything about his fainting spells.  And we're going to have our MRI schedule accelerated, so the new one will be before Christmas (normally it would have been at the end of February). But it all feels wrong and like we're going down the rabbit hole again.  The very fact biopsies are being mentioned once more shredded me, given the memories of how he couldn't walk for six weeks after the last one.

We were a mess yesterday.  It's impossible to say if the new oncologist is simply more optimistic about things and the old one is more of a pessimist (his charming bedside manner remains unchanged. When Christina asked if we should be worried, he responded "Well, you're worried already, aren't you?").  Perhaps they gave the MRI images a harder look and realized they were too optimistic in their initial assessment.  It was hard to get many details.  The oncologist was late seeing us and then only had about 20 minutes to spend with us before he had to rush to teach his class.  As is our usual method, Christina did most of the talking with him while I tracked Colin around the room.  Let me tell you, Colin was having a blast because, being 4, he loves nothing more than taking a room apart brick by brick, so I was pretty busy keeping him under control and only half able to listen to a conversation in my second language involving lots of technical terms.  So, there are a lot more questions than answers.

Today is going better, but yesterday brought all the old feelings back.  Initially, I told Christina I was doing OK, but then came the feeling of despair, this sense of being trapped in amber and the need to muster so much energy to do anything from getting out of a chair to changing Colin's diaper.  I worry about myself when I don't want to do anything - I don't know if it's a sign of depression or what, but when I'm lethargic, I know something isn't right.  All I wanted to do was sleep - rather, go unconscious - but I have three children to raise and a household to run and a job to go to (though I did call in sick yesterday).  I think I might have also been in a light state of shock.  And, as it always does when I have personal problems, my stomach started doing the watusi.  I've not really been able to eat much since the diagnosis.

That said, I'm cycling through all the emotions so much faster this time.  Is it just experience?  I spent the afternoon feeling sick to my stomach and the early evening feeling like a zombie and then I passed out for 20 minutes while the kids watched a show with Christina.  And then, as much as I wanted to go to bed, Christina talked me into going downstairs and watching bad 80s videos with her.  She suggested we have a drink and I said no, because I felt depressed and I don't like drinking when I'm feeling that way.  She then said we should at least have a vodka and, by the end of the conversation, I was feeling better enough that I had two beers (hey, they showed INXS and Michael Jackson!).  When Colin got his diagnosis in 2016, it took me about six weeks to cycle through all these phases.  Now I've got it down to about 10 hours (although I can still feel my stomach messing with me).

I don't know how we're going to do this.  We've decided not to mention anything to Emma and Noah until we get some clarity from the doctors, but it's going to be odd to be doing Christmas preparation with this hanging over us.  You can't stop your brain at times like these.  I've already wondered what happens if we have to go back to chemo (is that even an option?).  Do we get a new au pair?  Where would be put him/her (in an act of defiance against the universe, we turned the old au pair's room into a playroom for the kids earlier this year, daring it to make us need an au pair again).  How do I manage this with work? Walking home after dropping Colin off at day care (we're keeping him on as normal of a schedule as possible) I suddenly wondered how difficult it would be to find a suit for Noah quickly if we needed one for a funeral and then had to, essentially, slap myself in the face for even thinking something like that.  I'm a little messed up.  I can't speak to the specifics of how Christina is coping, but she's also having a hard time holding it together.

We're taking heart from the fact that Colin seems to be doing fine.  There are none of the signs from back in 2016 that initially led us to seek out medical information.  If anything, he seems to be making progress.  So long as he's running and jumping and hiding Lego pieces throughout the house, I'm going to choose to believe this is just a speed bump that we're going to have to get through, because that's our life now.  And, as I can't stress enough, the doctors have told us not to panic: This is simply something that needs to be watched.

Of course, that is easier said than done.

Some other stray thoughts:

- We figured out last night that Colin has a corn on his foot (Hühnerauge for my German readers), which might explain why he's suddenly so against walking any significant distances.

- He has learned to curse. Yesterday, he called me a "blöde Kuh" (dumb cow) while I was trying to give him his medicine, so we're at least making some developments in speech proficiency. Plus, it's always a relief when the bilingual child develops a potty mouth in the spouse's native tongue, not yours.

- The people at the day care are being troopers about this. They told us not to even think about pulling him out of the group. They're figuring work around strategies and, like us, doing everything they can to keep him from having fainting spells.  We actually went three days without him completely passing out (though there were a few lesser attacks in between).

- I neglected to mention this last week amid all the commotion surrounding Colin's fainting spells, but, in other bad news, one more child from the rehab month last year is dead.  That means that, less than a year after we were all there to get our heads on straight, three of 34 children are no longer with us.  I can't really wrap my mind around that.

And that's it.  I started these messages in March 2017 with an email titled "prayers please." I can only repeat that again today, from the bottom of my heart.

## Comments

Am so sorry and terrified over all that Colin and all of you have been and are going through. I wish it to turn well.
<3

*—Boris Babic, November 8, 2018*

So sorry to read this Niels, hang in there!! Crossing my fingers and toes that this turns out to be just a blip on his road to good health. A big hug to all of you from Nairobi.

*—Alexandra Mayer-Hohdahl, November 8, 2018*

So sorry to hear you had such an emotional day yesterday. Hope the situation is not bad and that you will have the energy and patience to go through the waiting (and keeping the Xmas mood as intact as possible!).

*—Sofia Gueorgieva, November 8, 2018*

Hang in there, Niels and Christina. Prayers are there, and by all means, keep writing.

*—Don Summers, November 8, 2018*

You're having a rough time and understandably so. Sending positive thoughts for Colin to make a complete recovery and for this just to be a meaningless blip. Good luck with all this stress and worry. Don and I are thinking of you and Christina.

*—Dan Wooldridge, November 8, 2018*

Jerusalem is praying for you!

*—Claudia Busch, November 8, 2018*

Prayers are coming your way. Let's hope this is nothing and they will keep a watch on him. Keep writing, please know we are all behind you and family.

*—Jeanne Clayton, November 8, 2018*

Very sad to read this, Niels. Praying for you and Christina and the kids. Stay strong, friend.

*—GF Santos, November 8, 2018*

As always you have my prayers and support. Don't be afraid to pick up the phone if you need a buddy to chew the fat with.

*—Marc Galmoud, November 10, 2018*

We're with you guys! I'm grateful for these posts, even if they contain difficult news, because, not only does your humor help my ab workouts (!), but also I love being a part of this kid's life, a boy I've never met, and really want to meet in this life. So yes, we're definitely praying.

*—Jeremy Cook, November 12, 2018*

## meltdown merriment

*November 11, 2018*

Today is the feast of St. Martin, the saint who came across a naked stranger and cut his cloak in half to clothe the man. In the days around this event, German streets are full of children parading with lanterns behind a person on horseback dressed like St. Martin. Then, at the end, everyone gathers around a bonfire and drinks mulled wine.  I don't quite understand how the mulled wine and bonfire come into the picture, but I've long since learned to just go with the flow when people offer you mulled wine.

We decided to go to the local march last night. We wanted to be at the church (where the march started) by 4:30 p.m. It took a while, because Colin and I had an extended debate about whether he should wear clothes for this outing (I'll let you decide who argued which side of that), that was only resolved when we agreed he would wear clothes, but Christina would be the only one who gets to dress him (and even that was a bit of a struggle). And we set out, around 4 p.m.

We forgot there is an Aldi along the way.

This is an important thing to know about Colin.  The older two are always after us to take them to Legoland or the pool.  Colin?  Nothing would make Colin happier than a two-week tour of northern German Aldis.  He loves them.  And he saw this one and he wanted to go inside, never mind that we were running late and didn't need anything.  So, being a 4-year-old, he threw a complete fit.  We had him in his buggy and we tried to push him away from the Aldi as fast as we could, but that just meant we covered more ground and exposed more locals to the sight of Colin being wheeled through our neighborhood, screaming "EINKAUFEN!" (SHOPPING!) and generally hyperventilating.

And all I could think the whole time was: 'Hey, at least this is somewhat normal 4-year-old behavior."

Also importantly, he didn't faint, which I always take as a good sign.

So, that's where we stand.  We pray for proper tantrums, because they show we can still have something like normal.

I won't pretend we're just coasting along.  We've all been varyingly unsteady since Wednesday, but I keep reminding myself that it wasn't bad news, per se, it was simply a reminder that there is a lot of uncertainty about this and now the doctors are more closely watching one particular uncertain thing.  I take a lot of solace in the fact that Colin is usually his normal self and is not showing any of the behavior that worried us back in 2016.  Even the fainting spells seems to be growing a little less frequent.  Today wasn't a good day, but he also dragged Christina out of bed at 5 a.m. because he wanted to watch a Lego movie, so he was very tired, which always makes the fainting spells more likely.  We had two days this week with no spells at all and several more where he started acting as if he was going to faint, but pulled himself out of it.  Yes, I'd be happier with zero spells, but I'll take whatever progress I can get.

# 48 hours into the future

*November 15, 2018*

The dream? Doctor's orders to stay in bed and do nothing but watch TV.

The nightmare? Doctor's orders to keep a child hooked up to an EEG for 48 hours and in bed the whole time.

It's going to be a long weekend, folks. We'll see if I emerge with my sanity on Sunday (we go in around 10 a.m. Friday, but I know there's no way I'm going to have time to blog tomorrow morning, which is why I'm doing this now).

So yes, the EEG is coming. I am skeptical it will reveal much. We have not sidelined the attacks yet, but they are growing a little less frequent and a lot less severe. I think it's been almost a week since the last really big one. The only one I've seen this week - Monday morning, and mostly revolving around whether he wanted to go downstairs or not - only lasted a few seconds. His primary day care minder logged two more today, but said they lasted about a second each and were more like overblown temper tantrums.

We have a lot of hope that he is learning to pull himself out of these things. I think we're also trying harder too, by not acting so panicked when he has them. Believe me, that is his first instinct, but having his parents and his siblings huddled around him urging him to breathe, breathe, breathe probably isn't the most calming thing in the world. So now, when it happens, we panic on the inside, but tell him to tell us what he wants and to get up off the floor. It seems to be working to some degree.

It's a little frustrating that, now that we have the hospital time booked, the rate is slowing down. Then again, not only will he and I have fun memories of me pinning him to the bed because there's only so much of a lead on his EEG cap, but that might provide the potential for some more meltdowns, so the doctors will at least be able to record them.

As for everything else, first I want to thank everyone who has called us up or sent an email or even just pinned a heart to this site. Every one makes us feel a bit better.

I'm not going to pretend we're high-fiving our way through our days. The latest MRI still wears us down in the strangest ways and at the most unexpected times. I'm seeing my therapist for the first time in weeks on Tuesday and I can only imagine what's going to come out at that session. But we take a lot of hope from the fact that Colin is acting normally through all of this.  We're taking a lot of hope in the fact that that the attacks are growing somewhat less severe. Perhaps the doctors were mostly concerned by the appearance of the spot on the MRI AND the attacks, and if one of those is going away, maybe the concerns are less as well?  Maybe it was all just bad communication between the first and second oncologists.  Maybe, maybe, maybe.

In the end, we don't know, but we've got a 4-year-old who spends most of his time doing his thing (which is strewing Legos all over the house).  He acts mostly fine.  That helps a lot.  I heard Christina talking about his first day of school with a friend at the weekend.  That would be, earliest, 2020 (and most likely a year or two later).  It's good to know that we can still think about the future with him.  We're looking for a speech therapist.  We're buying Christmas gifts.  We're a little roughed up, but we're also not flat on the floor in depression. I remain optimistic.  It's all I can do.

## Comments

GEEZ! 48 hour EEG? I don't even think my husband could do that. Prayers on steroids coming your way through the weekend.

*—Barbara Skipper, November 15, 2018*

And Colin hates wearing most hats...

*—Niels Sorrells, November 15, 2018*

# Magic!

*November 16, 2018*

Because the hospital is a magical place, they expect me to be by his side for the next 48 hours, so he doesn't disconnect himself from the EEG. At the same time, they only provide him with meals: I get coupons to use at the cafeteria two buildings away. The fun has begun: I'm on a diet!

Sent from CaringBridge iPhone app

## November 16, 2018

First they said show up at 8. Then they said 10. We were here around 10:15 and they didn't get us into a room until 1pm. The EEG equipment went on around 2. Helpfully, he only had one small fit today, unfortunately before the cap was applied.

We're six hours in. He doesn't have to stay in bed, but we can't leave the room. I'm going to see if we can put away the TV a little bit tomorrow. We got a new LEGO Batman set for the weekend, so I'm hoping that can keep him happy for a while. We're being filmed the whole time in the room, so I figure they'd like to see something other than him staring at a screen.

A thousand thanks to Ivonne and Marc for being willing to swing by with food tomorrow. There will be a thousand more if the food isn’t from the cafeteria. First thing when I get home? Writing a letter to the hospital about it’s ridiculous policy of not delivering meals for the parents. Giving me vouchers to use at a cafeteria two buildings away is useless to me if I’ve got a panic-prone pre-schooler on my hands, whose main focus right now is tearing off his EEG cap.

## Photos

Sent from CaringBridge iPhone app

## Comments

Bon courage for the remaining time! And indeed, a good idea to complain about the cafeteria system - they won't improve if they have no clue they are doing it wrong.

*—Sofia Gueorgieva, November 16, 2018*

Should I bring beer?

*—Stephan Roch, November 16, 2018*

Ah yes, the human bridge between hospital beds game! Creative!

*—Jeremy Cook, November 16, 2018*

## The cure

*November 17, 2018*

Apparently, the quickest way to cure a child of unexplained unconsciousness-causing panic attacks is to check him into a hospital where he can be hooked up to expensive equipment for two days of testing.

Sent from CaringBridge iPhone app

### Comments

Of course! How do you say Murphy's Law in German? □□

*—Jeremy Cook, November 17, 2018*

Amazing! Hmm....

*—Barbara Skipper, November 17, 2018*

Amazing! Hmm....

*—Barbara Skipper, November 17, 2018*

Had you but known...

*—Chuck McCutcheon, November 18, 2018*

That sounds about right. Sort of like how your car makes that disturbing sound right up until you get it to the mechanic.

*—Adam Spector, November 19, 2018*

## A few new questions

*November 19, 2018*

We're out of the hospital and in one piece (well, two pieces, we kept them from sewing us together).

It went about as well as a weekend in the hospital could be. I've already complained about the long time it took to get us into the room. The regular fight with food services (thank you again for all those who brought food to me, as well as to those who offered!) ... and the general ambiance.  All that said, we survived fairly well. Then again, Colin was asleep at 6 pm yesterday and slept for 11 hours. So, it all took its toll on him.

It was annoying. It was informative. It raised some questions. A lot of it was actually fairly relaxed and pleasant. We watched some movies together (to be precise, we watched the first 10 minutes of multiple movies multiple times, since Colin seems to have set points after which he no longer wants to watch certain movies).  We unpacked a new Lego Batman set around midday on Saturday and, honestly, once we had that on the floor, I could have nipped back home for lunch and I don't think he would have noticed my absence. Food coupon problem solved!

I'm not sure what the EEG results will show. They're going to mail us the report. A nurse helped me get the cap off with some effort on Sunday and, wow, I'm amazed he was so relaxed about the weekend given how tight that thing was on. He has bruises on each temple from the contact points. He must have had a headache. Also, they use a conductive gel to make it all work, and that hardens over time. It made the removal difficult, but also forced us to face the fact that, after months of no cooperation from Colin's side, we finally had to break down and give him a proper shower and hair washing. That was the scream everyone heard around 8 a.m. Berlin time.

One new wrinkle did emerge. During the last MRI, an anesthesiologist had pointed out that Colin seems to take very shallow, very spaced apart breaths when under. He suggested we have his blood oxygenation checked while we were getting the EEG. The oncologist agreed, so naturally she promptly forgot to relay the instructions to the ward where we were housed.  But Christina remembered on Saturday and it's a pretty standard piece of hospital equipment, so we put it on him after he passed out (at 7 pm, in bed with his new Batcave).

That's when things got interesting. The average person is supposed to have about 93% blood oxygenation. When sleeping, Colin's averages 80-85% (and can drop as low as 70%). This, of course, set off alarm bells among the staff. Unfortunately, it also happened just at the shift change, so the old team didn't want to start us on a course of action until they checked with the new team. By the book, they were supposed to hook him up to an oxygen feed with levels like that.  But we all agreed that would result in a night of screaming and no sleep. We gave him some nose drops, just in case his sinuses were blocked.  And they took blood to run more tests on his blood gas levels. When they confirmed that his blood levels were too low, we all compromised by putting an air mask very near to his face, which resulted in Colin spending most of the night shifting positions to get away from the mask.  Nobody really slept Saturday night.  If we did manage to get asleep, the air hose would come unattached and then we'd have to wake up to put it back together.  Or a nurse would come in and move the mask closer to Colin's face, forcing him to wake up and move again.  In a personal low, I woke up from a doze at one point, saw the nurse - who I thought had left the room - and screamed, waking everyone up too.  It was a trial on all of us.

Now we have to find out what it means.  If he's not sleeping properly due to low-level suffocation, maybe it explains why he's so tense and prone to fainting.  Maybe it explains why he's a bit developmentally delayed (he's too tired to do much of anything else). Who knows.  I must point out, my degrees are in communications and international affairs, not medicine, so I'm just clutching at straws here.

It must also be noted that, during the whole stay, he passed out only twice (and one of those was before they got the cap on him).  The only time he passed out with the cap on his head was when he woke up Saturday night to find the nurse drawing blood and, honestly, I have to say that's a perfectly legitimate moment to pass right out. Hopefully that was enough for the EEG team to shed some light on what's going on inside his head.

In other news, the next MRI has been set for Jan. 2.  It's going to be an odd holiday season, with that hanging over our heads.  I stress, Colin is acting totally fine, so I remain optimistic that what they saw on the last MRI was just a blip or one of those mysteries of medicine that does not have to be a tumor returning.  But it's hard not to have those down moments when I just see our world ending.  I keep them to a minimum.  I'm generally able to function in normal society.  But there are moments when it's hard.

And then there are moments where we play with the new Batcave for lengthy stretches. It doesn't quite balance out, but it's something.

## Comments

Hopefully they'll figure out how to raise Colin's oxygen levels and figure out the correct explanation to all these issues! You have not lost your sense of humour (sarcasm), I would treat that as a good sign. Have a good new week all of you

*—Sofia Gueorgieva, November 19, 2018*

Hopefully they'll figure out how to raise Colin's oxygen levels and figure out the correct explanation to all these issues! You have not lost your sense of humour (sarcasm), I would treat that as a good sign. Have a good new week all of you

*—Sofia Gueorgieva, November 19, 2018*

That is really interesting about the oxygenation! When mom got sick I purchased from Amazon one of those oxygen measuring devices that goes on your finger to ensure lack of oxygenation was never a problem for her. Prayers and blessings to you and your family!

*—Barbara Skipper, November 19, 2018*

Hallelujah for Batcaves!

*—Jeremy Cook, November 19, 2018*

Glad you made it out in one or two pieces.

*—Marc Galmoud, November 20, 2018*

## down time

*November 29, 2018*

Around 8:30 this morning, I was sitting on the stairs, just inside the entrance to the day care, holding Colin as he shuddered his way through a series of about a half dozen attacks, holding his breath, losing consciousness, coming to, repeating.  When he was done, he sat up, pointed towards the door of the day care and in we went to start his day.

I can't tell you how bizarre these attacks are to all of us.  Most of all, I suspect, to Colin. We take him to the hospital for 48 hours of screening, he only has one.  He'll have nearly two and a half days without incident, and then he's out because we tell him he can't play tablet at 6:30 a.m.  Today, Christina went out to a Christmas market and he wasn't happy about it, but he held it together.  This weekend we had almost no attacks.  I bragged about it a bit to our oncologist and pediatrician: Next thing I know, we had about eight attacks in 24 hours.

Christina worries, understandably, about how his heart will deal with this.  We're both trying to figure out some answers and find some coping mechanisms.  We're trying some homeopathy in the hopes it might calm him down a little.  We're doing what we can to keep his air passages free.  We're trying to structure his days so there are no surprises, but that's just about impossible.

As near as we can tell, he'll be set off by not getting his own way, but also when things don't go as he expects.  He passed out at day care Tuesday.  We suspect because Christina, me and the minder were all trying to get him psyched about the day at the same time.  Now we're trying to make sure no more than one person is engaging him at the same time.  Today, he had a brief spell at day care because one of the minders suggested he ditch his Cars cap and wear a practical hat.  Lesson learned: Let the kid freeze his ears off it it keeps him awake.  It's like parenting a land mine.

In between, he's fine.  After both attacks at day care, he's gotten up and waved us away.  Tuesday we had to take him home because they weren't sure they had enough staff on hand (people out sick) to keep an eye on him.  Today he walked off and played ... and then came back to say goodbye again.  It's a mystery.

Our second oncologist is on vacation for a few more days.  We have to look her up the second she gets back.  We have to figure out if we want to try anything to calm him down (we're not sure about that one, but think it needs to be discussed).  We need to figure out some way to get the phlegm out of his throat, because one of the problems seems to be that he hyperventilates a bit and then panics because he can't breathe. Turns out, despite the first oncologist pooh-poohing us, that his valproic acid can have the side effect of excessive phlegm.  Another side effect (actually, a sign of an overdose) is spells of fainting and shortness of breath.  We have got to get these people to figure out if this medicine is doing more good than harm, if the dose is right and if we really want to keep this up through September.  Personally, I'd love to be done with it yesterday.

I don't know if I mentioned: the next MRI is January 2, so prayers and thoughts for us on that day, if you can.

## Comments

Very interesting the possible side effects of valporic acid include the very behaviors that worry you. Prayers! “...Parenting a land mine.” Very descriptive!

*—Barbara Skipper, November 29, 2018*

I will keep you all in my prayers

*—Cynthia Meyersburg, November 29, 2018*

Sending you lots of prayers and hugs!

*—Lynda Schmitz, December 2, 2018*

# Over our heads

*December 3, 2018*

We're straining the limits of the possible here in Berlin.

Christina is currently in the hospital with Colin. About two hours after he went to bed last night, she heard him having trouble breathing. It was kind of like he was having an attack in his sleep, but it was also clear that his breathing passages were blocked by excess saliva, one of the side effects of his medicine. We panicked enough to call an ambulance.  By the time they arrived, he was breathing fine and we considered sending them away, but they looked at him and decided the case warranted medical review. They've since discovered he has some kind of pulmomary infection, which is not helping things.

Meanwhile, my leg has been bothering me for about two weeks.  It got a little worse on Saturday and then I woke up around 1 a.m. Sunday with blinding pain in my hip and upper thigh. There was no way to sit or lie comfortably, so I went to the hospital, where I got painkillers and muscle relaxants and told that this might be a pinched nerve or problems with my hip joint.  The medicine is working to a degree, but I'm still limping from place to place.  Plus, I woke up feverish last night, which has me wondering if that's another piece of the puzzle.

Poor Christina only slept about three hours Saturday night due to my problems and now she had to sleep in a chair in the intensive care ward with Colin last night, so she's probably a wreck.  She also left with only her phone, a change of clothes for Colin and some toys, so I've got to find some way to move around effectively and get a suitcase of stuff to her before I head to my doctor for a better diagnosis, all the while providing a minimum level of care for Emma and Noah.

People, I'm still optimistic that things will turn out well, but I'm reaching the point where I feel it's too much to juggle until we reach that point.  I'm serious: If you're in the Berlin area and have any means to help, whether it's a drive or a visit or a meal, I'll take it, because I don't see how I'm getting this done otherwise.  All I want to do is lie down and sleep, but I can't do that because of the pain and the need to take care of my family.

The plan is that Colin will be transferred to our regular hospital today, where we can yell at the doctors to please figure this out, because it seems blindingly obvious to us that the medicine they're using against the tumor's return is making it impossible for him to breathe properly.  We'll see if they see things that way.

## Comments

Hope all goes back to normal very soon!!!

*—Sofia Gueorgieva, December 3, 2018*

Niels, I wish I could fly up there to help. In lieu of that, do you know of any meal services I could use online (perhaps with an English page) so we can order a meal for you and the family? Either post it here or FB message me directly.

*—Jeremy Cook, December 3, 2018*

It’s a kind offer, but Noah’s food allergies mean we can’t take a lot of advantage of delivery services. Thanks!

*—Niels Sorrells, December 3, 2018*

Oh of course. Ugh, sorry about that.

*—Jeremy Cook, December 4, 2018*

sending love and a top-up to the strength you both already exhibit... xoxoxo if i were able i'd come help, also.

*—PJ Smith, December 3, 2018*

Dear God, that sounds like a nightmare. Sending prayers from DC for a resolution to the breathing problems and hoping the transfer goes smoothly. And hoping you get a diagnosis/relief from the leg pain. Liisa and Chuck

*—Chuck McCutcheon, December 3, 2018*

## Update

*December 3, 2018*

The doctors at the hospital don't see a sign of an infection in Colin's lungs, which means we might be spared antibiotics for now.  However, they see a lot of saliva/mucus in his lungs that is making it hard for him to breathe: Which is what we've been trying to tell the doctors at the regular hospital for weeks now.

The plan is for Christina and Colin to move to the regular hospital at some point today, but no details yet.

### Comments

Thank you for updating us on the latest - unfortunately, I am no longer in Berlin, but our prayers from Jerusalem are always with you.

*—Claudia Busch, December 3, 2018*

## the wounded and the maimed

*December 4, 2018*

So far this week, I've learned it's possible to get an 8-year-old and 10-year-old out the door to school, even if you can't really stand.  It's not fun, but it's possible.

But first: Colin's situation.

So, our regular hospital (Virchow) had no space for him, meaning he stayed once again at the hospital closer to us.  The silver lining here is that, after the doctors at Virchow discovered his night-time breathing problems a few weeks ago, they were working (albeit very slowly) to get him set up at a sleep lab in the nearby hospital (Lichtenberg). As luck would have it, our pediatrician had already signed the documents to get him into the sleep lab, because she knew it would be best to have this ready to go whenever Virchow got its act together, and Lichtenberg put Colin straight into the sleep lab, partially because that's the only room they had open.  If nothing else, we got one thing off of our to-do list. And we finally got the doctors focused on his breathing problems.  It only took us calling 911 to make that happen, he said bitterly.

He's not happy though.  They've got him on oxygen and with an IV.  The sleep study would have involved yet more sensors.  One can obviously question the quality of the sleep he'd be getting.  Then again, he got so little sleep on Saturday/Sunday, maybe he was wiped out enough that he just went under.

They are also working to clear his lungs.  I'm not clear on the details, but Christina said something about suction and it not being a procedure conducted under anesthesia, so I'm assuming Colin is going to have a lifelong fear of drinking straws now.  She said it is beginning to work: He's starting to cough up some phlegm, so that's helpful.

It is unclear if they are still going to try to transfer him to Virchow tonight.  Neither Christina nor I see the point at this juncture of heading over there.  Assuming he stays in Lichtenberg, we don't know for how much longer.

Moving on to the other family crisis (me), we are holding it together, to a degree, at home.  I managed to get to my doctor yesterday thanks to a ride from Saint Jens Brenner and am now outfitted with quite the supply of painkillers and muscle relaxants.  I think the working theory is that it is a pinched nerve, but it's still not 100% clear yet.  My next step is to get an X-ray, to see if this is a problem with the hip bone, or something more to do with soft tissues.

The pain meanders between my lower back, my butt/groin and my upper thigh.  I have to admit, the upper thigh pain is the least pleasant.  The other two versions are no fun either, but I can at least find a way to sit/lie with those that isn't excruciating.  When the thigh flares up - as it did almost all of last night, it's just game over.  There is no way to be comfortable.  So, I'm not only in pain, I'm barely coherent because I can't rest.

I've been given sick leave for the rest of the week.  At first I thought it was excessive.  Then I ran some supplies over to Christina yesterday.  Jens gave me a drive there, so that was fine.  Then I decided to take public transportation back and, people, the four blocks from the hospital to the train station nearly ended me.  I called neighbors to have them pick me up and drive me from the station near our house back home, because I'd still be crawling through my neighborhood, taking breaks to weep, had I tried it on my own.

I have no idea how I'm going to get to the X-ray.  I need to get to downtown Karlshorst just to pick up some stuff.  Trying to figure that out too.  Several people have offered to have food delivered here.  It's a nice gesture, but given Noah's food allergies, anything you send here will probably only be edible for me and Emma.  I'm keeping the house generally under control, but it's hit and miss.  My leg will hold out for whole half hour spells with no pain and then I get things done.  Then there are times where I just grab a chair and direct Emma and Noah to do stuff.  And, let's be honest, Noah is 8 and acted like I was asking him to scale the Himalayas when I asked him to empty a waste paper basket yesterday, so Emma is really the only one getting things done in this household.  She's also turning into quite a good nurse.  Yes, her solution to everything is to "put heat on it," but this is one of those situations where that's pretty darned good advice.

OK. I'm going to go see how quickly Amazon can get a cane or a Zimmer frame delivered to me and then I'm going to get on with my day.

## Comments

Good there is some progress on Colin's sleep examination and phlegm, and not good at all about your hip. Very good of Emma - but hopefully Noah too will start pitching in, and that all will improve asap!! !

*—Sofia Gueorgieva, December 4, 2018*

Wow! Prayers for you! I have to agree with Emma...keep heat on your lower back. These things don’t happen by accident when everything else is crazy. Take care of yourself. No one said parenting is easy....but they never told you that sometimes it would seem impossible! Take care!

*—Barbara Skipper, December 4, 2018*

# the devil we know

*December 4, 2018*

OK, the Lichtenberg hospital has decided to send Colin back to Virchow.  Christina preferred it massively at Lichtenberg, mostly because they finally took the breathing problems seriously.  But Lichtenberg says Colin has been a regular patient at Virchow and they don't want to set up two potentially competing health care plans.  The transfer will be this afternoon.

No idea how long he's going to remain in the hospital.  On Monday, they didn't think it likely that this was a bacterial infection.  Today, they say there is a decent chance.  Regardless, they've got to get the crud out of his lungs and treat it before this turns into pneumonia, antibiotics or not. There's been another suction event, which apparently requires three people to hold him down.  Christina says his mood is dark and he's more or less on a hunger strike, unless it involves chocolate cookies.  It's always frustrating when they put him on an IV, as he starts refusing beverages.  Yes, he's getting hydrated, but it causes a dry mouth.  Still, despite the setback of being sent to Virchow, it does feel like they're making progress.  Christina also reports that they're reducing the oxygen levels they're giving him and it seems like his breathing is still getting better, which is probably easier without the crud.

On the home front, I can report that, for the first time since Sunday, my leg only feels "sore" instead of in "agony."  Then again, I felt pretty good about my leg several times on Monday and then felt like death all night.  And let's not forget all the painkillers in my system.  I see my regular doctor again tomorrow.  The X-ray is scheduled for noon.

We're calling in the grandparents for assistance, because it is hard cooking for Emma and Noah when I can't stand.  We're also hitting up everyone we know for any favors they might want to render.  If you're in Berlin: Don't be shy.  I'm sure I can think of a job for you if you think you can swing by Karlshorst any time soonish.

## Comments

Niels and Christina, you are superheroes whether you want to be or not! I know it feels like “what else can we do?”, but your children are so fortunate to have you. I just said to John, these past few weeks/months for you been like our last year on steroids. I wish I was close and could drop in and help. Keep up the good fight and hugs to all. Susie

*—Carol Hamilton, December 4, 2018*

Many prayers!

*—Barbara Skipper, December 4, 2018*

Can those of us not in Berlin either a) send food that Noah could eat (not sure of the whole list of his allergies) or b) send something else? Is there a local service like care.com that could help? Looks like this is their German branch: www.betreut.de

*—Chuck McCutcheon, December 4, 2018*

## And on the third day...

*December 4, 2018*

I cannot believe this phase of this madness started less than 72 hours ago. I feel like I've aged a decade since Saturday.

Christina and Colin got into Virchow. Of course, as soon as they were there - admitted into the oncology ward, no less, all the doctors there were 'all tumor, all the time.' The way Christina describes it, she's had to grab nearly a half dozen doctors by the shoulders to give them a good shake and remind that, no, the main reason they're there right now is the fact that our child has panic/fainting spells and doesn't breathe properly at night, all of it possibly related to the anti-tumor medication he's taking. It actually took a visit by the pediatric neurologist - the one Christina hated with a passion in 2016 - to put an end to the dream of getting the follow-up to the MRI done this week, when he pointed out that it would be unnecessarily traumatic to a child dealing with something like pneumonia to force him into anesthesia, etc, etc.

Anyways, he's being treated with cortisone to open his breathing passages and there's debate about whether he should get oxygen regularly and, if so, how much. He's coughing a little more regularly, but I don't know if there are any more suction events in his future.

Christina is handling this all with a grace that I can barely muster on days when I have no crisis brewing. She's basically running the family from across town with her smartphone. If we dropped this woman into Yemen with a good laptop, she'd have that situation wrapped up in about 45 minutes.

On the homefront, we're coping.  I seem to be keeping the other two fed and clothed.  I even had it together enough to whip up a dinner for them, the only complaint being that the rice was "too dry."

My doctor had told me that, if the pain was manageable, I could cut the painkiller/muscle relaxant dosage to twice a day, instead of three times a day.  I did just that today and, I have to admit that, as of an hour ago, I didn't really feel any pain. My primary method of movement remained 'hobble mode,' but I felt pretty good. But, as I was getting the other two to bed, the pain has started again, but much less than yesterday. I feel myself dozing off as I write this, which I'm sure is a combination of the muscle relaxant and three nights of miserable sleep, so I'm hoping maybe I can pass out and get some actual rest tonight.  We'll see.

Other stray observations:

- Want a creepy day? Pack yourself on the sofa with painkillers and heating pads, at which point the talking baby doll manages to turn itself on. When you finally get yourself together to hunt it down, you can't find it, because some child has stuffed it into the stove of the play kitchen. Question whether your children will ever be employable as babysitters.

- Our DHL delivery guy, who is quite chatty, assures me that the problem with my leg is because I sleep in my boxers. It has something to do with drafts of air. i did not have the energy to follow this train of thought.

- Noah had first aid training in school today, so he thought it would be funny to return from school with a giant bandage wrapped around his head. For added effect, he played sick a little at first. I swear, there was a moment there when I thought Emma was the only one in this family who is going to live to see 2019.

- I shall keep passing out sainthoods. Along with Jens, the patron saint of those in needs of rides, there will also be Saint Katharina, the saint of delivering food to people in hospitals, Saint Maddie, the patron of getting children to their karate classes, Saint Nina, who rescues children's Advent calendars from the post office (even if it turns out to be a package of Bavarian sausage ... it's a long story) and, perhaps, Saint Marc, the patron of getting St. Nicholas supplies to children in hospitals.

People, I'm so tired, I think I might fall asleep before "Lord of the Rings" ends. Hey, you have your go-to movies when you're ill, I have my Tolkien.

## Comments

The DHL delivery boy must be a Balkans offspring. There is no enemy worse than draft around here. Running barefoot is the runner-up. So, pull your sweatpants well above your bellybutton, undershirt into the boxers, shirt into sweatpants, sweatshirt may remain loose, but only if all windows and doors are sealed. I'll send you some Sirogojno socks (https://www.facebook.com/454128181302693/photos/a.756701937711981/1489766964405471/?type=3&theater), to tuck your sweatpants in.
Repeat with all of the kids and make sure they don;t leave without a wool cap and their jacket hoods up and tied well vcovering enough of their faces to make sure they don't inhale the cold air directly.
I hope all of the crap hounding you Sorrellses will turn for the better very sqwiftly.
<3

*—Boris Babic, December 4, 2018*

He's Kurdish, does that count?

*—Niels Sorrells, December 4, 2018*

Probably. Hang on, Niels. Socks are on the way!

*—Boris Babic, December 4, 2018*

If I was there I would hug each of you and cook the most amazing dinner that I could muster . I would run your errands for you, see that the kids get to school, and see that you sleep. Prayers...and more prayers. Thank God for the helpers you have. We care. Barbara

*—Barbara Skipper, December 4, 2018*

I just watched all three "Lord of the Rings" movies again myself. Them's good medicine

*—Lea Ann Schnakenberg, December 4, 2018*

Hope you can get some sleep. Sending good thoughts.

*—Lynda Schmitz, December 4, 2018*

So how'd you sleep?

*—Jeremy Cook, December 4, 2018*

## moving targets

*December 4, 2018*

About 10 minutes after I posted last night, all the doctors had a pow-wow where they essentially came to the conclusion that "Hey, even though he's an oncology patient, the pressing concern now is about his breathing problems."  So, they transferred him to a ward dealing with pulmonary problems.

I know I'm being mean here, and my temper is perhaps a bit on edge due to the pain, but it is tempting to drive out there - muscle relaxants or no - and deliver a round of backhands.  Colin was in the emergency room at least twice during the autumn with breathing incidents.  We told every doctor we could about this.  They saw how bad his breathing was during the EEG and he was admitted to another hospital on Sunday because of breathing problems.  And yet, they still put him straight back into oncology.

Don't get me wrong, I appreciate their enthusiasm for treating and monitoring the tumor remnants, but you've got to deal with the most pressing problems, and sometimes listen to the parents before you end up in an emergency room. Gah.

So, as of late Tuesday, he's in a pulmonary ward. And, even there, they're talking about things like hyperoxygenating him, which sounds more like a method for developing an awesome Batman villain than curing a child's breathing problem.  Maybe that is a good route to go given Colin's apnea, but we would like them to first make sure that the lungs and breathing passages are free before they start doing the fancy stuff.  Oh well.  We'll see what today brings.

As for me, I ended my day around 9 p.m., high as a kite with muscle relaxants, and feeling pretty optimistic about things, since I could almost shuffle through the house without pain. Then I made the mistake of lying down in bed and woke up around 2 a.m. with pain levels pretty much where they were 24 hours earlier.  So, it's nowhere near as bad as Sunday, but I've definitely regressed.  I don't know what I've got, but any malady that gets worse when you lie down in bed is a pretty awful one, from where I stand (or slouch in the corner of the sofa, to be most accurate).

I got down to the sofa, which is much more comfortable because I can lean/slouch instead of lie, and dozed until about 5 a.m. and just got up for more pain medication, so I at least went 10 hours between doses.  My hope is that I can now get myself to a point in the next 40 minutes where I don't openly weep from pain while I prepare the kids for school, which I think is doable.  Today: blood drawn at the doctors and a noon X-ray.

## Pneumonia

*December 5, 2018*

They finally transferred Colin to the new ward at 3 am. When they attempted to give him an oxygen mask, he resisted, so he's now sedated. The doctors have officially given the diagnosis of pneumonia and are at work trying to get the mucus and phlegm out of his lungs. Christina's description of the amount and texture of the stuff they're pulling out is horrific.

As you can imagine, Christina is a mess.  I just got the news and I feel like I've been punched in the stomach.

I do not understand how we had him in the emergency room twice for these problems and no one noticed this. Every time he goes to a doctor they listen to his lungs and the verdict has always been that his lungs were clear. Now we're learning that he has so much junk in his lungs that parts of the organs were getting no air.

I remain optimistic. As low as my opinion is of the hospital's organizational capacity, they seem to know what to do once it's time to embark upon treatment. But the fact remains that, on Sunday, we had a kid running around doing his thing. Today we have a kid sedated with doctors excavating his lungs.

I do feel like we're going down a rabbit hole again and I just don't know where we're going to find the strength for this one more time. We'll find it, I just don't know where.

We're calling in the grandparents a day early. I have my X-ray at noon and I can only hope that it doesn't turn up as some kind of bone fracture that's going to leave me hospitalized as well. We'll take any prayers you've got in the mean time.

## Comments

Oh, Niels. I am so sorry. I am praying for you guys!!!

*—Lana Spangenberg, December 5, 2018*

Oh man, I am so sorry. This is indeed awful. Praying now.

*—Jeremy Cook, December 5, 2018*

So sorry to hear - but good the doctors are doing something about the situation, and good they are busy clearing lungs. Bon courage for everything, hope your Xray comes with positive news

*—Sofia Gueorgieva, December 5, 2018*

Here's hoping for at least some good news on the Xray front.

*—Chuck McCutcheon, December 5, 2018*

## We'll take all the prayers you've got

*December 5, 2018*

I don't really have the words to describe how awful this is. Colin remains under sedation while they try to get his breathing under control. Christina is coping at the hospital by herself, but she's a mess. I want to sit and weep most of the time, but can barely move thanks to the muscle relaxants. And I have to keep something of a happy facade for Emma and Noah.

The doctors at the hospital are not making any of this easier. They have now brought up the theory that the breathing and swallowing problems might be a sign of the tumor returning to growth. We will know after the MRI, which is hopefully tomorrow.  I refuse to quite believe it, but then I don't see why the doctors would throw this idea out there if they didn't have some foundation to stand on.

We're a mess people. I've been telling myself since 2016 that I would need to prepare for the day, should the tumor return. And, even though I don't quite believe the tumor is back, just having that possibility so close has me aware that there's no way to prepare oneself.

Oma & Opa should be here in 2-3 hours, which should help me out a lot. At least I'll have a ride to the hospital. My X-ray was a painful experience, mainly because of the positions I had to get into for the technology to work. Annoyingly, they might not have the results until Monday.  I hope we can all wait that long.

## Comments

I’m so sorry to read of this Niels. It’s all overwhelming but I know you will get through this. Tell Noah and Emma that you’re sad and sometimes you need time to sit and think. They’ll be happy to help out, like big kids. Then go to bathroom or bedroom and cry whenevet you need to. It sounds insane but it helps. I understand what it’s like and it’s not easy. Keep praying and stay strong despite all the pain you’re in. I am thinking of you and hope it’s all better soon.

*—GF Santos, December 5, 2018*

Hang in there, Niels and Christina! The calvary's coming, and there's lots of people out here who love you, who are thinking of you and who are praying for you.

*—Lea Ann Schnakenberg, December 5, 2018*

Stay strong. We are praying for Colin and all of you now. Hugs

*—Lynda Schmitz, December 5, 2018*

Please take care, we are all praying for your family!

*—Jeanne Clayton, December 5, 2018*

Our prayers are with all of you.

*—Claudia Busch, December 5, 2018*

In the 9 months since Steve was diagnosed, I have tried to be strong for him, and that has been the hardest. I cried in the shower and in bed at night after he was asleep. It shook my whole being....we did not see it coming. He has had 5 chemos, 4 major surgeries, and a procedure that also required anesthesia. We took a big hit financially. Now we are at the 3 month monitoring point....more appointments, more scans, and a procedure that requires anesthesia. What I learned from this is that I must take care of my health and stress level if I am going to help him. In order to do that I truly had to surrender to my God and turn it over to Him. He will see me through this no matter what happens. I am devastated and strong at the same time. I pray for your health, and I pray for your emotional well being, and I pray that you find peace in the middle of the chaos. Love you! Keep writing. We care.

*—Barbara Skipper, December 5, 2018*

Sending healing thoughts to Colin and all of you. I will say a prayer for Colin and for relief and blessings for your family. I can only try to imagine what you're going through. It seems overwhelmingly terrifying and painful. Hope that good news will make it all go away soon.

*—Dan Wooldridge, December 5, 2018*

## small rays of hope

*December 5, 2018*

Oma & Opa arrived last night, so I no longer have the entire household to manage. And a member of our church group dropped off a giant pot of chili to keep us alive, which actually pushed me over into tears of gratitude for a few minutes. As I write this, Emma & Noah are unpacking their December 6/St. Nicholas loot, so we're keeping some version of "normal" going on over here.

I just had my best night in almost a week. I still woke up in sweats, but I managed to stay in my own bed all night and even lie flat on my back without noticeable pain. Now that I'm up, I can still feel it, but it's nothing like the last few days. I'm becoming more and more convinced that I have coxitis fugax (Schnuphusten for my German friends, irritable hip for my non-Latin-speaking friends). Yes, I know, it's primarily a childhood malady, but I keep reading that it does happen in adults. Also, all of the symptoms line up. Also, I just can't imagine that a fractured hip, a pinched nerve or a slipped disc would give up the fight so easily.

Colin remains under sedation. The MRI is scheduled for around 4 pm, but these time tables slip. I still refuse to believe the doctors concerns about the tumor returning, but I guess we're going to have to see what the image shows.

Thanks for everything, everyone. Even a little heart on this page gives me a little boost.

## Comments

Hüftschnupfen!?! Stay strong!

*—Stephan Roch, December 6, 2018*

Oh yes. That's a better spelling of the German word!

*—Niels Sorrells, December 6, 2018*

Following your every post, and sending prayers for strength and healing. Stay strong! Glad that St. Nicolas visited to help with Emma and Noah to give all some cheer.

*—Lisa M, December 6, 2018*

Let me know if you could use some adult English-speaking company, and I'll drop over again! Keep your spirits up.

*—Marc Galmoud, December 6, 2018*

## MRI now

*December 6, 2018*

The MRI is apparently happening right now. Please adjust your prayer schedules accordingly.

Sent from CaringBridge iPhone app

## A round for us

*December 6, 2018*

Oh my God everyone, I'm off the alcohol while I'm processing all these muscle relaxants, but I need every one of you to stop right now - I don't care what you're doing - and have a drink of something strong on our behalf.

The MRI results came back: No change whatsoever since October.

This means the prevalent theory is that the spot they can't explain is likely cell degradation still being caused by the 2016 radiation therapy.  More importantly, it means all the problems he's been having of late were not caused by the tumor.  And it means that the likelihood the medicine they had him on all this time - which we've been openly wondering about for 2-3 months now - is the culprit is much higher.

I would like a formal apology letter from the hospital. I doubt I'll get that.  At the very least, Christina tells us that our head oncologist, who is teaching now, has to wear a bowtie for that gig and it makes him look like a total dweeb. It's not the revenge I would have picked, but it will do.

And we're stopping the valproic acids.  Indeed, he hadn't gotten any since Sunday since there was just no way to get the stuff in him after he got to the hospital, his mood was so bad.

We are not done with this particular slog yet.  He is still sedated and still on a breathing machine.  Now they have to slowly remove him from the breathing machine to see if he can breathe normally on his own.  There's not a lot of concern that this will be a problem, but it is a hurdle.  Then we have to see if he breathes normally at night now, now that the gunk is out of his lungs.  And we have to make sure the bacterial infection is completely gone.  And we have to make sure that, once he starts breathing again, that the gunk doesn't re-accumulate.  I don't know how long it is until he's off sedation and I don't know how long it is until he's out of the hospital.  They're also putting him on cortisone for a while, which is what made him so grumpy and hungry back in 2016.  I hope it's a short-lived experience.  We have to brace ourselves for a future in which he sleeps with a breathing machine.  I don't know what this means for Christina and I and our jobs and I don't know what it means for his further attendance at day care, etc.  All I know is that it feels vaguely Christmas miracle-ish.

I continue to limp, but that just doesn't feel like the main topic right now. So I'm going to go, because it's muscle-relaxant o'clock.

## Comments

So happy to hear the good news! It is a Christmas miracle, just when it was needed most. I hope things continue to get better.

*—GF Santos, December 6, 2018*

So happy for those really good news! I really keelp my fingers crossed that it will be the silver lining for all the rest shall get well really soon.

*—Antje Lein-Struck, December 6, 2018*

It's only 10 AM here but will drink on your behalf at the appropriate hour. Glad to heard there is some good news - finally!

*—Chuck McCutcheon, December 6, 2018*

Dangit, I'm outta beer! Guess I'm having a rum and Coke tonight to celebrate this great news!

*—Jeremy Cook, December 6, 2018*

Hooray!!!

*—Marc Galmoud, December 6, 2018*

Answered prayers!

*—Barbara Skipper, December 6, 2018*

So happy for this outcome. Here's a toast to Colin and the Sorrells family (with coffee!) !!!!

*—Dan Wooldridge, December 6, 2018*

So pleased to hear all this good news and hopefully all the rest will go back in order pretty soon !!!

*—Sofia Gueorgieva, December 6, 2018*

Yesss - so glad about the good news and prepared for more... news... drinks,... whatever...

*—Claudia Busch, December 6, 2018*

You guys deserved some good news after the week you've had... I'm so glad to hear this. xoxo

*—Michelle Lee, December 6, 2018*

# A ways to go

*December 7, 2018*

I had my first run out of the house in days today, with the primary mission of seeing Colin. He was passed out the whole time, and he's covered in IVs and monitors, but looks pretty good, all things considered. We are beginning to worry that he's developed a resistance to sedatives after all his years in the hospital. No matter how much the nurses give him, he remains somewhat reactive to stimulus. If voices in the room get too loud, he'll move his head and lift his hands.  This morning, a nurse found him on his hands and knees in the bed: He'd somehow loosened his restraints even while doped.

There was a nice doctor there while I visited and she took a ton of time to talk us through everything. It is possible that the mucus in his lungs accumulated quickly, which would explain why so many doctors didn't notice any problems in the preceding months. It was quite a serious infection, with at least two different kinds of bacteria. She wouldn't/couldn't say how much lung function was obstructed, but it was "bad." That said, he's doing much better.

Which isn't to say that there's not a lot of road left to travel. He's on a breathing machine that pumps oxygen at 65% pressure (excuse me if I'm mangling the technical terminology).  There's about 21% oxygen in the air, so that leaves some slack for Colin to pick up. It will be days before they take him off sedatives. It will also be days before they even let him try to breathe on his own. Then we have to see how well he breathes. Then we have to see if the mucus starts building up in his lungs again. If there's been any permanent damage, Colin might have to learn to live with an air mask at night or, if we're unlucky, some kind of tracheotomy.

It's still better than the alternative. The doctor today would not be drawn into a discussion about whether Colin's valproic acid was responsible for his current condition. A neurosurgeon also visited earlier today and said that his department also sees no change in the tumor.  And now there's some weird talk between neurosurgery and oncology about thinking about whether they want to offer us a "debulking" of Colin's tumor, which Christina points out is a very PC way of saying "We'd like to cut your child's head open and poke around in his brain."  All we know is that they specifically did not want to try to cut out the tumor in 2016, so we'd want to know what has changed and what benefits/risks there are before we even start thinking about such a procedure in 2018.

We're still angered at the oncologist. Yes, we knew the procedure was experimental when we agreed to it and we knew there were risks.  But when we started listing problems - problems which are listed as possible side effects on public websites - and the oncologist didn't think to jump in or say something ... well, one can't help but wonder if the doctor was more interested in research than in Colin's well-being.

Christina is holding up remarkably well after almost a week in the hospital. She has a private room for now, though there's no guarantee she'll get to keep it for the duration.

I'm still hobbling. I tried to cut back on the painkillers yesterday and was awarded with a 3 am wake-up call of pain.  No X-ray results today, so I guess we'll know Monday.  I'm not too worried about it, but I keep seeing some version of events unfolding that will end up with me also in hospital for some kind of surgery.  What a December.

## Comments

Sorry for your troubles, but glad things more positive. Keep up the good fight!

*—Marc Galmoud, December 7, 2018*

What thoughts and possible choices you have. Prayers and know that we care and love you all.

*—Barbara Skipper, December 7, 2018*

# In the hope that this week is better than last

*December 10, 2018*

My source at the hospital tells me that they are slowly weaning Colin off sedation and heavily oxygenated air. Removing the sedation began yesterday, and he's apparently already half awake. When I saw him on Friday, they were pumping in air with 80% oxygen. The number has shifted a lot over the weekend, they'll bring it down and then put it back up if his blood oxygenation starts declining. But, in general, every time they lower it his body will go along with the flow for a good long while, compensating for the reduced oxygen input and still keeping his blood levels fine. Of course, his lungs are very tired after the week they just had, so they will stop playing along after a few hours, but we just see this as him working his way back up to normal. At last count, his air supply was 30% oxygen (as opposed to the 21% we get from the air we breathe normally).

The doctors still have not laid out a timetable for when he'll be fully awake and off the machines, etc. I doubt they can give us one. We just have to see how Colin meets each hurdle and where that leads us.

I had an active weekend, if you count walking three blocks to a neighbor's house as "active." I remain stuck in the same rut: I wake up every morning feeling better than the day before and feel better as the day goes on.

Then I go to sleep. And, after about four hours of lying down, I wake up in pain, dreaming of a Christmas wish list consisting entirely of 1) a new hip and 2) a small vat of codeine. And when I wake up, I feel worse than I did when I went to sleep, but usually better than I did 24 hours ago.

My doctor saw the X-ray and there's no sign of anything broken or misaligned or inflamed. It was a quick email he dashed off on a Sunday, so he failed to lay out any next steps for me. Physical therapy? See an orthopedist? More pain medicine? I've got a message out to him and await a response. I'm off to the hospital, where I'm told Colin is waking up much faster than the doctors would have expected.

## Comments

So happy to hear about there being an improvement on all fronts - keep it up!!! Take good care all of you!

*—Sofia Gueorgieva, December 10, 2018*

I look forward to hearing how the little guy's doing this week. Really hoping you guys can experience some Christmas joy soon, perhaps even in surprising ways!

*—Jeremy Cook, December 10, 2018*

Here's to a better week!

*—Lynda Schmitz, December 10, 2018*

# A breath of fresh air

*December 10, 2018*

Things are moving fast.

When I got to the hospital for a visit, around noon, Christina said they were thinking about taking out the breathing tube today. An hour or so later, a nurse said it probably wouldn't happen today. As Opa was driving me home, Christina texted that they were going to remove it within the hour. And now it's out.  He's breathing on his own power, though he is getting a 40% mix of oxygen via a mask, but that gas is not being pushed in with any kind of pressure. Christina says his blood oxygen saturation is at around 99%, and that's he's pretty understandably wiped out.

But, all in all, good news.

Nothing new with me.  After providing me with a diagnosis, but no next step, my doctor has gone silent. I called the office, and got yelled at by one of the nurses for emailing the doctor on the weekend and making him work during off-duty hours, like it's my fault the dude looks at his smartphone at home.

Anyways, I'm having my usual routine of feeling much better during the day, but dreading how I'll feel tonight when I try to lie down.  We'll see.  Onwards and upwards.

## Comments

"like it's my fault the dude looks at his smartphone at home."

Gut-bustin lol. If only I could hear how the nurse sounded in German, a language that frankly already sounds harsh to me if someone's reading Dr. Seuss.

*—Jeremy Cook, December 10, 2018*

# complication

*December 10, 2018*

Christina just called me, a little past midnight, to come to the hospital. The mucus is landing in his lungs again. There are concerns that his coughing reflex is damaged. He might need to be put back on the breathing machine. No idea how bad this is, but it certainly doesn't feel good.

## Comments

fingers crossed...

*—Jens Brenner, December 10, 2018*

Aargh, if it's not one thing it's another...

*—Chuck McCutcheon, December 10, 2018*

## there and back again

*December 10, 2018*

I'm back home after my midnight run to the hospital.  They've put Colin back on the breathing machine.

In my opinion, it's still too early to draw any conclusions. I heard something cough-like when I walked in, but he clearly was not coughing enough to clear the mucus still left over from his pneumonia. That said, after the week he's just had, he seems too weak to do much more than breathe.  He was coughing just fine before this all happened, so it's too early to say what's going on.  If his coughing/gag reflex is damaged, it will be a significant hurdle (anyone with a medical background: Please weigh in).  But I'm not convinced that he just not too exhausted to cough properly.

Christina is also under the impression that they might have rushed him off the breathing machine. Earlier Monday, the mood was "Tuesday at the earliest."  Then they took him off Monday.  Maybe he just needed more time.

The point is: who knows.  The good news is that he breathed pretty well with minimal support for the few hours he was off the machine, so we've at least got that covered.

# some focus

*December 12, 2018*

It's telling how upside down our lives have become that, upon getting a recommendation from our doctors regarding surgical options for Colin that a choice that would have probably left us sobbing hysterically back before all this now elicits a "Well, that's not so bad" from us, three years into this nightmare. I do wonder whether any of us will ever be normal again.

So, he's been back on the breathing machine since early Tuesday morning. His levels are all stable. They have ended his course of antibiotics and they are pretty sure that they've cleared the worst out of his lungs.  What we learned Monday during the brief extubation is that he can breathe just fine, but he might have a problem coughing, which is a necessary step in keeping his lungs free.

For now - probably by Monday, at the latest - the doctors want to perform a tracheotomy. This will allow them to get him off the breathing machine, while still allowing access to his lungs in case they need to be cleared.  Going this route also has the benefit of letting us see if his abilities to breathe, swallow, cough and gag return on their own.

Given that he could breathe fine on Monday, that's not much of a worry.  He was also eating just fine the day before they put him on the breathing machine, so that does not seem like it will be a problem. He was also coughing (I can't remember any times when he would have been expected to gag) just fine in the days before the hospitalization, so there is hope.

The question then becomes if he was "effectively" coughing. The doctors say their worry is that he is not, which would explain the build-up of mucus in his lungs.  It means that, while he's still able to cough, his body was not doing it well enough to protect the lungs. They also admitted though, that the situation was probably not helped by the valproic acid, and its side effect of increased mucus production.

Now, if he shows problems with any of these reflexes, this will confirm the oncologists' fears that there is something going on with the tumor that is causing pressure on the nerves that control these reflexes. They say that, even though the tumor does not appear to have grown in size, the new area of activity - which still seems to be a delayed reaction to the radiation therapy - could be causing an inflammation which is causing tiny disturbances outside the area of the tumor. And it doesn't take much to set the nerves jangling in that region.

To find out if that is the case, they are going to try a PET-CT scan. I know little about these, but they sound finicky. It might confirm there is no living tissue in the area. It might confirm there is living tissue in the area. It might provide no useful information. It could provide inconclusive information.  We'll have to see.  They'll likely perform this test also in the next few days.

Incidentally, Colin was considered for this test more than a year ago, but the insurance wouldn't pay for him to be anesthetized during the procedure, so we skipped it. But I guess that's neither here nor there, as there was no sign of activity in 2017.

Now, if the scan shows signs of living tissue, it's obviously bad. They say they have one medical therapy candidate that involves a drug injected into the veins (charmingly, it comes with its own set of non-dangerous side effects, which the oncologist opted not to go into). The other would be surgery. Clearly, we're hoping to avoid both of these options.  Christina and I are obviously not doctors, but, given the malignant nature of this tumor, it's hard to believe that it would have sprung to life more than six weeks ago and then just dawdled in the same corner of Colin's brain since then, not doing much of anything.  Then again, this is a very strange tumor.

If they don't find anything with this new scan, it could mean they just aren't capable of finding the answer. It could mean that the problems were more strongly linked to the valproic acid than they'd like to admit. It could be a simple mechanical problem.  Last night, while I was looking this up, I came across study after study stating that many people often have problems swallowing and coughing after they've been intubated for more than 48 hours.  I'm talking about half an hour of Google research here, folks, so this is not a mystery of the universe.  The doctors admitted that this could be the case, but, given his history, they still suspect the tumor.

I want to trust the doctors, but I'm having trouble doing it right now people.  We banged at their door for most of the autumn worrying about his ragged breathing and his fainting attacks - both of which are easily linked to the medicine - and we were essentially ignored.  Now that we've got some problems that could easily be explained by the medicine or his treatments of the past week, they want to go big on the tumor again.  I can't shake the feeling that they realize they've goofed and, in order to shut us up, we're being offered a super shiny new brain scan to allay our fears.

So, we really only know the next step or two. I don't know if we'll be back on something chemo-like within a few months or if this is just going to be a question of week of a tracheotomy that turns out to resolve itself. I don't know when/if he can go back to day care and what demands caring for him will place on us and our ability to return to work. I just don't know.  I know it's too much.  Like I'm really feeling that I don't think I can take one more thing going wrong right now.

I'm heading to the hospital for a few days starting tomorrow to spell Christina.  We'll see how my leg reacts to a return to hospital beds. The pain has almost entirely evaporated and the more I walk, the better I get.  The only exception remains lying down, which becomes unbearable after a few hours of sleep.  Maybe today, where I've had long stretches of no pain, will turn into a different night-time experience, but it all remains to be seen.

## Comments

What a dog fight! Keep slugging though, and never fear about dropping a line for whatever support you may need.

*—Marc Galmoud, December 12, 2018*

# The tracheotomy

*December 13, 2018*

Tomorrow is the day he gets his tracheotomy. He’s third on the operating schedule, so probably around 10 am.
I’ve got such mixed feelings about this. I didn’t get into parenting to let my kid have exciting new surgery, but it’s really our only way forward. Hopefully it provides us with some quick answers. If not, we might be looking at some tough questions soon.

Sent from CaringBridge iPhone app

## Comments

I will say a prayer that everything comes out alright! Keep positive.

*—Marc Galmoud, December 13, 2018*

Prayers from all of us to all of you!

*—Barbara Skipper, December 13, 2018*

I'm sending prayers to you guys!

*—Jeanne Clayton, December 13, 2018*

Sending good thoughts.

*—Lynda Schmitz, December 13, 2018*

Us too.

*—Chuck McCutcheon, December 13, 2018*

## silver linings

*December 14, 2018*

On the plus side, hospital beds remain uncomfortable enough that you wake up so ridiculously early that you still get to your kid in time to say goodbye for surgery, even when they move up the surgery time two hours without telling you.
Surgery has begun. Come back in two hours, they say.

Sent from CaringBridge iPhone app

## out of surgery

*December 14, 2018*

He’s out of surgery. Seems to be resting comfortably. They warned me he’ll be out of it most of the day. He has to work off the surgical sedation, then they have to start phasing out the sedation he’s been on the last week while minimizing withdrawal.

Sent from CaringBridge iPhone app

## Comments

Hope all develops according to plan! Bon courage!

*—Sofia Gueorgieva, December 14, 2018*

You are in our thoughts and prayers.

*—Barbara Skipper, December 14, 2018*

You guys have had a hell of a couple of weeks. Sending big hugs and positive energy your way.

*—Michelle Lee, December 14, 2018*

I'm thinking of you and Christina and praying for Colin

*—Lea Ann Schnakenberg, December 14, 2018*

## slow start

*December 14, 2018*

The doctors kept him pretty heavily sedated today, so not much happened. They’re happy with his progress and slowly weaning him off painkillers and the breathing machine.
He did cough twice today, which was exciting given all the talk of compromised reflexes. The doctor still said it remains to be seen if the reflex is active enough, but this is still something different than having no cough reflex any more. It feels like a small victory.

Sent from CaringBridge iPhone app

## Comments

Small victories - we'll take em!

*—Jeremy Cook, December 14, 2018*

# Another slow one

*December 15, 2018*

Colin pretty much slept all day. I had kind of thought he’d wake up today, but the nurses all say this is normal. After all, he’s recovering from pneumonia and just had surgery, so he’s entitled to be a little wiped out. The only major development is a fever he’s been fighting for a few days now. But that seems to finally be breaking: Down 1 degree Celsius in the last six hours.

Sent from CaringBridge iPhone app

## Comments

I'm wiped out just hearing everything he's been dealing with. He's a trooper

*—Lea Ann Schnakenberg, December 15, 2018*

I think you all deserve a bit of down time. Glad the fever's down.

*—Marc Galmoud, December 15, 2018*

# The long version

*December 17, 2018*

My updates have been brief of late because I spent three nights in the hospital with Colin. The reception there is patchy and, dear God, I hate typing any more than I have to on an iPhone.

He's stable, but wiped out. I keep mentioning to the doctors that I'm surprised how long it's taking for him to wake up, and they keep responding that they are doing this very slowly, so I guess there's a method to the madness. They have to withdraw the cortisone (being used to reduce the swelling around this new, unexplained spot in the tumor mass) and the opiates (to reduce the pain from the pneumonia), along with a whole other host of medicines. Given that, and the fact he's recovering from a surgery and pneumonia, which I understand can leave even the strongest person flat on their back for days, I guess it's not surprising that he has barely enough energy to open his eyes most of the time.  He's also developed a fever, which the doctors say might be a sign he's picked up a virus along the way.  Overall, the motto is 'slowly, slowly.'

It's not natural sitting next to a child lying so still.  Yes, I got an insane amount of reading done in the three days I was there, but I'd rather have a child showing some signs of activity. I tried to count the number of tubes and wires attached to him, but it's such a tangle, I lost count. It's hard to tell how intrusive the tracheotomy is going to be, as they transferred the breathing machine from his mouth to the new opening. Since it's all foreign material, it's hard for me to gauge when the machine ends and the tracheotomy begins. For the record, the doctors say he's doing almost all of his breathing on his own, and his oxygen saturation levels are great.  The machine is mostly there for support. So, maybe we have that nightmare behind us.  Maybe.

Also, for the surreal portion of this blog. Try not sleeping well for three nights because of a mix of an uncomfortable bed and leg/back pain. Then sit next to your sick child and fall asleep with your head resting on his mattress. Then have a nurse turn on the radio so you wake up to Tom Jones' "Sex Bomb." See what that does for your outlook on life.

I had a talk with our hospital-appointed psychologist on Thursday.  The topic being, what do we do when we no longer trust our doctors?  It almost seems like a silly question, because what choice do we have but to trust the doctors.  But still, but still... Every time they suggest something these days, there's a voice in my head asking "Is that what's best for Colin, or is this a way to cover the mistakes we're pretty sure your colleagues made?".  She says there is the option to permanently switch oncologists (and I do find the new one a whole lot more comforting, though I've only had one meeting with her), but the guy with whom we're having the trouble is the brain tumor specialist. There's also the option of sitting down with him and the psychologist and having a mediation, but that wouldn't be until he's back on full-time duty in a year.  Christina has also brought up the idea of requesting a review, not because we necessarily want anyone in trouble, but because we'd like to spare the next family this trauma.

We're slowly trying to prepare the family for Christmas in the hospital or a delayed Christmas or some combination of the two. Christina told Emma and Noah about the tracheotomy on Friday and they quickly put the pieces together, so at least they won't be completely sideswiped should we end up pushing everything back. A big determinant will be when Colin gets out of intensive care. So long he's in that ward, he can't receive visitors younger than 14, which rules out any gathering of the whole family. The doctors have said their goal is to get him to a more general ward as soon as possible, but I don't know what's required for that to be a possibility. I assume he needs to be off the breathing machine, at a bare minimum.

In other less important good news, my leg suddenly began feeling a whole lot better yesterday. I still don't know what specific thing caused the pain, nor do I know what caused the improvement, but I'll take it (though it would have made me marginally happier if the improvement hadn't happened the day before we finally got an appointment for me with an orthopedist). It's still not perfect.  There's discomfort. I'm still limping. Some positions are definitely better than others.  But I stayed in my own bed for about eight hours, with only mild discomfort (and no pain medication), which is something.  I might have even slept through the night if Noah hadn't shown up around 2 a.m. Sharing a bed with him, you might as well have an octopus in there with you. He gets very clingy in his sleep, which is annoying on the best of days, extremely troubling when it involves a whole yoga routine to switch from your right to your left side.

The super special PET CT scan is set for 9 a.m. on Thursday. Speaking for myself, I'm not that apprehensive about it, simply because the new mystery spot has remained so stable. Also, I'm keeping my expectations low, as the doctors have said that they results can be so mystifying. It will be another piece of the puzzle that will determine if we have to eventually consider another surgery or a new round of chemotherapy, but, for now, we're just focused on making sure he can breathe, swallow and cough.

Christina is in the hospital for one more night, I'm taking over again on Tuesday. Beyond that, we have no plans, other than that we need a Christmas tree at some point.

## Comments

Thanks for the update, Niels. I'm constantly wondering how Colin, you and the rest of the family are. I'm thinking about you all the time!

*—Lea Ann Schnakenberg, December 17, 2018*

Thanks a lot for updating - if there is anything we can do from the distance to support you, please email. I will leave Jerusalem Friday afternoon, arrival in Tegel at night.

*—Claudia Busch, December 17, 2018*

Get well and get well soon, both of you. Love to all the Sorrellses.

*—Boris Babic, December 17, 2018*

You and your whole family are very much in my thoughts and prayers.

I don’t know what I would do about the loss of trust in the doctors. That is troubling.

I am glad to hear that Colin is breathing so much better. Slow and steady sounds like a reasonable approach to me.

Maybe a local friend or church member could facilitate getting a tree to your home for the family to decorate?

(((□□)))

*—Cynthia Meyersburg, December 17, 2018*

Ahh, wish I were there to go buy a Christmas tree for you guys...and then sit down with you to a nice hefeweizen and schnitzel.

*—Jeremy Cook, December 17, 2018*

With Steve’s cancer this year, we learned all oncologists are not created equal. We have been blessed with an amazing oncologist/surgeon team this year. 8 months ago we were told he had only 8-12 months...now it could be years (waiting on results of most recent biopsies). .... I think a review might at least get everyone talking about Colin’s case again. Here, where Steve is... every month oncologists get together and review their toughest cases. We also have learned that despite the progress in cancer treatment there is still a lot of unknowns because each case is so different. We continue to pray for wisdom for those treating Colin and comfort for you and the entire family. We love you all!

*—Barbara Skipper, December 17, 2018*

Thinking of you and your family. All the way from Peoria, Illinois, we are hoping for you and Colin to get better. Slow moving is the pace I guess. Keep your hopes up, praying for you!

*—Jeanne Clayton, December 17, 2018*

# Day sleeper

*December 17, 2018*

I managed to swing by for a few hours this morning. Not a whole lot has changed in his status. They've removed the urinary catheter and the IV feed into his neck, so I think he's down to an oxygenation monitor, EKG monitor, an IV in his arm, a feeding tube and, of course, the tracheotomy, which is currently plugged into the breathing machine.

But he's doing most of the breathing on his own and, generally, keeping his oxygenation rates past the magic number of 93.  I saw it dip to 90 once or twice, but he quickly corrected and got it back up.

He's still on barbiturates for the pain, so I imagine his head is still spinning. But there's a lot of pain and it's important to ease him down after the days on opiates. That said, his general status seemed improved to me.  All weekend, he was lying very calmly, but with a kind of faraway look, as if to say "Dear God, what just happened."  When I was there, he seemed to be sleeping normally.  It's a subtle difference and, what do I know, perhaps it's all in my head.  But he seemed more at peace today.

And now Christina tells me he's woken up a little bit today and he would like some explanations about what's going on. His mood is, understandably, dark.

I managed to see the orthopedist. In good news, my leg is still sufficiently messed up enough to get his attention. Indeed, I think I hurt myself again with one of the tests he made me do. He says there seems to be something blocking nerve signals, but it doesn't look like a classic case of back pain. So, he's going to try to squeeze me in for an MRI at the earliest possible date. Who's up for another Sorrells Medical Mystery?

## Comments

Personally, I don't like the mystery genre

*—Lea Ann Schnakenberg, December 17, 2018*

Geez! That is “piling on”! ....When a parent of a sick child, also has health issues at the same time! Prayers.

*—Barbara Skipper, December 17, 2018*

## Good days and bad days

*December 18, 2018*

Nothing's really happened today. We've had neither good news nor bad news. Nonetheless, it's been one of the hardest days we've had in a while.

It will surprise none of you to hear that Christina is the strong one in the relationship. She's now been in the hospital since Sunday afternoon (I visited for a few hours on Monday). Colin had an EEG test today, as they try to sort through the question of his reflexes, if they're compromised and, if so, why. We also got a visit from the oncologist, who told Christina that he's never seen a case like this, where the reflexes degrade so slowly. Again, I'm holding out hope that there are non-tumor explanations for this, but I also realize I'm grasping at straws. But there are some studies that you can find without too much Googling that hint at other reasons he might have problems coughing, if he ever did (Christina and I both remember him coughing in the autumn, though neither of us could tell you if it was what the doctors would call an "effective" cough).

Anyways, it's hard on her. And she's stuck in an intensive care ward room with minimal wireless reception, so she's pretty much on her own. And Colin is waking up, which is a good thing, except he's becoming more aware of what's going on around him, and he's upset by the changes. He wants to know why he can't speak. He's horrified every time they have to suction his mouth (there's nowhere for the saliva to go right now). He certainly seems to have had a fainting spell or two while he was in the hospital as he panics when they suction him. That said, from where I was sitting, it also looked like he was recovering more quickly, which is probably easier now that his lungs are cleared.

And then she calls me for support, and it's not like I have anything helpful to say. And then I start worrying. And I can't go to her, because I have to be here for when the kids get home from school. Today, the in-laws went on an expedition to see downtown Berlin. It was announced at the last minute and, suddenly, I found myself alone in the house. People, ever since I had kids, I've dreamed of being home sick (my leg still bugs me) by myself, because every time I get sick I always have a sick kid with me. I had plans to watch movies and read books and maybe nap. People, it was hell. I don't know what to say to people when I meet with them these days (I was the depressing one at Noah's class Christmas party yesterday, telling everyone about tracheotomies and brain tumors), but I lose my mind when I'm alone.  After dinner, I'm going to go to the hospital and spell Christina for the night, and I'm terrified.  My stomach feels like it's about to turn inside out.  I think once I see him and have something to do, I'll be fine.  But the idea of being alone with him in that room is enough to make me want to have a panic attack.

At least the fact that I'm writing is a sign I'm feeling better.  I've been thinking about writing this entry all day and couldn't bring myself to go near the keyboard.  But the in-laws and the kids are home.  We just talked through the worst-case scenarios for Christmas and the kids have agreed, in principle, that they would go to Bavaria with the in-laws for the winter break so they can get a little down time and the in-laws are back in their normal surroundings and maybe - just maybe - Christina and I can catch a breather, focus on Colin and maybe even get him home and figure out how we're going to run this operation if we have a child with a tracheotomy (and, if we're particularly unlucky, one who's in need of suction and maybe a feeding tube).

It's so easy to succumb to thinking about worst case scenarios in these situations.  I'm trying very hard not to, but it's so easy to see the bottom just fall out.  I know you're all thinking of us and I can ask for nothing more, but I feel we've got a bit of a dark time ahead of us before we emerge into the new unknown.

## Comments

We're with you, Niels, even in the dark times. I'm so sorry for what you guys are facing.

*—Jeremy Cook, December 18, 2018*

Wishing that things turn around positively for Colin soon. Prayers for you and Christina.

*—Dan Wooldridge, December 18, 2018*

Thinking of you and Christina and sweet Colin.

*—L Smith, December 18, 2018*

Please tell Christina if she needs to call someone for a midnight chat, dial me - I'm available anytime.

*—Michelle Lee, December 18, 2018*

## onwards, upwards

*December 18, 2018*

I didn’t make it to the hospital until about 8 pm yesterday. If it’s OK with everyone, I’m going to blame that on my father-in-law, even if that’s not the entire truth. I spelled Christina and sent her home so she can make it to a doctors appointment today. I then sat with Colin for about an hour.
Everyone, it was the best hour of my day.

Yes, he mostly slept, so I didn’t have any of the stress Christina has been having as he struggles against his medical care and with his new implant, but just being here with him helped. It’s odd, in the hospital, where I have almost no control of the situation - and where I dread being - I feel almost serene. Being home right now leaves me a basket case. I’m going to head to him now, as soon as I shower.

In other good news, I just slept 7 hours with only minor leg discomfort, and this in a hospital bed! Granted, I took a painkiller before bed to be on the safe side, but I’m still filing this under good news.

Sent from CaringBridge iPhone app

## Comments

It warms my heart to think of you next to his bedside and it being the best hour of your day. Precious moment. And yay for sleep!

*—Jeremy Cook, December 19, 2018*

It seems you are less anxious when you are next to him in hospital because you know what is happening. Maybe this drop in stress is what is helping your leg. Hope the improvement continues!!!

*—Sofia Gueorgieva, December 19, 2018*

# MRI madness

*December 19, 2018*

Well, tomorrow will be another in a string of big days. The PET-CT scan is at 9 a.m. for Colin. The doctor described it to me as, basically, an MRI, with a pinch of radioactive tracer for added sparkle (I might have embellished those words). Then I've got mine at 2:15 p.m. Perhaps we'll get some answers for Christmas. Maybe even some good ones.

I can't say I'm not worried about Colin's MRI, but I'm not losing much sleep about it. Even the oncologist I don't like pointed out that no active tumor would manifest itself on Oct. 29 and then sit around doing nothing through Dec. 6. So, if this turns out to be an active tumor, it will be something for the medical journals. Right now, the oncologists are sticking to their theory of inflammation brought on by a degradation, itself a delayed reaction to the 2016 radiation therapy.

As harmless as that sounds, if the inflammation is causing swelling that is messing with Colin's reflexes, they are going to have to do something about it. That means new rounds of chemotherapy or surgery.

Of course, I stress the "if" in that sentence above. I am still not convinced there aren't less scary explanations for all this and am glad that the doctors are giving him time to recover from the pneumonia and tracheotomy to see which functions come back on their own now that he's breathing better and his lungs seem to be clear.

He remains on the breathing machine. The breathing specialist told me today that, if it were removed, he would probably breathe fine on his own for 10-15 minutes, but then get distressed as his lungs get tired. It's an uphill battle recovering from pneumonia. He's on the right path and doing a lot of the work on his own.

He's halfway through the standard recovery time for the tracheotomy. The tube is still laid in such a way as to prevent him from speaking or eating, to facilitate recovery. That said, I noticed today that he wasn't drooling, not did saliva bubbles form at his mouth, as they had been doing. I also didn't see any nurses swabbing out his mouth. It's not proof of anything, but maybe he is swallowing the excess saliva, which gives us hope that he is still swallowing. And I'm still excited about the nurse's comment that he coughed on Friday.

He doesn't do much of anything, but he's got a ton of pain medication in his system, to say nothing about fever-lowering medication and some mild sedatives. Nonetheless, they keep turning down the volumes. I did see today that he is still capable of having his panic attacks.  He was not happy at all when the physical therapist began working with him.  It's awful to watch a child upset who can't make any crying or screaming noises. But then he made the face I associate with his panic attacks and his oxygen levels dropped, so those were the familiar signs of his panic attacks. That said, when he had his panic attack in the hospital in November, his saturation rates dropped to about 25%. Today they never dropped much past 80%, and they recovered quickly.  Maybe before he was only holding his breath a little and then having trouble recovering because of his compromised lungs.  Maybe, maybe.  But, honestly, between the breathing machine and the medications, there are so many variables it's hard to say how he's responding to things now in a way much different than he was before.

I feel better having spent most of a day with him.  Christina is now alone with him most of Thursday as, aside from an MRI appointment, I've got to shepherd my team to buy a Christmas tree. I'll see them again Friday and then we have to dive into the Christmas weekend, even if it's looking increasingly like only half the family will be home for Christmas.

## diet plans and bureaucracy

*December 20, 2018*

No results yet on either of our tests today. I can tell you this: If the problem with your leg means that lying flat on your back with your legs extended is a master class in pain, then 10 minutes in an MRI feels like a really long time.

Christina reports that Colin is waking up more and more. He's letting her know which books she should read and which she shouldn't. But it's still slow going.

I've now had the second person in two days comment on my weight loss. I stepped on the scales today and can confirm that I'm probably on the Sorrells Stress Diet, which does take the pounds off pretty quickly, but is probably not good for long-term health. I am trying to eat. Oma just made spaghetti, and I managed to eat a pretty large portion. Also, thanks to Saint Michelle, I have a stock of Matt's Cookies here in Berlin. My love for these cookies is probably one of the main things I took from my bachelor's degree days in Illinois. I'm sure they have roughly zero nutritional value, but they are making up a large part of my caloric intake these days.

Oh, and in annoying bureaucracy: I wrote the letter to the hospital a few weeks back complaining about their policy of not providing in-room meals for parents.  I wrote it in

English, since my last complaint letter (about the horrible intake clerk on the day we discovered Colin's tumor) got a perfectly adequate response. This time, my use of English seems to have confused everyone. The letter showed up to the complaints department. By the time someone looked at it, Colin had been admitted. They figured the letter was a complaint about service in the ICU (even though the letter was dated from before Colin's admission to the ICU), so Christina got to spend the morning explaining to the ICU administration team that we adore each and every one of them, we just think the hospital's meal policy is absurd.

Hey, if you can't get expedited test results, there's always some hospital bureaucracy to keep things interesting.

Oh, and we got a Christmas tree today.

## Comments

O Tannenbaum! Prayers and love!

*—Barbara Skipper, December 20, 2018*

# So, this is Christmas

*December 21, 2018*

The initial result from the PET-CT Scan is back. The tumor mass is showing no signs of life, so we can stop worrying about that for a while. It is good news and we are happy. That said, we still don’t know what prompted the pneumonia. The doctors still assume the new spot is inflammation and swelling brought on by a delayed reaction to the radiation therapy. But that doesn’t tell us what role the valproic acid played in this or whether his reflexes are compromised.

The next plan is for Colin (and Christina) to head off to rehab, so they can check his reflexes and help rebuild weaknesses. It’s about an hour and a half away and he’ll be there several weeks. There was brief talk of him leaving tomorrow already, but departure is now the 27th. So we still have to figure out how we’re going to have Christmas for Emma and Noah while half the family is in the ICU, but that seems more manageable a problem than it felt like a few hours ago.

Sent from CaringBridge iPhone app

## Comments

A marvellous piece of news re the scan results - hopefully you all have a lovely time during Xmas whatever the arrangement!

*—Sofia Gueorgieva, December 21, 2018*

Hooray for the scan results!!! (((♥)))

*—Cynthia Meyersburg, December 21, 2018*

Really glad to hear about the scan results!

*—Jeremy Cook, December 22, 2018*

# And then things started happening very quickly

*December 22, 2018*

I'm back at the house now after our whirlwind day and a half of good medical news and sudden announcements of rehab.

First, Colin is making decent progress. Today was the first day he showed interest in any toy: his Lego Batman. He didn't do a whole lot with it, aside from taking off its mask and trying to throw it as far away as possible, so those instincts are still present. He also discovered that he can use the Batplane to pop the breathing machine tube off of his tracheotomy connection. It's astounding how it only took us a few weeks to go from "Oh my God, he's on a breathing machine" to "Oh, let me pop that back into place."

The physical therapist also came and got him to sit up on the edge of the bed and then in my lap, for about 20 minutes. He's also trying to speak and nodding his head yes or no to let us know things. It's huge progress, given that he was lying there like a lump just a few days ago.

As for me, the MRI was on Thursday and, given the holiday, I might not know for a few days what's up with that.

Now, to recap Friday.  We had really not expected anything special.  I packed up a bunch of stuff for Christina in the morning, in the expectation that these were things she was going to need for the next few days in the hospital.  I got there around 10 a.m., planning to stay until dinner, buying her time so she could run errands and make phone calls to insurance companies, etc.  About an hour after I got there, the head of pediatric neurosurgery showed up, a guy who reminds me unfortunately of Rick Santorum, even though they look nothing alike.

He's the one who shared the news that there is no sign of life in the tumor. Given that, he said the surgery option is pretty far off the table. He didn't address the question of the medicine therapy, but, after St. Melissa, the patron saint of medical research, looked up the medicine for me, I can pretty much say safely that this is not something they're going to use unless there's an actively growing tumor. It sounds like Ebola in pill form, given all the potentially bleeding as side effects.

They still haven't had the official meeting of all the heads of departments for the final, final word on the tumor, but I can't imagine Dr. Not Santorum would share this with me if he wasn't pretty sure. It's also a little frightening though. I don't think I fully realized how certain the doctors were that the tumor is regrouping, given that their two main treatment options outlined last week were both ways to fight an active tumor. It does mean we're a little bit back at first base.  We know the tumor is dead. We know Colin had pneumonia. The doctors think either the tumor itself or this recent flare-up hurt his cough reflex, but we don't know this.  We also don't know what role the valproic acid played in increasing mucus production (and the doctors don't want to talk about that at all). I think it's likely that Christina is right and our problems stem from a combination of suppressed cough reflex and a bad side effect from the acid.  But we still haven't ruled out that it was just the acid or simply really bad luck, etc. etc.  It bugs me a little bit that the doctors keep rushing to "tumor" before they rule out simpler options, but I'm also well aware that I'm grasping at straws a bit in hoping for simpler answers.

The move to rehab came as a surprise, as no one had mentioned that before Friday. There was even a brief period where they thought that Christina and Colin would head out there today (Saturday), which prompted Christina to rush home and pack a bag. Departure date is now Thursday, and the doctors say he'll be there for a few weeks.

It means Christmas is going to be a divided affair for us.  I'm going to head to the hospital Christmas Eve and stay with Colin while Christina comes home for German Christmas with the family.  I'll then go home that night and do our small American Christmas early on the 25th.  Oma & Opa will return to Bavaria on the 26th and then Emma, Noah and I will negotiate winter leave here in Berlin.  Come January 7, we'll have to improvise.  The kids will go back to school.  Oma & Opa might come back.  We might have some kind of home health care set up by then.  I might return to work.  And then we'll have to see how long Colin stays in therapy and what his abilities are upon his return.  We don't know if he's going to be able to return to day care or what that will mean for our ability to work.

Right now I'm focused on Christmas.  I've never had one away from my family, either my parents or my wife and kids.  I certainly never thought I'd spend a Christmas Eve in the ICU.  It could all be so much worse, but this just feels like one more slap after so many hits from this damned tumor.

## Comments

Yep, must feel like a slap indeed. But slap it back by having a damn good Christmas the best way you can. I'm hoping and praying that in some way this year will provide beautiful moments and memories.

*—Jeremy Cook, December 22, 2018*

Well, rehab sounds a lot better than ICU. And the good news Dr. Not Santorum had sounds like a Christmas present to me. Wishing you and the family a happy holiday, even if it's far from ideal.

*—Dan Wooldridge, December 22, 2018*

I’m so sorry your family has to deal with this. Thinking of you guys.

*—Daphne Retter, December 24, 2018*

Sending the entire family big American-sized Midwestern hugs and lots of prayers.

*—Erin Taylor, December 24, 2018*

Thinking of you!! Sending lots of hugs and good wishes to you all.

*—Molly Land, December 24, 2018*

# Merry Christmas all

*December 25, 2018*

The bulk of the separated Christmas has come and gone already. This is not meant in any way to be a slam on those who have divorced or grew up in families of divorce: But this felt like how a divorced family would mark Christmas. One parent here with half the family. The other parent there with the other half. Handing off the kids in the middle of the night, etc.  I haven't had a divorce, nor do I want one (Merry Christmas, honey!), so I kind of resent having to go through what feels like a divorce Christmas when I didn't seek one.

That said, it went as well as could be expected.  I got to the hospital around 11:30 a.m. and stayed for about 12 hours so Christina could have Christmas Eve (Germans exchange gifts on Dec. 24) with her parents and Emma and Noah.  Colin and I just hung out.  I was a smidge disappointed.  He had perked up a little with his Lego Batman on Saturday morning and Christina had shared a couple of videos from Sunday where he was really going at it with even more Lego figures.  But, by the time I got there, he had already sat by himself in a chair for about 45 minutes and then had a pretty bad fever. Then the doctors set the breathing machine controls so we was doing most of the work by himself.  He remained alert the whole time - I even got a smile or two out of him - but, between fighting off the fever and breathing largely unassisted, he didn't have a lot of energy left for Legos. So, we read a lot of stories.  We commiserated with the nurse about the way the hospital set up a Currywurst stand on the campus giving out free sausage to staff as a holiday perk, which sounds really nice, except the free Currywurst was only available during the hour when just about every nurse is busy getting patients ready for lunch. We played a little Lego.

The night nurse was a little disorganized, even forgetting Colin's dinner and only getting it to him an hour and a half late.  So, it wasn't until just past 9 p.m. that Colin was bedded down.  He fell asleep instantly, so I went to the little room Christina has to microwave some leftover spaghetti and wait for her to show up.  And sitting there, on Christmas Eve, eating leftovers in a fairly featureless hospital room, listening to Christmas music on my phone, I thought this should be one of the most depressing moments of my life.  But it was actually kind of OK.  Yes, I'd like a child who is a whole lot healthier, but I see improvement and I do believe that, once he gets to rehab on Thursday, we'll see progress.

Random details from doctors:

1) I forgot to note this from Dr Not Santorum. He said the presumed inflammation is an odd thing. Sometimes when they finish their collapse, the patient ends up better off.

Sometimes worse. So, we have to see how this plays out. Presuming there was damage to the cough reflex (and others), there's no way to tell right now if it can repair itself.

2) One of the ICU doctors (whom I'm convinced is in Weezer) tells me there is actually no test to tell if a person's cough reflex is compromised. So, they're basing a lot of their diagnosis on what we've told them about his behavior and what they've seen since he's been here. I only point this out because they've only seen him with pneumonia, recovering from pneumonia, intubated and with a tracheotomy. Again, I'm grasping at straws and I'm not saying they're wrong with their diagnosis, I'm simply saying it seems to me that a diagnosis based on parent's observations and these conditions is one that might still need refining.

3) That said, the nurse last night showed me a little about how to suction the tracheotomy. At one point, while he was inserting the suction tube, he told me that a normal child would have coughed at this point, so that does indicate something is not entirely right.

4) We have no idea how long the tracheotomy will be in at this point. It could be a rest of his life thing. So, we are going to have to learn about it.  I have not wrapped my mind around it yet.  Case in point: the suctioning. It means inserting a tube through the incision point and, well, suctioning. I have no idea if this is something we're going to have to do every day, every week or only when he's sick. He seems to have a cold right now, so he's got secretions in his lung. A normal person would cough this up. They also say that, were he coughing properly, he could get it out himself (this confuses me immensely, since I thought they had set up the trach right now so that nothing was passing between his lungs and his sinuses). Saint Liisa, also of archival research, found some information about restoring cough function for me and they have said this will be a focus of the rehab, so we'll just have to see where it goes.  But the point is: We're not going to know how normal a life he can lead until we get a grip on how long he has this tracheotomy and how much daily care it will require.  I'll tell you this: Imagine how well you'd think a 4-year-old would react to someone sticking a suctioning tube through a hole in his throat and then multiply that horror by a very large number. That's how much Colin enjoys the process.  He's taking it with more aplomb of late, but it's not going to be any fun if we're doing this at home multiple times a day.

I've got to go and help build giant Lego sets everyone. Merry Christmas.

## Comments

I admire how you are able to keep positive in it all. Keep up the good work. We're rooting for Colin and all the family!

*—Marc Galmoud, December 25, 2018*

Merry Christmas from the States. Thinking of you & your family and sending prayers.

*—Rich Mayer, December 25, 2018*

Merry Christmas from the States. Thinking of you & your family and sending prayers.

*—Rich Mayer, December 25, 2018*

Merry Christmas Niels. And good luck with the legos! Here's hoping that 2019 brings great things for Colin.

*—Lisa Caasko, December 25, 2018*

# The hospital administrator's revenge

*December 25, 2018*

Two days before the transfer to the rehab facility, the hospital has decided it needs the room Christina's been staying in for three weeks. They'll switch her to a different room, so she's not homeless. Someone clearly felt the need to make things a touch more complicated.

Also, Santa came through the ICU today. Colin got a Play-Doh set. A 4-year old. On a breathing machine. With Play-Doh. What could possibly go wrong?

## Comments

Sending you all much love and hugs today - know it's far from what Christmas ought to be, but it sounds like you are making the best of the circumstances. So glad to read the news about the tumor, that is a relief.

*—Michelle Lee, December 25, 2018*

Merry Christmas! Love you all! Play Doh....hmm....

*—Barbara Skipper, December 25, 2018*

May God shower your family with his blessings, love, strength and faith. I haven't seen u since I was married to Don. I will keep you all in my prayers and hope for total healing! Love to all.

*—Kathleen Guthrie, December 25, 2018*

## Bon appetit

*December 26, 2018*

Well, Oma & Opa got in their car after breakfast today and are back on their way to Bavaria. No set date on when they will return, so, for the time being, it's Emma, Noah and me against the world. Christina and Colin are still set for a transfer to the rehab facility Thursday morning. The three of us will visit them as often as we can, but it's too much driving to force on Emma and Noah every day. And, once school resumes, the weekends will be our only option.

It's going to be more work for me without Oma & Opa, but my leg is feeling tons better (no diagnosis yet though) and I think it's good for us to return to something like our normal routine.  I'm nowhere near as good a cook as Christina, but former roommates can attest that I can keep a house clean. And it's not like I've never prepared food in my life.  We'll survive.

The big news - and this being the holidays, I expect everyone to go and get a drink to celebrate the moment - is that Colin has starting eating solid food again. Yesterday some pudding. Today some cheese.  So, he's swallowing.  Indeed, he's swallowing despite some lingering pain from the surgery and with a post-surgery cuff around his neck constricting that part of his body, and with the feeding tube still down his throat.  If he can swallow under those conditions, I'm optimistic it's not long before we graduate back to schnitzel. Now to see how the other reflexes are faring.

### Comments

Merry Christmas and Happy Boxing Day, Niels. Yay about the swallowing. I had enough mulled wine yesterday, so I'll see how I feel tonight and hope to raise a G&T in his honor!

*—Jeremy Cook, December 26, 2018*

I will put in a drink order my my friendly neighborhood bartender - me!

*—Lea Ann Schnakenberg, December 26, 2018*

I am so thrilled to hear about his progress!

*—Molly Land, December 26, 2018*

## Private transport

*December 26, 2018*

The hospital has let us know that tomorrow's transport to the rehab facility will only have space for Colin and his equipment. No luggage. No parent.

Sigh.

It's not that I mind getting up early and driving Christina out there (it will actually be the most time I've spent with her in weeks). I'm also curious to see the site. It's just the principle of the matter: You have a 4-year-old on a breathing machine with a known history of anxiety and you can't make space for his mother to sit next to him for an hour-long drive? Instead, he gets to sit with people he doesn't know from Adam, having no idea where they're taking him and whether or not his mother will be waiting for him at arrival? This system tests my patience, people.

### Comments

Dislike, dislike, dislike!!!!!
I am happy and hopeful because he is eating and doing well enough to graduate to the rehab, that he is healing, but I agree with you about they should find a spot for his Mama to sit with him.

*—Cynthia Meyersburg, December 26, 2018*

Hopefully you can complain about the badly thought-out transport arrangement - nothing will improve if they don't know that people don't like it. (If you have the energy to complain, of course!)

*—Sofia Gueorgieva, December 26, 2018*

Asking for something they don't have or not gonna do: "Nicht in programme!" I gave lots of free and unsolicited customer service training to abrupt Germans. Can they give him something to calm him for the ride?

*—Dan Wooldridge, December 26, 2018*

I do often think that Germany does not deserve its reputation for logic and rationality

*—Lea Ann Schnakenberg, December 26, 2018*

I can't believe this would be allowed. That is truly awful.

*—Chuck McCutcheon, December 27, 2018*

## The Brandenburg days begin

*December 27, 2018*

Well, we got Colin and Christina transferred to the rehab facility. It, of course, came with the degree of disorganization we've all come to expect from these things.

The transport was supposed to leave at 8 a.m. Sometime before that, someone clued in and thought "Wow, this kid might flip out if he's all alone in an ambulance for an hour with people he doesn't know," so they sedated him heavily.

I managed to get Emma & Noah to the hospital by 7:45 a.m., which is, essentially, an act worthy of a parenting Nobel prize right there. Of course, the doctor who was supposed to ride with him got called away for an emergency, so we all waited a while, before it was decided that a very senior doctor, who reminds me Hazel Edwards, the high school math teacher we all feared, would ride with him. At this point, it came up that there would be space for Christina in the ambulance (but not her luggage).  But, since Colin was unconscious and Emma and Noah have barely seen their mother this month, she decided to drive with us.

The facility - the Helios Klinik Hohenstücken (https://www.helios-gesundheit.de/reha/hohenstuecken/) - seems nice. It's in a sort of rundown part of the city of Brandenburg and surrounded by more Soviet-era high-rise buildings than I've ever seen in one place for a long time. But everyone seems nice there.  They seem to cater to a wide range of problems and ages, but they seem prepared to handle it with every kind of therapy I've ever heard of (dog therapy!), plus things like a pool, a billiard table, a riding stable, etc. etc.  It seems like a hard place to get bored.

Colin is starting his stay there in a slightly less intense intensive care ward than he was in at the hospital. The main difference is that we don't have to put on disposable gowns each time we enter the room.  I guess they'll use the initial time - no idea if we're talking days or weeks - to assess him and then graduate him to more normal surroundings so they can get him up on his feet and learning to work with the tracheotomy, etc.

Colin's take on the place is mixed. He had two of his panic/fainting spells within the first few hours of being there. This seemed to surprise the doctors in the new facility, who had not been told one thing about this, even though it's all Christina and I have been talking to the hospital doctors about since September.

We'll see how the diagnosis works out. The doctor we met today was very nice.  But, as all doctors understandably do, her entire focus is the brain tumor remnants.  And, of course, my argument is not that we should ignore that, but I still can't shake the feeling that there are other things at play here. From what I understood, she was saying that the panic attacks (where he stops breathing) strengthen the case that he has a sleep apnea that is being brought about by the tumor remains somehow shutting down his breathing in the central brain area.  I'm willing to discuss that as a theory and try to figure out how to work around that, but, when he first started having these panic attacks in 2016, we were told they were episodic apnea and completely unrelated to the tumor. This would be something really new to me if they were somehow linked. The fainting spells are always brought on when he panics about something.  If he is indeed not breathing enough at night, what's causing that then?  And, if they're linked, how come the day time spells always have an obvious trigger?

She noted the sleep study he did at the beginning of the month in the first hospital, pointing to his miserable breathing scores there.  But the people in the sleep lab at the time pointed out that another test would be necessary because he was so sick that there was no way to really be sure if he had an actual breathing problem or if he was really sick.  And it was less than 48 hours after that that he was diagnosed with pneumonia. I'm willing to hear opinions from anyone, but it seems that this kind of test was not conducted under the best of circumstances.

Then I asked what role the valproic acid might have played.  She answered that it shouldn't have, since it's designed to help control tumors.  Then why was he taken off the medicine within days of being hospitalized!

Listen, I am not in denial here. I get that something is wrong. I'm seeing that he might have a problem coughing and I can understand how the brain tumor is involved. But I need to see some logical answers, and they're not forthcoming.  I feel like every doctor working on this case only has half the puzzle pieces they need, either by design (no one wants to talk about the valproic acid) or by omission (to this date, we know of no one who has seen the results of the 48-hour EEG back in November). Combine that with the lingering mistrust I have and it's hard for me to be convinced by the doctor's arguments when they start saying things they insist are absolutely certain. But I get that I'm not the most reliable source here either. I have a vested interest in hoping that they're all wrong.  I'm spending my time hoping Dr. House shows up and says something like "Oh, he has a copper deficiency" and then everything is solved. But I get that's not going to happen.  At best, this is mostly me going "Ooh, remember that one thing Dr. House did the one time?" which is probably of little value to anyone, medically.

To end on a positive note, I saw significant improvement when I came in this morning. He was sitting up and broke into a big smile and wave when he saw me (until now, he would just kind of stare at you).  And then when he saw Emma and Noah for the first time since December 2, he just lit up. And he stayed that way until he started trying to hit Noah because Noah was getting into his personal space.  Ah, siblings....

## Comments

Probably irrelevant, but panic attacks can happen while a person is sleeping.
Still holding you all in the light, and glad Colin is showing improvements!!! (((Hug!)))

*—Cynthia Meyersburg, December 27, 2018*

Yes, there seems to be a lot of confusion about Colin's current symptoms. As I recall from my initial reading, Colin's tumor is very rare. I wonder if any of the doctors there have ever seen this type of tumor before. Therefore, they might not really know what to expect 2 years after initial diagnosis. Wow - Colin has really been through a lot in those 2 years, as had the entire Sorrells family.

*—Don Summers, December 27, 2018*

Remember...the people who know the most about a child at any point in time are the parents. You have the complete picture of your child...not any one doctor....and oh the conflicting information they provide. Stay strong and continue to be Colin’s advocate...and love, love, love him....even when it’s difficult. Take care of your yourself in the midst of all the chaos. Prayers and Love!

*—Barbara Skipper, December 27, 2018*

What a thing to be happy for sibling squabbles! Somehow we missed that that you were going through this. What a grueling, challenging time. We'll be keeping you in our thoughts. Doug and Kathryn

*—Kathryn LaPointe, December 27, 2018*

I’m not sure if they exist there, but we had luck with the “hospitalist” (like a generalist who just works at the hospital) helping us crack through some of the confusion during a twisty time of ours. The confusion and questions must be exhausting on top of your already exhaustion. I am so sorry you are all going through this.

*—Kerri Kennedy, December 28, 2018*

## would of, could of

*December 28, 2018*

I happened to look at the family calendar today and noticed this would have been the day that we would have been at the hospital getting ready for the MRI - the follow-up to the scary October MRI - had not all the pneumonia and worries about degraded reflexes swept us away on a new trail of worry. It's such a strange form of nostalgia: Remember when we were only worried about the tumor?

Anyways, Day 2 at the rehab facility seems to be going OK. He has now been approved to eat soft food, which is a bit anticlimactic, since he was already eating food at the hospital.  But now the expert says it's OK.  And there seems to be a vibe that they maybe rushed the move to solid food a bit at the hospital.  Indeed, there seems to be a general vibe of bitterness from the rehab facility.  Not with us, but at the hospital.  Like, maybe they didn't tell the rehab facility precisely how much intensive care Colin still needed and maybe there's a sense that intensive care shunted off Colin a bit quicker than was medically advisable.  What can I say?  Nothing would surprise me any more.

The doctor at the rehab facility started sharing more theories about Colin's status with Christina, but Christina shut her down and asked if they would please, please, just review Colin's files and watch his progress the next few weeks and then we can make diagnoses based on the actual case. They agreed, which feels good.  Because I'd like them to really look at this before making their minds up that it's one thing or another.

Also, my complaint letter to the hospital about their parental meal policy was finally answered (Charmingly, to a Mrs. Niels Sorrells). They basically apologized for the problem, but said that, due to technical limitations, there was no way they could ever provide food for the parents in most of the wards. The mind really boggles.

The kids and I head back tomorrow for another visit/supply run. More then.

## Dropping acid

*December 31, 2018*

It is becoming very hard keeping up with the blog, between the semi-regular runs out to Brandenburg (about 1.5 hours one way) and just keeping a household running, especially when 2/3 of the family members present seem to be either actively destroying the house or collapsing into heaps the second you ask them to, I don't know, pick up a towel or something.

Colin seems to be doing well at the rehab facility. When I saw him on Saturday, they had further reduced his oxygenation on the breathing machine, to 24% (so, just three percentage points higher than what we've come to start calling "surface air"). He's being left on his own for long stretches, breathing-wise. The machine is still attached for emergencies, but he's doing the heavy lifting. That said, at night, he seems more than happy to sit back and let the machine do all the work, which is reinforcing the worries about sleep apnea.

The staff at the rehab facility continues to be a little surprised by how much care he needs, but he's still on track to jump into full rehab on Wednesday. He's been outfitted with a mobile breathing machine, so he can run around, and has something like a little wheelchair now. The key thing, for the moment, is that we're getting him out of bed. Then we get him out of the intensive care ward where everything can be a bit more relaxed and he's forced to run and jump yet more. I asked if we had just wasted the last week at rehab, if he's not really starting full therapy until Jan. 2. But Christina assures me that the time was well spent. The doctors are getting a feel for him. They're figuring out how much/little oxygen he needs. And he's been signed up for all the programs coming his way starting Wednesday.

So, the care is excellent. The diagnoses ... those keep driving us nuts.

On Sunday, Christina came down to Colin's room to find out that he'd had a panic attack in the middle of the night, apparently because he couldn't roll over. Of course, physically, Colin is capable of rolling over. He just couldn't do it thanks to all the tubes in him.  They got him through the attack and, at some point in the conversation, the nurse referenced Colin's anti-epilepsy medicine.  So, Christina checked the chart and, yes, they've put him back on valproic acid.

People, I don't want to be the typical American, but man, I want to sue someone so badly these days.

What seems to have happened is that the rehab clinic doctor was surprised by the intensity of the first panic attack on Thursday that she decided that maybe he would be better off returning to the medicine.  Bear in mind, this is also the doctor who said that the panic attacks were probably linked to the sleep apnea.

I just don't know.  Maybe this doctor has figured everything out that has eluded the doctors at Charite for the last few months.  But, bear in mind, ever since he had the first panic attacks in 2016, we were told those were due to episodic apnea, and that those had nothing to do with the tumor.  Also, he was removed from the valproic acid because the doctors thought the increased mucus production made him more susceptible to pneumonia. Another fun fact I found poking around on the internet? Guess what drug can contribute to sleep apnea? Go on. I dare you. Take a guess.

Of course it's valproic acid.  Valproic acid seems to be responsible for everything from hives to annoying co-workers.

Again, I'm not discounting the very real possibility that his reflexes have been compromised by the recent activity near the tumor.  But we don't know that.  And I can't figure out why they can't just let him recover from the pneumonia (and, apparently, the valproic acid) so they can get a baseline and THEN start figuring things out.  Instead, they want to put a lot of weight on the fact that his night-time oxygen saturation was so miserable.  I can only ask in response: Does that seem so implausible in a child who was in the middle of developing pneumonia?  Especially if they were on a medication that seems to promote both mucus production and weight gain that could produce obstructive sleep apnea? If not, can someone please explain it to me in straightforward terms (And no, doctors, this does not mean you need to switch to English with me, just keep the medical German to a minimum. And yes, most doctors, my German is better than your English. I really felt the need to say that, just once)?

In short, things change. Others stay the same.

We're getting geared up for New Year's. To keep continuity, our friends Stephan and Sabine and their kids are coming over, just like they do every year.  The kids will have playmates.  We'll make some food.  I'll probably spend the evening telling Sabine and Stephan how I've once again rediscovered my complete empathy for single parents, because it is hard running this whole show by oneself. Hope everyone has a good one.

## Comments

May your time tonight with Sabine and Stephan be sweet! I'll be thinking of you guys from Mt. Kenya!

Oh, and I can so relate to the whole, ya know, can ya even pick up a towel thing?! Drives me nuts. The older I get the more I want to probe my parents with questions like, "Okay, did I do this too? And when did I learn to do it on my own? Was I also really so lazy as to not be able to put a toilet paper roll on!?!"

*—Jeremy Cook, December 31, 2018*

Hope you all have a good time bringing in 2019 and good luck with the doctors - they really seem confused, to put it mildly.

*—Sofia Gueorgieva, December 31, 2018*

This crappy year is expiring. I wish you a much better, even boring year ahead.

*—Boris Babic, December 31, 2018*

I hope 2019 is indeed a New Year for you. Here's to Colin getting better and all of us staying healthy

*—Lea Ann Schnakenberg, December 31, 2018*

Thinking of you and wishing for illumination, answers and healing in 2019. You sound like you are doing a good job holding it all together, but I can't imagine any bit of it is easy. Hugs.

*—Marci Roth, December 31, 2018*

Hmm...you make some excellent points. We had a crappy year, and we had excellent doctors. You win the contest (crappiest year) that you didn’t know that you entered. I could say something stupid like some day you will look back on this year and smile....NOT! We offer prayer and love and know that we care. Please God, be with this family and their doctors....bring forth the answers and treatment that heals Colin. Love...Barb

*—Barbara Skipper, December 31, 2018*

Here's looking to a simpler, healthier and just plain easier year for you all!

*—Marc Galmoud, December 31, 2018*

## EEGad

*January 2, 2019*

Nothing much to report today. We would have gone up to the clinic for a visit today, but Colin had to have an EEG and we decided that might not be the best time for a visit? Why does he need another EEG when he just had a 48-hour EEG in November, you ask?

They lost the results.

Yeah. I'm kind of sadly shaking my head as I type this. Because, once you strap a 4-year-old into an EEG cap so tight that it leaves marks for about a month afterwards because you want to see if his panic attacks are a symptom of his brain tumor or something fun and extra on the side, you don't want to hold on to that data too tightly.

Sadly, I don't think this even makes my top hospital goof. That still remains the time they lost a bag of chemo (again, something you don't want to track too closely). The EEG will take second place. Third goes to the time the hospital lost power. Not Berlin. Not the neighborhood. Just the hospital.

Christina reports Colin is making lots of progress. He keeps eating soft food and has had his IV removed. They're keeping the feeding tube in to be on the safe side. He's sitting up in his chair more now (so getting out of his bed) and had four separate therapy sessions today, so they are starting to get serious. I'm negotiating my return to work next week, but it's hard finding shifts that are useful to my employer but that allow me to keep half an eye on Emma and Noah. It's not quite normal, but it's feeling less abnormal, if that makes sense.

### Comments

I am so sorry you have a top ten list of mishandled care. Ugh. Hope Colin continues to be a little better every day.

*—Kathryn LaPointe, January 2, 2019*

## speak easy

*January 4, 2019*

Yesterday, I heard Colin speak for the first time in a month. It's a gurgly kind of voice and you have to have an idea about what he's saying to understand him properly (though "Mama," "Papa" and "Batman" - the holy triumvirate as it were - all come across pretty clearly), but it's still speaking. There will be some practice needed before he can speak as clearly as before: the tracheotomy is a fiddly thing. Also, his voice sounds different this way. It's still identifiably Colin. And there's the gurgling. But there is a different tone to the voice that will take some getting used to.

Nonetheless, it was speaking and it was good to hear.

Christina said, as soon as they reset the tracheotomy to allow speech, it took him about five minutes to figure out again that he could speak. They don't leave it set on speech mode all the time right now. We don't understand why and probably would not be able to follow the answer if they did explain it to us. But we'll take what we can get, knowing it's probably going to be a little more every day.

Of course, questions linger. I mean, in a best case scenario, by the time he gets used to speaking this way, they're going to say "You know what? We can close this back up and let him get back to doing things normally." But there's no way to tell at this point if that's the outcome headed our way.

He's getting better with the breathing machine. He's spent long stretches of time - five, six, seven, eight or nine hours - with the machine at a very low setting, essentially only serving as a backup. Yesterday, he went 10 minutes without the breathing machine on at all. One doctor is apparently convinced we can ditch the whole machine, but everything is done very slowly at the rehab facility to make sure they don't cause additional damage, so the weaning process will also be a prolonged thing. Also, bear in mind, as great as his breathing has gotten, he's been doing it all sitting or lying down. We'll have to see how well he breathes and oxygenates when he starts running around. He only stood up on Thursday, his first time since the start of December, so that's another hurdle to face.

Another mystery. When he eats now, the food will sometimes get kicked back up into his tracheotomy. I thought this was impossible given how things were set up. But the nurses say this is a sign that he's coughing. How well he's coughing is an open question, but it's still a foundation to build on, if nothing else.

Nonetheless, he's giving it his all. And his mood is so good (unless they try to give him a bath, which sounded like a mini-recreation of D-Day the way Christina tells it, with Colin playing the Allies and this one poor nurse taking turns playing the Nazis and the French resistance) that it's hard not to be optimistic. He can have up to four therapy sessions a day (and who knows if there won't be more as he gets stronger) and spends most of his down time playing tablet or Legos.  Yesterday, he brightened up as always when he saw his siblings and enjoyed finally unpacking his Advent calendar. He has yet to even see the bulk of his Christmas gifts.

That said, so much remains unknown. I doubt the doctors have finished laying out their competing theories as to why all this happened. Christina is right there at the front lines and she doesn't always get why the doctors are doing this or that to him. And, when I show up, we're spending most of our time trying to stop the older two from climbing on top of Colin, so I don't have a chance to get from Christina what she knows, so basically everything they're doing there is a mystery to me.

I go back to work tomorrow. They're being very good about letting me negotiate my shifts week by week until I have some better overview. Weekend shifts will be hard. Obviously, everyone at work is getting sick of covering all the weekends that I didn't work in December. At the same time, if I go in for a weekend shift, it means finding care for the children. Plus, the weekends are my only chance to get the kids up to Christina once school starts on Monday. On top of that, I have to go grocery shopping at some point. And I ought to start taking the kids on visits to secondary schools, which are starting this weekend, so we have an idea of which path Emma is going to go on, academically, after she finishes 6th grade in 2020.

It's all manageable, but, my God, it's a lot some days. It took us until 9 p.m. to get home from our visit yesterday. Both kids needed showers still. And I still had two baskets of laundry facing me before I could sleep with a clear conscience. We still don't know if we're going to get some kind of home help (the insurance company does not make this easy), and so we're just going to persevere.

Colin's stitches from the tracheotomy come out today. Not a major medical milestone, but still something.

## Photos

## Comments

So great to hear about the advances, but the difficulty in getting good information is so frustrating I'm sure. I love the story about the bath though - go Colin!!

*—Molly Land, January 4, 2019*

I get tired just reading what all you and Christina have to do! Many prayers. Thanks for Colin’s pic in the wheelchair with the trach. He is so beautiful. Prayers for his health and comfort for you and Christina. Much love, Barbara

*—Barbara Skipper, January 4, 2019*

## unknown unknowns

*January 6, 2019*

Oh come on, are you even a blogger if you haven't used Donald Rumsfeld as inspiration once?

So, another visit to Brandenburg today. His mood: chipper. His Lego collection: sprawling. His ability to defy the doctors: impressive.

He remains a bit of a medical mystery. One of the main reasons for the tracheotomy was to separate his sinuses from his lungs. This way, his lungs get a chance to heal from the pneumonia and the doctors get time to assess how well he swallows and coughs while not allowing any more mucus to enter the lungs. The way the implant is set, he should not be able to speak or aspirate anything into his lungs (either food or mucus).

People, he's talking. He's not going to get any awards for eloquence, but he's saying key words like "Mama," "Papa," "Emma," "Noah," "Flash," "Batman," and "los!" The last of which roughly translates to "do it now if you know what's good for you." He also managed to curse out a doctor a little bit, which is probably not something we should be encouraging, but it was honestly adorable.  He seems to have found a way to build up so much pressure in his lungs that he's pushing air past his vocal cords, regardless of what they put in there.

On the downside, it means things are loose and some food is making it into his lungs. He coughs it up (or manages to push it up with the vast amounts of air pressure he produces), so we're not seeing any permanent harm, but this is something we'll have to keep an eye on if we don't want any more lung damage.

So, it seems the doctors are on to something with their concerns about the swallowing and coughing. As for breathing, he's doing that like a champ. He's being unhooked from the machine once or twice a day and he's doing just fine. Even when he's on the machine, it's mostly a backup. We'll have to see what happens at night time when they start weaning him off then.  Only then will we know if this sleep apnea theory is right ... or if he was just having problems breathing because he was busy developing pneumonia.

Our thoughts are turning to how long he'll remain there.  His regular physical therapist pointed out that the standard stay is three weeks, though almost everyone extends by one week. That would be Jan. 17/24.  But, since he didn't really start getting any therapy (aside from efforts to wean him off the breathing machine) until Jan. 2, that would seem a very expedited schedule. I mean, he's still in the rehab facility's version of intensive care, so he's a little cut off from everything.  We'll see.

I had my first day at work on Saturday.  I'll now work mostly from home for two weeks and see how I can swing things when I start returning to the office regularly the week of Jan. 21.

In our other ongoing medical mystery, I still have no idea what's up with my leg. This is my best depiction of my conversation with the orthopedist's office on Friday.

Niels: I saw the doctor before Christmas and he sent me for an MRI. Do you have the results?

Receptionist: Yes, but i can't tell you what they say, because I'm only a receptionist.

N: That's fine. Can I make an appointment to see the doctor?

R: He can see you on the 11th.

N: So, in a week.

R: No, Feb. 11.

N: (long pause) You know, he sent me for an MRI because it seemed kind of urgent and now I don't get to find out what the deal is for five weeks?

R: Life's kooky like that (that's a very loose translation on my part).

N: Let's start again.

R: Gladly.

N: The doctor has seen my MRI results?

R: Oh yes.

N: Can I assume he would have called me had there been anything serious?

R: Almost definitely.

N: So, I probably don't have cancer?

R: Almost certainly not.

And that's when I gave up and took the Feb. 11 appointment.  I'm going to try to call back tomorrow and see if I can make headway not that I'm mentally prepared for the fact that they like to keep MRI results secret. After I hung up, I called my family doctor to see if he could lean on the orthopedist for results. Unfortunately, the nurse who is mad at me for emailing the doctor with questions answered. I can't tell if she's playing dumb or if just actually dumb, but every time I suggested they contact the other office for the MRI results, she responded that they didn't have the results.  Which was kind of the point of why I was asking them to call the other office.  But, clearly I was distracting her from her Whatsapp feed when I called, so I hung up.  I might end up calling there again tomorrow and hoping the other nurse - the one who seems interested in patient welfare - picks up the phone.

## Comments

Isn’t it crazy how quickly we size up who to talk to in each doctor’s office in order to get results? It shouldn’t be so hard. Continued prayers.

> *—Barbara Skipper, January 6, 2019*

# progress, of sorts

*January 7, 2019*

Well, I got the orthopedist to agree to see me on January 24, so things are moving ever so slightly forward. Even better, I got them to fax the results to my family doctor and, despite some grouchiness from the nurse there, I can call him around 2 pm tomorrow so he can tell me if there's anything I need to know.

Even more exciting, Mrs. Sim, our hospital-appointed psychologist tracked down the EEG results. They showed nothing out of the ordinary and they will send them to the rehab clinic as soon as they transfer them from 8 track (or wherever they hid it) to a more accessible format. At least this means their epilepsy theory can finally be put to rest and they can take him off the valproic acid with a clear conscience.

Christina is feeling a bit abandoned in the rehab clinic. Not by us, but she has not seen a regular doctor in about five days, which does seem a little lackadaisical. She's seeing lots of nurses and therapists, but it would be nice to talk to someone with an overview of the situation. Colin's swallowing problems weigh on her. He gets most of the food down the right tube, but you only need a little in your lungs to cause problems. Can he be trained to eat properly? It's questionable. An adult could probably learn the skills. Colin is almost 5, but functions more like a 3 year old. Can he be taught these skills? Christina questions whether the therapist assigned to him is the best fit, since she doesn't seem equipped to deal with someone as young as Colin (She's apparently already complained that she can't do her job if Colin doesn't work with her. Like, "Welcome to the toddler years, my friend.")

If he doesn't get it down, we will have a rough time ahead of us until he learns to eat properly. It could mean a stretch - years even - of a feeding tube. Here's hoping they find a way to teach him or they get a tracheotomy in him that does keep the food where it's supposed to be.

I'm off to see Colin's pediatrician, because we have no idea if she's been briefed on any of what's happening. Then the kids and I have to go to the library to explain why we've had their books since October. Look, we've been busy.

## Comments

Library books -- the least of your worries, but ugh, another thing to deal with. I'm hoping you guys can get some good sleep on top of all this.

*—Jeremy Cook, January 7, 2019*

## rooms and viewpoints

*January 7, 2019*

I got in to talk with Colin's pediatrician. She didn't tell me anything I didn't really know already and it was not the most uplifting conversation I've ever had.  Nor was it depressing.  It was very much matter-of-fact.  He's got a hard road ahead of him.  It's not going to be easy.  It is going to have an affect on our day-to-day life.

That said, she put a lot of the last few weeks into perspective.  She trained as an oncologist before opting for pediatrics, so a lot of the big words thrown around by the hospital doctors make sense to her, but she's used to explaining things to new parents, so we worked through a lot of the diagnoses and suggestions of the last few weeks and suddenly it didn't all seem quite as chaotic or pointless as it felt at the time.  It made sense that the one doctor focused on this or thought the one thing might be important when she pulled it all together for me.

She said she would be surprised if Colin is home before mid-February. She also said she knows how to contact various services that will help families with special needs.  For example, if he has to sleep with a breathing machine, there's a nursing service that sends someone over every night to monitor his breathing so the rest of the family can get some sleep.  Fine, it means a farewell to privacy in our home, but it is also an option to help us take care of him.

Back at the hospital, Colin is moving along.  He got transferred to a new room, still in the intensive care ward. The key difference seems to be that someone needed his old room because that is the one where the nurses can keep an eye on him most intensely.  I suppose it's a good thing that he's no longer the sickest in the ward, but it's faint comfort.

A therapist watched him eat lunch and says she is convinced Colin can swallow just fine. The problem we're having right now is that he eats so quickly that some food ends up in the wrong tube.  How you convince a 4-year-old to eat slower (insert joke about Sorrells men, eating habits here) is beyond me, but she seems to have a plan.

He also had another fainting spell today. I have to admit, I haven't seem him have one in so long, just because we've been separated so much of the last six weeks that I forget sometimes these are still a problem.  But they are, so it's one more piece of the puzzle we're going to have to sort through if he's going to have anything like a normal life.

As for the trip to the library: 72.50 in overdue fees. Man, that feels like a new low. Worse, the one magazine Colin destroyed back in November. They won't let us just pay for it.  As penance, we've got to find a new edition and gift it to the library.  German librarians: They don't mess around.

## Comments

German Librarians...are they like the ones here who don’t want anyone to touch the books? Thank goodness you are finally getting information and common sense perspectives. Prayers continue!

*—Barbara Skipper, January 7, 2019*

Your experience with the pediatrician makes me think again how med schools should force aspiring doctors to do some time in peds, just so they can learn how to communicate with most other human beings. Amazing how most peds I've known can take really difficult concepts and make them clear.

*—Jeremy Cook, January 7, 2019*

Great news that you've found someone to translate the doctorbabble into a human language. And for your information, librarians are hard-nosed everywhere. I wanted to get some transcripts from my undergrad college. To get them, I first had to pay a fine (that I disputed at the time) for a book that I borrowed 20+ years ago!

*—Marc Galmoud, January 8, 2019*

# medical mystery show

*January 10, 2019*

Well, we all continue to plug on, mystifying the medical world at every turn.

Colin is making progress. Christina reports that they wean him off the breathing machine a little more each day. She said he was off it for a six-hour stretch today. He's also getting out of his hospital room a little bit, if only to the therapy rooms.

The medical team seems a little more unified than the one back at the hospital, but there are hiccups. There was yet another debate about whether he needed the valproic acid, and I am beginning to wonder why we keep being cursed with conversations about this stuff. There also seems to be a fight between the doctors and the therapists about the speed at which he's reintroduced to more solid food and is allowed to have his trach set so he can speak.

The eating remains a challenge. If he eats slowly and with concentration, everything goes where it's supposed to. But he's 4, so being slow and concentrating are not in his job description. Right now, the therapist has to be with him for every meal to keep him focused. Today she couldn't make it, so he got all his nourishment through the feeding tube and was, understandably, depressed. The therapists also tend not to work on the weekends, so we'll see how this goes.

The paperwork continues. The secondary insurance turned down our application for a home helper, but that could be a good thing, as it green lights us to go to youth services for assistance, and they might pay more. But who knows how quickly the wheels of bureaucracy will grind. We just got recompensated for the 48-hour EEG, so I paid that bill, only to have his 655-euro ambulance bill from December 2 arrive a moment later. Heaven knows what's going to happen when the bill for the three-week ICU stay shows up. Everyone is very understanding, but there's a point where the hospital wants to be paid and the insurer is in no rush to provide the money and I'm in the middle wondering how many of our possessions we need to sell to cover the expenses until we're liquid again.

My leg might remain the greatest mystery of them all. The orthopedist has the MRI results. He won't telephone me to tell me what they say. His receptionist is not qualified to speak to me about it. They faxed it to my family doctor, but his nurse (the nicer one, even) says he's not qualified to discuss the issue with me. Nor will she tell me what it says. She just says it's very important that I get to an orthopedist and I'm all "Trying to get to him is like a second job to me at this point." I guess we just wait until the Jan. 24 appointment and hope my leg doesn't fall off in the meantime. It's mostly back to normal, but there are odd moments of weakness. And today, when I swung it over a bench, I got one of the more memorable leg cramps of my entire life. People, I cannot be responsible for my actions if the orthopedist tells me in two weeks that I really should have gotten this thing treated sooner.

## Comments

Geez! That is the only word that comes to mind at the moment.

*—Barbara Skipper, January 10, 2019*

## Add it up

*January 12, 2019*

And today, we learned that a 22-day stay in the ICU costs 62,336.41 euros.

I don't want to get political, but I'm so glad I live in a country with a social safety net, no matter how much the bureaucracy annoys me at times.

### Comments

Hope the insurance settles it quickly, and may everything else is going well!

*—Sofia Gueorgieva, January 12, 2019*

Holy social safety net medicine, Batman.

*—Chuck McCutcheon, January 12, 2019*

Wow!

*—Barbara Skipper, January 12, 2019*

Niels, I am dreadfully behind on your updates and catching up now. Hope the New Year brings with it joy and strength to Colin and the whole family. (I feel for you with medical bureaucracy. Our insurance paid half million US$ for 1-wk ICU for pediatric heart surgery in NY hospital...15yrs ago.)

*—GF Santos, January 21, 2019*

# A lot to swallow

*January 16, 2019*

Today's entry is going to start with blue mashed potatoes and end with a plague of pine needles.

We've been worried about Colin's swallowing for a few days now. I remember back in December, as lal the diagnoses were coming in wrong and just not the way we wanted them, when the one thing we could hold on to was "Well, at least he can swallow properly, no matter what the doctors think." It's hard to think that was only a few weeks ago, because it turned out we weren't entirely right. Then again, nor were the doctors, and they're paid better than we are.

I won't pretend to understand the mechanics, but the way they've inserted the tracheotomy is supposed to allow them to block his breathing passage so he can breathe through the trach while food goes undisturbed down the non-blocked tube. But he keeps finding ways around the blockage, which means food ends up in his air passage. He manages to cough it up (a very good step, considering our other concerns in December), but we don't want any food anywhere near his lungs, given his recent brush with pneumonia. We've had several tearful conversations in the last few days as we try to ponder what this is going to mean.

The thing is, as Christina points out, we can keep him alive if he's not able to eat regularly. It would mean a feeding tube, probably directly into his stomach. So, we're not quite talking life or death here. But how do you explain to a kid who's almost 5 that he won't be eating regular food any more? Especially a kid with a known history of wandering around the house and eating anything he finds that looks OK to him. As we pondered this possibility, we were seeing an end to family trips, an end to inviting people over, an end to eating together as a family.  Yet, at the same time, it's not like we can take Emma and Noah (or us) off food, so what do we do?

And I know there are people in Congo right now who would be happy to get any food right now, regardless of whether they had their whole family together or not, but it is still daunting, after the last three years, to ponder yet such another major change to our life. It feels crushing.  Like, I would not wish this path on any of my friends.  Not even my enemies.  Yet I'm also tired.  Like I'm ready to tap out and have someone else take over. But who in their right mind would?  So, here we are.

Anyways, the plan today was that Colin would get lunch, but only after they somehow inserted a camera into his throat to watch him eat.  I was not there.  I will not pretend to understand the logistics.  And, somehow, this required the food to be blue.  I do not know why.  But as Christina told me later via Facebook: BTW, dyeing mashed potatoes blue and calling them Mr. Freeze potatoes does not increase his wish to eat them

Hey, he's a Batman fan. It probably seemed like a good idea at the time.

So, they did the test. He is not eating properly.  But he's not eating badly enough that we're thinking about surgery or feeding tubes.  The job will be to convince him to eat slowly and with concentration, so he can make sure everything goes in the right place.  It's going to be tough.

I know I spent most of the midday terrified of the answer.  I wish we could, just once, get an "Everything's fine," but I suppose we'll just have to make do with "We're still working on it."

We cope with everything else.  Working from home so I can be here when the kids finish their day has its challenges, but it is manageable.  I took the kids to some open houses at secondary schools on Saturday, so they could check out where they might one day be going to school.  They were bored and I was overwhelmed and, honestly, it would have made so much more sense if Christina was there, as she halfway understands the German school system.  Then I had to work Sunday, so Saint Marc took them to a computer science museum and will be rewarded with baked goods some day, when things are a little calmer.

It continues to be an odd life.  I finally had to sit down with the kids and apologize to them for being so short of temper all the time, because I miss Mommy and Colin, I told them.  They seem to understand.  It's hard keeping the house running.  It's hard keeping the marriage feeling like it's more than Colin's medical team some days.  We watched the Matrix together on TV two nights ago.  Well, not the whole movie, just the scene where they blow up the entrance hall, which is more fun for me now, because I imagine it's me blowing up the hospital. (Which emailed me back on my suggestion of providing sandwiches to parents stuck in hospital rooms. I will send your email to the responsible department to check if it is possible to realize your suggestion.  was the response. As if I'd suggested they install a nuclear fusion reactor in the room)

I keep the house together, barely.  We took the tree down yesterday.  There were needles everywhere, I thought.  But, to defy my mother-in-law in spirit, I didn't clean them up right away.  Then I opened the back door to shake out some needles.  This is when the doorbell rang, as a neighbor was coming to pick up a passage.  I opened the door to hand him his package, creating a massive draft.  Now there were really pine needles everywhere.  I suspect we'll be finding them until 2025.  It is at least not dull.

My leg continues to function. I routinely get pins and needles sensation all up and down the leg, for reasons I can't figure out.  It definitely happens when I lock my knee (and for everyone about to tap out a situation, I have figured out that I should not lock my knee so much), but then at other times too.  And I still have random moments of weakness in the leg.  I don't know why.  And no one will give me an answer until next Thursday.

And that's our life.

## Comments

I don’t even know where to start. If things ever get to the upside and you start seeing improvements ...an upswing....maybe you can then at least take a deep breath. Prayers and love! □□

*—Barbara Skipper, January 16, 2019*

Wishing you a moment or two of calm and peace in between the chaos and confusion. And hopefully some clarity soon, both about Colin's situation and about your leg as well!!

*—Molly Land, January 17, 2019*

Hoping that things will get better soon. Poor little Colin must be so frustrated. Said many prayers for him and your family.

*—Dan Wooldridge, January 17, 2019*

# going positive

*January 18, 2019*

I know I can sometimes emphasize the negative in this blog. Sometimes there's nothing else to emphasize. That said, there are small pinpricks of joy. I don't know how Caringbridge updates for everyone, but I changed his profile picture last night to, honestly, one of the more adorable pictures I've seen of him in a while.  He is getting out at the rehab facility.  He is having some fun.  Maybe there's even some progress. Christina shared a video with me of him playing with Legos - and maybe I'm seeing things where there is nothing to see - but without the valproic acid in his system, he seemed more focused than I'd ever seen him before.  Maybe, maybe.

Sunday and Monday were absolutely rough.  There were tear-filled phone calls and real worries that Colin was going to have a feeding tube into his stomach.  The fears have marginally receded.  Christina reports three good days in a row.  Still, no idea when he'll get out of there intensive care ward, to say nothing of when he might be back home.

My mother-in-law is going to return to Berlin tomorrow to help us out for a 10-day stretch.  It is prompting a little burst of cleaning on my part right now, as I fear a crescendo of "Ach du lieber Himmels" when she comes through the front door if the place is not up to her standards of cleanliness. Let me be clear: the place is not a dump. I simply have somewhat lower standards.  But, if I clean the place thoroughly, perhaps I'll find all the Lego pieces that got left here when Colin rushed to the hospital in December so I can bring them to him and he can have his figures the proper way. He grows tired of a Flash figure with Batman pants and a Wonder Woman with the completely wrong hair.

After that I'm off for a week while the kids have their winter break and then we're negotiating whether one of my nieces might fly out and help us out for two months.  Also in there, our old au pair, Ricardo, returns to Berlin.  He's going to have his own thing going on, but I'm confident it means I have one more person in Berlin I can rely on in case of an emergency.

We'll head to the hospital on Sunday for our first visit in two weeks. The oncologist has set aside a block of time to speak to me and Christina, so maybe we'll get some answers.  Though, to be honest, I've grown used to speaking in possibles, not certainties.

## Comments

There are a lot of possibilities today for Colin! So glad you are getting the much needed help. Wish we were all closer and could help. Steve is much better these day; however, not up to a transatlantic flight yet. Prayers and love.

*—Barbara Skipper, January 18, 2019*

Yay, great stuff to hear!

*—Jeremy Cook, January 19, 2019*

# Up and running

*January 20, 2019*

I got one of the best text messages of my entire life this weekend. As a bonus, it was from Christina.

> We just returned from a little excursion to the gym. There were some other kids there and Colin took off like a shot, walking and kicking footballs around. I was too busy running after him with the monitor to take pictures. It was great!

So, he still has some get up and go. Of course, he collapsed exhausted after that, but it was his first time up and running in weeks, albeit with at least one monitor attached to him.

Then I showed up today with kids and Oma in tow. Colin was lying on the bed while the nurse readjusted some tubing. She finished as we walked in and he sat up, arms spread, in perhaps the heartiest welcome I've ever received.  It was a world of difference today. Bear in mind, I hadn't seen him for two weeks.  Today, it felt more like hanging out with my son than with a patient.

The first hour or so went very well.  The kids had a blast.  Then Christina and I met with the doctor and Oma said things continued to go very well.  Starting with the third hour, things went a bit downhill.  Colin got a little annoyed with the extra attention.  The older two started going through the toys he has at the hospital and began negotiating to see if they could take those home (because we have no toys back here in Berlin, you know). We still have our suspicions that they smuggled some Lego pieces out of the hospital, but we don't know how. Oma patted them down and found nothing.

After that, we realized we were behind schedule with Colin's treatments.  And we couldn't keep the older two out of the room while he ate, which is something that really requires no distractions.  So, we were all a little frazzled at the end.  Then again, I have to ask myself, was it that much different than having the three of them at home for a day?

The talk with the doctor was good.  I learned nothing in particular, but got some new insights.  My main takeaways:

- It's going to be at least three months before we even start thinking about taking out the tracheotomy, and there are no guarantees it won't be in for a whole lot longer
- The theory about an inflammation causing the problems is still out there, but he pointed out it's just a theory. He said he actually thinks it might have been damage caused directly by the radiation therapy.

- We'll never really know, because there is no MRI that picks up this kind of detail
- He's going to be at the clinic for at least three more weeks
- He thinks the panic attacks (no, those have not gone away) are linked to the tumor, in that the tumor damaged parts of the brain stem that would regulate breathing, meaning when he holds his breath for a temper tantrum, it starts a spiral that is harder for him to work out of than it would be for the average person.
- He also thinks the panic attacks are a good sign, as it shows Colin is still working to assert his opinion (we see this as a very glass half full way of looking at the situation).
- The nicest part was the comment that, seeing as Colin has now been cancer-free for two years, the average oncologist would start grouping him with those people whom they wouldn't worry about a re-emergence of the tumor. No, it's not a guarantee, but it sure sounds nice.

Whenever he returns home, he's going to keep on needing a ton of therapy. Before this latest round of awful started, he was already seeing a physical therapist twice a week and a behavioral therapist once a week. I suspect that list will grow.  The doctor also told us we'd be entitled to 24-hour home health care given his condition. It would take some pressure off of us, for sure, but ... goodbye privacy! And this is all before we even figure out if there is a way for him to return to day care, or if that's even advisable or if they would even be up to caring for a child with Colin's needs.

Still, we're in such a better place, mentally, than we were a week ago.  But, my, that's a steep hill to climb ahead of us.

## Comments

that sounds very, very nice

*—Kathryn LaPointe, January 20, 2019*

# A few more things

*January 21, 2019*

I write these entries on the fly and usually remember about a half dozen things I wanted to say after I write.

I forgot to note that the doctors have outfitted Colin with a new tracheotomy tube that seems to include a much better stop, so food is being prevented from getting into his lungs. It's also tight enough that he can't speak past it. Sadly, when it's unblocked and he can speak, it's much harder to understand him. He was actually more comprehensible when he was speaking past the old blocked trach. But we'll get there.

Now I can't remember if I mentioned this, but the doctors said that, whatever caused the damage, there is really no way to confirm it with modern technology. All we can do is keep an eye on him and track what progress he makes and compare it to what problems he encounters. The tumor is so rare and - as near as they can tell - this interplay of brain stem tumor, radiation therapy and delayed nerve damage so unusual that everyone is feeling their way through this. They cannot rule out that the condition is degenerative.

On a further depressing note, I sat down with the kids before bedtime and asked if they had any questions about Colin's condition, as they hadn't seen him for two weeks and he was acting much differently than the last time they saw him. The first question came from Noah: "Is he dying?" So, you can see this has not stopped wreaking mental havoc on all of us.

But, in a final bit of good news - and a bit of a shout-out - I might resolve my library drama tonight. The magazine Colin tore up was from a German's children show "Die Sendung mit der Maus" (The Show with Mouse). I cannot think of a good US analog. There are certainly very few Muppets involved. It's a mix of cartoons and songs and the hosts answering questions about the way the world works. Many of the questions come from children. The same guy who hosted the show when Christina was a kid is still in charge and they do get to the core of things. Shortly after arriving in Germany, Christina had me watch an episode focusing on the question of how contestants in the Tour de France urinate when they don't have time to stop for fear of people getting ahead of them. I mean, if ever a question needed answering... (it seemed to involved bottles and a degree of flexibility and control of a bicycle that I lack).

Anyways, I wrote the show a whole sorry email about our situation and they first responded with a packet containing a ridiculous amount of swag from the show. It was so much that I just dropped some off at the day care, because my kids only need so much. They also sent three replacement magazines, one of which goes to the library this evening. So, well done mouse show!

## Comments

Mouse show to the rescue! I'm sorry for all the other news in here and the painful emotions they bring you, but I'm glad you've had some good luck, too, thanks to a good ole Maus.

*—Kerri Kennedy, January 21, 2019*

That is actually very sweet about the Mouse show. Sounds like they do some useful public service ;-)

*—Liisa Ecola, January 21, 2019*

Gotta get me some Mouse Show!!

*—Jeremy Cook, January 21, 2019*

## the secret is out

*January 24, 2019*

To recap, my back/hip/leg began bothering me on Dec. 2 and I had my MRI on Dec. 20. Today, I finally got to meet with my orthopedist to get my diagnosis. To all you people out there - my father-in-law, my buddy in real estate, the lady who cuts my hair - who were all so certain I had a slipped disc, I say to you "Ha! This is why we have medical professionals to diagnose these things."  Because it wasn't a slipped disc.  It was a precursor to a slipped disc.  An almost slipped disc, if you will.  The point is, it was very important I wait nearly two months so a doctor could tell me something that, basically, everyone else in Berlin had almost (but not quite!) figured out just by hearing me whine about my pain.

The real medical mystery is why no one could tell me this over the phone, because it took him about three minutes to explain it to me and it wasn't particularly technical. Also, he gave me a prescription for physical therapy, which is super useful, as I've felt no pain or had any problems with the leg since Tuesday.  Just in time!

In other tragic medical news, my correspondence with the hospital about meals for parents continues.

Another recap: Back in November, I wrote them and said it was borderline cruel to make parents go hunting for food in the hospital if they were also expected to stay in the room 24/7 with a young child to keep an eye on the patient.  After some bureaucratic confusion, the hospital wrote back that there were technical limitations keeping them from delivering warm meals for both parent and child.

I wrote back: How about just bringing the parents' sandwiches.

This week's response: Unfortunately, it is not possible to provide sandwiches for family members with the food transport cars to the wards.

There's more to the letter, but that's my favorite line. It makes me think they attempted a sandwich delivery in the past (using food carts) and it led to an awful 22-cart pile-up near the X-ray room that cost three nurses their lives, and another two with PTSD every time they see a sandwich. Alternately, I just see nurses doing pratfalls every time they're asked to carry a sandwich. Bear in mind, this is not a slam on nurses: Just nurses who work at this hospital.

So, there's that.

At least the insurance kicked into high gear and reimbursed us for the 60,000-euro bill within a week of Christina filing the claim. We're momentarily liquid ... until I get the bank to approve my transfer limit request so I can actually pay the bill. But until that happens, I feel ... well, not rich, but at least not broke.

Colin keeps making progress. They added music therapy to the mix today, which seems to have prompted a fainting spell. But, then again, lots of things prompt fainting spells. But the therapists are getting more hard core, kicking Christina out of the room and then working with Colin one-on-one. I keep getting videos of him eating potatoes au gratin or riding on a stationery bike or what-not, so they're definitely keeping him busy. We'll see them again on Saturday, when we try to see if we can help Colin with his Lego supply problem. We have no idea where the Legos that went missing last week have gone to, but we found a Batman and Joker head lying around the the house, so that's got to improve his collection a bit, right?

Otherwise, we keep at it. Oma has been here a week and, wow, our house is clean. I think she alphabetized our candy drawer. But we're getting along well and, if you ignore the drama this morning where Noah got a plastic pull cord stuck on his finger two minutes before he was supposed to go to school, all is going well. The kids are looking forward to only one more week of school before their winter break. I'm handling work. It's not going quite as smoothly as it did for me in 2016 when I returned after the initial diagnosis. Then, going to work really helped me take my mind off my problems. Now ... that's not working so much. But, it is better than some of the alternatives.

## Comments

The Legos fell down a wormhole and are at my house. My kids are all teenagers, and I'm still stepping on them.

*—Kathryn LaPointe, January 24, 2019*

My grandson Ryan has a cabinet with drawers for his Legos so that he can sort and classify all of the pieces ad infinitum. He can find a piece on the floor and give you the technical name before filing it away. He announced last year that he was over Legos...until I asked him in December what he wanted for Christmas. He said, there’s really nothing else he wants other than Legos....just make sure they are 3 in 1! Ryan goes to high school next year. In Texas, high school students must have an area of specialization, but Legos is not a choice. So Niels...I so get the Legos deal! By the way...regarding your back....physical therapy really works; however, I have a feeling that your calendar in currently more than full. Prayers and Love from Texas. Your Cousin, Barbara 8-)

*—Barbara Skipper, January 24, 2019*

Maybe there is some union anti-sandwich rule?

*—Chuck McCutcheon, January 24, 2019*

Major lol picturing that sandwich cart pile up! Oh, hospitals!

*—Jeremy Cook, January 24, 2019*

# tuning in

*January 27, 2019*

We drove out to see the Brandenburg division of the Sorrells family on Saturday. It was a good visit.

I can't say if it's the therapy or the lack of valproic acid or the slow recovery from the pneumonia (or a bit of everything), but each week when I see him it's like they've rolled a new child into Colin's room (though they all eerily look alike). He's so much more engaged than he was a few days ago. He picks up his Legos (the ones that weren't disappeared) and will work with them for ages.  He directs you where to sit and will both give you assignments and listen when you give him suggestions. Maybe my memory is foggy, but I don't remember him being anywhere near this level back in November, when he was full of anti-epileptic medicine.

I still find it very hard to understand him, but Christina says it takes practice.  We took him to the gym - a dream of Emma and Noah's - but he quickly decided that was too much for him. We then had coffee, where he tried to steal my cake.

You can tell he's still recovering.  He prefers to be in his bed or in his wheelchair.  But he can get around and walk if required to do so.  He's also eating so much better, so long as he has his trach blocked (and has someone next to him reminding him to slow down). It feels good to see recovery after the last few weeks.

And finally, another picture. Because I simply cannot ever see enough pictures of Colin in the ball pit.

## Comments

So glad there is wonderful news! May there be more soon!

*—Sofia Gueorgieva, January 27, 2019*

This warms my heart to read. Hugs!

*—Lynda Schmitz, January 27, 2019*

So glad to hear how he's progressing! Love the ball pit pics!

*—Marci Roth, January 27, 2019*

Love the pic! Progress is always good!

*—Barbara Skipper, January 27, 2019*

My mom wanted me to tell you that she lit a candle at church today for your family. Sending lots of thoughts and prayers your way!

*—Maddie Sheesley, January 27, 2019*

Great to see him in that ball pit!

*—Jeremy Cook, January 27, 2019*

This is great news and very hopeful. Love the ball pit picture!

*—Dan Wooldridge, January 28, 2019*

## our new team

*January 31, 2019*

Christina had a talk with the social worker at the rehab center this week. The upshot is that we're going to be eligible - and most likely getting - 24-hour nursing assistance for Colin when he returns home.  They've started the application process, but said it can take six to eight weeks until they have a team lined up.  So, I guess that's the timeframe we're looking at before he returns home.  I'm not happy that it means more time away. That said, Christina said he would probably benefit from another four weeks of the therapy.  It is doing a lot of good.

It's going to mean a lot of adjustment.  We might pull all the stuff out of my little home office and set up a tiny bedroom for him there so he and the nurse have a place to be at nights that's a little separate from the rest of us.  We have to figure out what this means regarding kindergarten and his other therapies and, really, every other aspect of our life.  It dawned on me: Will we be able to take vacations?  I know this isn't the hot issue right now, but, seriously, do we have to convoy with a van full of nurses now if we overnight anywhere.  If so, can we have the other kids ride in the van with them? (Hey, you have to ask)

Christina says he's gotten a cold and it can be dire with the tracheotomy. The mucus can get so thick he passes out because he's not getting air.  Further proof, I suppose, that we are going to need a nurse around for these kinds of problems in the near future.

## Comments

An acquaintance of mine whose daughter has 24-hour nursing has a nurse that comes to school with her and either travels with them on trips or stays at home with her. To accomplish the 24 hours...there are actually two nurses. In the US, Social Security Disability will pay for the nurses because it is less expensive and better for the patient to be at home rather than ongoing inpatient care. They take care of g tubes, Trach tubes, changing diapers, oxygen, injections, and medical emergencies (seizures in this case).

*—Barbara Skipper, January 31, 2019*

I can only imagine how comforting it will be to have a pro around to help and to answer questions once he comes home. I’m so glad to read this!

*—Kerri Kennedy, February 1, 2019*

Nice to see the birthday photos. Hugs.

*—Lynda Schmitz, February 10, 2019*

# down time

*February 8, 2019*

This morning, I noticed there were toothpaste stains all over my bath towel. I confronted the children. Both denied using my towel to wipe their mouths.

"Maybe Colin did it," one of them offered, helpfully.

Ignoring the fact that Colin hasn't been anywhere near the house for more than two months and I don't think he could reach this particular towel - both of which suggest my children think I'm pretty dumb - it was sort of good to see some things haven't changed at all. I mean, what good is a little brother if you can't blame everything on him?

So yes, we went off on our vacation and we returned in one piece. The final two hours of our drive there were harrowing thanks to a storm I had not realized was coming. But we made it and had about a foot of snow the whole time. The children, who had been wishing for snow since November, got tired of it after about 20 minutes, but this place has an indoor pool and playgrounds and special programs for the kids. We did a lot together. They did a lot by themselves. I dozed a whole lot.

It's not quite possible to thoroughly enjoy a vacation like that when you know your wife and youngest are stuck in a clinic. I'm not going to pretend I was morose the whole time (You get all the beer you can drink included in the price of the room. Come on!), but there was a thick vein of guilt through the whole vacation. It didn't help that Christina had several bad days in there. Colin's cold turned into a doozy, meaning he either missed a lot of therapy sessions or was in no mood for them when he did get there. Also, there was almost very nearly a glitch with Christina's paperwork that would have meant she would have had to use all her vacation time for the time she's been away from work since January 1, but they sorted that out today. So, to recap, I'm at a resort in Bavaria listening to my wife tell me how the therapy doesn't seem to be working. It's not a great way to feel good about oneself. And I shouldn't complain: I got to go to the resort.

We're talking about switching place for a few days, though it might not be for a few weeks. Given that Christina will have done about 95% of the hospital stays since this all started, it's hard to paint myself as Husband of the Year for being willing to take three or four nights in a few weeks, but we have a lot to juggle. There's also the real issue that Christina has by now learned how to handle a lot of Colin's basic care, while I know next to nothing. Also, I'm not proud of this, but I'm terrified of being with him. I mean, Colin is a delight, but I am beside myself with fear that something will get twisted or clogged up and I won't know what to do - or not even recognize it properly - and then game over. But we'll cross that bridge when we get there.

For now, the plan is to go up tomorrow to finally celebrate Colin's birthday. We stopped by on the way to and from vacation, but those were both rushed visits. Hopefully we'll have a little time together tomorrow. Even better, maybe neither of his siblings will boost some of his new toys amid the celebration. At least, if they do, they shouldn't be able to blame him for the heist.

## Five years and a week

*February 10, 2019*


LEGO
76069

We got out to the clinic yesterday to finally have a family celebration for Colin's 5th birthday. He'd already gotten a Batman/Superman/Lex Luthor Lego set on actual day (about his eighth Lego Batman, but who's counting?), but we still had plenty of gifts and Batman-themed cookies for this visit. He seemed to love everything he got and, aside from the usual stress of having so many children around so much medical equipment, everyone seemed to have a good time. As we sat down in the room for dinner that evening, it dawned on Christina that this was the first meal we'd had as a family since December 1, which was sobering.

He is becoming less like a patient and more like a child every day. This is, obviously, a good thing. But it brings with it its own set of difficulties. For most of December, he seemed barely aware of his surroundings.  For the first part of January, he was very attached to Christina and always happy to see me, but more in a "Oh, look who's here!" sense.  The last two visits he's really begun to put things together, and, when it comes time for me to head home, he quickly realizes that this is not only me leaving, and me taking Emma and Noah with me, but also the fact that he's not leaving the hospital.  He gets very upset and I worry now that he's going to have one of his fainting spells as I try to leave.  So, you can be glass-half-full about this and be happy that the father-son bond remains strong, but it makes the end of the visits just gut-wrenching.

Having Emma and Noah there presents its own set of problems. Ever since the Case of the Disappearing Legos, we've had to watch them like a hawk with Colin's toys. And, even though we have a metric ton of Lego back home, all they care about when we get to the hospital is Colin's new Legos.  Colin barely lets Christina touch his Legos, so you can imagine how upset he gets when his siblings start noodling around with them. There's a lot of drama.  And a lot of machines start pinging.  And then the kids act try to make it seem like it's funny, which makes it even worse.  I've strongly thought about trying to come out for a visit without the kids, just so there's less madness and so I can get some more time with Colin.  But then Christina wouldn't get to see the other two.  In short, there's no good solution.

Colin is still getting over the last of the cold. It's impossible to say if this was just a particularly bad cold or if all colds are now going to be this bad.  The cold means his speaking module remains blocked, which is frustrating for everyone.  And yet, despite his breathing passage being blocked, he manages to get food into his lungs if he's not careful eating.  It's maddening.  Worse, Christina and I are at such different levels of understanding about why things are being done to him.  She's there a whole lot more than I am and getting information straight from the doctors.  I get most of my information from her, and that's assuming we have 10 minutes where we're not on Lego Sentry Duty for us to talk.  So, I'm way behind on the learning curve and don't really understand the whys of a lot of what's going on.

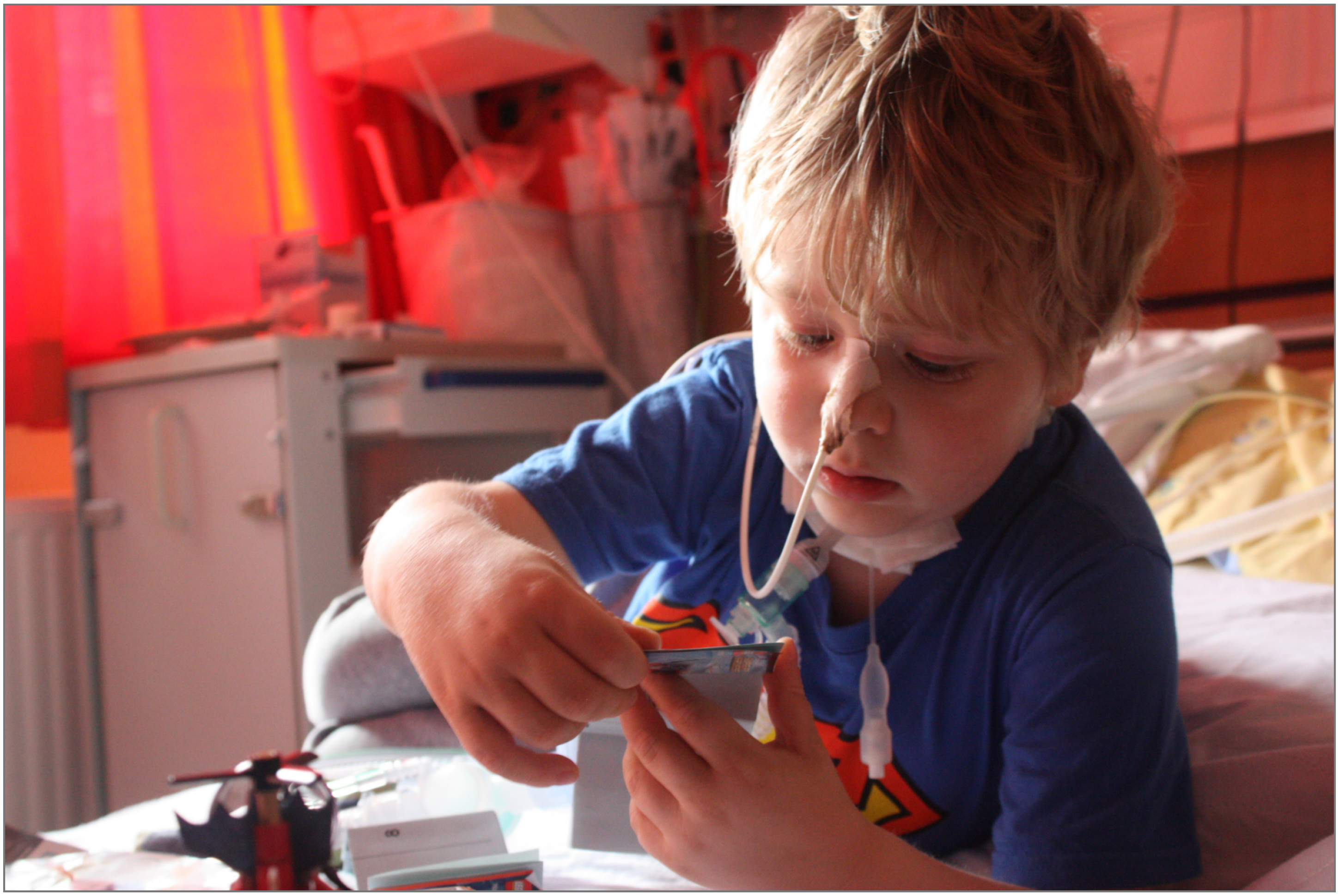
He continues to have the feeding tube because the doctors think he's not drinking enough water on his own.  But we're getting his levels up and are optimistic that will disappear soon. He also is supposed to wear the monitor on his toe so they can keep an eye on him as he recovers from the cold.  The oncologist had actually suggested getting rid of the monitor right before he got sick, so let's hope we're not hanging on that for too much longer.  And that just leaves the tracheotomy and the breathing machine, which he probably will not be hooked to full time, but we're going to need it nearby, all the time, just in case.

No word yet on when the nursing team will take up positions here at the house.  The process has already been on for two weeks, but we were warned it takes an average of 6-8 weeks to sort this out. Colin has begun enjoying therapy a little bit - and especially playing in the clinic's day care, so maybe as he gets better, he'll get more out of the sessions.  But I think we all agree that it's reaching the point where being home would do him a world of good, since we can do a lot of this therapy right here in our neighborhood.

As an added bonus, my niece, Rebekah, arrives on Thursday from Alabama.  She's going to stay with us for two months and help us keep an eye on Emma and Noah (and also Colin) so we can get through this process of adjusting to whatever the medical establishment throws at us.  The help will be appreciated and we're just so grateful she can carve this time out of her life to help us.

And, finally, my bank has sorted itself out and has now approved a temporary limit increase for online transfers, so tomorrow, I essentially liquidate my checking account and pay the giant bill from the intensive ward stay.  Mercifully, the money has already arrived from the insurance company.  Then, we get to wait and see what the bill from the rehab clinic is going to look like.  Yikes...

## Photos



## Comments

Happy birthday big cute boy! Hope things continue looking good!
Good to hear about the arrival of your niece and that some problems seem to be finding a good resolution - may this be the case for the rest as well! Take good care all of you

*—Sofia Gueorgieva, February 10, 2019*

Happy birthday, Colin!
He's really grown up since I last saw you all. Many greetings and take care.

*—Claudia Busch, February 10, 2019*

Wow, he is really growing! Were it not for the NG tube he looks like a perfectly normal five year old in these pictures. Hope he can go home soon.

*—Don Summers, February 10, 2019*

So great to see those pics!

*—Jeremy Cook, February 10, 2019*

Loved seeing the pictures! Hang in there!!

*—martha stanley, February 10, 2019*

Hope you’re home & starting a new routine soon. Legos & all!

*—Rich Mayer, February 10, 2019*

He's so darn cute, you all will get through this, one step at a time.

*—Jeanne Clayton, February 11, 2019*

## on and on

*February 11, 2019*

After the birthday party, the three of us got back to Berlin very late ... where we found the letter from the hospital announcing Colin's next MRI appointment.

I suppose there was some naive part of me that assumed, after the clean bill of health from the PET-CT scan in December, that we were done with MRIs.  Of course, that doesn't make a lick of sense. No matter how good the prognosis looks now that we are nearing the three-year mark of Colin's cancer, we still have to check these things. But, after a pretty nice day of birthday fun, it was just one of those reminders that this keeps going on and on and on.  The MRIs are necessary, but I hate them so.  There's a lot of fuss. There's a lot of waiting. There's listening to the doctors explain - again - how the sedation could be harmful by itself. There's always that tension waiting for the meeting with the doctor, hoping this isn't the time they say "We're sorry to tell you..."

Christina reported a challenging day on Sunday. Along with the package of him becoming more aware and acting like a 5-year-old is the reality that he hates all the wires attached to him.  I mean, who wouldn't?  Because, like all fine German medical institutions, this place insists Christina leave our child in the room by himself while she gets herself meals, she's taken to leaving him with toys or a tablet while she grabs food (hey, at least it's in the same building this time). Yesterday, he wouldn't let himself be put on oxygen when she left.  When she returned, he had freed himself from his wheelchair and was waiting for her in the hallway. Yes, it's great he can do all this stuff, but it remains nerve-wracking.

He also doesn't want the breathing machine at night. They attempted it last night, but found his lips quickly turned blue. I know we didn't want to believe the doctors back in December when they said he had nerve damage, but it has become impossible to escape the reality that he does.  To be clear: He can breathe and swallow and cough. The question is whether his body does all of these things automatically, especially when he's tired or distracted.  And it's looking like, when he's tired, his body might not trigger breathing at a healthy pace.  I don't know if this is a skill that can be taught. But it looks like he might need a long-term breathing machine, not to provide oxygen, but just to make sure he breathes.

As for me, the tearful farewell on Saturday involved a lot of picking him up. Bear in mind, it's been just a month or so since I could walk without pain and, having hefted this child, my back has been going "Hey, remember me?" ever since then.  I'm not in pain, I'm just very aware of my back right now. All I know is that, these three days of me and the kids by myself are going to be difficult, but at least, this time, I'm capable of walking without pain while juggling all of it.

We have the strangest conversations these days. It's odd how our thoughts keep turning to "How will we have a vacation like this?" which just seems like it shouldn't crack our Top 10 list of worries, but keeps on doing it. It's obvious Christina and I don't know whether to be relieved that we will probably have full-time health care (assistance!) or horrified that we have to have a full-time non-family presence in our home (lack of privacy!). Nothing about it feels quite right. Then again, we've gotten used to things not feeling quite right for a while.

## Comments

You officially have my permission to worry about whatever you want to.

*—Liisa Ecola, February 11, 2019*

Yes, you have permission to do whatever you think you need to do to keep your sanity within the insanity. Lol

*—Barbara Skipper, February 11, 2019*

## Dear Universe

*February 12, 2019*

We thought it was over the top when you decided Colin had to have a brain tumor, but we forced our way through it.

We even thought we'd beaten it, until a few months ago, until this business with the delayed reaction nerve damage caused by either the tumor, the treatment, or a combination of the two. But we're working our way through it.

You seemed to be overdoing it when, in the middle of all this, you decided my back had to go out as well. 'Why not have a simple catastrophic illness in the family when another member can have a debilitating one,; I'm sure you thought. 'It'll be a challenge,' I'm sure was your thinking.

And then, just to make sure we hadn't forgotten you, you made sure that Colin gets to recover to a degree from all this, but it requires a six week (and counting!) separation of Emma, Noah and I from Christina and Colin. Well played.

It probably did not escape your attention that, thanks to a ton of help from friends and family, I was keeping all the plates spinning and (just) keeping everyone getting to school and work and their various extracurricular activities while making regular runs to Christina and Colin, both to see them and to keep them in supplies.  It was quite a lot of work, in case you were curious.

And then, for Wednesday, February 13, the last day in which I had to juggle all these balls by myself for the conceivable future. The day before I get help from America to whack all these moles, the final day of this stage of the madness ... you let the teachers in the kids school go on strike? I'm going to choose to believe you see it as character-building to let my silly plans fall down around my ears, as I get to call in sick to a day of work that was already going to be abbreviated so I could rush home and make sure the kids aren't left alone too long before I drag Noah kicking and screaming away from the TV and to karate class, but, honestly, I was kind of OK with the plan.

In short, by my count, there are about 6 billion+ other people out there on this planet. Even assuming several billion of them have much worse lives than mine (it's not hard to picture), that still leaves you a solid 1-2 billion others to pester.  Respectfully, I submit that it's their turn.

Thanks. Peace out.

## Comments

I'm not sure I'd address the universe as "dear" with all of that. Wow.

*—Liisa Ecola, February 12, 2019*

Wow! I wouldn’t have seen that one coming! Thank goodness relief is on its way! I always say that we need the valleys in life to appreciate the peaks. But you didn’t have just a valley, you had a hurricane and earthquake and a tornado thrown in for “fun”. One good thing about Texas is that, by state law, teachers cannot strike. That seems almost unamerican, but it’s true. Hopefully, your reinforcements will be arriving soon and helping you and Christine see the light at the end of the tunnel (and it’s not a train). We pray for you and your family every day. Love you guys!

*—Barbara Skipper, February 12, 2019*

Co-sign.

*—Kathryn LaPointe, February 14, 2019*

# noses and hoses

*February 13, 2019*

We have a milestone today. Look: Our first picture of Colin without a nasal feeding tube in more than two months!

Now we just need a haircut for him.

The social worker wants to meet with Christina tomorrow, which makes us think she has an update on getting our health team together for Colin. Hopefully the update is that they have one, but we'll see.

He has moments where he does really well in therapy. He has moments where he all but says "Get me a restraining order against this therapist." He's 5. His mood is variable. But it still feels like positive progress. Christina reports he's spending more time without the breathing machine (because he hates it) but he's keeping his saturation rates up by himself. We also had another incident where he removed the breathing machine and his monitor and strolled out into the hallway when he was briefly left unsupervised. If anything, I think this will be an incentive for the rehab center to get him out of their facility ASAP, before he starts showing other kids how to pull a Houdini.

We survived the day of the school strike. Emma spent the day at a friend's house. I finally got Noah to a bike shop so we have a bicycle for him now that allows him to bike without kneeing himself in the face. And it's less than 24 hours until assistance arrives from the States.

## Comments

That is such a sweet picture of Colin. And....progress!

*—Barbara Skipper, February 13, 2019*

## Another plate spun

*February 14, 2019*

In today's mad dash, my niece showed up at 10:40 a.m., I was late to meet her and then work called around 1 p.m. begging me to come in because two people had called in sick.

So, I gave her the barest of breakdowns of how the house worked ("Don't feed Noah eggs" and "There are some rules about using the dishwasher, but I usually don't remember them.") and then left.

She assured me it would all be fine and, if all is well, they'll all be home asleep when I get back from this impromptu late shift. At the very least, Rebekah said Noah remembered her: When he saw her he said "Hello" and then "Do you still have that shark game on your phone?" Aww ... cousins.

Christina's meeting with the social worker was cancelled, so we don't know what they were going to tell her. But she did get to talk with the oncologist who says he sees no reason why we shouldn't let Colin spend as much time without the breathing machine as possible during the day (but probably keep him on it at night). Furthermore, he said he couldn't see why Colin couldn't go home at the end of February. Bear in mind, of course, that's just an opinion of what's medically viable. I don't think anyone is sending him anywhere before we have a medical team in place, so we have to focus on the organizational side of this before we get to the doctor's orders.

## Comments

Just discovered this and feel you'd appreciate :) https://www.mcsweeneys.net/articles/top-dinner-suggestions-according-to-a-three-year-olds-eating-habits

*—Maddie Sheesley, February 16, 2019*

Sounds like Colin is making slow progress despite all the setbacks that insert themselves into your lives. Stay strong and brave.
Remember my mantra: DIFFICULTIES ARE GIVEN TO US TO OVERCOME

Prayers, Phylles

*—Phylles Lagarde, February 17, 2019*

## hello and goodbye

*February 17, 2019*

For anyone wondering, Rebekah is still alive after surviving the lightning round of Sorrells Madness, Berlin edition. Her family comes with its own share of medical adventures, so she's taken it with a fair bit of aplomb (and a healthy dose of jet lag), but I'm hoping things can calm down now, after I essentially left her alone with the kids for 72 hours after her arrival in Germany. As near as I can tell, she's only made one rookie mistake: She's allowed them to watch episodes of this superhero show called "Young Justice," so now they're going to her with half of the superhero questions. Given that I've spent the last week mulling the answer to "If someone shoots a normal speed video of someone moving at superspeed, what speed does the Flash see it at?" I can assure you all that, that way lies madness.

But it means I'm getting fewer superhero questions for a while, so I'm happy with that.

We had our weekly visit to the clinic and he continues to amaze me.  He's up and about a whole lot more.  He's even venturing outside from time to time.  He's doing much better with his swallowing and, generally, just acting like a little boy.

His cognitive skills are also up, which is both wonderful and terrible.  When we went outside, he found our car and came close to threatening a sit-in until we let him get inside so we could take him home. We only lured him inside with the promise of playing on the tablet.  Then, when it became clear the kids and I were getting ready to leave, he began to start packing his Legos in his wheelchair (he can walk, but it's good to have the chair around), because he figured he was not going to miss this train out of Brandenburg. It took a lot of convincing, and a bear hug from Christina, to keep him from following us out the door. On the one hand, it's great, because I don't think he would have made the connection between "it's time to leave" and "I'll pack up my Legos" a few weeks ago.  On the other hand, it's torture watching him get upset as he realizes he's not leaving.

The general consensus seems to be developing that he's ready to leave the facility. We just have to make sure that we've got his support network in place at home before he goes.

In further bright notes: More than a week since his last panic attack!

As for me, I had my first physical therapy on Friday. I expected to have to do a lot of exercises and yoga and was happily surprised when I discovered it was mostly massage. I can get behind that.

## Comments

Wow! What a difference a week makes! Continued prayers!

*—Barbara Skipper, February 17, 2019*

So good to get this update, and knew Rebekah could "control" the Berlin Sorrells well!! Praying for the family reunion of Berlin Sorrells soon!!!

*—martha stanley, February 17, 2019*

First upbeat message for a long time - hope this trend keeps up! Take very good care, all of you

*—Sofia Gueorgieva, February 17, 2019*

I am especially delighted that he made the connection and started packing up his legos. It will be a joy when he can pack them up on the day he can come home. He will be so happy!!

So happy he is showing such important gains. □□

*—Cynthia Meyersburg, February 17, 2019*

Wow, a week since the last panic attack. That is wonderful!

*—Jeremy Cook, February 19, 2019*

I am picturing him packing up and enjoying the bittersweet loveliness of all that implies! I hope the reunion at home soon follows.

*—Kerri Kennedy, February 20, 2019*

## ever so slowly homeward bound

*February 22, 2019*

We're going to meet our first team of caregivers on Monday to see if we all think we can work together with Colin. I say "first," but they're also the only team Christina has contacted that has any availability. Speaking to various insurers and social workers, Christina has alternately been told to shop around until you find the right one and to take the first one you find, because you never know if there will be another. Here's hoping we don't despise each other at first contact.

There's still no definitive word on Colin's departure. It's more of a gut feeling that the doctors think he's OK to go. The nurses are certainly getting taxed by him.  Gone are the days when he would lie in bed waiting for people to look after him.  If he think he's been left alone too long (if Christina takes 10 minutes to get coffee, for example), he'll head out the door and start wandering the halls of the clinic to look for her, unplugging himself from the breathing machine if necessary.  It all sounds very cute, if you ignore the potential health ramifications of a 5-year-old manning a breathing machine.

But I think we're all ready for this to happen.  Heaven knows, we somehow managed to send Noah out the door without a note he needs on the same day Emma left the house too late for a field trip, so we clearly need Christina around to establish some order again. And the school is set to strike for two days next week.

I also went to the day care center's meeting for parents and had a good talk with everyone there.  They're all hoping they can get Colin back, but there are a lot of medical questions to sort out first, like so much else in our lives.

## Comments

Bon courage!!! It's a good development

*—Sofia Gueorgieva, February 22, 2019*

Hang in there, you are getting there, one step at a time.

*—Jeanne Clayton, February 22, 2019*

Good luck with the transition! I think it's wonderful that Colin is (nearly) ready to come back home. Hoping and praying for good outcomes and a return to both parents and kids living under the same roof again.

*—Dan Wooldridge, February 24, 2019*

## the long haul

*February 26, 2019*

There comes a point, where you're sitting in a physical rehab facility, meeting with the administrators of a care team helping you plan your son's long-term rehab plan, and you notice that Amy Winehouse's "Rehab" is playing on the radio, and you just want to pull the writer aside and say "This is too meta."

But, there we were. And, after waiting a beat to make sure that this wasn't the moment where I learned that I was just in a twisted version of "The Truman Show," on we went with the meeting.

We spent nearly two hours talking to them.  They seem very nice.  Of course, the big test will be whether we get along with the team of nurses they put together for us.  It sounds like a very tough balancing act for all sides.  This team will be in our home for 24 hours a day, watching Colin, but trying not to get too involved in our lives.  The nurse will take meals separately and not be expected to help out around the house with chores.  It will be strange. I assume we are allowed to make eye contact.  And it's not as if I can imagine that we'd just actively exclude this person from day-to-day activities.

It will not go quickly. I love my to-do list.  Terrifyingly, I spend more time with it on my iPhone than I do with actual fun apps. But this is one daunting to-do list.  They have to put together a team.  We have to make sure we can all get along.  We have to make sure the house is outfitted with a breathing machine and a monitor and suction devices (to name a few things) and the room has to be cleared out for Colin. The doctors have to sign off on all this. I don't know how long it will last before we're set up.  The nursing team also thinks they'll be happier taking over the guest room upstairs than the office downstairs. The office was admittedly small, but this means that the nursing care will take place right in the middle of the more private part of the household.  And then we have to see how it works in practice.

He continues to make progress. After walking all through the complex on Sunday, he proceeded to sleep 12 hours (Christina was so happy) and then participate fully in three different therapy sessions. It's good.

The only bonus of seeing him so rarely is that I get a rock star's reception every time I show up.  It's all bear hugs from Colin, followed by a moment where you can see he's thinking about turning to Christina and saying "I know you've waited hand and foot on me for the last three months, but Daddy is here now and we have some guy stuff to do, so you can take five." But he knows which side his bread is buttered on, so he doesn't go that far.

# car trouble

*February 28, 2019*

So, today was going to be a nice day. At least as nice as our days go. I was off work, so I was going to drive out to Brandenburg to spend the day with Colin and Christina. As a bonus, they're having a Carnival party at the clinic, so Colin and I were going to go as a Green Lantern/Superman duo. The pictures would have been wonderful.

I left early. I only wanted to stop at the dump to get rid of a bunch of things accumulating in our laundry room. That went fine. I left the facility, turned right into the street ....

and crashed the car.

Yeah, because I don't have enough on my plate.

I have no idea what happened. I would not have turned into the street had I seen traffic veering at me, but clearly there was a car there somewhere. All I know is that I got into the lane, there was a crash, and suddenly my front fender and bumper were hanging off the right side of the car. It took forever. The fire company was there. The police claimed they were there right away, but they weren't, so we had to wait about an hour for the second car to come. While we waited, other people leaving the dump ran over both our warning triangles, so that livened things up. The other people, after the initial shock, were super nice and came over once or twice to make sure I wasn't about to pass out, which was good, because the fire department guys showed no interest in me whatsoever. Fun coincidence: The two women in the car were picking up the guy, who was just out of the hospital, while I was on my way to a hospital. We bonded over that.

The police eventually came and said the burden will probably fall on me, as I was the one entering traffic. I questioned that and they said nothing has been decided yet. I honestly have no idea what happened, but have many questions. I know some of my regular readers are employed in the German legal world. I will happily take any advice you have. The goal is not to get out of anything that is legitimately my fault. I just want to know how to make this go away as quickly as possible with as little fuss because, seriously, I just don't need extra paperwork or expenses in my life right now.

Speaking of extra expense, the care team we met with on Monday drafted a proposal that says we would have to pay 3,000 euros out of pocket a month for their work. Everyone at the clinic says that is insane and they've never heard of anyone having to pay anywhere near those kinds of sums. The team has not responded. But a second one has come out of the woodwork and said they might be able to work for us after all, so perhaps they can put together a proposal that won't bankrupt us.  Suffice to say, this is already causing us plenty of stress before we have to figure out how to sort through the car insurance paperwork, figure out if our car is salvageable and organize a rental car for the duration, to say nothing of rearranging the upstairs in advance of Colin's eventual return.

Until the next disaster....

## Comments

The VERY LAST thing you needed. I am so sorry! Hopefully it can get resolved quickly, and very glad you weren't seriously hurt. Hang in there.

*—Marci Roth, February 28, 2019*

Ay-ay-ay! So sorry to hear this happened. You are right, you did not need this extra hassle. Now that it has happened, hope you deal with it as lightly and easily as possible!!! And with everything else too!

*—Sofia Gueorgieva, February 28, 2019*

So you're not injured, right? At least that is something to be grateful for. But certainly an enormous hassle. So sorry to hear it.

*—Liisa Ecola, February 28, 2019*

No one had any obvious injuries. Now we wait to see if anyone develops whiplash, I suppose.

*—Niels Sorrells, February 28, 2019*

Oh, man that SUCKS and a half.

*—Kathryn LaPointe, February 28, 2019*

I would say this warrants a “piling on” penalty”! Glad you are ok. Sad you missed the event with Colin and gained another annoyance.

*—Barbara Skipper, February 28, 2019*

## escape plan

*March 2, 2019*

I would be lying if I said I understood it all, but the first caregiver company now says that the 3,000-euro-a-month payment would be covered via the insurance. They seem to present this as the most obvious thing in the world and also seem uninterested in talking with us about why they presented this as out-of-pocket expenses. Regardless, we have that promise down on paper and the second team never returned Christina's calls, so it looks like we've got a caregiver team.

Even better, they seem to think they can get us up and running at home by March 13 or 14, which means Colin would be a short-timer at the clinic.

It's obviously very exciting, but I'm not quite circling the day in red on my calendar yet. These medical dates have a way of being pushed backwards and who knows what all else could go wrong in the process? But at least there's a light at the end of the tunnel.

In other positive developments, he's begun having some meals while his tracheotomy is unblocked, meaning that it's his personal control of his body that keeps him from aspirating food, as opposed to him being physically blocked from aspirating.  It seems that every now and then a crumb goes down the wrong way, but he manages to cough it back up.  So, maybe his coughing reflex wasn't as badly damaged as the doctors led us to believe.  Tim will tell.

Regardless, he'll probably have the trach for a long time yet.  At least until he's old enough so we can explain to him why it's important for him to eat slowly and think carefully about how he's swallowing.

I had a rough Thursday as my body processed all the adrenalin and the prospect of extra paperwork. But my neighbor Markus took me over to his house for a few beers, so that helped. And then I got my nerve together and picked up a loaner car from our car assistance service and drove it home. It's been ages since I was so nervous about driving a car, but I got it home in one piece, so maybe I have that fear behind me now.

As for all the paperwork, the good news is that we're good Germans and have about 82 different kinds of insurance, including one that pays for us to hire a lawyer to deal with all the other insurance companies. It's a little Kafkaesque, but if it keeps me free of the paperwork, I'm fine with it.  I meet with him on Tuesday.  I remain convinced that the accident wasn't all my fault.  I simply don't see how the cars sustained the damage they did if I was where the other driver said I was.  But a friend of mine who is a cop said that, basically, since I was pulling from a driveway into a street, I'm the one who will get the blame.

By means of perspective, my cop friend was a guy I met at this family rehab we did in 2017. They were there for his son, who was recovering from leukemia. But his wife was also a breast cancer survivor.  And now her cancer has returned and they're basically counting the days she has left.  That's the thing about cancer that hurts the most, I suppose: Someone always has it worse than you.

## Comments

It is always good to have a light at the end of the tunnel when you have every reason to know it is not a train! Hang in there. Glad the money issue resolved itself. Continued love and prayers.

*—Barbara Skipper, March 2, 2019*

# another day, another disaster

*March 9, 2019*

I really need to start reading other blogs on this site to find out how other people fare with these life-threatening situations. I'm sure they're all full of the fears and worries and terrors of these diseases. But I wonder if another price of admission to this club is a never-ending series of minor disasters that leave you with little choice but to think the world is out to get you. The kind of days where the best thing you can say about them is "Well, at least I didn't get any blood on my new shoes."

To sum up: I took the family swimming and ended up with a seven-hour hospital adventure where I got my nose repositioned, Noah was not diagnosed with a concussion and our rescuers nearly ended up being hospitalized.

You see, there's this indoor waterpark about an hour outside of Berlin.  It's very nice. The kids have been asking to go there for months now.  Yesterday was a holiday in Berlin, but not in the surrounding state, so I thought there was a chance it would not be ridiculously overcrowded (that was wrong, but that's not relevant).

We drove an hour to get there.  We waited an hour in the line.  We got in and splashed around for 20 minutes.  Then Noah and I went down the water slide in one of their tubes.  At the last curve, we got turned around so we were facing backwards and, when the tube made impact with the water, Noah's head snapped backward and got me right between the eyes.

So, I knew right away that wasn't good, because of all the pain.  I was quickly aware that my nose was bleeding.  It was only when I noticed other people in the pool pointing at me in fear that it dawned on me that I might be bleeding a bit more than I thought.

I made it to the lifeguard.  She handed me wad after wad of paper towels and put a bandage on the gash.  We managed to stop the bleeding.  Both the lifeguard and Rebekah told me the nose really didn't look good.  Emma helpfully said it looked "like this" as she made an S-shape pattern in the air with her finger.  We had lost track of Noah in all this, but when we showed up, saw he had some slight abrasion on the back of his head.  He also complained of some minor pain.  Rebekah was all "
Go to first aid."  The lifeguard said it was my decision if I wanted to stick around in the pool, but noted that the nearest hospital was a 15-minute drive away.  Noah was, of course, not eager to leave the pool.

I decided Noah and I would go.  There was no first aid station in the pool, which is kind of surprising, so we headed to the car, since no one in the pool had suggested they might call an ambulance for us. On the way to the car, I called Christina, who told me I was not to driver under any circumstances, so I finally called an ambulance.  The drivers got us to the hospital, during which time we a) all agreed I probably shouldn't have driven and b) learned that ambulance crews show up at this pool somewhat regularly for this kind of accident.

I got both Noah and myself admitted.  They had me to an ear, nose, throat doctor pretty quickly.  It was a bit complicated, as he was working without a nurse, which is why I get to research getting blood out of clothing today, and he was not a native German speaker.  Since I'm not either, there were a lot of words neither of us knew, so we stumbled a bit.  Anyways, I got painkillers, a ton of gauze up my nostril and then he repositioned the nose, since it was only dislocated, not broken.  The deal then was that I had to sit for half an hour and, if it didn't start bleeding again, I wouldn't get admitted for the night.

Well, the half hour passed, during which time I realized neither Noah or i had eaten since breakfast.  I couldn't leave, so I sent him to the cafeteria, but he said he was suspicious of all their food and only came back with some gummis.  When the doctor saw me again, he pulled everything out and then hit me with the suction tube.  I've seen Colin get suctioned regularly since he got the trach and am learning how to perform that on him myself.  Having had someone suction my nostril, I have a world of empathy now for Colin about how that must feel.  Anyways, the suction pulled out a blood clot, which started a new geyser of blood.  I got a bunch of new gauze and was told that we would wait 15 minutes again before making another decision about whether I was going to stay overnight.  I didn't think this was fair, as it hadn't been bleeding until he started poking around, but I was at a disadvantage.

Fifteen minutes passed, he pulled out the gauze.  Some bleeding resumed, but it was only a small wound inside the nostril, so he said he could shut that down by cauterizing the wound.  Yes, I've had the inside of my nostril cauterized and that's a sentence i never saw myself writing.  Noah refused to leave the room while they were doing this, so heaven knows what lifelong fears he's going to have of rhinoplasty in the future.

During all this, Rebekah and Emma are still at the pool. They had fun for the first six hour or so, but there comes a time when every amusement park gets old.  But they couldn't leave because a) I had the money and b) when we changed for the pool, Emma's boots ended up with my stuff, which was now in the car.  They eventually retreated to the lobby, where some grouchy attendant periodically reminded them that they would have to pay before they left, while offering them precisely no water or assistance.

Meanwhile, I had placed an emergency call to my friend Stephan, who binned his Saturday plans to come out and rescue us.  His son also had a strange infection on his thumb, so he figured he would have a doctor look at it while he was headed to the hospital anyways.  So, Stephan and I met with the boys in the waiting room so a doctor could cast one look at Noah to make sure he had no concussion and to see what was going on with Stephan's boy.  Of course it took hours and, by the time they got to Stephan's son, the infection had gotten worse and there was talk of keeping the boy overnight, which would have complicated the plans to drive us home.

By this point, it was 9 p.m.  We'd gotten to the pool at noon and to the hospital at 2 p.m.  My ride home was not preoccupied and no one thought I should be driving anyone anywhere.  We got a cab back to the pool and rescued Emma and Rebekah.  Meanwhile, Stephan and his wife worked the phones and got an entirely different friend to rearrange her Saturday night and drive the hours out to Fuerstenwalde to save us.

This might have been my dumbest day ever.

Meanwhile, Christina and Colin sit tight in the clinic.  The rough plan is for us to bring all their stuff back on Wednesday, while the care team sets up their equipment here.  Then he comes home Thursday.  Apparently the forms have been signed, which is impressive, seeing as how all the doctors at the rehab center have either retired or gone home sick in the last few weeks.

In general, Colin is doing great.  His cognition is through the roof and he is very active.  He has a slight cold right now, which is always worrying when you're dealing with someone who so recently had pneumonia, especially one at risk of swallowing too much mucus into his lungs, but he's being treated.  We are back to the problem with him eating though.  He generally eats fine.  But, every day or so, he'll get some crumbs down into his lungs.  He coughs them back up, which we thought was good.  And, bear in mind, this is what the doctors and therapists had been telling us to do.

Then, about a week ago, a few people at the clinic started randomly talking to Christina about how this might not be a good thing, since there's no way to tell if he's getting all the crumbs back up, which could make him at risk for another round of pneumonia.  So, the specter of him being taken off solid food is back in the room.  That's upsetting all by itself.  I'm almost more upset by the "by the way" nature of the way this information was conveyed to Christina.  I think medical professionals should speak among themselves and present a plan to the parents.  I don't like them just sharing stray, off-the-fly thoughts.  But I think the problem here is that Christina is usually so calm and collected and competent that the doctors there just sometimes forget she's a mother on the edge who will have a breakdown if enough people casually suggest to her that her son might have to go back on a feeding tube.

We'll have to see.

We also did have a chance to meet with the leader of our health care team.  She seemed nice and made lots of good points and noted that there were some things that should be done for Colin daily that aren't being done right now, probably because the clinic nurses have too much to do.  It will be weird having the team in the house, but I'm almost getting the impression Colin will get better care at home if he has one person doing nothing but caring for him.

I'm going to go and spend the rest of the weekend trying to remember to breathe with all this going on.  I don't know what I did in a former life, but to have this hit me during allergy season means it must have been something awful.  I also have to get the rental car back tomorrow.  Thank goodness I spent 120 euros to keep it for two extra days so I could leave it parked an hour from my home.

## Comments

WOW! This might be your most entertaining post yet. Maybe you could write a movie script..? Glad that everyone's ok and things are moving forward. Happy to come over if you need an extra pair of hands □□

*—Maddie Sheesley, March 9, 2019*

This sounds too adventurous - the reason I seldom go to water parks or down water slides. Hope all healing is quick and uneventful!

*—Sofia Gueorgieva, March 9, 2019*

Sorrell's rescue team no. 1 (my son and I) is almost ready again to pick up the rental car with you in the next few days. But we have to go back to the emergency service to fix or renew the bandage on the finger, which magically loosened overnight. Thanks to the cookies (Oreo!) we brought with us, we all didn't starve yesterday. And above all it was nice not to be alone in such moments, even if the attempt to help you didn't work out perfectly. I am not a believer, but since yesterday at the latest I pray even harder for you...

*—Stephan Roch, March 9, 2019*

Definitions of resilience
1 : the capability of a strained body to recover its size and shape after deformation caused especially by compressive stress
2 : an ability to recover from or adjust easily to misfortune or change
3: Christina and Niels (and Colin and Noah and Emma)

*—Michelle Lee, March 9, 2019*

"Life isn't about waiting for the storm to pass... It's about learning to dance in the rain"

*—Stephan Roch, March 9, 2019*

Man, Hollywood couldn't make this stuff up. Crazy! So sorry, Niels. Keep breathing!

*—Jeremy Cook, March 11, 2019*

When Martin was in the hospital/still so ill af home with me inexpertly nursing him, I managed to drop my keys (including an expensive condo gate key) down a sewer and leave our iPad in a cab (never to be seen again). And then someone rammed our parked car overnight and didn’t leave a note. All of which is to say that when the fickle finger of fate finds you, sometimes it does seem to just linger there and say, “Let’s see what they do if I make this happen to them now.” I’d say you’re more than due for some fresh luck! Keep the faith....

*—Kerri Kennedy, March 11, 2019*

# Hurdles and hopes

*March 10, 2019*

I thought I should write a bit about Colin, seeing as how this is his blog. There is no denying that he has the more serious events going on in his life these days ... but my, it has been easy to get distracted by our never-ending disasters back here on the home front.

So, he has a cold.  It does really seem to be just a cold.  Unfortunately, when you're fresh off pneumonia and have a trach, there is no such thing as "just a cold."  It doesn't seem to be as awful as the one he had a month ago, but there is still enough mucus to keep everyone there busy.  He had a fever and the start of an ear infection last night, but they loaded him up with antibiotics and he seemed much better this morning.  Here's hoping it fades quickly, because I can't see the clinic releasing him if he's in the midst of a disease that's affecting his breathing so severely.

Our other hurdle is the aspiration issue.  We remain confused by this, as the doctors encouraged us to start feeding him solid food.  And for six weeks, Christina did, reporting each time she found a crumb or so in his tube that he had coughed back up out of his lungs.  And now, as of a week ago, they have declared this a problem.  And it makes sense: No food should be getting in the lungs.  We just can't figure out why they were so nonchalant about his for a month and a half and then, just as we were getting ready to take him home, decided it's a serious problem.  They're going to do some more tests and X-rays in the next few days, but there is the possibility that we might have to consider a feeding tube if we don't think we can feed him safely.  Because if any food remains in his lungs, it's a pneumonia danger.  And if we go that route, I can't imagine he'll get out of the hospital quite so quickly.

But let's all cross our fingers and hope it doesn't come to that.  The plan remains: Tuesday, they deliver his equipment to the house (apparently I will learn how to use an oxygen concentrating machine to fill oxygen bottles: For those of you who follow this blog solely to see what disaster will befall us next, I would recommend tuning in this day); Wednesday, my friend Jens and I will head up to clear the bulk of their stuff back to Berlin; and then, on Thursday, cross our fingers, he'll be home.

But that's the ideal plan.  I want it so badly, but I'm not going to believe it until they're both here.

Meanwhile, back at the home front, we've gone 48 hours without a major incident.

We're very excited about that.  My painkillers remain my friend and I managed to return the rental car without major incident.  Tomorrow I see a doctor to find out if I should even go back to work with all this going on in my face, and somewhere in there I'll find time to get Colin's room ready for him.

Pray for Thursday, everyone.

## Comments

Praying for Thursday!

*—Marci Roth, March 10, 2019*

It's marked on my calendar!

*—Jeremy Cook, March 11, 2019*

Sending so, so many healing thoughts and good wishes.

*—Kerri Kennedy, March 11, 2019*

Prayers!

*—Barbara Skipper, March 13, 2019*

# a step backwards

*March 11, 2019*

Well, it doesn't look like Thursday is going to happen.

We finally managed to get Christina, the oncologist and the speech therapist in the same room. I couldn't be there because I was trying to get a doctor to look at my nose here in Berlin, but I listened in.

It was a strange call. From my recollection, it started off with the doctors talking about how Colin's doing pretty well with the eating and how we might want to keep at it in the hopes he gets it right, without any aspiration.  But then Christina asked a series of questions which, to my mind, seem to be things that the doctors should have though of themselves.  Like, aren't we running a risk of major lung infection? And what about all these studies showing it's not safe to eat with a blocked trach?  So, in the middle of it, they did a 180 and now the most likely plan is that Colin is going to get a feeding tube into his stomach so we can keep him nourished while minimizing the chances of aspiration.

No, we're not happy with this development. About the only way I can console myself is that we're a week from the three-year anniversary of his diagnosis.  Back then, I didn't think Colin would live to see the summer of 2016.  If we now have to embark on a world where he can't eat regularly it's miserable, but it's not death.  It will be hell to make him understand why he cant eat.  It will be a nightmare feeding ourselves and the other two kids without making things worse for Colin.  It's one more surgery coming just months after a point when we really, kind of started hoping that we might have a normal life ahead of us.

It also means he's in rehab for at least another week, and that's devastating for us all, Christina especially.  It also raises fears that we won't be able to hold on to our care service if we ask them to wait another week before starting their duties.

The bright side, such as it is, is that this is not necessarily a life sentence.  There is still hope that he can learn to eat normally. From this perspective, the problem is that Colin, when hungry, starts wolfing down his food so quickly that some goes down into his lungs because his impaired nerves can't switch back and forth between eating and breathing quickly enough.  The thinking then is that, if he gets a certain percentage of his calories directly into his stomach via the feeding tube, he won't be as ravenous at meal time and might slow down.  Then he might be able to think about chewing and swallowing and maybe his body will train itself so that, after a while, everything will automatically go in the right direction.

But that theory only works if a lot of things go right, and I can't help but think there's some hopeful thinking involved.  The fact remains, Colin's situation is pretty unique and, no matter how confident the doctors sound, they are making a lot of educated guesses. What if, as Christina wonders, the larynx isn't closing properly at all and saliva is seeping into his lungs?  What if the training of the swallowing process doesn't work and, as the speech therapist says, he becomes prone to acid reflux, which could theoretically end up in the lungs and cause serious problems?

There's too many ifs.  I still believe there's a solution to all the problems, though it's hard to think about what quality of life Colin is going to have to keep everything working.  I never marked Thursday in red, because I've grown too used to disappointment, but I had really allowed myself to hope, just this once, that things might work the way they wanted.

But that's not life with cancer. So, one we go to the next step.  There's an X-ray today and a swallowing study tomorrow that will give us a better idea of our options.  Who knows?  Maybe we'll even get good news.

## Comments

Oh, I know you must be so disappointed . But your wife sounds amazing in asking all these questions to get the doctors to come up with the best possible plan for him. You're overdue for some good news, I hope it comes soon. Hugs to you all, especially Colin.

*—Marci Roth, March 11, 2019*

You guys are amazing parents!

*—Jeremy Cook, March 11, 2019*

Good that the doctors were facing different 'what if' questions- the sooner, the better. After this meeting, they will certainly make sure that everything possible will be done to prepare things right and to avoid any complications at home.

*—Claudia Busch, March 11, 2019*

You are an amazing team! Keep going, one day, one week at a time!

*—Jeanne Clayton, March 11, 2019*

I can only reiterate the previous suggestion - one day at a time! And keep all the positive energy in the forefront! You're doing great.

*—Marc Galmoud, March 12, 2019*

# backtracking

*March 12, 2019*

This feels too much like March 2016 or December 2018 for my taste.

All the old fears are back.  We're scared. We're mystified.  My stomach is offline. Christina finds ways to hold it together when she's with Colin, but says she's essentially on the edge of a breakdown every time she's away from him (*though - adding this in after the fact - just as I was about to send this, she called and we had a decent conversation where we weren't both in tears. She's the strong one in our relationship, so if she can keep it together, I usually can too)*. So much of the optimism we've built up during these months of therapy has just evaporated. We feel like we're back to square one. And there are people trying to shove maps in our hands showing us which way to go forward, but we're too scared to look.

So, the X-ray yesterday confirmed that Colin once again has a minor lung infection, almost definitely brought on by inhaling food. It's not as bad as the pneumonia that landed him in the hospital initially, but it's still worrying.  It also raises questions about whether or not he had pneumonia in February, also possibly brought on by aspiration.

It strengthens the doctor's argument that he should get the stomach feeding tube. We'll know more about what decision to make after they perform another chewing/swallowing analysis today. But we're hung up on the fact that the therapists want him to keep on eating orally even after he gets the tube, because the long-term goal is that he does eat normally again.  And that sounds very nice, but dare we give him food orally if every bite puts him at risk of another bout of pneumonia?  The therapists seem very much "He'll figure it out," but the fact is that he's 5, and he's a 5-year-old who was, until very recently, on some pretty heavy drugs that suppressed a lot of his cognitive abilities. There are all kinds of programs out there that help people learn to swallow and what-not, but you have to be able to sit and follow them and we both have our reservations that Colin is able to participate all that much at this stage in his life.  In 2-3 years, almost definitely.  Today?  We're not so sure.

Of course, then the therapist - who we're going to say ranks low on the scale of medical professionals with good besdside manners - fires back that, if he's not eating regularly, he's at risk of developing acid reflux, and if that gets in his lungs we're about to enter a whole new world of hurt.  Christina is left thinking: No matter what I do, I'm going to screw this child up.  And she's in tears and I'm stuck at home dealing with my nose and the children and the car and it's just miserable.

That said, I just did some research and see that, yes, acid reflux is a danger, but hardly a given.  Also, it's treatable.

So, just like in December in the hospital, we're questioning any advice we're being given and we're losing faith in the doctors.  This is all against the backdrop of some bureaucratic infighting at the hospital that seems to be drawing a lot of the staff's energy and causing a wave of resignations.  It's bad enough that it has been reported on in the local newspapers and they've hung signs up about not continuing any therapy after a certain point.  Christina has also been told that they're not taking any more patients.  So, you begin to ask yourself: Are they really looking after his best interests, or are they trying to shove him out the door because they don't have the manpower to deal with him?  I grow tired of not being able to trust the people who are supposed to be helping Colin.

Christina texted last night that they expect 2-3 more weeks in the facility.  I forgot to ask if that's 2-3 weeks from now, or 2-3 weeks from when the feeding tube is laid.  Either way, it's another blow to morale.  The only silver lining there is that I had not promised the children Colin's return this week.

In about our only glimmer of good news, the insurance company has agreed to pay to get our car fixed. I'm not attached to this car and would gladly take a new vehicle, but I don't have the time or energy to go on a car hunt right now, so it's nice not to have to worry about that.

## running to stand still

*March 14, 2019*

It's hard to get a bead on how I feel these days. It's this unlikely combination of optimism about the future, while also feeling like the rug has been swept out from under us. It's wanting to know the future, but simultaneously being scared of it.  We're probably in a better state than we were earlier in the week, but things are still bumpy.

On the one hand, when Colin went into the rehab facility on Dec. 27, he was on a breathing machine and an oxygenation monitor and getting fed through a nasal feeding tube.  He spent the next three months making visible progress, losing all of his monitors and tubes on the way (at least during the day time), and we were at the stage just a week ago where we were truly certain he was going to get out of the clinic today.

And today, he's back on a breathing machine, hooked up to an oxygen monitor and getting his food through a nasal tube.  I spent the day at the clinic with him and Christina. When I showed up around 10 a.m., the plan was announced that he would get the stomach feeding tube at 9 a.m. Friday.  Three hours later, that became Tuesday ... and we'll have to call on Monday to make sure that doesn't change.  So, once again the timetable slips and we wonder when we'll ever get him home.

It's very hard knowing what to think.  On the one hand, the doctors aren't cruel.  They wouldn't be setting us up with the feeding tube - which will give us the room to breathe to help him train on his chewing and coughing - and a care team and sending us home if they thought he was a terminal case.  But as Christina points out, it feels like we're taking a piece away from him at a time.  He needs a machine to breathe.  Now he can't eat.  And he can't speak because the trach is blocked most of the time, out of concerns that mucus will run into his lungs.  We don't know how soon - if ever - any of these situations will be rectified.  And the whole time, there's the thought hanging in the back of my mind from this conversation with the doctor where he said they couldn't rule out that the condition is degenerative.  It's hard to feel optimistic when this is the hand you've been dealt.

You wonder.  As far as we knew, he was chewing normally all the way through November.  Why does food now end up in his airways?  Is that a sign of degeneration?  Did we just not notice it (silent aspiration, it's called).  Or is the situation stacked against him in the facility?  He's tired because he wakes up in the middle of the night and won't go back to sleep because he's alone in a hospital room.  He has the trach in his throat, which protects him, but also changes the contours of his anatomy.  Now he's got the nasal feeding tube again?  How can one swallow properly with all that going on?  As one of the therapists noted, he's here to learn to cough, but how can you learn to cough when you've got a trach down your throat and it's blocked half of the time?

I've got so many questions about the swallowing.  Part of my confusion stems from the fact that Christina gets the bulk of the information from the staff, but when we see each other, we're usually herding children, so she doesn't have the chance to pass the information on to me.  Phone conversations often get taken over by household business.  I've probably been happier not knowing a lot of things, on one level, but there was no reason to ask, because it appeared he was getting better.  But now it's looking like the speech therapist couldn't do the real swallowing therapy she wanted, because Colin is a pre-schooler and not always inclined to cooperate.  That's understandable.  Though it's annoying now that she seems to wash her hands of the whole thing, acting like the whole problem is her uncooperative patient, and ignoring the fact that he's not mature enough to know what to do.

And I still can't shake the belief that, if anyone had listened to Christina the last few months, during which time she told them ever time something landed in the trach, maybe we could have gotten to this point sooner, rather than building up our hopes that he was a short timer.  Which is when you start worrying that the staff is just too focused on the personnel problems at work to be doing their job 100%.

At the same time, I remain optimistic.  We'll get him home.  He'll get better rest.  We have a speech therapist lined up with whom we've worked before (Emma went to this office a few years back). We can feed him without worrying about aspiration, but still have a way to do the therapy.  it feels like it will be a lot of work, but manageable.  But it feels like we could have been at this point weeks ago if people had been paying attention.

I focus on the positive.  He's learned a lot about how to control his breathing.  He went weeks without one of his attacks (he's had a few in the last few days, but they've all been prompted when the medical staff was trying to perform tests on him and I can't fault a kid for freaking out under those circumstances.  Even the one I saw today, I have to say, he didn't seem to go down as deep as before and he bounced back a whole lot better.  His cognitive skills seem better and, even if he can't physically speak right this moment, he's better at making his point.

The feeding tube should go in on Tuesday.  He'll need a week to recover.  Our care team remains on standby and is tentatively set to start working with us at home on March 28 (do not mark your calendars yet).  I'm getting my stitch out tomorrow and the car should be ready to be picked up next week.  Maybe we're turning a corner.  But I'd be lying if I said we weren't terrified about the chances of everything still blowing up in our faces.

## Comments

Easy for me to say...but take one day at a time. A year ago they told me that my husband had 8 months to live....I fell apart. A wise friend told me that there is always hope for improvement. ...not to give up...and to take it one day at a time. Now we are a year out, the inoperable became operable, the Procedures were successfull. We are weathered and battered by the last year, but we came out the other side. I pray the same for you, Colin, Christine, and kids.

*—Barbara Skipper, March 15, 2019*

## Adjust your schedule

*March 15, 2019*

They have now moved the surgery to 9 a.m. on Monday. I have no way of telling if it will now stay at that time, but it's what we're working with for now.

I'll probably go out to the clinic for a few days so Christina doesn't have to get through the surgery by herself. It's only a minor one, but she's done too much of the hospital heavy lifting the last few months. And Rebekah seems to have a handle on Emma and Noah, or at least as much of a handle as one can have on those two.

Otherwise, my stitch is out and my nose appears to be straight. I am allowed to finally wash my fae again tomorrow. Now that's some progress there. We have a stomach bug going through the house, which had me laid up for part of the morning. I still pulled myself together to get to my therapy appointment, and I got a whole five minutes of time with my therapist before the teacher's aide called to say Noah was down with the bug. For someone who really never thought he would need therapy, it is astonishing how disappointed I am when I can't get in a session.

We're still seeking answers, but most people can only tell us to take it a step at a time. We're reaching out to see if there are any support groups for people with children who require feeding tubes, but, as usual, we're in a strange situation. Most kids on tubes tend to be severely mentally impaired or have had the tube since they were infants. They don't remember a time when they could eat normally. Colin has all his mental faculties, and he's going to be ticked when he realizes he can't eat. That might turn into good motivation as he does his swallowing therapy, but it means a pretty bumpy road ahead for all of us.

## Comments

May you have strength when you hit those bumps!

*—Jeremy Cook, March 15, 2019*

## Surgery OK

*March 18, 2019*

Our 9 am surgery appointment took all day to get going thanks to forgotten blood tests, etc. But they finally got going at 1:45 pm and were then done in less than a quarter hour. Doctor seems happy. Colin seems OK, but is still heavily sedated. More on the day when I’m home with my laptop.

Sent from CaringBridge iPhone app

# Adventures in Brandenburg

*March 19, 2019*

I'll say this for Colin. After having yet another surgical procedure on top of everything else he's endured, the child can muster surprising amount  of physical strength when he wants to keep you from doing something to him that he's not signed on to. It's kind of like grappling with a mutant mix of gorilla/octopus.

So, it's been a busy few days.

I left the house on Sunday to take the train to Brandenburg.  Somewhere on the walk to the station, I had the St. Patrick's Day train of thought that has come to typify the day for me: "Oh, it's St. Patrick's Day ... I'm not wearing green ... if it's St. Patrick's Day, then it's the anniversary of Colin's cancer diagnosis."  So, that colored my mood on the way out there.

That said, Sunday was low key.  On the one hand, we're so numbed to putting the child through medical procedures, they're almost commonplace to us.  On the other, we're about to put our kid into surgery.  And, for added fun, we can't eat or drink in front of him.  But we still made the best of it, because it was to be the first night Christina and I would have a chance to hang out as a married couple since December.  And since Colin usually crashes around 8 p.m., we'd asked the nurses for a restaurant recommendation and just needed the child to fall asleep and for a cab to come.

So, of course, Colin managed to stay awake until about 9:40 p.m., at which point it was far too late to go restaurant hunting, since the clinic is nowhere near anything.  We ended up, instead, competing in the "Dumbest Date Night Contest" by spending 24 euros on a round trip taxi ride to the nearest McDonald's so we could shell out 20 euros for their finest meal.

Surgery day started off very slow.  It took the doctors at the clinic two tries to get a needle into Colin, and then that one was too shallow or something, so it was only good for getting medicine into him, not blood out.  The transport was about half an hour late and then, when we got to the hospital, they needed three more tries to get a blood sample from him, because they'd neglected to run a test at the clinic. After the first try, it dawned on me that they had drawn blood on Thursday, when we thought the surgery would be Friday (the hospital pushed the surgery back because they were worried about putting in a feeding tube less without giving him enough time to recover from the most recent bout of pneumonia). But it turned out that they hadn't run the one test required for this surgery, so he got poked two more times.

Then we waited until 1:45 p.m. for a surgery that was supposed to have been at 9 a.m. They did take him down pretty punctually at 1:45 p.m. and told us that the procedure would last a quarter of an hour. Christina and I didn't believe a word of that, because we've been doing this for three years, so we went and had lunch.  Upon returning to the waiting area, we learned that it had, indeed, only taken 15 minutes and Colin was already back in his room.

The rest of Monday was hard, because they hadn't put him completely under for the surgery.  He bounced back pretty quickly and was pretty wiggly, so we had to do a lot to keep him calm and still. On the good side, he crashed around 8 p.m.  On the bad side, he woke back up around 3 a.m.

The hospital sent us back to the clinic pretty early on Tuesday, once they were happy the incision looked OK and after they gave him some water through the tube.  We only got held up after some senior doctor wandered in and gave us a 10-minute lecture about all the pros and cons of a feeding tube that really felt like the kind of talk we should have had before the surgery, but what are you going to do?

And then we got back to his room and it was pretty much like before.  He seems in no discomfort.  I'm not even sure he realizes he has a new tube. He's back to focusing on his Lego collection and wresting every minute of tablet time he can get from Christina.

The plan still calls for him to come home on March 28, barring some new horrible development.  We have lined up a speech therapist for him (who seems a little horrified that they let us keep feeding him during the early stages of swallowing therapy) and just need to get the room set up for him. Transportation will be difficult, as he will have a wheelchair for moving around (he can still walk, it's mostly a precaution).  Unfortunately, the last swallowing test was performed on him while he was in the wheelchair.  Now he would not get back in that chair even if he were promised a personal tour of every Aldi by its owners.  We tried today and, I'm telling you, had someone just put a feeding tube in my gut, I don't think I would have been able to plank with the intensity he did.  But he would not bend at the waist to sit down, no matter what we tried.  That's going to be an interesting road forward.

In a further complication, the mechanic won't promise that my car will be fixed and ready before March 27, which has a little nervous about conflicting schedules.  We'll just see what happens.

As for me, I'm returning to work tomorrow, for the first time in two weeks after all this nonsense. I'm mostly fine, but the nose is still sensitive, especially if a child trying not to be put in a wheelchair strikes out at your face, just as a totally random example.

## Comments

Jeez! Continued prayers your way.

> *—Barbara Skipper, March 19, 2019*

This in no way addresses any of your problems, but there are cookies en route in case binge eating is warranted.

> *—Liisa Ecola, March 19, 2019*

> And speaking of cookies, I can order more Matt's at any point in time...
>
> *—Michelle Lee, March 19, 2019*

# Colin in hospital

*March 20, 2019*

Colin drifted off to sleep while Christina was getting him ready for bed and, suddenly, his oxygenation levels won't go back up, no matter what the doctors do. He's being sent to the hospital.

We don't know what this means.  We're both messes.  I'm heading out to Brandenburg with the last train.  We'll take any prayers you've got.

## Comments

So sorry to hear that! Hope this will be fixed soon!!!

> *—Sofia Gueorgieva, March 20, 2019*

You have all my prayers!

*—Jeanne Clayton, March 20, 2019*

God bless you!

*—Antje Lein-Struck, March 20, 2019*

Prayers!

*—Barbara Skipper, March 20, 2019*

Prayers my friend, and lots of them.

*—Lisa Caasko, March 20, 2019*

Sending love and prayers.

*—Erika Dickstein, March 20, 2019*

Praying so hard for him and all of you!

*—Marci Roth, March 20, 2019*

Sending prayers

*—Lynda Schmitz, March 20, 2019*

Hi Neils
I’ve been following you with care and concern for several mo the but never posted. Holding you in prayer now. I am Paul Stanley’s wife, sister in law to Donna Sorrells. We live in Nashville

*—Kymberlee Stanley, March 20, 2019*

Hi Neils
I’ve been following you with care and concern for several mo the but never posted. Holding you in prayer now. I am Paul Stanley’s wife, sister in law to Donna Sorrells. We live in Nashville

*—Kymberlee Stanley, March 20, 2019*

We love you and are sending prayers.

*—L Smith, March 21, 2019*

## vigil

*March 20, 2019*

The doctors do not know what’s going on. His breathing passages cramped for some reason. It took anti-epileptics to calm them down. He has been stabilized. We’ll be with him all night. We have to see if he wakes up.

Sent from CaringBridge iPhone app

## Comments

Sending you all much love, Niels.

*—Kerri Kennedy, March 20, 2019*

I am thinking of all of you and sending you my love and support.

*—Molly Land, March 20, 2019*

Sending so many prayers.

*—Lisa M, March 20, 2019*

More prayers. Many more.

*—Marci Roth, March 20, 2019*

(((❤)))

*—Cynthia Meyersburg, March 20, 2019*

Love and prayers! Take care.

*—Barbara Skipper, March 20, 2019*

## awake

*March 20, 2019*

He just woke up and is acting like absolutely nothing unusual has happened. He’s mostly interested in my Flash T-shirt. But this just raises more questions about what happened last night.

Sent from CaringBridge iPhone app

### Comments

Bizarre, but what a relief!!

*—Liisa Ecola, March 21, 2019*

## medical mystery

*March 21, 2019*

We have no idea what’s going on.

Last night, when Christina called, the doctors considered him such a critical case, they didn’t dare transfer him any further than the hospital in Brandenburg (there was talk of sending him all the way to Berlin).

When I showed up at midnight, he appeared to be sleeping peacefully, with all of his saturation levels more or less in the green.

Now he’s been awake two hours and is acting like nothing unusual happened. Mostly, he’s just annoyed by the IV and the extra sensors. But he found the LEGO Batman movie on Christina’s tablet now, so that seems to be taking the sting off of things.

Sent from CaringBridge iPhone app

## the 96-hour wait

*March 21, 2019*

Colin needs an MRI. The hospital can’t organize it before Monday and he can’t leave the hospital before then. We’re figuring out a plan, but it’s liable to be annoying for all, seeing as we’ll be in a strange intensive care with a parents room in a different building.

Colin is tired and getting bored with the limited entertainment options, but doing well. Honestly, if I didn’t know about last night, I wouldn’t be thinking twice about his health (besides the obvious, I mean).

Sent from CaringBridge iPhone app

### Comments

ugh. Long weekend! At least he will be closely observed in the interim. Thinking about you guys.

*—Marci Roth, March 21, 2019*

Ugh ugh ugh. Thinking of you.

*—Kathryn LaPointe, March 21, 2019*

Hi Niels,
ich drücke euch ganz fest die Daumen.
□□
Liebe Grüße Katja

*—Katja Reif, March 21, 2019*

What a weekend it will be, prayers to you guys, hang in there. It has been a very scary few days.

*—Jeanne Clayton, March 22, 2019*

## a rough 48 hours

*March 22, 2019*

About 48 hours ago I left the house in a panic that Colin wasn't going to survive the night.  Tonight, I just told the other two that if I have to reach into the toilet again and clear a clog because certain unnamed people think it's necessary to use the equivalent of Cleveland's annual toilet paper requirements for a trip to the toilet, that toilet paper will be rationed until everyone leaves the house and gets their own place to live.  What a pair of bookends for a 48-hour period.

I couldn't meet my therapist today because of the excursion to Brandenburg.  At one point, he asked me how I was coming down off the fear that Colin was about to die and trying to find some optimism.  I told him that the sad truth is that this is about the third time I've had a night like this in the last four months, so I'm not sure if I'm getting used to it or if I'm just better at finding sources of optimism than the average person.  But still, the answers that I give to some questions scare me sometimes.

So, on Wednesday night, after a fairly active day, and while Colin was still recovering from a virus, the two of them had their bedtime routine.  Colin drifted off while Christina was reading a story, and she figured that was it for bedtime.  Then they noticed that his oxygen levels weren't keeping up where they should be.  Then they noticed they couldn't wake him up.  And that's how they ended up in the hospital, with Colin getting some anti-epileptics.  As near as we can tell, he has some kind of attack while sleeping that cramped his air passages so badly that, despite the breathing machine, he simply wasn't getting enough oxygen.  Christina said that, for all appearances, he was sleeping peacefully.  He wasn't obviously having a seizure or any discomfort.

The CT scan showed nothing.  He had an EEG today.  No idea what that showed.  And the MRI is on Monday.  I have to admit, I'm skeptical it will show anything conclusive.

He's been fine since he woke up on Thursday.  He had as busy a morning as he can have when stuck in a hospital bed.  He fell asleep around 3 p.m. with no incident.  He woke up around 4:30 p.m., asking for his trach to be suctioned and had a pair of back-to-back panic attacks during that, but those were the kinds of attacks we've long since learned to expect from him since August, even if the rate at which they happen has dropped off dramatically.  And then he was his normal self and didn't fall asleep until 11:20 p.m.  It was much the same today: Legos, movies, story time, puzzles.

Christina and I have talked.  It's clear to us that we have no way of knowing if this was the first such attack.  I mean, honestly, if you get a kid to a point where he's lying peacefully in bed and he's not linked to a monitor, you just assume everything is for the best.  It's one more thing we're going to have to factor into our new life with him.  At this moment, barring some horrible news from the MRI, we're still assuming he's coming home on Monday.  The doctor said they're doing the MRI not because they're worried about the tumor, but because they want to see if there is any new obstruction of the brain stem.  As Christina said, depressingly, if it means he has a life with seizures, one can learn to live with them: They're not a death sentence.  It's astounding what good news we can fish out of these situations.

I doubt we'll have MRI results on Monday, as the data will be sent to the Berlin hospital for analysis. Indeed, I suspect it will be one of those deals where, if we hear back right way, it will be bad news, because they'll need to get it to us immediately.  If it's all status quo, they'll just let us sit on tenterhooks for days until our scheduled meeting.

I keep saying I don't know how many more times I can do this, but I guess the answer is that I'll have to keep finding ways to do it so long as it keeps happening.  I know I got the call on Wednesday and it wasn't even a question that I was going out to Brandenburg, because Christina can't be asked to do this by herself.  At the same time, I can't believe I packed a halfway useful overnight bag, my hands were shaking so bad.  And then taking that late train to Brandenburg, I kept worrying with half my brain about what would happen if Christina called me in the train to tell me he was dead and wondered if I would just melt down in front of these strangers in a train.  The other half of me worried that Christina specifically wasn't calling because she knew I would melt down in the train and was just having the doctors keep him on life support long enough for me to show up and say goodbye.  I'm glad neither option turned out, but I do wonder how long until we will all be something like normal again.

That said, I got the toilet working.  So one small victory.

## Comments

It is, indeed, astounding how you can fish good news out of such situations. How the baseline for a "good" day for one child is literally "not dead" while simultaneously having to run a household for the other two children who try to increase capital expenditures by vandalizing the plumbing, a perfectly normal childhood endeavor. The dissonance must be immense. Thank you for the update, and I know you will keep on keeping on because, you know, what else would a father do?

*—Kathryn LaPointe, March 22, 2019*

Don and I are thinking of you and your family. This has been a terrifying week. I always pray that the worst is over for Colin and that he can just get back to being a normal kid. He couldn't have asked for more dedicated parents.

*—Dan Wooldridge, March 22, 2019*

I don't know what else to say/do except to send you all the warmest of hugs and most positive of thoughts and the best karma... and I know that falls short of what you really need. xoxo

*—Michelle Lee, March 22, 2019*

I'm encouraged by the way you're seeking as much help as you can, whether through therapy or the continued use of this blog. As I get ready to perform a wedding today in Nairobi, I'm praying that your marriage can be strong in all of this.

*—Jeremy Cook, March 23, 2019*

There can be no greater fear than being fearful of losing a child. Your feelings are normal, real, and expected. The greater issue is that the fear has been prolonged beyond normal limits due to, IMHO, the uniqueness of the illness and the universal bureauracracies of hospitals, It is good that you have a therapist to speak with...when each next crisis allows it. However, only you and Christine know what this reality is like. Save these journal entries. You are helping the rest of us already. My favorite Bible verse, that has gotten me through some dark days is: “I can do all things through Christ who strengthens me.” I had to reach outside myself. Hang in there. Barbara

*—Barbara Skipper, March 23, 2019*

## Saturday night, Brandenburg

*March 23, 2019*

I’m not saying this is the best weekend of my life, but you can still find ways to have fun in the ICU.

EEG results came back showing nothing conclusive and one doctor has already told Christina that he doesn’t think the MRI will give us any answers either. He continues to be his normal self, like nothing happened. He’s just tired.

There’s a dream that he’ll crash in the next hour and Christina and I might get to step out and check out Brandenburg’s Saturday night life. Christina deserves a night out in general, but perhaps doubly so after finally breaking down for the first time in three months last night and buying a bottle of beer, only to get back to her room to find there is no bottle opener there.

Sent from CaringBridge iPhone app

## Comments

You both deserve at least a lovely night out. ♥

*—Cynthia Meyersburg, March 23, 2019*

Unfortunately, Brandenburg is a tough town for late-night eating. Colin didn't go to sleep until after 9 p.m. We found three restaurants still open. But the first had already shut its kitchen, the second was too expensive, and the third was closing in 10 minutes (but they let us order takeout). So, we ended up watching TV in Christina's room before I had to catch the late bus back to the rehab clinic so I have a roof over my head.

*—Niels Sorrells, March 23, 2019*

Don't all Germans carry beer bottle openers on their keychains?

*—Jeremy Cook, March 23, 2019*

They should. They really should. This one will start to anyways. □□

*—Christina Sorrells, March 24, 2019*

Thinking of you all. Love the picture with the bubbles. So sweet.

*—Lynda Schmitz, March 24, 2019*

# the sacrifice of an oven

*March 25, 2019*

Our oven broke on Saturday.  I am hoping that, given the universe's need for us to have a disaster every week or so, that this will count and we're off the hook again for a little bit.  Please don't tell the universe that the oven is under warranty and it took the repair guy about half an hour to fix it.

Also, given that the rate of our mishaps is growing longer, could we schedule the next one for a lot further in the future? Maybe around 2079?

So, Colin and Christina are back at the rehab facility.  He had the MRI without incident, if you ignore the part where it took five people to hold him down while the doctor put an IV in.  We're getting the usual runaround: It's going to take until Thursday until everyone has a very close look at the new MRI and compares it to the past results to see if there's been any change anywhere.  So, we're a bit on tenterhooks.  That said, I do believe that, had anyone seen anything horribly obvious, they would have let us know by now.  Also, Wednesday night's seizure aside, there is nothing in Colin's behavior indicating deterioration.

The plan remains for them to come home on Thursday.  We are all, of course, very excited.  At the same time, we are facing the realization that "Oh crap. This is happening."  I was supposed to use the last few days to get Colin's new room ready. Instead, I've been shuttling back and forth between Brandenburg and Berlin.  We have no idea how we're going to incorporate the home health care workers.  We have no idea how we're going to keep Emma and Noah from being too rough with Colin.  We worry about how Christina and I are going to get used to having the other around after a four-month break.  One gets used to having complete control of the television, that's all I'm saying.

Nonetheless, if luck holds, this will be the last night I had to trek from the rehab site to the tram stop - a very odd walk that includes the rehab center, a clutch of new houses, a cemetery, a super-creepy bar, a smattering of Soviet-style high-rises and, if you're lucky, some feral cats and rabbits.  Walking from the tram to the center in the dark might be one of the scariest things I've ever done and, if I ever figure out a good contact to Hollywood, I'm going to get in touch with the producers of "The Walking Dead" and tell them to move their crews here, because this place has 'zombie apocalypse' written all over it.

I've not written about work much in the last few months.  Returning to work this time has been harder than in 2016.  But they remain awesome.  Last Wednesday, I told the team that things seemed to finally be under control.  And then I promptly disappeared with the fright about the seizure.  But, even though I'm on the roster for tomorrow, we've all agreed that I'm going to keep on being sick - well, technically, caring for a sick child - on paper so I have the time to get the house in shape and then figure out this new reality awaiting us.  Thus, if you need me Tuesday, I'll be deep cleaning the house, trying to get it spit shined to German Hausfrau standards.

## Never start a land war with the German bureaucracy

*March 26, 2019*

I was once told that World War I started because Germany had some battle plans that could only be implemented if everything went according to the grand plan. And when Germany moved some of its troops by train towards Russia (I think), they automatically had to move their troops towards France, which was at that point not involved in fighting with Germany.  But they took it badly when Germany sent troops their way - even if they were just following the plan - and what might have just been a two-country fight turned into a world war.

I have no idea if this is the way it happened or if it was just something someone told me once. I don't even remember where I heard this. But I've got to tell you, it's starting to ring true.

It's important to remember that, before the run to the emergency room last week, Colin was set to return home on Thursday.  That was still our plan when we left the hospital yesterday.

What we didn't know is that the hospital had, for a brief while, thought they weren't going to be able to get Colin's release papers together in time and that he was also going to have to spend Monday night in the hospital.  They told the rehab clinic to tell them this.  The rehab clinic figured that, if Colin wasn't coming back until Tuesday, there was no way he was leaving for home on Thursday.  So, they called the home health care service and told them it was all going to have to wait until Monday.  With that knowledge, the home health care service reassigned the workers who would have been at our house this weekend.

And then Colin did get released on Monday.  But no one told us about this flurry of phone calls.  Nor did anyone make a subsequent call to say "Never mind."  Nor did anyone ever ask us what we actually wanted.

But, the point is, even though the doctors say that there is no medical reason for Colin to stay at the rehab - even if the MRI comes back with bad news, he'd have to go to the hospital, not stay at rehab - we have no home health team until Monday.  So, Colin gets a few more days of pointless treatments and a weekend at the clinic to just hang out. And then we try for Monday.

Work, bless their hearts, has just told me to stay home because they just worked out a whole plan that doesn't involve me being there.  And I do have a sick note from Colin's doctor.  So that's at least covered.  And, since I didn't get to spend this weekend getting Colin's room ready, I now have a little more room to breathe.  That said, I did clean the entire house this morning in anticipation of their return, so I'm going to have to work to make sure that sparkle sustains through Monday.

It makes the Rescue from Brandenburg a little more difficult.  My friend had been set to take me out there tomorrow so we could clear all their belongings out with his big van. He might not be free on Sunday.  So, if you have time on Sunday and a large spacious vehicle, you might be hearing from me quite soon, because there's a chunk of clothing, toys and medical equipment I have to liberate from Brandenburg before I can get Colin home. Volunteers welcome.

## Comments

*Heart* your employer - despite the challenges of dealing with the German bureaucracy, dealing with this in the United States would be a worse nightmare, financially and in terms of leave and other logistics. I know that is little solace when you're in the thick of things, of course.

*—Michelle Lee, March 26, 2019*

# The first homecoming

*March 27, 2019*

GALAXY
B RD 1507

We have a car again.  And it's so clean.  And they gave it the new car smell.  And its front fender is attached.

My, that's a before and after shot to give one pause.

So, we'll call this Step One towards Restoring Normality in Our Household and hope everything else goes so easily.  Thanks to all of our insurance, it only cost us 450 euros (though Christina probably properly predicts that our insurance payments are now going to skyrocket).  And when I noted that I would need a new warning triangle because the old one got run over during the accident, the mechanic threw a new one in for free.  Now I just need to figure out what the lawyer is doing regarding this case, because I haven't heard from him in weeks.

On the Colin front, the good news is that he's spending increasingly more time both off oxygen and the breathing machine, indicating a good recovery from the most recent pneumonia.  Christina says he's also more aware of his limitations now and will ask for the oxygen when it's needed, so that's good. The doctors also say we can unblock the trachea canal, which means that, if he lets us (a big if), we can put out the speech attachment and he can speak.  We have to figure out precisely what this means.  One of the reasons the trach was blocked was to make sure mucus, etc doesn't get into his lungs.  But no one has explained if that problem has ceased or if it's only something we need to worry about when he's got an infection.

There is also an annoying rumor going around that the MRI they did on Monday was not detailed enough for the needs of the oncology department in Berlin.  This despite the doctor in Brandenburg (we call him Benny) saying he knew that they had to up the calibration because of Berlin's needs and how this wouldn't be a problem since they routinely do MRIs for Berlin when it gets too crowded there.  Let's hope it's just a rumor.  Otherwise, that four-day stay in the hospital - which led to the delayed homecoming for Colin and Christina - was pretty pointless.

## Photos


STOCKMEIER CHEMIE
REIFEN HERO
10

## Comments

Insurance, Lawyers, Hospital, Rumors....what could go wrong? Lol. With much love!

*—Barbara Skipper, March 27, 2019*

Do you have any more appliances willing to absorb some chaos? Microwave volunteering as tribute?

*—Kathryn LaPointe, March 27, 2019*

Hope to hear about Colin riding in that car soon!

*—Jeremy Cook, March 27, 2019*

# rugs pulled out

*March 29, 2019*

We heard a lot of things we didn't want to yesterday.

This is the hardest time I've had in a while composing a blog. In many ways, I feel like we've been pushed back to Square One.

The MRI results are in. They're confusing.  There are signs of renewed blood vessel growth in the tumor. This could be a sign the tumor is active again.  There's a couple of other things it could be too, but few of them are particularly good, or even neutral.

If the tumor is back, it means December's results were junk. It also means we have few options left to us. There were two procedures they outlined back then, neither sounded reassuring.  If it's continued decomposition after the radiation therapy, it would be odd, since it's really been too long since that therapy for results to still be manifesting. Regardless, the last decomposition resulted in the swelling that landed us into our current situation. There's not a lot more pressure the brain stem can take at this point.

For now, we know very little. The oncologists and the radiologists and the neurologists all have to sit down and look at the picture together.  That will be on Tuesday.  On Wednesday, we'll meet with the head oncologist and hear what they think.

Otherwise, he's still set to return home on Monday.  We're worried now that he's going to have a week at home before he's thrown back into the hospitals, but we'll take what we can.  It's a very weird game of mental Olympics, preparing for what should be a happy homecoming, knowing we might be at the precipice of something awful. Unfortunately, this is our path and we have to push through.

We're not telling the kids anything, obviously.  Christina and I are both rough.  I certainly wonder if I'm going to be able to eat anything today.  That said, the simple act of getting up and writing this is making me feel better.  And, as luck would have it, I have a meeting with my therapist today, so I guess he's going to earn his paycheck today.

We take a lot of solace in the fact that Colin is acting perfectly normal (well, under his current parameters) and is in a general good mood. Please pray for Wednesday. Please pray that this all turns into a fluke. Just keep us in your thoughts.

## Comments

I’m so very sorry to read this Niels! I wish you and Christina lots of strength, and am keeping my fingers crossed that it is just a fluke.

*—Alexandra Mayer-Hohdahl, March 29, 2019*

My heart aches for you guys. I'm so sorry for this news, but also the uncertainty around it, which seems to never end. Really hoping the therapy session is helpful for you.

*—Jeremy Cook, March 29, 2019*

My heartfelt prayers are with you.

*—Lisa Caasko, March 29, 2019*

Thinking of you. You've all had so much more than your share. I hope good news is coming.

*—Daphne Retter, March 29, 2019*

Oh, no! Not at all what any of us are hoping for Colin and all of you. I am so sorry you all are on this terrible roller coaster. Your family is in my thoughts and my prayers. I hope that the doctors can figure out the best possible way to help Colin. (((( <3 ))))

*—Cynthia Meyersburg, March 29, 2019*

Hi Niels and Christina, this is such torture, no parent should have to travel down. And certainly no sweet baby child. I am thinking and hoping for something good to come Wednesday. But be strong - one foot in front of the other, and take every good day Colin has as a small victory. I'll be with Incle Don and cousin Barbara next week and we'll be sending our collective love and prayers. Love, Susie

*—Carol Hamilton, March 29, 2019*

All my thoughts and prayers are with all of you. What an emotional rollercoaster, praying for good news next week.

*—Jeanne Clayton, March 29, 2019*

I'm praying for you guys right now. Lots of love to all.

*—Anne Custer, March 29, 2019*

## a ramble

*March 29, 2019*

I'm mostly posting to clear my head.  Therapeutic blogging, if you will.  No real news to share.

I'm doing better.  I don't know what my therapist does exactly, but it works for me.  And then I went to the gym for an hour, figuring that if I could get my body working again, maybe I wouldn't feel so weak all the time.  Both seem to have done me some good.  My appetite is diminished, but I am at least eating.

Christina reports that Colin is a ball of energy.  He spent the morning running, jumping and (unfortunately) trying to bite her.  Then she left him alone with a movie for half an hour while she went to get lunch and found that he had taken the opportunity to nap, which means that he will never go to sleep tonight.

Christina says she's having bad moments here and there, but is just moving through. I think this is the only way to do things. We can only operate in 12-hour cycles. She's got to get all the paperwork for the home health care service done. I've got to get the house clean. I did actually have it sparkling on Tuesday, but then the return date got pushed back and I made the mistake of letting Emma and Noah back inside, so we've got to redo some of the work.

In one piece of good news I forgot to mention, Colin is going to be brought home by ambulance. I am a little sad that I won't be the one bringing him home, but I was honestly very nervous about having him and all his gear in the car and how we would negotiate the drive if he had any problems on the way. This way he has paramedics with him and I get the morning to clean the house.

I remain optimistic, though it is getting harder. The kid seems to get every bad hand there is. When I returned from Australia, he was a relatively healthy cancer survivor. Now we're trying to figure out how well he can breathe/eat on his own and whether this new MRI result heralds something awful. Every step forward leads to two steps back. And just when we think we've adjusted to him with a trach, we have to learn to accommodate the feeding tube. And then we wrap our minds around that the specter of cancer's return is back on us.

I find myself thinking thoughts I bounced around a bit in December and seriously pondered in 2016. What do we do if the cancer kills him? How do we function as a family? How do we function as a couple? How do we shelter the older two children from this? Should we shelter them? Please understand, I'm not assuming he'll die, but I also understand I have to work through the worst-case scenario on some level so I'm not taken by surprise should it happen. I've got obligations to Christina, Emma and Noah and I can't fall apart if the worst happens. But I also know I'll need to grieve. I have no idea how one does that.

That said, I'm taking a lot of hope from the fact that he's acting like a pretty typical 5-year-old. Then I remember that, when we got that first MRI result in March 2016, had you told me that morning that he had cancer, I would have laughed at you. He seemed so healthy then. Outward appearances aren't always truth.

In a further setback, they've put him back on the valproic acid, but at less than half the dose he was on before. This time it's not being used for it's anti-cancer properties, but because it's known to reduce the risk of convulsions, and they are trying to minimize the risk of whatever happened last week happening again. Still, my heart aches that we're giving him the stuff again. Strangely, the doctors say that they wouldn't expect a tumor in the brain stem to cause convulsions. That would normally be caused by a tumor elsewhere in the brain. Unfortunately, the MRI gave very precise detail in the brain stem region, but less of it in the greater brain.  They see nothing suspicious in the rest of the brain at the lower resolution, but one wonders and fears what a higher-resolution peek at the rest of the brain would show.

The fact of the matter is that, if it's cancer, we're pretty much out of luck, barring a medical miracle.

If it's further degradation after the radiation therapy, that's strange.  But maybe we can work around it, though one shudders to think how much more of a load he can carry should that bring new complications.

And if it turns out just to be a weird reading on the MRI, we'll thank our lucky stars.

All I know is that I'm hanging out with a friend tonight, because I need a moment.  And then I'm taking Emma and Noah out to Potsdam tomorrow, because these two deserve a childhood. And then Rebekah and I head to Brandenburg on Sunday to pick up the bulk of their gear so they can return home on Sunday. Universe: It would be helpful if you could just let these plans fall the way we've laid them.

## Comments

Hey! Universe! Let the Sorrells fam have a nice day, okay?

*—Kathryn LaPointe, March 29, 2019*

I think we know parenting will not be easy; however we could never have imagined how difficult it is. I have worked with students who have dealt with family illnesses. It impacts everyone in the family. Even the ones that seem not to understand. Each member needs to know the family unit is strong, and as difficult as the challenge is, that the family will remain no matter what happens. I know the stress is enormous...it is great that you have someone to talk to. Prayers and love . Barbara

*—Barbara Skipper, March 29, 2019*

Sending you so many good and positive thoughts.

*—Lynda Schmitz, March 29, 2019*

I'm no expert but in dealing with grief it seems friends and relatives are a good start. They bring over food, they talk less, offer hugs. I say, enjoy whatever reassuring uplifting moments now AND take the food and hugs from your friends and family. Count me in for some of that.

*—Marc Galmoud, March 30, 2019*

## Homecoming

*April 1, 2019*

Ten minutes after arrival.

Sent from CaringBridge iPhone app

## Comments

<3

*—Boris Babic, April 1, 2019*

Superman...and super parents. Sending you all my love. -Erin

*—Erin Taylor, April 1, 2019*

YAAAAAY! Go Colin!

*—Michelle Lee, April 1, 2019*

I'm so happy for all of you!

*—Jeanne Clayton, April 1, 2019*

Superkid! No April Fool's Day there!

*—Jeremy Cook, April 1, 2019*

## Homecoming 2

*April 1, 2019*

We’re learning it’s a little difficult to keep him in one room during his feeding time, hence the tablet. Plus, first brotherly contact in weeks.

Sent from CaringBridge iPhone app

## Comments

It is so good to see him home!

*—Marci Roth, April 1, 2019*

Yea!

*—Barbara Skipper, April 1, 2019*

So, so happy!

*—Jeanne Clayton, April 1, 2019*

So good to see them together.

*—Jeremy Cook, April 1, 2019*

## home occupation

*April 2, 2019*

We've had a mostly happy 24 hours.

The ambulance arrived with Colin and Christina around 1 p.m. on Monday and he was in a mood. You could tell that he was convinced he was being carted off to some new medical facility where even meaner doctors were going to do even crueler things to him. He was pitching a complete fit as they pulled him out on his stretcher and kept it on right into the house.

At which point he had a "waitaminnit" moment, before starting a slow inspection of the entire place, like he wanted to make sure it was his house, and not a clever reproduction.  And then we played for the rest of the day, reading books, using his toy chainsaw to cut off Rebekah's legs (a highlight) and sorting through all the superhero figures.

He'd had an awful night of sleep Sunday into Monday, so he passed right out on Monday, waking up quite early for yet more.

It's going to be a challenge.  Because of all the time he has to spend on a breathing machine or with a feeding tube hooked up, there will still be large stretches of time where he's limited to one room or the other. But we've got the machines set up in two different rooms, so that gives us some flexibility.  And it's still home.

As for our state of mind, it's difficult.  I don't know if I should be happy about the homecoming or sad that we're starting a vigil.  It's too many directions to be torn in at once.  But he's happy, so that counts for a lot.  If you overlook his obvious conditions (the trach, the feeding tube) he seems really healthy.  Who knows?

Medical mishaps continue to plague us.  They were supposed to be home a full hour earlier on Monday, but when the ambulance showed up, they announced they had no room for luggage.  Christina had a small suitcase, a bag full of medical supplies and a box of Legos. It's not like she was trying to transport all of our possessions. She put her foot down and they got another one for her.

Meanwhile, we've met two of our minders. Katharina was here yesterday while we were getting set up and is back for today's day shift. Hannah, who did the overnight shift, has already called in to say that she doesn't want to do the job any more. We're kind of clueless what threw her, and now worried that on Day Two of this adventure we're going to be stuck without any kind of overnight support. So it goes.

## Comments

LOVE THAT COLIN HAD A SUCCESSFUL DAY AT HOME.! Hope the evening minders get their act together. Uncle Don and Waynette send their love.

*—Carol Hamilton, April 2, 2019*

It's a blessing that he's home and playing like a normal kid. (Sorry about Rebekah's legs!) The minders and overall routine are a process of adjusting and readjusting, not that you guys aren't tired of doing and hearing that. I think you and Christina are real champs! May everything continue to improve!!!

*—Dan Wooldridge, April 2, 2019*

# the late shift

*April 2, 2019*

Well, the home health care service couldn't pull together a replacement person for overnight at such short notice, so Rebekah and Christina are going to split up night duty while I have to make sure I'm up in time to get Noah out the door which, admittedly, is something I've gotten out of practice at doing ever since Rebekah came out to help us.

I don't write enough about Rebekah in this blog because - honestly - there's been so much else going on the last few months. But she arrived about six weeks ago - and is leaving in about two (sob!) - and has pretty much run the household ever since. The kids are into her. Everything is clean. We're fed. She puts up with my penchant for watching Babylon 5. All in all, a great niece. If you can get a niece just like her, I highly recommend it.

Anyways, that's our night ahead.  I feel like a bit of a slacker for not doing the late duty, but the fact of the matter is that I am nowhere near as versed in the various ports and tubes that Colin has as Christina and Rebekah are. Also, getting Noah out the door in the morning can be a hassle, so it's not as if I'm coming off completely unscathed. (Emma's away on a week-long field trip)

Colin had a mostly good day. He slept from 7 p.m. to 3 a.m.  I found him with the now-vanished nurse at 5 a.m. and kept him busy until about 9 a.m.  Then I went downstairs for a break and he promptly crashed, until about 2 p.m.  So, we'll see when he sleeps tonight.  That said, he pretty obviously needed the sleep, after some pretty restless nights the last few days in the clinic.  And I do believe the human body tends to shut down and relax a little bit once it gets safely home.  We'll see.

I think having him sleep so long gave me a little too much time to think today, so I've been a bit off. Plus, this doctor-nurse team came to visit us.  They're from the palliative team, a word which I associate with end-of-life, but which they're quick to point out is mostly about improving quality of life amid health issues.  So, I know where they're coming from, but the word weighed on me.  The point is, I've been a little rough today and heaven knows what's coming at us tomorrow.

That said, once he woke up, Colin has been go, go going.  And he's warming up nicely to Katharina, the nurse who stayed, so yay for that.

## Comments

Thankful for the tender mercies....the small wins in the middle of Change. Continued prayers that the nursing situation stabilizes, Colin continues to improve, and you establish a satisfactory new normal. Life is like that. Much love your way!

*—Barbara Skipper, April 2, 2019*

First of all, hurrah for Rebekah, what an amazing niece and human being. And a hug and hurrah for the nurse who stayed. And, I'm guessing it might be good riddance to the nurse who didn't, definitely don't want someone around who isn't up to the task. But what a bind she put you in! I hope they have a new person in place for you pronto. Seems 100% understandable that these days are rough. A lot of adrenaline. A lot of new responsibilities. Too many unknowns. But, so much love. Both there and around the world coming toward you.

*—Marci Roth, April 2, 2019*

I agree: Palliative is a terrifying word.
But that is just because palliative care so often gets blurred with hospice care.
Thankfully, they are *not* synonymous.

Like your doctor indicated, palliative care is *not* just for end of life situations. Palliative care also is common for people who have chronic conditions, to do whatever can be done to improve quality of life and make it so the person can participate/enjoy as they work on healing/curing/recovering. For Colin, surely the intention is to help make a difficult situation for a child as good as possible, so that the other medical folks can focus on helping him recover.

((((Praying for comfort and healing for Colin))))

*—Cynthia Meyersburg, April 2, 2019*

## piece of cake

*April 3, 2019*

Oh people, strap in. Even after our most recent few nose-breaking, car-crashing, MRI frightening, breath-stopping adventures, I think we outdid ourselves today.  I'm so tired.

The main news is that the doctors still don't know. Comparing all the recent MRI images, they can't say conclusively if it's getting bigger or not. The area picking up dye seems to be gaining more settled borders and higher saturation, but beyond that it's unclear. We'll have to keep a close eye on him and he'll have another MRI in about a month.

Now: Our day.

Let me be clear, I never wanted to be a trapeze artist, because I don't enjoy the idea of premature death and I probably lack the body and skills for it.  But I am really getting the sense of what it must feel like, spinning out into the air, hoping that the handle is waiting for you when you get there at the agreed-upon moment.

Bear in mind, I've mostly felt like dog food since Thursday. Every step I take feels like I'm moving underwater. Every meal is a fight to get down.  Every day has been a lot of antacid and willing myself to keep moving.  Today I had to get Noah out the door by myself because Christina and Rebekah did the overnight shift by themselves, and it was just a series of willing myself to do one thing after another.  Make the sandwich. Prepare the oatmeal.  Eat your breakfast.  Etc. etc.

Once Katharina showed up it turned into a blur of getting ready for the trip. Bear in mind, we have to pack supplies for his breathing and his eating.  That means oxygen, a breathing machine, emergency packs, tubes, bottles, syringes, etc.  It's like bringing a pharmacy with you.  We also had an unpleasant hour when we realized we didn't know how to fill up the portable oxygen tank and none of the tips we got from the manufacturer helped.  But we sorted it out, which we'll see later, was entirely for reasons of irony.

We made it to the hospital for our 11 a.m. appointment, which meant that, of course, the doctor didn't see us until 1 p.m.  The upside was that the oncologist who annoys me is on a business trip, so we met with the one I like and who seems to know how to work with kids.  We got our news and I immediately felt better, even though it's far from conclusive, and we got ready to leave, say around 2:45 p.m.

We decided to get cake.  We felt we deserved it.  There's a nice place on the way back from the hospital.

We found the place and a nearby parking space.  And, just as I parked, Christina and Katharina noticed that Colin, who had been chattering just a moment ago, had fallen asleep.  And since he wasn't attached to either oxygen or a breathing machine, he was having a severe apnea.  We broke out the emergency bag and Katharina got his numbers back up.  We then fired up the oxygen machine and immediately realized we didn't have the proper tube for connecting Colin's breathing machine to the oxygen.  We decided to block his trach, because it meant whatever oxygen he was getting from the breathing machine was escaping through his sinuses.  But then, since he was asleep, we put the oxygen in a tube directly into his nose, but then realized that wouldn't work since he was blocked.

Mind you, we're doing all of this while we're driving towards home, with the idea that all the machines we would need were there.

Except we hit a construction site and got turned around, so we were suddenly heading west, not east.  And Colin's numbers were dropping.  So we called the hospital and said we were heading back towards them.  But, just as we were about a block from the hospital, the nurse told Christina to connect Colin directly to the breathing machine and, if that worked, to head home.  It did, so we headed home.

Except then the numbers dropped again and Katharina was having to use a handheld pump to keep his numbers up and it was rush hour traffic.  "This is insane," said Christina, and I couldn't disagree.  Meanwhile, Katharina is all in the back seat going "I can pump him alive for the next hour!" and we're all, we appreciate that, but we'd rather not try, especially since prolonged pumping can be bad for the lungs.  I was meanwhile saying we should pull over into some parking lot and call an ambulance, since they'd have oxygen.

Instead, we decided to turn around again, into a different flow of rush hour traffic and head back to the hospital.  We called ahead and took him straight to the emergency room, where they stabilized him.  And then they called intensive care - where we're essentially frequent flyers - who loaned us an oxygen tank with the proper connections before sending us home, once again into the rush hour traffic.  I think we pulled up to the house around 5:45 p.m., but at least Colin was oxygenated and in a good mood the whole way.

The moral of the story? Don't get cake. Double check your medical supplies. And don't doubt Katharina's ability to pump a child to life all the way through Berlin and back.

As for the tumor, we don't know.  I take a glass half full approach that they can't confirm growth and they see no sign of any tumor spreading anywhere else in the brain. Christina points out that this is hardly a bill of clean health.  We'll have to keep a close eye on him and rush him to the hospital if anything weird happens.  But I take heart from the fact that this is the second doctor in a month who, after reading his medical report, was surprised by how feisty and active he appears in person.  I mean, for all we know, the hospital in Brandenburg might just use a different brand of dye than the one used in Berlin and that's what is causing all the problems.  Yes, there could be a tumor there. But if there is, it means it manifested itself sometime between May and October and has, since then, had slight, if any, growth.  It's been a strange tumor from the start, and maybe this is it just continuing to be strange.  I don't know what's going to happen, but for tonight at least, I'm going to have a stiff drink and food (which reminds me, it's 7:30 p.m. now and I haven't eaten since breakfast) and try to be as happy as I can about the whole situation.  And then I'll hope that today's Commute From Hell might have been the universe's last stab at driving us nuts for a while.  I can always hope.

## Comments

Maker’s Mark Whiskey would be my drug of choice...lol.

> *—Barbara Skipper, April 3, 2019*

Oh, what a day! Can't even imagine. You guys are such troopers.

> *—Jeremy Cook, April 3, 2019*

# Colin and his team

*April 4, 2019*

Well, I thought for a brief moment today that we didn't have any bills in the mail, and then I saw the rehab already had its first one to us. It's a steal: Three months of caring for Colin (and providing room and board to Christina) for a steal at 57,667.11 euros. If memory serves, that doesn't cost a whole lot more than one month in intensive care. Who knew it was that intense?

We've now met three members of Colin's team (excluding the one who bailed). Katharina seems unfazed by anything we throw at her, including the possibility of a ride across Berlin with a suffocating child. Aldin did last night's duty and seemed pretty competent. And today we've met Maya, who also seems to have her act together. Nonetheless, they're all new people, so it's going to take a while until Colin doesn't look at them sideways and run screaming. I do think once he gets used to them and back into a routine (which is going to involve a lot of therapy), it will be easier. But I think we've got a rough 4-6 weeks ahead of us. Christina has to show every member of the team how things work. She's got to show me half the stuff still. And we have to make sure we all get along, since these are strangers hanging out in our home every minute of the day.

Colin continues to enjoy being home. Every day he finds new toys - ones he hasn't seen since November - and it's like a mini-Christmas. However, if you say the words for "outside" or "day care" he shooshes you, so he's still not in the mood to try out his entire new routine.

It's hard fitting it all in. We don't feel right eating in front of him, so we're eating in shifts or just forgetting to eat. There goes the family meal. Noah has already complained about feeling ignored amid all the fuss. We'll see how things work when Emma returns from her trip tomorrow. I'm still overwhelmed by yesterday's trip to the hospital, so when the question comes up of whether we're going to Bavaria for Opa's 75th birthday, for example, all I want to do is curl up in a fetal ball. I have no idea how we're going to do kids' birthdays or anything more exciting than a run to the zoo.

I am planning to return to work on Monday. We'll see how that goes. Christina is confident that, with a nurse in the house, she can get through the weekdays. Weekend shifts are a little scarier, so we'll have to see how that goes. If you live in Berlin, don't be surprised if we reach out to you to find out if you might want to help us keep our household running for an hour or so while we do the business of keeping Colin up and running.

## churn

*April 5, 2019*

As in stomachs. As in staff turnover.

Well, we're five days into this adventure and it still takes some imagination to figure out how this is going to work long term. We just got a call from the home health care team that yet another employee quit, and this is the one who was going to start with us tomorrow during the day and do 13 more shifts this month.  I don't know what's up with this company.  So, Christina just called everyone she can think of, but I fear we've got a rough ride ahead.

To recap, the worker we met back in March quit before she could join our team. She said she was going to be the team captain, of sorts.  So it raises a lot of questions about why she drove all the way out to Brandenburg if she had an inkling she was resigning. Katharina, as far as I know, is working tonight and the rest of her shifts.  Then Hannah quit after one shift.  Aldin was apparently parachuted in to help us and is not supposed to be a regular member of our team.  Maya, who is with us right now, told us that she's handed in her resignation and quitting at the end of the month.  And now this.  You kind of wonder where all these people are going to and whether we can get the number of one of those services.

On a day-to-day basis, we're coping fairly well.  There are mishaps.  There are areas where we have to reach an understanding with the home health care team.  There is exhaustion, but we're moving through hour by hour.  But we need a service that's reliable if we're going to do this.

And then there's the watching. There's the trying to figure out what's going on with him. Is there a tumor coming back?  Is there something else going on in his head?  Was that wobble some sign of a disease coming back or just because he's tired and has barely been out of bed for the last four months?  It's all so subjective, but it messes with your head even when you do have a halfway reliable team in place.

And then it's just exhausting.  Colin needs to be fed five times a day. That can mean he's hooked up to the feed for about an hour and a half at a time, during which you need to keep this 5-year-old halfway in the same position.  Then he'll get tired because it's a lot of exertion for him or maybe his oxygen levels are low, so you've got to get him hooked up and he might not want to accept the sensor or the tube and that's a fight, and you're worried the whole time that he's going to have one of his fits and black out.  And this is when you have a nurse helping you.

In short, if anyone knows anybody in the Berlin health care network who can jump in as an intensive care home health nurse, we'll be more than happy to hear from you.

## Comments

Oh man you guys, I am so sorry. What is up with this provider company?! I wish I knew anyone at all there and could help.

*—Marci Roth, April 5, 2019*

## the next to fall

*April 5, 2019*

Well Maya, who had done her job just fine yesterday and today and even had the energy to argue with Christina in the final 10 minutes of her shift about the best way to treat Colin, called work about 20 minutes after leaving today and announced she would be on sick leave Sunday through Tuesday.  I don't know how many shifts that leaves us down for the month, but it's enough to give me pause.

Christina is much more confident than I am that we'll fight our way through this.  She's been living this for the last four months, so she's got a different perspective than me.  I just see my son dying because he slips off his air hose one night and there's no one on duty to put it back on. I don't know how we're going to pull night shifts.  I don't know how we're going to do the basics of caring for the other two.  I don't know how we're going to feed the team.

The fact of the matter is that watching Colin is a full-time job.  It's often enjoyable and there are long stretches where all you really have to do is keep an eye on him.  But it takes up all your time.  And that's before the moments where he threatens to have a temper tantrum and you have to get him on oxygen before he passes out and stops breathing.  And then there's remembering his five feedings a day (and making sure that he doesn't tangle up his tube while getting it).  And there's also making sure all of his supplies are kept clean and neat.  And this is assuming something terrible doesn't happen, like he pulls out his trach or his feeding tube.

I'm exhausted just contemplating it all.

Christina has called a bunch of other services. Some have given us glimmers of hope, but we're at least handling this all alone during the daytime Saturday and Sunday - perhaps also Monday - before we have a hope of someone being airdropped in.  And then who knows if they're going to stay or not?

## Comments

Prayers...and more prayers....and turbo prayers.

*—Barbara Skipper, April 6, 2019*

## home alone

*April 6, 2019*


AUSTRA
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MEGA

We had our second day of our first week of home health care with no nurse and, I have to say ... it was kind of nice.

I won't lie.  I was nearly catatonic last night about the whole matter and woke up with a sense of dread about the day that was not on par with discovering your child has a brain tumor, but it was up there on the Richter scale.  I started the day essentially counting the hours until Katharina, the night nurse returned.  I forced my way through each activity, just hoping to hell that I wouldn't do anything that would result in his death.

I don't know if it was by design or if it just happened this way, but I spent the bulk of the time on Colin duty, just following him around, sitting with him while he was getting his feed, etc. etc.  I got more practice suctioning his tracheotomy.  I learned a few things about setting up his feed.  I still know next to nothing about his breathing machine, but I'll get there.  And at a certain point, I realized I wasn't even counting the hours until Katharina's return.  I was just helping my kid through his day.  And we were having a fair amount of fun, except for the part where I wouldn't let him take apart Noah's Ninjago castle and then Colin sent me to my room.  We even got him outside in the garden for two longish stretches.

And, you know, it's doable.  It would be more relaxing with a medical professional on the premises, but it's doable.  And we had no attacks or medical emergencies today, so I'm sure I would be singing a different song had we had any of those.  But in some ways I felt it was one of my best days of being a father, simply because I was forced to be right on top of him the whole day.  And yes, I know that sounds like helicopter parenting, but these are extreme circumstances.  But, before Colin got sick, I was the kind of Dad who would bring a magazine to most playdates just because I knew at some point the kids would ignore me and I would want something to do.  Today, I just spent time with Colin and we, frankly, had a blast.

Which isn't to say that there aren't kinks to work out of the system.  We're trying not to eat in front of Colin, but, for me at least, it means I'm practically forgetting to eat.  And when we manage to eat with the other two, it's way too late in the night.  Also, spending a day on Colin duty meant I had to ignore Emma and Noah a lot more than I like.

Also, it's exhausting.  And it's not like Christina got the day off. My watching Colin did not buy her time to sit and lounge, but to clean the house and cook dinner and check the kids' homework.  So she's tired.  And I just sat through a late dinner with the family tensing up when the kids took seconds because I want them in bed so I can have a kid-free moment before I flame out.

So, I don't know what's going on with the home health care team. We seem to have bonded with Katharina and she doesn't give any impression of leaving soon.  She says she's even working on a friend who's a nurse in Slovakia to move to Berlin so she can help "take care of Colin."  Some of the administrators with the company have taken over the shifts for Sunday and Monday after Maya's sudden illness.  And apparently the boss of the company will be here on Wednesday to review the situation.  We'll have to see.

For now, I've made the decision to apply for long-term medical leave starting on Monday.  It buys me the freedom to stay at home and help until we get this situation sorted out.  And it gives work a fair deal since it frees them up to  hire a temporary replacement.  Also it means they don't have to deal with the madness of me being able to show up Monday, not Tuesday and Wednesday, maybe on Thursday and who the hell knows about Friday.  It will be best for all of us.

Ricardo, our old au pair also swung by today and it was great having a familiar face around.  Everyone in Berlin: I don't know what favors we'll be begging, borrowing and stealing in the next few months, but I will say this.  Swing by.  Check to see how we're doing.  Maybe check first to make sure we're not up to our ears in it, but you know what I mean. We might not need anything tangible at that particular moment, but just knowing that someone is here caring for us is such a huge mental lift.  I mean, if nothing else, maybe you can sit and watch TV with Colin for a moment so we can go to the bathroom. Maybe you being here buys us time to eat a sandwich. Maybe you're running to the junkyard and can take along a bag or two of all this medical packaging accumulating in our house because, I swear, we're going to drown in the stuff soon. I promise: No one will ask you to suction the trach.

And yes, those are pictures of Colin in our backyard with an inflatable rocket. Don't judge how we spend our Saturdays.

## Photos

AUS
AUSTRALI
TEX
3...2...1...

## Comments

What a great place to be on this journey with Colin! When my husband was so sick last year, a good friend whose husband had ALS, told me that you will still make memories ... good ones....during the illness, which we did. We crossed paths with some amazing people, like you have with Katharina. Try to focus on that as much as possible. Love, Barbara

*—Barbara Skipper, April 6, 2019*

Love hearing about the day. I know that experience where you feel so overwhelmed by the idea of something coming up but actually once you get immersed the scary feeling melts away. Anyway, yay for a good day! Susie

*—Carol Hamilton, April 6, 2019*

Dude, helicopter away! This time calls for it. We hope beyond hope that the day will come when you take your magazine along again, but for now, may those rotors be strong...and with enough fuel to give you precious moments with Emma and Noah. My prayer is that the shorter moments you get with them are of such a high quality that it makes up for the time they're missing. May you not be riddled with guilt about that. You guys are amazing parents and Emma and Noah are going to be okay.

*—Jeremy Cook, April 6, 2019*

# the night shift

*April 9, 2019*

So, one of the administrators from the service took over Maya's shifts on Sunday and Monday and kept us afloat.  There was a lot of talking about who might jump in to cover other shifts and who might be hired and how we'd cope.  I could have sworn that, when he left yesterday, the situation was that we only had three uncovered shifts for the rest of the month ... and there might even be a solution for the two of those.

Well, nope.

It turns out there's no one on the hook for the night shifts tonight and tomorrow.  Or, if there is, no one has told about it (there was talk about a grand plan a day or so ago, but we weren't given details).  So, guess what Christina and I will be doing from 7 p.m. to 7 a.m.?

I'm not in love with the plan, but I'm not as terrified of it as I was a few days ago. Christina plans to sit/sleep with him until about 3 and then I'll take over.  Given that he's next to me on the sofa right now and hasn't slept since he woke up around 7 a.m., the hope is that he'll pass right out between 7 and 8 and sleep until about 6.  Christina will have more work to do than me, but she knows how to run the equipment.  I'll just have to figure out how to start the 6 a.m. feed and how to detach him from the breathing machine should he wake up and start moving around, but Katharina (who actually prefers to be called Katja), will be here by 7 a.m. to pick up the bulk of it.  Also, we need to stay awake/alert.  Ick.

If I could believe that this was the last time this would happen, I would be calmer.  But, given that they seemed to have hired amateur hour for our initial team (which is why three people could quit the first week with next to no warning: They were all on probation), one wonders what the second generation will look like.  Sure, they might line up a team, but what keeps that team from sticking around for only a day and a half?

So, we'll see how long it all takes.  I'm on sick leave for the foreseeable future so we can keep everything running until Colin warms up to his team, once we have a team.  I can see a universe where this works, but not until we have our group in place and Colin gets used to them. And that's going to require them being present.

Colin's doing pretty well.  His mood is great, except for the occasional bouts of 5-year-old drama.  We are noticing a lot of coordination problems with him.  Feet slipping out from him while he's walking.  Hands slipping out while he's crawling.  We have to keep an eye on it.  There's no way to avoid the possibility that this could be something linked to the tumor or the tumor site.  But we also have to note that a) he's still recovering from pneumonia and tired, b) he's getting more activity here in any given day than he got in about a month at rehab: It's just a blur of exploring the house and the garden, which means the kid is tired, and c) he's back on the valproic acid as of about two weeks ago, and that stuff comes with so many side effects, including dizziness and clumsiness.  I'm not saying we're ignoring the worst-case scenario, but there's a lot of other possibilities out there too.

## Comments

GRUELLING! At least your home, so you don't have hospital noise/food/interruptions to contend with, but still. Your karma points continue to mount! Susie

*—Carol Hamilton, April 9, 2019*

Have you thought of rewarding them at the end of their shift with a stiff drink? A nice shot and conversations about Elvis with Mr Sorrells?

*—Jeremy Cook, April 9, 2019*

## find me some ether

*April 10, 2019*

Well, we're up and running after our night shift, if in a kind of zombie-like fashion.

Christina was with him until about 3 a.m.  I took over then.  He woke up at 3:30 a.m. and would not settle back down no matter what I did, leaving me to wonder how on Earth we've set up a hospital ward in our guest room, yet lack a simple ether-soaked rag for such situations.  Christina noticed all the commotion around 5:45 a.m. and then we just gave up on getting him back to sleep.  And then he crashed for a three-hour nap at 10 a.m.  Maybe that puts him on track for some kind of normal sleep schedule for the next day or so.

The service has found someone named Sonia to take over tonight.  Honestly, so long as she's not the kind of nurse who axe murders the other occupants of the house when she's not caring for Colin, I no longer care about her qualifications.  I don't know if she's going to be a regular member of our team or if she's just being airlifted in for tonight. Again, I don't care.

We are meeting potential new members of the team. Sylvia was here earlier.  She seemed competent, but had certain reservations about taking over with a sick child like Colin as her last patient just died. She had cared for him for three years and he was six and a half.  We understand whatever she decides.

And the other person will be here in a few minutes.

We continue to be confused by coordination issues. I can attest, after he kicked me out of his bed last night when I tried to cuddle with him to get him to sleep, that he has no problems with strength in his legs. And I've seen him get up and walk with determination three times in the last 24 hours, so he can certainly walk when he wants something. Other times, he's all wobbly. The doctors are not convinced about our concerns that it's the valproic acid, but they've also agreed to cut the dose, so long we have some other anti-convulsive on hand in case he has another attack like he did last month.

## Comments

Go Sonia!

*—Jeremy Cook, April 10, 2019*

Update: Apparently her name is Zofia. So long as she's not an axe murderer...

*—Niels Sorrells, April 10, 2019*

## walkabout

*April 11, 2019*

Well, if Zofia was an axe murderer, she didn't bring her A Game last night, because we're all still alive. Actually, she was the sweetest of the nurses yet. Her only drawback seemed to be that she was easily befuddled by the medical machines, but that actually gave her and me something to bond over. And she promised to be back next week.

Tonight we met Ermin, who is down for a lot of shifts this month, so here's hoping he doesn't have second thoughts about all this. He also seems to be the second-friendliest member of the group we've met so far. The only suspicious thing about him is that he doesn't want our wi-fi password, which has been in high demand from all the other nurses right off the bat.

As of right this moment, we have no idea if we have a nurse for tomorrow's day shift. They've been a little cagey about that, which is annoying. If nothing else, yelling at the service tomorrow if no one is here by 7:30 a.m. will give Christina an opportunity to let out some aggression built up during the last few months.

It continues to be a struggle, but we have lots of good moments.  Today I was thinking it had been a week since he had an attack of any kind.  And then I didn't let him watch "Curious George" when he wanted to and there we were.  But he had a lot of of fun aside from that.  He was very vocal today.  And curious.  And he seemed to be walking much more steadily than he was the last few days.  Go figure.  Just yesterday, we'd mentioned our concerns about his gait and whether it was related to the valproic acid.  She fired back that it sounded like something more likely to be related to the tumor, which is always a nice kick-in-the-gut moment.  But she talked to the oncologist - the good oncologist, the one I hope never has to give our case back to our main oncologist - and they agreed to lower the valproic acid dosage.  I honestly don't think the good oncologist thinks much of valproic acid.

And then, of course, before we had a chance to lower the dosage, he starts walking much better.  Don't misunderstand, he can still be terribly wobbly, but there was a lot more walking with purpose today.  And chit-chat.  Who knows?  I'm choosing to take it as a good sign.

I think that's the strangest part of this.  We just don't know if we're preparing him for a life with these disabilities or keeping him busy so he can enjoy his final months.  It messes with your head.

And then you realize you don't have time to think about what's going on with your head.  My wife has many wonderful qualities, but who knew she could also be a medical administrator?  Every time I turn around she's breathing fire down the phone at someone to figure out what the nursing staffing is or why the right forms haven't gone to the insurance or when we're going to get his wheelchair.  There's so much to do.  And some forms have to go to the insurance.  And some forms have to go to the pediatrician before they go to the insurance.  And others just get filed.

The garbage company is going to hook us up with a larger trash bin tomorrow, which will be a godsend, because we are drowning in packaging these days.  Today they sent us some new diapers to try out.  One parcel the size of two shoe boxes, containing two diapers, each in shrink wrap.  Take that ozone layer.

And I stepped on the scales today and realized I've dropped something like 5 kilograms in the last few weeks, down to a weight I don't think I've had since before I had children.  I can't recommend the diet, but I'm eyeing my skinny jeans for the first time in ages, so that's something.

## Comments

Definitely a good sign. Because I said so, even if the universe doesn't. Hang in there, fam.

*—Kathryn LaPointe, April 11, 2019*

Very unique nurse who isn’t interested in the WIFI Password!...Watch that one! Lol
God Bless you and Christine! What troopers. Never give up pushing the system!

*—Barbara Skipper, April 11, 2019*

It has probably been just around a week since I started reading your posts, but every time I do I strap in for a wild ride. And you don’t let me down. You and Christina are my new heroes. And we are all cheering you wildly on. GO TEAM COLIN!!!!

*—Claudine LoMonaco, April 11, 2019*

RIPPED skinny jeans? You just might become a hipster!

*—Jeremy Cook, April 11, 2019*

## fears and doubts

*April 14, 2019*

We're about two weeks into this experience and I'm scared as hell to admit that I'm not sure if we've even figured out yet how hard this is going to be.

There are so many dimensions to the difficulties we have to fight through.  We have a patient who does not care about his medical needs, he only wants whatever has sparked his interest that moment: a tablet, a Lego set, Play-Doh. Even on days when we have a nurse here, we're running ourselves ragged trying to keep all the bandages changed, the medicines put in, the child entertained.  If we don't do it right, not only does his health suffer, but he has a fit, which can lead to a pause in breathing, which is what we're trying so hard to avoid.

We have two other children who are not mature enough yet to understand what Colin is going through, much less what we're going through.  A day or so ago, Noah stopped me in the hallway and said, effectively.  "Wow.  Colin has had measles, a brain tumor and pneumonia.  That's almost three times he's died."  They process this all on such a different level than Christina and I do, and when we ask for quiet or cooperation or something else so we can focus on Colin, it's rarely forthcoming.  Because they're children.

We have our fears.  He is walking less and less and, when he does, with less stability. Rebekah got back from her European tour today and noted that he wasn't crawling at all when she left nine days ago.  Now he spends a lot of his time frog hopping from one place to another.  We simply don't know what it means.  He has strength in his legs. When he's interested in something, he can stand up and maintain his balance and walk from A to B.  Often, when he seems to have trouble walking, it's not like he lacks balance, but like he's more focused on screwing around with tippy toes or sliding his feet around.  But we don't know what it means.  We can't rule out that this is the tumor or the swelling playing havoc with his brain stem, and that's terrifying.

We have our heads to keep straight, which is not all that different from the fears. I wake up most mornings not quite dreading the day, but wondering how on Earth we're going to do this.  We both feel like we've become shut-ins, since so much of the day is spent chasing Colin around the house, taking care of his needs.  We see no one except the kids and the nurse.  We barely see one another, as we have to stack our days so one of us is eating while the other one is with Colin.  If i'm going to shower, Christina needs to be on Colin duty, etc. etc.

We have our logistics.  There is so much to get done here.  We've often not had dinner until after 7 p.m. the last few weeks, and this is during a two-week spell where one of the older ones was away on a multiple-day field trip.  But we can't keep that up once school resumes after Easter break.  Trying to get anything done around Colin's food schedule is a hassle.  I still have nightmares about our trip to the hospital two weeks ago, and I'm aware that, after Easter, we're going to have to be getting him to a lot more therapists on a much more regular basis.  Every trip out of the house requires so much machinery, and has to be timed around the feeding sessions.  I have no idea how it will work.

I spend a lot of time wishing I was not here, not because I don't want to take care of Colin, but because I figure just about anything would be easier.  But what am I going to do?  Head to work and worry about semicolons?  I won't have my head in that game. We're planning Emma's birthday party right now - I assume I'll be the adult chaperone when it happens - and I can't figure out how I'm going to be able to enjoy the day when I have to worry the whole time about what on Earth could be happening back at the house.

If you look past the walking - and we still don't know if it's just exhaustion or a lack of interest - we have some good moments.  We're trying, as of today, to limit his screen time and make him take naps.  He had too much screen time at the hospital, because what else was there to do with him?  But now he treats it as a God-given right, so we've got to cut the cord, no matter how dramatic that might end up being.  As for the naps, we have to keep him on a sleep schedule.  We've had far too many nights of him waking up before 5 a.m. and then refusing to nap, and then turning into a zombie around 4 p.m., one who can only be kept awake with large infusions of Ninjago.  We have to get him into a schedule.  It doesn't help that the weather turned cold this week, so we've not been able to get him outside.

Katia is with us today and just got him down for a nap by herself.  She's such a godsend.  Ermin just finished his third night and seems completely unflappable.  I guess we'll meet some other potential members of the team in the coming days, but we also have a few days where we're on our own.  We'll see how it turns out.

I don't want to give anyone the impression that I'm out of hope.  Yes, the walking worries me and I can't ignore the potential reality, but I also haven't seen anything that tells me all other options are ruled out.  I still have hope.  But this family has already been through hell two or three times with this cancer and its side effects.  I don't know how many more dips we can take in that pool, nor how many more we can handle before we become unhinged.

## Comments

My heart hurts for you guys, but I'm also so glad that you're able to process all of this, Niels. Sure, I imagine there's way more to process, but can I venture to say as an outside observer?: the way in which you process all this even in this blog shows a lot of self-awareness and knowledge of your own limitations. Also, the grace to simply acknowledge that Noah and Emma are, well, also children, is a huge gift to them. I'm so impressed by you guys!

*—Jeremy Cook, April 14, 2019*

So so so hard. Even with your eloquent and moving descriptions, I can't even imagine the weight, the worry, the effort. I'm praying for your appliances, and your family.

*—Kathryn LaPointe, April 14, 2019*

My heart aches for you, too. I cannot imagine how hard it is for each of you. I get a small taste reading your words and recalling caring for my mother when she was ill, but I realize what you are enduring is vastly harder than the closest I can imagine. Overwhelming and terrifying and hard. Hard, hard, impossibly hard.

Also like Jeremy, I am impressed by the empathy and compassion you find for Emma and

Noah, who are children and can see the situation only through their own perspective.

As for Noah... Do you really have to cut the cord on the screen time? If and when (and I am preying for when) life improves for him, maybe reduce then? Then perhaps you could use it to motivate PT activities? But in the meantime, just use it to help him get through what are terribly difficult times?

I am praying and sending lots of love.

*—Cynthia Meyersburg, April 14, 2019*

I try to understand by comparing your experiences to mine taking care of an elderly mother who could no longer understand why we had to change bandages or cut toenails. Taking care of a husband with advanced cancer and crying at night after he fell asleep so that he wouldn’t know how scared I was. I try to compare...but I know that I come up short...not even close to what you and Christine are going through. My heart breaks for you. Prayers and Love. Barbara

*—Barbara Skipper, April 14, 2019*

Oh Lord... mercy, patience and strength here..... overflowing. You care about the weak and the weary. We are all like little children to you. These are the least of these

*—Kymberlee Stanley, April 14, 2019*

One foot in front of the other. Sending my hope for strength and calm. Susie

*—Carol Hamilton, April 15, 2019*

My heart is breaking for you and your family. Just keep going, a day at a time, you will figure things out. I'm glad you can express yourself this way. Hug Emma and Noah lots, even though they are getting big, they will know what that means. You are all in this together and you have our support from around the world.

*—Jeanne Clayton, April 15, 2019*

## Step by step

*April 16, 2019*

Suddenly, he's walking better. It is not a great and is absolutely one that screams for physical therapy, but he is taking steps again. It just happened Tuesday and has continued into today. I suspect it will be one of the many things to which we'll never get an answer. Did the original walking problem develop because the doctors reintroduced valproic acid? Did the sudden return to walking happen because we insisted they lower the damage? Is he feeling stronger?

We don't know. It's a mystery, but the kind that gives me a lot more hope than some of the other mysteries we've had the last few weeks.

Sleeping is turning into a problem. He seems to have chosen 6:30 a.m. as his wake-up time, which would be manageable. Except, if we don't let him take a nap, he gets desperately tired by mid-afternoon, by which point it's too late to let him take a nap. And this is a child who runs the risk of stopping breathing if he's tired. But if we let him take a nap, he then gets wired and doesn't fall to sleep until around 11/11:30 p.m. (and then still wakes up at 6:30 a.m.). Either way, it doesn't feel like we're getting enough sleep in him and, for a kid this sick, you'd think he'd conk out with a little less of a fight.

It brings me back to how we feel like we're being reintroduced to the hurdles of having a newborn in the house, except this time we're five years older and way out of practice. Also, while we're juggling this, we have the older two to manage. Emma seems to move through it all with grace, even if she seems to not understand at all what's going on here. Noah is becoming more and more prone to outbursts, and we don't know if that's fear expressing itself or anger that he's not getting enough attention or what. All I know is that Rebekah heads back to America tomorrow and - thanks to the capriciciousness of the home health care schedule - we're alone every day (7 a.m. to 7 p.m.) this week except Wednesday. A friend might come by on Thursday and our old au pair Ricardo might visit on and off during the Easter holidays, but it's going to be a lot of juggling keeping everything in place until we return to 24-hour care on Sunday.

That said, we had a nice Monday. A few days ago, the doorbell rang, Colin said "It's Simon" and marched to the door to tell some mailman or some-such that he wasn't Simon. So, we invited Simon over and, as my kids do, Colin mostly just did his own thing in Simon's vicinity, but it seemed to make Colin happy. We even had him outside for about 20 minutes, slaying soap bubbles with a light saber. It felt sort of normal, and that was nice. Simon's supposed to come back Thursday and, once he gets us from his nap, we'll have the rest of Tuesday to sort out, hopefully walking at a brisk pace.

## Comments

Everything sounds very difficult! But kudos to Emma for feeling instinctively how to behave, good about the hope regading walking, and may you manage well this week and enjoy Easter at least a bit even if without regular outside help.

*—Sofia Gueorgieva, April 16, 2019*

Here's to hoping for more slaying of soap bubbles! ▯▯

*—Jeremy Cook, April 16, 2019*

Progress! It must feel good in the middle of the exhaustion. Hang in there! Barbara

*—Barbara Skipper, April 16, 2019*

## And then there were five

*April 17, 2019*

We are officially down a Sorrells in Germany as of today.  My niece, Rebekah, finished her two months with us, a period during which she single-handedly kept the family from going under more than once.  There were a few moments of denial in the last days.  Even she and her Dad briefly pondered whether she could stay with us a bit longer.  And I certainly thought about just refusing to drive her to the airport.  But the fact of the matter is that she has a life back in the States and, theoretically, we have a team of nurses to keep things running.

Of course, the loss of Rebekah is even more daunting given the bad week our staff shortages have left us to deal with.  Katia had to call in sick Monday and Tuesday ... and then overslept today.  And then we have no day shifts from Thursday through Sunday.  At the very least, we have the night shifts covered, so no all-nighters, but it's going to make the days hectic.  At least we've got several friends who hope to drop by in the next few days and give us an extra hand for a few hours here and there.

Theoretically, we're back to 24-hour coverage starting on Monday.  We'll see how that shakes out.  I think this company means the best, but they make a lot of assumptions about how the staffing will work.  They promised some guy named Stefan would be here on Saturday.  Nope.  They've interviewed at least three other people for our team - and are apparently already asking them when they can start - without waiting for them to quit their old jobs or sign contracts.  Also, they're apparently going to rearrange the teams a bit.  After all, if they give us a team of fresh hires, we run the risk that any of them could quit at a minute's notice.  Hopefully they can get a veteran or two on our team so we have a smidgeon of continuity.

I spent part of the morning just dreading life without Rebekah.  There's just so much she's been doing for us.  But I had a talk with myself while I was driving back from the airport (it helped that there's massive construction on the highway, so I had plenty of time) and just told myself that it's simple.  We have to keep Colin's medical needs met, which is daunting, but really not all that complicated.  Should something terrible happen, we call emergency services.  Beyond that, one of us is always on top of Colin and then we just have to make sure everyone is fed, everyone is bathed and that we do the basic cleaning.  Everything else will just have to wait.  It will be tiring.  It will be busy.  But it is what we have to do until we get this team halfway running.

We're going to see if we can get the older kids to help out a bit.  After some complaints that "all the chores" were ruining Easter break, we did get them to hang laundry for us outside.  It was the first chore they've done this week, but it seemed to have been successful.  And everyone survived.  The laundry too.

And we kept the afternoon fun.  After Christina went shopping, we did more light sabers in the backyard.  Then we pulled out Emma's robot chameleon (don't ask) and spent a good hour with Colin alternating between being terrified of the robot, and being concerned it wasn't getting enough to eat.  His walking remains stable, but he prefers to crawl.  And when he agrees to let us put on the trach tube that allows him to speak better, he's quite good at making plans to control robot chameleon infestations.

## Photos


BVG
BUS X9 ▸ S+U Zoolog. Garten 3
via S+U Jungfernheide
BUS 109 ▸ S+U Zoolog. Garten 4
via Kurfürstendamm
PAPERBACKS
TASCHENBÜCHER
WorldShop
WIR LIEBEN BÜÜÜÜCHER
POCKET SHOP

## Comments

The team approach with the older kids is a great idea. When our daughter was in elementary school she was diagnosed with Dyslexia. Everything had to be read to her. Her older brother fondly recalls pulling his share of the reading shifts. Sounds like your nursing provider needs better access to substitute nurses. I know Colin must be happy to be home and you and Christine must be happy to have him there. Prayers for Colin’s continued improvement. Barbara

*—Barbara Skipper, April 17, 2019*

## full house

*April 20, 2019*

You know your life has taken an odd turn when the delivery man shows up and he's carrying three packages containing 3,000 surgical gloves for your home use.  That's how things are going at Casa Sorrells.

So, we started Thursday convinced we would be alone for the 7 a.m. to 7 p.m. day shifts until Monday.  It's not as if we were thrilled with the prospect, but we'd resigned ourselves to it.  It's certainly not as if we called the lawyers out on the care team.  Thursday we got through with some help from our friend Stephan and his family.  On Friday, our old au pair Ricardo came to keep us afloat.

And then, on Friday afternoon, Christina got an email with a new schedule and suddenly we have every shift covered through the end of April.  Go figure.

Emin was here at 7 a.m. today, as promised, even though the last time we saw him he said he was supposed to work at someone else's house today.  It's good, because Colin is building a rapport with Emin, but this is the first day shift Emin has had, so Colin gets to see him at a point where he's not either trying to fall asleep or waking up.  Nonetheless, one feels guilt.  Emin tells me the family he'd been scheduled to work with today has even more staff shortages than we do: They just had seven days without any coverage of any kind.  Again, we didn't kick up a fuss, so I don't know if this means we're seen as a higher priority or in greater need.  But one feels a little bad realizing you're getting full coverage when someone else isn't.

Colin is doing mostly well.  He has moments where he walks like a champ.  He has moments where he has legs of rubber.  Christina asked me today if I thought he was getting worse and I honestly had no opinion.  Sometimes it seems better, sometimes it seems worse.  Interestingly, there was a glitch with his feeding tube today, so the 9 a.m. dose of valproic acid drained right back out.  I have no problem with that, as I hate the stuff.  I also can't say there was a magical change in his personality today, but he did seem a lot more focused at play.

To wit, you'll see in the picture that he suddenly developed an interest in Playmobil today.  His firefighter were a sideshow.  The main attraction was my set of a Döner Kebab salesman.  Unfortunately, in Colin's world, every time a potential customer shows up to ask for a sandwich, the salesman skewers him or her with the knife.  it's a dangerous business.

Otherwise, we're trying to get ready for Easter.  It feels to me like Easter has become our cursed holiday.  Three years ago, we shipped Emma and Noah off to the grandparents while Christina, Colin and I celebrated in the hospital.  This year, Colin can't eat and Noah's never been able to eat eggs, so that takes a lot of the shine off of the festivities.

Also, we're going to have to schedule any Easter egg hunt around his feeding schedule. It could be a bit busy. But we'll have to make it as normal as we can for the other two. As always, Emma is handling everything with aplomb. Noah remains on a short fuse: Every interaction with him runs the risk of ending in tears or a fistfight. And you get that's it's all stressful for him, but you also don't have the emotional reserves to help him through it.

## Comments

I love the picture of Colin □□
And I am glad you are getting coverage. Maybe the choice to cover your family first is because you essentially are newly home and overwhelmed? Or maybe Colin is younger? Or the scheduling person thinks that with three children at home, you most need help? Or you are a nicer family or more conveniently located family, so more people want to work for you? Who knows? I don’t know— I wish everybody were covered 100%— but I am especially happy your family has help!!!

And for Noah, Is they’re any way to get him some sort of extra support? Maybe a counselor/therapist? (As you don’t already have 117 things to do daily... sigh.)

□□❤

*—Cynthia Meyersburg, April 20, 2019*

So happy you are getting the in home help that you need...pray it continues!

*—Barbara Skipper, April 20, 2019*

Thanks for the pic.
Man, Colin puts the Soup Nazi to shame! Peter also pretty much battles with anything and everything. □□□□

*—Jeremy Cook, April 20, 2019*

## Fake news!

*April 21, 2019*

Well, as anyone who has been following our adventures could have probably guessed, 7 a.m. came this morning and no daytime nurse showed up.

I really should have known.  Christina certainly did, but I chose to be optimistic.  The guy on the roster - Stephan - is apparently a buddy of one of the administrators from our service who agreed to cover a few shifts.  A week or so ago, he popped up on the Easter weekend rotation, but then it came through the grapevine that he wasn't going to be able to take time from his regular job this weekend.  That's when we originally dropped to four days without daytime help.  Then he reappeared on the roster, and I figured that something must have changed on his end.  Christina scoffed and said they had just forgotten to take him out of the roster.  Score one point for pessimism.

Nonetheless, it is astounding how we take this all in stride after three weeks of this business.  No daytime minder?  Oh well, let's change the bandages and set up the feeds ourselves.  I was nearly catatonic at this prospect two weeks ago.  Now we just call it Sunday.

Of course, as luck would have it, Christina and I were up a little late getting Easter stuff ready.  And then we stayed up a little later having a beer and watching "Fawlty Towers." So we were in bed around 12:30 a.m. and then he woke up around 5 a.m.  I honestly don't know what he's running on.  On Saturday, he woke up around 6:45 a.m. and then powered through until about 9:45 p.m.  Best case scenario, he might have dozed off on the couch between 6 and 6:30 p.m., but never for more than a few minutes at a time, because I was trying to keep him awake until a 7/7:30 bedtime at that point.

Anyways, he's now passed out on the sofa next to me and we're learning that, between his insane sleep schedule and his 95 feeds a day, that it's very hard to coordinate any Easter program.  We're going to be lucky if the kids hunt eggs before nightfall.

That said, when Christina and the kids went over to the kitchen this morning for breakfast, he insisted on joining us.  There was a little drama as he tried to scarf some food, but one we got him some toys and then a tablet to play with, he seemed OK sitting with us while we ate.  It wasn't a great feeling on my side, but it was better than excluding him from all the meal times.

I wish I could something with clarity about his status.  So far as I know, he got the valproic acid as prescribed last night and this morning.  Yet he still seems sharper mentally than he has been in weeks.  And he continues to keep trying to walk whenever possible, though he is quick to revert to his leapfrog mode a lot of the time.  We get our house visit on Tuesday and these will be topics to discuss.  I want him off the valproic acid and I am wide open to anything like melatonin that might regulate his sleep schedule.

Ah well.  We're going to let him nap a little bit.  Ricardo is here and, at some point, Easter will begin.  Since Colin can't eat, he has an Easter basket full of toys, so here's hoping that lets us power through the rest of the day with as little screen time as possible.  Happy Easter!

## Comments

Niels I may be totally out of line here because ADD isn't even on the same scale as what you are dealing with. When my kid had difficulty falling asleep and staying asleep I found some children's guided sleep meditations that really helped them. I found them on YouTube and played them through a Bluetooth speaker so they weren't distracted by the screen. You said "wide open" so I hope I am not overstepping. You are all so strong and in my prayers.

*—Lisa Caasko, April 21, 2019*

Happy Easter (even if the egg hunt is a little haphazard). When you wrote about how much energy Colin has, it sounded very hopeful to me, even if it takes a lot for you to manage it. And if he needs to practice walking, he's got the juice to keep trying. It doesn't sound like he has any after effects from the surgeries or treatments that depleted him (although can't say the same for you and Christina!). I was curious about the spring weather and if you have concerns about him being active outside with the other kids.

*—Dan Wooldridge, April 21, 2019*

Happy Easter, Niels! Much love to you, Christina, and the kids. I love seeing photos you post of Colin. He’s gotten so big and looks like such a great kid. You are doing an amazing job and I only wish I were there to help. Stay strong friend. Thank you for keeping us all involved. ❤

*—GF Santos, April 21, 2019*

Happy Easter! The news about your adjustment after two weeks is great to hear. Not that it's easy, but I'm looking forward to hearing how more adjustments bring even a bit more peace to your lives.

*—Jeremy Cook, April 22, 2019*

# Easter

*April 22, 2019*

So, I think we had a good Easter.  Between the fact that Colin can't take food orally and Noah is allergic to eggs, we had to play down a lot of the chocolate and eggs part of the festivities.  That meant the kids got a lot of toys.  The good side of that was that they were all very occupied and remain so: We got a good number of Colin's feeds done yesterday and today without any help from the TV or the tablet. The bad side is that Emma and Noah think Colin's gifts are the best and have spent most of the last two days trying to "borrow" his stuff.  And he's very territorial about it. There's been some drama.

I even tried to distract him by pulling out the Doner Kebab salesman to see if he wanted to skewer some customers.  It only distracted him for a moment, but led to the memorable line from Emma to her brother: "I'm going upstairs to get more people for you to kill." Easter in a nutshell, I said.

In some ways, it grows easier. I notice that I'm taking time every now and then to read or space out, which I certainly didn't do the first week. That said, Ricardo was here the last two days and now Christina's parents are here for a few days, so we're getting a lot of help. And, according to the roster, we have health care lined up for the next week or so (we'll see).

In other ways, it grows harder. I can only speak for myself, but I have no medical training. It is maddeningly challenging trying to keep up with a kid and all his medical needs when you don't know what all is necessary. And then it's your own kid and you have no idea what his diagnosis is and you're trying to order special beds and wheelchairs for him and you can't shake the thought: Will he be alive when it all arrives?

I never claimed to be a perfect Dad. I like time away from my kids. I mean, I really like time away from my kids. And sometimes I'll only play with them 20 minutes before I need a break and other times I can go for hours. But there comes a time when I want a break - where I'd just long to go to work and fuss about a semicolon - but I'm not going anywhere because we have no nurse and someone has to make sure he's getting his food. And in the background, Noah is nagging me to get something for him and Emma is complaining that Colin won't let her look at his new toy and all of her stuff is boring beyond description, and I feel this rage welling up where I just want to yell at the kids and say "Do you have any idea how serious this situation is?"

And I know I can't do that, so I don't. And I should be grateful that he's a relatively easy patient to handle - if you overlook the business where he just won't sleep at night - but you also find yourself just sitting in a corner looking up to God and asking for a quick check to make sure if you didn't accidentally end up in someone else's life, because this isn't the one you signed up for.

I'm not going nuts, but I am seeing how I could if this doesn't get better soon. And I believe it will. And I still don't believe the fears about the cancer returning. But it's still a long hard slog right now.

Tomorrow the doctor's will come for a home visit. Main topics: Can we get rid of this valproic acid poison; Is there anything we can give him to get his sleep back on track; and can we do something so we're not spending 10 hours a day with him hooked up to the feeding tube.

Oh, and to answer some questions: 1) Noah is seeing a therapist. He's been with her for a year or two now. In the autumn, she said he was doing well and the appointments went down to just once a month. We might up the frequency. 2) Colin is allowed to go outside, so long as it's not raining and it's above 10 degrees Celsius. 3) There is no such thing as overstepping if you have an idea or a thought on how we might attack the various problems we're dealing with. I'm open to all suggestions.

## Photos

SHE JUST SMILED AND GAVE ME VEGEMITE SANDWICH
Polizei
Hubschrauber
playmobil

## Comments

I should have guessed you already had Noah seeing a therapist. You and Christina are amazing!!

*—Cynthia Meyersburg, April 22, 2019*

Your feelings and thoughts are certainly normal and similar to anyone that has dealt with kids or dealt with a “catastrophic” family illness. I got the term catastrophic from our health insurance carrier as we exceeded our yearly out-of-pocket maximum and entered new financial territory. Even though we are now on the “upside” of Steve’s health crisis...once the rug has been pulled out from under you....your world is changed forever. It is not all bad by any means....you “see” more clearly what others are going through and more willing to step up as needed. You become more empathetic and caring. You and every member of your family enter a “new normal” on many levels. Our thoughts and prayers continue with you and your family as you tred on this journey. Barbara

*—Barbara Skipper, April 22, 2019*

As I've said or alluded to before, the fact that you're even able to express all this shows that you're not going crazy. I think any healthy parent needs time away from their kids. It's like how on the plane they tell parents to put on their oxygen mask first before the child's. We laugh and think, "Yeah, right, like I would do that." But it's actually true. We'll be no good to them in a crisis if we don't get our oxygen. So go take some big gulps of it!

*—Jeremy Cook, April 24, 2019*

## Wild things

*April 23, 2019*

I worry a little about myself that when new things come up, I can't even muster fear or anger or apprehension any more.  It's just a series of eye rolls and a lot of "oh dear lord"s these days.

So, the tracheotomy tube has to be replaced every three to four weeks, for reasons of hygiene. We kind of wanted the last switch to be last week, but we had a series of hurdles.  First of all, the replacement tube didn't show up until right before the Easter holiday.  Then the doctors who do house visits didn't pull off a visit last week.  So, we all agreed today would be the day.

The house visit doctors showed up as planned.  But that was about the only part that went right.  Colin has had a problem with the tracheotomy for months now, with excessive tissue regrowing at the incision site, potentially blocking the airway and even growing around the tube, preventing it from being swapped out.  The German doctors and nurses call it "wilde Fleisch," which translates to "wild meat" or "wild flesh," which I'm certainly hoping isn't the phrase we use in English.  Katia has been worrying about the growth for weeks now, because it easily gets irritated and infected.  The doctors had been told about this and, after taking one peek, said this is not something they were prepared to tackle during a home visit.  Guess which family gets to make a hospital run tomorrow?

The only upsides to this are that Katia gets to tell everyone how she was right all along and, if we have to go out to the hospital, maybe we can run by this Korean chicken place we all became obsessed with back in December.  The doctors left around 4 and told us we should know the plan in a few hours.  When we tracked them down around 7, we learned that the appointment is at 8 a.m. tomorrow.  Not only is that earlier than we'd hoped, but it comes right when our nurses swap shifts.  We'll have to drag poor Ermin with us all the way across the city (at least it takes us closer to his home) and then Katia will hopefully meet us as the hospital early tomorrow.  If we're lucky, the doctors will be able to clear it up quickly and put in the new trach and we'll be home by midday.  If we're unlucky, it will turn into a bigger procedure and Colin gets a night or two in the hospital.

We also face issues with the tube.  Should the tissue have closed the hole too much, we might not be able to use the trach we have on hand.  Then the question becomes if we can find one that fits and works with Colin right away.  The one he uses is very flexible, which is important, because Colin is a lot more active than some people who have trachs.  Beyond this, something has gone awry with the company that produces the trachs, meaning we might not get replacements before June.  That might just work, but, should we have any issues, and need an extra backup or two, things could get ugly.

Otherwise, we cope.  He's been very tired today, but that's because of his ridiculous sleep schedule (not falling asleep until 11 p.m., waking up around 5 a.m.).  He's been very clumsy.  Is he exhausted?  Is it something with the tumor site?   It's hell living with these thoughts.

Oh, and back to the doctors, this is our third house visit.  Each time, it's been a different doctor-nurse team.  They've all been charming, but we are starting to wonder how this home team is supposed to develop a rapport with the doctors if they never send the same person twice.

OK.  Heading to bed soon, as tomorrow is going to start early.

## Comments

Just a note with hugs and good wishes for a smooth day tomorrow. And I hope you all get some rest tonight.

*—Marci Roth, April 23, 2019*

# Where the wild things aren't

*April 24, 2019*

Our morning run to the hospital went about as well as it could. We're already back home and he has his new trach tube put in. However, we will have more time in the hospital in the near future.

We aimed to leave at 6:30. It was more like 7 a.m. when we left, meaning we squeaked onto the hospital grounds just as the clock struck 8 and it was time for our appointment. We rushed to the ear, nose, throat division ... where they had no idea we were coming. That led to about an hour of clearing things up to get us into their system, so I don't think we saw a doctor until about 9:30 a.m.

Ignorance is bliss, because I found the doctor fine. But Christina was a moment or two from unleashing the fist of death on him, because a lot of the conversation was him asking things like "Why don't you change the trach more regularly?" and "Why do you block with water?" Like Christina is just freelance making these decisions, as opposed to DOING WHAT OTHER DOCTORS HAVE TOLD US TO DO.

The business with the water block is a touchy one. Since he does not have full control of his swallowing, there is always the risk that saliva will drip into his lungs. Or, if he has acid reflux, that could get in there too. The preference seems to be blocking the tube with air, so nothing gets through. But when he's blocked with air, he speaks as if his airway is completely free, so you wonder how much protection an air block provides. Which is why the doctors had us switch to blocking with a water bladder. But, as today's doctor pointed out, should that bladder burst, even three milliliters of water in his lungs could cause some havoc. Basically, we've got our choice of how to wreak havoc with his health, and the doctors can't agree which is worse.

Anyways, asides from annoying Christina, the doctor wasn't too horrified by what he saw. Yes, there is excess tissue and he removed a bit of it with acid. But he got the new trach in and said the tissue isn't hardened and should be easy to remove. But it will have to be done as an inpatient procedure, probably sometime next month. It might be three to five days in the hospital. On top of his day in the hospital for the MRI and two more days where the pulmonology wants to keep him in house to get a better grip on his breathing abilities. We're going to ask if any of this can be combined, but are not counting on it.

In another fun twist, the problem with the trach we've been using has been upgraded from a production problem to they don't make it any more. And why not? Anything else would have been easier.

## Comments

Sorry to hear you'll have more hospital days in May! Hope they can I deed optimise those and that there is a simple solution to the tube shortage!

*—Sofia Gueorgieva, April 24, 2019*

Good grief. I think that is one of the most frustrating parts of the health care system - you get different advice from different doctors and you as a lay person are supposed to sort it all out and decide who to believe. If there is any research we can do on trach suppliers let me know.

*—Liisa Ecola, April 24, 2019*

Anyways...just shows medicine is not the exact science we would like it to be. Many prayers for little and big miracles. Love you!

*—Barbara Skipper, April 24, 2019*

Ugh, so sorry! Doctors! But did you at least get some Korean chicken!?!?

*—Jeremy Cook, April 24, 2019*

# Hospital turf war

*April 25, 2019*

We seem to have started a tiny civil war between the palliative team and the ear, nose and throat division at the hospital. You know, because everyone needs a hobby.

The palliative team called yesterday afternoon to ask how the hospital visit went and I told them about the air vs. water blocking question and how that was causing us some concern. They went and did some research and called Christina back to say a) the trach in question isn't even designed to be blocked with air b) there has never been a case of the water bladder with that model bursting c) it's been tested with up to 50 milliliters of water and d) we only use 3 ml. At one point they were asking for the name of the doctor we met, giving us the impression that a tense conversation was about to begin.

Of course, it's all moot since it looks like they're going to have to find a different trach for us anyways, but at least we clarified the point.

We did not manage to get our Korean chicken since the hospital was too efficient this one time, meaning we left the grounds well before the restaurant opens.  Next time.

And we talked to the doctors about melatonin on Tuesday, they promised to get us some and it was here on Wednesday.  He got his first dose last night and slept for nearly 12 hours.  Granted, he was beyond exhausted when we put him down last night, so that probably helped, but we've had plenty of times when we've put him to bed in an advanced state of exhaustion and he still bounced out of bed after four or five hours.  Whatever.  Anything that minimizes 5:30 a.m. wake-up calls is good in my book.

The downside is that the extra sleep seems to have built up his reserves of strength, meaning we've spent the last two and a half hours trying to wrestle a pair of pants onto him.  Katia also wants to give him a shower today, but I'm worried that's going to lead to someone having a concussion in the bathroom the way he's going.  He has so much strength, but when he walks or crawls, his legs and arms routinely slip out from under him.  I want to see what a physical therapist says, but it doesn't look like a balance issue to me so much as a coordination one.  Just one more thing to eye nervously, I suppose.

## a whim and a prayer

*April 27, 2019*

I long for a day where I think I have nothing to blog about. Honestly, I thought I was having one of those days yesterday.

And then Katia turned on us.

Hopefully it's just a one-time thing.  Hopefully we were all just having a bad day.  But ick.

So, around 3 p.m., Katia calls Christina to say that, even though she had the late shift Friday into Saturday, she needed to leave early - like midnight - because she had to get to a family gathering in Poland. It's problematic because that means Christina and I are responsible for the child from midnight to 8 a.m. - when we should be sleeping - and, really, she didn't know about this family gathering until Friday afternoon?

That said, I'm willing to believe that with all the schedule changes, this Friday shift snuck up on her, because she was not originally down to work last night.  But still, it's shocking she didn't try to sort this out more than a few hours before her shift.

Furthermore, she had promised to show up an hour or so early for this shift because she wanted to show Emin how to change the bandage on Colin's feeding tube and because she was supposed to meet with a pair or nurses who might join Colin's team. The nurses had to cancel on us, but we still thought Katia would show up early because we had heard nothing different.  Also, we had planned to give Colin a bath as part of the bandage change, and Katia is very big into bathing him.  Also, he needed one.

But she didn't come early.  She showed up at 8 p.m. on the dot.  And we kept Colin awake (he should have gone to bed around 7) for the bath.  And then she asked why we'd kept him awake.  She said she told Christina she wouldn't be coming early.  Christina had no idea what she was talking about.  Things got kind of frosty.

It took until 9 p.m. to get him to sleep, and then Christina and I went straight to bed because she was going to take over at midnight and I was going to take over at 4 a.m.  When Christina sent Katia on her way, she got the impression that Katia had not given Colin the melatonin and - BING! - he was awake at 3 a.m.  I don't know what he's running on, but he powered through the morning and didn't go down for a nap until 12:30 p.m.  Christina and I are now in appropriate zombie mode.

Like I said, here's hoping this was just a one-time thing, because Katia has been our rock.  But it brings up a lot of questions about our relationship, because we're terrified of ticking her off for fear she jumps ship, but we also need to maintain order.  It's awful.

That said, Colin had a great few days.  On Thursday I was thinking to myself how I could almost see juggling all this with a regular work life if we just had a team Colin liked.  Even on Friday, when I was by myself with him and Emin for about six hours, I thought things were going OK.  He's been pretty chatty (not necessarily understandable, but chatty) and has even been a whole lot braver about standing up and walking.  Yesterday he spent a half hour standing at a shelf in our living room playing with his fire crews.  That's huge.

Conversely, his crawling seems worse.  His right arm continuously slips out from under him.  I don't know if it's a balance issue.  To me it looks like coordination or muscle weakness, but, then again, I don't want to see him having balance problems, because that's too close to the problems he had when the first tumor scare started.

Christina's parents have been here the last week, taking our house apart (and putting it back together). I barely see them, because I'm chasing Colin around, but they have been keeping us afloat, as Rebekah did until just before Easter. Now that they're leaving tomorrow, I wonder how we'll do this. Just getting dinner on the table is a debacle most nights, because Christina does most of the cooking and Colin so rarely lets her out of his sight.  Yes, I could do more of the cooking, but then Christina is on Colin duty 24/7 and, honestly, she needs a break from it, even if it is just half an hour chopping things in the kitchen. I'll say it again to anyone in Berlin: Whenever we've had people stop by, it's been a relief. It's hard for us to think of concrete things people can do around the house for us. Everything to be done is either stuff that we have to do, like medical bills, or is just too big to wrap our minds around (someday, we are going to have to rip up our entire lawn and start from scratch, for example), but we welcome the break from our reality and the extra distraction it provides Colin.

### Comments

I so wish we were nearby. We would be there! Prayers

*—Barbara Skipper, April 27, 2019*

## Going viral

*April 30, 2019*

This was the week that we were going to start Colin back on his various therapies and get some structure into his life ... and then along came the pain virus.

I have no idea where it came from. All the nurses seem healthy and Christina, Colin and I barely leave the house. But my stomach started acting wonky during the weekend and the older two kids were complaining about their throats hurting. And then Colin just wouldn't wake up on Monday morning. Apparently he was up and about between 2 and 5 that morning, so it was not that shocking to us when 8 a.m. rolled around and he wouldn't stir.  But we had physical therapy at 9 a.m., so we pulled him out of bed.

Not only was he not happy about being woken up, but he had no strength.  He was like a rag doll, barely able to lift his head or even sit properly.  I made a comment that he was acting like he was drunk and Christina, who usually shushes me when I make such comparisons about the children, agreed.  We called in the doctors.

As luck would have it, I'd spent the morning feeling increasingly rough and had already worked out with Christina that I would lie down for a nap after we returned from physical therapy.  As the morning progressed, I lost all energy.  I was freezing.  My arms had a pins and needle feeling.  And all I wanted to do was lie down and keep my eyes shut. Assuming he and I had the same thing, I can completely understand why he didn't want to move yesterday.

But we didn't know that yesterday, and when the doctors came they said what we had been thinking: Either he's got a very bad flu that's wiped him out, or it's the tumor sparking up again.  It's a hell of a world to live in where your choices for childhood illness are "Oh, he's got a cold," or "Oh, he's going to die," with nothing in the middle.

Nevertheless, we're all perking up.  By the end of yesterday he was able to sit and kneel again and today he's been playing in his room with his Duplo all day and crawling and even trying to take steps again.  This is huge, given how much visible progress he made from Thursday to Sunday in the walking and standing department.  Emma stayed home sick today with similar complaints, but she's already up and running, so she either bounced back quickly or took the opportunity to fake a disease whose major symptom is "feeling awful." As for me, I lolled around in bed most of Monday and did the same for a good part of Tuesday morning.  Around midday, I decided I should try to eat and, since then, it's been going well again.  I have to say, there was a period in there where I was terrified that this was not a physical problem, but the beginning of a bad bout of depression.  And all I could think was that we do not have time for me to sink into a funk.  This is not to pooh-pooh depression.  We don't really have time for any kind of illness right now.  We're working at our limits.

The downside is that he didn't get physical therapy yesterday or behavioral therapy today.  We also had to skip his haircut (he so needs a haircut).  Nor did I make it to my therapist, which means I've had a clean sweep of cancelled appointments in April.  The upside was that, since I was down for the count and Christina was doing everything by herself, he got to spend a lot of time with Emin.  While they're still not close personal friends, he's a lot more tolerant of Emin than he was 48 hours ago. And, while neither Christina nor I enjoy palming him off on the nurses, the fact of the matter is that he's going to have to get used to being alone with the nurses from time to time if this is ever going to work.  Maybe it was a blessing in disguise.

We'll see what adventures tomorrow brings.  We just noticed that Katia is down for the overnight shift, as well as for tomorrow's day shift.  I'm just going to assume that means we have no coverage during the day tomorrow, but we have friends coming to visit, which means we can leave some of the household-running to them (thanks in advance Stephan and Sabine!) while we do the medical work for Colin. Or maybe we'll see some fresh new face tomorrow at 8 a.m., ready to become one of the next in our Murphy Brown-esque line of assistants.

## Comments

All I can say is "Vitamin C" - it works wonders!

*—Marc Galmoud, April 30, 2019*

# More of the same

*May 1, 2019*

Katia just called to say that her son broke his foot playing soccer in Slovakia.  She has to go out and help him, because it's a pretty nasty break.  And she's got the day shifts for the next six days.  Sigh.

I can't even get upset about this any more.  I'm just numb to it all.  I feel better, Colin is working his way through his cold symptoms and Christina and I can pull it off for a day here with him, if we just cut out everything but the essentials.  But yeesh...

## Comments

Ugh, of course! So sorry.

*—Jeremy Cook, May 1, 2019*

# The Sorrells School of Nursing

*May 3, 2019*

Well, we're awash in new faces and names right now, learning who will be jumping in to help us in Katia's absence, which days we're on our own and, even, learning a thing or two about who is running the nursing agency to which we're contracted.

We still have no idea when Katia will return.  Christina is guessing mid-month.  She has the son with the broken foot, who is 16, and a 22-year-old daughter, who is prepared to jump in to look after her brother. But Katia, understandably, wants to be around to get things settled.

We were on our own Thursday and, even though I was filled with dread about the whole thing, it went OK. Today we met Ricardo, whom we were told was a brand new nurse with the company. Well, that's not quite it. I figured they meant he had just got his nursing degree on Tuesday. But no, he's been a nurse for 25 years, he just started with the company this week. And, interestingly, he's the new deputy administrator. That job was filled by Nick when this all started. Back then, Nick did the scheduling. Until one day, we were told Nick does not do the scheduling any more. And now Nick is no longer with the company. We asked no questions, but there is a theory that the parting might not have been amicable and maybe there was something Nick was doing to cause so many people to quit in such a short time. Ricardo said this is not how things are supposed to work in normal situations and said that, unfortunately, we had signed on with the company at an "exciting" time. He did not promise that things will get better immediately. However, he mentioned a nurse who is supposed to start with our team soon. And we were told there is another full-time member joining our team on June 1. Hope springs.

There was also talk that some guy, Muhammed, might be in next week, as he also just got his degree and will be joining the team, but maybe that information is all wrong. Anyways, it now looks like he's not coming until month's end.

Then we're on our own during the daytime Saturday through Monday. Ricardo will be back on Tuesday and then he'll retreat into administrative functions while, hopefully, our regular coverage fills in.

However, I would be remiss in not mentioning our primary Ricardo, our former au pair. He lived with us in 2016-17 and just returned to Germany to pursue, of all things, a nursing degree. Ever since Sunday, he's jumped in on an almost daily basis - even if just for a few hours - to keep our heads above water, running errands, keeping Emma and Noah from each other's throats, and even keeping Colin's medical log updated so the night nurse has some idea what happened during the day. Honestly, we're looking into seeing if we can get him extra credit at school for all this. He's been a lifesaver and I can't thank him enough.

Otherwise, we cope. Colin is still a little gunked up after his illness earlier this week, but generally firing on all pistons. We just need to find a way to get him to sleep through the night reliably, because I'm sure that lack of rest is a big problem with him. There are rumors that the doctors are coming around to our argument of getting him off the valproic acid. I might ask what they think about anti-anxiety medicines. I don't see a ton of improvement, but I don't see him backsliding. And, as Rebekah told me before she left, he is making progress, but I might not necessarily see it.

I worry a little about my mind still.  I made it out to my therapist today for the first time in a month and, after some talking, am coming more and more to the opinion that I'm suffering from loneliness.  Yes, I'm in a house with people all the time.  But I'm usually sitting on top of Colin, who isn't much of a conversationalist.  And while I'm doing that, the rest of the household is in other places.  We tend to eat separately, since Colin's trach problems make family meals a nightmare.  And when he sits to watch TV during his feeds, he'll tend to watch the same show over and over, which has caused the older kids to flee the room during his TV time and led Christina to use it as her food prep time.  Having people over is a logistical nightmare, but always a welcome distraction.  But not everyone can make it over at the drop of a hat and, honestly, at a certain point you start wondering if people are just scared to visit you, because what do you say to the guy who's afraid his kid is going to be dead before the year is out?  I think it's paranoia on my part, but, given that I feel like I'm suffering from high-grade cabin fever, maybe it's just a natural symptom.  I do know this: as nice as it was seeing my therapist today, I was almost more excited about the time on the S-Bahn, reading and listening to music.  It's the simple pleasures you miss.

## Comments

If I were you, I'd crave public transportation as well.

*—Kathryn LaPointe, May 3, 2019*

Yep, take those simple pleasures!

*—Jeremy Cook, May 5, 2019*

# The company we keep

*May 3, 2019*

I really need this nursing agency to stop with the drama and just stick to, you know, nursing.

Tonight's schedule called for Stephan to be on duty.  Stephan, as far as I know, does not actually work with this company, but for a different agency, but had agreed to jump in and do a few shifts as a favor for Nick, who may or may not have been fired by the company in the interim. He did two shifts a week or so ago and made a very good impression. Then, around 7:15 p.m., Stephanie (the apparent survivor of the power struggle for control of this nuthouse of a company) called to say that Stephan probably would not be coming as he had gone to the gravesite of his recently deceased father this afternoon and had something like a nervous breakdown.

Oddly, Christina and I didn't even blink or shrug. There was no joy to it, but a sense of "Oh well, guess we're pulling an all-nighter." I'm not even sure I stopped folding laundry when Christina broke the news.

A half hour or so later, Stephanie called to confirm that she had not been able to find someone to jump in. Even Emin - who is one of the nicest people I've ever met - basically told her to sit on it when she asked him if he could pull yet another shift at short notice. So, she was going to come in and do a night shift for us. She just had to drive home - halfway across Berlin - and get some stuff and she'd be by around 11 p.m. to start the 8 p.m. shift. Again, i shrugged, only stopping long enough to wonder how fit a person who had been up all day doing office work would be for a night shift.

About a half hour later, she called again. So, Stephan had recovered from his fit, but not enough to work tonight. However, he's willing to jump in on Saturday, taking a shift off Emin's hands. That was good enough for Emin to agree to come in and do the Friday night shift after all, but it would take him a while to get out here. I only had the strength to ask Christina what she thought about letting the guy who had a nervous breakdown 24 hours earlier watch Colin for a night. She shrugged.

If we had any choices, we would be with a new firm in a heartbeat. But they all seem to be in the same situation and, honestly, we've begun the process of letting him get to know Katia and Emin. We're not very far down that road, but we have started. Switching teams, were it even possible, would mean going back to zero.

So, it's 9:30 p.m. now. Christina and Emin are trying to get Colin to sleep, which will take forever, as he napped. I'm going to have dinner and then wrap gifts, because Emma turns 11 tomorrow. And then I'm going to wonder - and I don't want to minimize the grief Stephan is experiencing about his dead father - how I'm not the one having a nervous breakdown in the midst of all this.

## Comments

Jeez! As if you don’t have enough stress! Prayers!

*—Barbara Skipper, May 3, 2019*

Sorry to hear you continue not getting reliable help :(
But hope this won't be in the way of Emma having a lovely time today - a very happy birthday to her!!!

*—Sofia Gueorgieva, May 4, 2019*

## a hard day's night times three

*May 7, 2019*

Well, it's been a long few days. The low point might have come around 5 a.m. Monday when events conspired to have both me and Christina in Colin's room trying to lull him back to sleep.  At which point we noticed that the night nurse had drifted off to sleep. At least we got someone to rest that night.

So, Emin jumped in Friday night and that was a rough night.  Ricardo helped us out all weekend, but it was still hectic.  And then, on Saturday night, it turned out that Stephan has now been shunned by the team and is no longer on the roster.  Instead, we got Eryan.

How to say this.  Eryan seems really nice.  Like, I think he would make a good neighbor.  I think he'd chat with you over your fence and alert you to little things like "You might want to prune those back" or "I noticed that one cat getting into your kids' sandbox again."  I'm not sure how much I trust him as a medical professional.  He seems to have a problem with either basic instructions, the German language, or machinery.  Perhaps all three.  But we've had several instances where Christina told him to give Colin 270 ml of food at 8 pm, which, to him, became, give him 500 ml at 10 pm.  We just don't know.  It's not like he panics when Colin perks up in the middle of the night.  But he doesn't seem to do anything.  He lets the machines beep.  He comes to get us if he's overwhelmed.  He doesn't ask if he's confused, but tries to figure out some weird new approach that is, usually, wrong.

Between it all, I think Christina got about two hours of sleep both Saturday and Sunday night.  I didn't do a whole lot better.  And then, remember, we didn't have a day nurse Saturday through Monday.  It was exhausting.

As luck would have it, Colin was up at 3 a.m. Monday morning and we could not get him back to sleep.  We offered to put him down for a nap multiple times, but he refused. And, at some point, we realized he was just going to have to tough it out.  So, I got him to bed shortly after 7 and waited for Emin to show up for his shift, hoping that, even if this night were also awful, Emin would at least be able to control the chaos, as he always does.

And then it was 8 p.m. and Eryan was in front of our door and it seems they changed the schedule on us and I almost cried right then and there.

At least last night went much better.  First, he was exhausted, from being up since 3 a.m.  Second, we changed his melatonin dose.  I don't know what factor worked, but he slept almost 13 hours, which was a small blessing from heaven.  We'll see if the trick repeats itself tonight.  It has to, as Eryan is on duty again tonight and, as I told Christina, Colin has to get better before long, because if he doesn't, I'm going to murder someone from this nursing service, and I refuse to go to jail over these people.

In other updates, we got him to both physical and behavioral therapy this week.  He remembered both therapists and their offices and did OK enough, considering he hadn't seen either of these women since November.  And the stimulation seems to do him good.

Questions have been asked about whether we're worried about autism.  I don't know. My only experience with autism is seeing "Rainman," and I don't see Colin that far along the spectrum.  He certainly likes things a certain way and will have a meltdown if things are not done that way, but I'm not sure that's full-blown autism.  After all, he will allow his routines to change, just very, very slowly.  We also still don't know what effect, if any, the valproic acid has on this.  We're supposed to talk to the visiting doctors tomorrow about it.  They at least seem open to our concerns about the stuff, though have made no promises they'll take him off anti-epileptics.  At the very least, they're willing to let him try a different one: levetiracetam, which Wikipedia tells me is known for not having a lot of bad effects on people.  That said, there is a longish list of possible side effects.

As for bureaucracy, we just found out today that we might have forgone 6,000 euros from the insurance that we should have gotten because we gave primary care to Colin for almost three years and he's officially disabled.  But you don't get the money unless you make a new application every month, and no one ever told us to do so.

In other bureaucracy, Christina checked on the status of his bed and wheelchair yesterday and found that no one has moved on the application because they need further information from us.  But no one ever asked us for the further information.

We still don't have a date for the additional surgery on his tracheostomy.  Nor do we have any hope that we're going to get his next MRI before June 20.  That said, I take comfort in the fact that I'm seeing little improvements every day and it's been six weeks since the last MRI.  If the tumor is reforming, it's moving pretty damned slowly.

## Comments

Wow! Truly an exhausting schedule. In times like this I turn to prayer and wonder why God has so much confidence in us humans to handle illness, bureaucracy, inept medical technicians, and general craziness. Praying for relief for you and your family! Barbara with love ❤

*—Barbara Skipper, May 7, 2019*

Giant hugs!

*—Jeremy Cook, May 8, 2019*

# Melatonin madness

*May 8, 2019*

Well, we're on Day 2 of our new melatonin regime and he's averaged 11.5 hours of sleep a night, so there's no complaints on that front.  The new problem might be that 2 ml of the stuff might leave him so zonked out that he's sleepwalking through his day, which is a problem because, when he's tired, his body forgets to process oxygen properly.  He just crashed for an unexpected nap and, when we put on the monitor, we got saturation figures that were well short of the 93% you're supposed to have.

We'll have to see.  I won't lie: I love sleeping through the night, so there's the temptation to just keep him on the higher dose and to ask no questions.  Beyond that, he's had so many bad nights in the last few weeks, maybe the melatonin is just forcing his body to finally catch up on all the sleep he's forgone in the last few months.

I do know I don't believe it's anything to do with the tumor.  Tired as he's been, he's been able to pull himself up and walk when he wants to. He stood for about 20 minutes yesterday because doing so let him look over Noah's shoulder while Noah played tablet. He even climbed into the bunk bed today (with help).  And, if he's just tired, it's a problem we can solve with oxygen in the short term.

The visiting doctors were here again today.  They're so cheerful.  Every time they come over it's like a little party.  Christina serves coffee.  We chit-chat.  We exchange humorous stories about times patients didn't cooperate.  Then we change Colin's bandages or something.  Fine, it's not a traditional party, but it's the best we get these days.

The first order of business was the hypergranulation around the tracheostomy incision, which is getting a little worse.  They still haven't gotten us an appointment yet for when they're going to do this surgery, which is annoying.  So, the visiting team looked at that. Some of this hypergranulation has also started around the incision for the feeding tube, so that also took some attention.  No way to tell yet if that will also require a little extra surgery.

Topic 2 was the anti-epileptics.  The order has come from oncology that he has to stay on them for now, so we'll switch to the new one that supposedly has fewer side effects. But we told them we're not entirely happy with it.  They did say this is not necessarily a lifelong thing and they will work to have a neurologist dragged into the team to look at it, since no one has ever figured out yet what caused the March 20 seizure.  And we're going to keep the dosage low.  We'll see.

As for me, I'm having the oddest moments, one where I'm not completely depressed. Yesterday I felt strange for a few hours until I realized it was my appetite bothering me, a sensation I hadn't felt since March 28.  Today I actually wanted to get in the shower (bear in mind, I have been showering, but until today, it's been me forcing myself through the motions.  Today, I actually thought it might be an enjoyable experience.)  Of course, my feeling better about life has no bearing on Colin's outlook, but it does make dealing with the problems somewhat easier.

And, ending on a good note, Eryan finished his fourth and, for now, final shift.  It was heartwarming, starting the final shift with me showing him how to turn on the breathing machine, as I forced myself not to ask how he'd been operating it the last three nights without this bit of knowledge.  Also, Christina didn't kill him when she found him smoking on the front steps holding the front door open, allowing all the smoke to seep into the house.  That's why she's going to heaven.

## Comments

Hurrah for sleep! Hurrah for a few moments of feeling ok. Hurrah for Eryan's departure (WTH?) I hope you have many more of these small good moments today and going forward.

*—Marci Roth, May 8, 2019*

## a list of woes

*May 9, 2019*

Well, I learned the true face of terror last night.  It was 7 p.m. and our day nurse had to leave (there had been a misunderstanding about the shifts, so she didn't know she was supposed to stay until 8 p.m.). Emin wouldn't be there until 8 p.m., but that was fine. We can handle an hour by ourselves.

And then the doorbell rang.

I figured Emin had somehow learned that the day nurse was leaving at 7 and decided to show up an hour early, because he's precognitive that way.  Instead, I opened the door and there stood Eryan.  Oh dear God, my heart sank.  I was not ready for another night with the village idiot.  I mean, seriously, if this were a TV show, his character would be based on Manuel from "Fawlty Towers."

Well, it turned off Eryan had just wandered off with one of our house keys and wanted to return it.  So, we sent him on his way and Emin showed up around 8 p.m. and then, because Colin took a nap, it took until midnight to get him to sleep.  So, that's a day in our lives.

I'm a bit less upbeat than I was yesterday.  Shortly after I blogged, Colin started wiping out a lot while crawling.  It's like his arm just slips out from under him.  Now, he's been doing this ever since he got home, but it seemed more exaggerated than before.  Maybe he's just tired with all the melatonin in his system.  Emma also came down with a fever today, so maybe he's fighting off something.  But there's always the fear that this is some sign of the tumor returning.  I don't know when we'll ever be able to shake that fright.

Adding to his worries, the doctors are transitioning him from the valproic acid to the new medicine. But that involves having him on both for a week before they transition the valproic acid out of his system. That seems weird to me, like the kind of things club kids curious about mixing drugs will do in their free time.  But we'll follow doctor's orders for now. The question is whether this will make him even more drowsy and out of it.

It's a chore. I used to think I'm a good writer, but you wonder how good you can be if you can't even describe how you feel. I don't sit around worrying about him, but it sits there in the back of my head all the time. I have moments where I function nearly normally and moments where I want to go fetal. I'm surrounded by people in the house all the time, but feel cut off from the world.  I complain that I'm lonely, but then also wish everyone would leave me alone.

I miss my wife.  We're together, but we seem to only have about three minutes a day to spend together, and that's spent discussing nursing of insurance problems.  I miss my kids, because I have no time to focus on them.  But when I try to spend time with them, I find I can't work up the energy to care about what they're talking about.

I have good moments with Colin.  But a lot of my job description these days is trying to keep him busy so Christina can get work done.  It's the most thankless job in the world, trying to keep him in the living room when he's in Mommy-seeking missile mode and trying to get to her in the kitchen. And you can only manhandle him so much, given the trach, the feeding tube and his tendency to pass out when things don't go his way.

When we do play nicely, it's all rules.  We're allowed to play with these Legos, but don't look at those. I'm allowed to make a puzzle, but only if he can smash it the moment I'm done.  Sometimes we can play with cars, but there's a list in his head of which ones I can touch, and it seems to change every day.  Every now and then I'm allowed to read to him, but rarely.  Just about any time I suggest a toy that's not on his daily approved list, I'm rejected.  It's tiring.  And all I can do is keep at it and hope that this switch in medications, whenever it is completed, gets us a kid with whom we can communicate.

OK.  We're finishing up today's medicine and food and then we'll aim for a bedtime that, if we're lucky, doesn't stretch out until midnight again.

## Comments

It is true that a serious illness , physical or psychological, can take a life of it own in the family home. Most of us can handle it....for a defined period of time. Your situation seems to know no bounds, and you have no one who can help you even improve the situation. You go from each small upswing to the next downswing...not unlike a rollercoaster. With Colin it is impossible to determine what is going on...there are just too many variables. It would be interesting if a child therapist (like you need another team member) could observe Colin’s behaviors and give you some insights on what may be adaptive behaviors, because of all he has been through at such a young age, and how to deal with them. Prayers for you, Colin, and Christine every day.

*—Barbara Skipper, May 9, 2019*

## Missing Persons

*May 11, 2019*

Eight a.m. came this morning, and no day nurse with it.  We sent Emin home around 8:20 a.m. and then, until 6 p.m., had no idea what had happened to our day nurse.

It turns out Katia is still in Slovakia. Her son's condition worsened a bit and she couldn't leave him and I guess she was so busy that she couldn't call us or work to inform us.  So, we're on our own tomorrow as well.  And then she's not in the rota for a few days, i think, and then we'll see.

I guess it was kind of nice not having the dread beforehand of knowing we'd have a day without a nurse.  And, in some ways, a weekend without a nurse does let us have something more like a family atmosphere.  But it's still hectic.  And I'm going to say that Colin got far more screen time today than I'd prefer.

I'd say he mostly had a good day.  He was certainly more talkative than usual and had several good moments where he took longish walks from point A to B inside the house.  There was a rough hour or so there where we hooked him up to monitors to see how his saturation was doing with no assistance, with a breathing machine, but no oxygen, and then with the full shebang.  Except for the final version, his levels are pretty rough.  And that could mean a lot more time in his life on breathing machines.  I knew this beforehand.  I'm aware of this.  But somehow, having the monitor out and having that conversation left me a depressed mess for an hour.  But then we played and read the Gruffalo, so that helped.

In bureaucratic fun, the health insurance company sent us a letter asking us to be patient, they're working on the request for a wheelchair for Colin.  The simple fact they took the time to send us this letter - as opposed to acquiring the actual wheelchair - is kind of impressive.

## Comments

Impressive! Prayers...

*—Barbara Skipper, May 11, 2019*

## Guessing games

*May 12, 2019*

He had a pretty good day today.  He tried a few new things.  He walked further unassisted than he has in the last month and a half.  He was very vocal.  Friends came over and he played with their 4-year-old for a few minutes, which is the most social I've seen him be with a stranger in ages.  He's nowhere near where I want him to be - or to where he was last autumn - but it's still improvement.

Of course, this starts the gears turning.  Why now?  What has changed?  What does it mean?  My non-medical theory is that the new anti-epileptic is blunting the worst effects of the old one, but I see how silly that sounds even as I write it down.  You just wonder if this is a good sign, or just the universe letting us get our hopes up as it sets us up for yet another major disappointment.

Tomorrow we meet Mohammed (Mo-Mo, I'm told he likes to be called) who will apparently be the third full-time member of our team.  We're not sure if we have a night shift.  Stephan - the guy who bailed after the nervous breakdown at his father's grave - is down on the rotation, but we heard the boss is so mad at him she kicked him out of the company.  Not so fast, we say.  No, we weren't happy about that night either, but who are we to judge how someone copes with grief?  And, anyways, if our choice is between no one and Stephan, we're going to be big fans of Stephan.

I keep hoping maybe this week will be the week that gets us through all this.  My mother-in-law is coming on Tuesday to help out for a week and then Christina and Colin go into the hospital for two nights at the end of the week so he can get started in a breathing therapy program.  When that's done, maybe the fourth person on the team will have joined, Katia will be back in Germany and maybe we will have our heads on straight.  I keep telling myself this, but I'm getting too used to the universe pulling the rug out from under us just when I think it's going to be OK.  I mean, I look at the last few days with all the absences and I honestly don't see how I'm ever going to get back to work, or at least in any kind of reliable fashion.  And I want to return to work, I just can't leave Christina and say "Keep the kid breathing all day" and then be on my way.

We are supposed to start cycling the valproic acid out of his system starting tomorrow.  I have hope that once we get rid of that he might chill out about a lot of things (letting us use the finger sensor on him, letting us brush his teeth, letting him stay in a room by himself for a moment, letting him leave Christina alone for more than three minutes) and make our lives significantly easier.  But I also keep telling myself not to build my hopes up too high, just in case the universe has other plans.

Aside from the fact that we did the nursing agency's job all weekend, it was a good two days.  Once Ricardo heard about our lack of Katia, he came out to spend the weekend with us, putting together a Mother's Day cake and keeping everyone in coffee.  Honestly, I don't think we'd still be a functioning family without his regular visits.

My friend Marc also visited on Saturday, whereas Claudine and her family and Sabine and a lot of her family came on Sunday.  I can't tell you how much I enjoy these visits.  Just hearing about other people's lives - people who have been outside this house in recent memory! - is so nice.  It really helps me get through these days, even if, like Marc, you show up in the middle of us having what those in the industry call "compliance issues" with our patient, who did not want to sit still any longer for his feed.  And then Marc stayed and it turned into a properly nice night filled with Amaretto, which might explain why I could barely function until about noon today.  At least I hope that's the reason, because I'd rather not be suffering from depression if I can help it.

## Comments

Sounds like some progress and flashes of normalcy, which is all any of us ever want no matter what creates the chasm. Continued prayers!

*—Barbara Skipper, May 12, 2019*

I so wish I could be one of those visits!

*—Jeremy Cook, May 14, 2019*

## the nurse

*May 13, 2019*

A prospective nurse for our team showed up for his interview today by motorcycle. I needed to get that sentence out of my system.

Sent from CaringBridge iPhone app

## Comments

I think I'd take somebody who showed up on a skateboard at this point...

*—Liisa Ecola, May 13, 2019*

Take her.

*—Boris Babic, May 13, 2019*

Him.

*—Christina Sorrells, May 13, 2019*

Was he wearing a helmet! That would tell you all you need to know! Lol

*—Barbara Skipper, May 13, 2019*

But did the nurse have a sidecar on the motorcycle?

*—Cynthia Meyersburg, May 13, 2019*

# Layla

*May 14, 2019*

There's apparently an employee at All Care, the nursing agency, named Layla. I only learned about her existence yesterday. It seems she might have been on vacation a lot during our early weeks. Here's some hope that was part of our problem.

Christina had a longish conversation with Layla yesterday during which Layla expressed shock that: we'd had days without nurses; that we were willing to go a day without a nurse if it meant that we had a night shift; and that no one in the main office had offered to jump in to fill all the unmanned shifts we'd had since April 1.  Basically, everything we've come to expect from this company is unacceptable to her.  Hopefully she has the wherewithal to improve things.  I don't know where she stands in the heirarchy, but she sounds like a force of nature.

Christina had to talk to her because it became clear that, even though they had parted ways with Stephan after his breakdown, no one had thought to find other people to fill the shifts he was still slotted to fill this month.  There was a lot of back and forth and Layla said she would find someone.  Within half an hour, she called to say that "Gereon" would be in Monday night.  Later in the afternoon, Christina wondered out loud if she might have said "Eryan," which turned out to be the case.  So, in good news, we had a warm body in the house last night.  In bad news, it was the village idiot again.

I wonder if he's just bad with technology. All the devices we have beep here and there when you're turning them on and off.  There's no way to set up the food pump without at least two beeps.  But every time Eryan is left alone in the room, it's like a techno concert just broke out in there.  Thanks to the melatonin, Colin sleeps through it, but it doesn't actually induce sleep for the rest of us.

Anyways, Colin survived the night and maybe this time we're done with Eryan.  Momo is back today and he and Colin already seem to have a rapport.  Colin has already sat and played with him and allowed himself to be carried.  It's kind of impressive.

Coincidentally, we had the first big drop in the valproic acid dose yesterday.  Just saying. Here's hoping we keep getting this down on a weekly basis.

As for the rest of our team ...  We still don't know what's up with Katia.  Everyone is perfectly understanding about the fact that she had to go home to Slovakia to take care of her kid.  People are less understanding that she's been incommunicado and didn't warn anyone she wasn't available for her shifts last weekend.  It looks worse because those missed shifts came just before this week, when she was supposed to be on vacation, so there's a bad look to it.  I'm torn.  If she keeps flaking out, I don't need her on the team.  On the other hand, I'm so worn out by this process that I'll take anyone with a pulse.

Christina and I had a rare moment to speak last night and she said Layla told her at least two other people are prepared to join our team starting in June.  The motorcyclist (who had a helmet, but no sidecar, but did say he's happily take Colin for a ride) seemed very nice.  He has training in helping people wean themselves from breathing machines and he seemed very competent.  A bit squirrelly, but not to the degree that I don't think we could work with him.  We'll see what he decides.  He made no promises as he left, but said he had a good feeling about us.

Emin comes tonight. He seems able to keep the machines silent. And then Christina and Colin are in the hospital Wednesday and Thursday night for his introduction to breathing therapy. I keep having flashes where I think we might pull this off, but I do hope I'm not deluding myself.

## Every breath he takes

*May 17, 2019*

I read recently that some scientists believe that depression is actually an evolutionary tool used by the psyche to convince people to give up jobs or goals that are hopeless. The weight of it is designed to make you just quit, so you invest your energies towards a goal that has a chance.

I have really mixed feelings about that theory, now that I've officially slipped into the ranks of those diagnosed with depression. It's no surprise I suppose, given everything that's been going on. But it is a noticeable difference, this transition from "My God, this sucks" to "All I want to do is sit on the sofa and sigh."

I was actually not on board with the theory that I had depression - I mean who wants that diagnosis - but my doctor says it fits.  For about a week now, I get up and get the older two ready, which takes up all my energy.  Then I sit down on the sofa and stare for 1-3 hours.  I'll get up if something major happens or I'm needed.  But if I'm not, I just go away mentally.  My therapist says this kind of morning depression is common and that we're going to start trying to treat it next week with some medication.

I don't want anyone to worry that I'm thinking about doing something stupid.  I still have my wits about me.  I just need some help to get through this phase.

As for our overwhelming challenge, he's currently in his room decidedly not going to sleep, a major curiosity since he's been awake for 14 hours, bar a half-hour nap on the way home from the hospital today. He didn't even get to sleep the whole way home because we had to stop at the mechanic's and drop off our car for a loaner when we realized our battery was fading. The theory is that our alternator is about to go out.  But what a strange moment in our lives.  We decided to head home without a nurse because we were feeling scampish and then we found ourselves in the middle of the street, transferring Colin and all his breathing apparatus from one car to the next, acting like it was the most common thing in the world as the receptionist helped us fasten the car seat into the loaner.

They did a lot of tests on him in the hospital.  They checked how he breathed on his own.  They checked how he breathed with only oxygen.  They checked how he breathed with the breathing machine and oxygen and then with the machine but no extra oxygen. If I'm getting this right, the consensus is that he's actually getting enough oxygen, but his body isn't getting rid of the carbon dioxide properly.  Its unclear if this is a physiological problem or a neurological problem or something he can teach himself to stop doing eventually.  It means he's probably going to have to spend slightly more time on the breathing machine than he has been doing, but he is allowed to be off it for up to an hour at a time.  And, who knows, the tests were done while he was reclining in bed watching the tablet.  Maybe his levels are better if he's running around chasing siblings. Then again, we can't perform the blood tests here at home to check his blood levels (or, at least, we probably shouldn't), so maybe we'll never know.

But at least we feel like we might have gotten some pointers in the right direction. They've now set his machine to give him more inhalations per minute, which they hope will help drive the carbon dioxide out. He's also going to get an vaporizer attachment for his breathing machine, because an X-ray showed there is still some gunk in his lungs and that's keeping some parts of the lungs from performing.

In all, the hope is we can get his carbon dioxide levels back to normal and teach him how to keep them there.  Too much carbon dioxide can fuzz the brain ... and he's already got enough of that going on with the anti-epileptics.

It also raises questions about why none of this was done back in the rehab when they were trying to ascertain how well he could breathe.  But it's starting to look more and more like, if not three wasted months, at least three months not used to their full potential.  We really like the doctor at this new hospital though.  When faced with a bunch of contradictory results (his oxygen rates were better off the machine than on?) he said, look, we treat the patient, not the monitors and the results. That was good to hear.

In bureaucratic news, the insurance company requested the bed recommended for Colin and suggested a bunch of cheaper models.  However, none of the cheaper models are height-adjustable, meaning that Colin would be unable to get into any of them on his own.

I think it's just part of the mindset where health care assumes that a child on a breathing machine is going to be immobile and lifted into bed anyways.  None of the models really work for a child as active as Colin, who bolts about, but also needs oxygen and feeding tubes.  And it's a good problem to have in the long term, even if it makes caring for him right now a nuisance.  There was another boy in his room today who looked a few years older but was barely responsive.  Yes, it's easier to keep him hooked to the machines, but this would not be the outcome anybody wants.

And then I look at the situation and realize our "glass half full" version of the story is that, at least our child isn't in a vegetative state. And then the depression makes a lot more sense.

Still, there is hope. We're cutting the anti-epileptics.  Perhaps we're on a path towards getting his oxygen levels up and his carbon dioxide levels down.  Maybe this will get his cognitive skills where they need to be.  We met a lady in the hospital - and she seemed to have had a lot of health problems behind her - who said she also had a trach as a kid and she eventually learned to breathe and eat so it was no longer necessary.  There are plenty of scenarios where Colin could be that person as well.  But it's going to take a lot of energy to get him there.

## Comments

I pray for God’s healing of your depression. I was diagnosed with it as a young adult and treated for it with therapy and medication. Depression is more common than most people realize. I pray for your healing and for Colin’s healing. Love you all!

*—Barbara Skipper, May 17, 2019*

May you have the energy to get there!

*—Jeremy Cook, May 18, 2019*

# Nomo

*May 19, 2019*

So, Momo had a bad night with Colin because Colin wouldn’t sleep. An hour after his shift ended, Laila called to say Momo doesn’t want to be on our team any more.
Sigh.

Momo has almost every night shift for the rest of May. We’re waiting to see what the nursing service figures out.

Sent from CaringBridge iPhone app

## Comments

This doesn't sound good. Not at all... Hope there will be a good solution!!!

*—Sofia Gueorgieva, May 19, 2019*

Momo, you disappoint. So sorry!

*—Marci Roth, May 19, 2019*

Oy □□

*—Cynthia Meyersburg, May 19, 2019*

Ugh! So sorry.

*—Jeremy Cook, May 20, 2019*

Sounds like he wanted an assignment where he could snooze most of the time. Prayers for finding a replacement! Barbara

*—Barbara Skipper, May 20, 2019*

# This mess we're in

*May 20, 2019*

Well, let's focus on the positive first.

Colin is having a string of very good days, if you're willing to overlook his abysmal night-time sleeping habits.  He's speaking more.  He's sitting and playing with concentration, to the degree that we've been able to get entire feeds into him while he just doodles along with his cars.  Yesterday he hid a car behind his back, told me "It's gone," and then pulled it out saying "Here it is."  I didn't see associations or speech like that a week ago.

Today, we parked three blocks from his physical therapy and, because his wheelchair is in the car that's in the shop, I was going to carry him.  But he walked the whole way and back, more walking than he's done since he's been back home.

As for me, I'm feeling oddly better.  I haven't had a deep morning depression for a few days now.  And I haven't even started taking the medication yet (we just picked up the prescription today). I actually feel weirdly calm (weird because: read the rest of the blog).  The main source of tension is my meeting with the insurance's medical team tomorrow, who have to agree with my doctors that I am indeed long-term sick.  If they don't, I'll have to go back to work and I have no idea how the family will pull that off.

Enough of the positive. Let's focus on the normal, everyday nightmares.

For example, the fact that Colin is more vocal is apparently one of our problems.  Sometime in the wee hours of Sunday, he told Momo to sit down in a chair.  Momo apparently felt insulted by that and used it as one of his reasons for no longer wanting to work with us.  The rest seems to be concerns about the team we have working here, as such.  He said he got different instructions from Christina and his colleagues about medicines to use, couldn't find things and felt the record-keeping was sloppy.  I feel very judged by all this, even if I had no control over it.

Anyways, he's not coming back and now the problem we have is that he had a ton of shifts before the end of the month (Mercifully, he has none in June. We just have to hope the two new people introduced into the roster that month actually stick around).  To wit: We have no night-time nurse tonight.  I should be excited about this.  Instead, it's just "Oh, I'm going to wake up at 3 a.m. and watch Colin."  And, if the past few days are any indication, that means I'm going to be playing with Colin from 3 a.m. until 5:30 or so.  It's a good thing he can play with concentration these days folks, because I'll be a bleary mess (though it should make my argument that I'm mentally ill more convincing when I go to the insurance company later that day).

The last time I had to do one of these, I was scared out of my mind, trying to figure out how I'd stay up all night.  Now I'm just going to doze next to him, if that's an option.  I mean, he's breathing so much better since they reset his machine and, honestly, I'll hear the alarms if they go off.  You can hear them from anywhere in the house, which is one of the reasons I'm so tired all of the time.

Hysterically, our new case manager from the nursing agency wants to meet us at 8:30 a.m. tomorrow, knowing full well that we'll just have pulled a shift she couldn't fill.  That should be a testy meeting.

With our car in the shop, we don't know if we can use it to get to the medical pre-checks on Wednesday for Colin's surgery, to get the tracheotomy incision cleaned up.  We're working on some kind of transport, just in case.

Awfully, they have confirmed that surgery for Thursday (no promises yet on the MRI), but we have to check with the intensive care unit Thursday morning to make sure they have a bed for him.  If they don't, this planned surgery is called off and we have to attempt the whole adventure again at some point in the future.

And, bear in mind, we don't know if the nursing agency is going to be able to fill many of our shifts in the next 10 days.  I don't even want to think about what happens if this surgery doesn't happen and we're suddenly home on days they were expecting us to be in the hospital and had already reassigned staff.  I just kind of foresee Christina and I being full-time nurses until June, with Emma and Noah being left to fend on their own for the duration.  I can't wait to see how I feel about the situation once I start taking the anti-depressants.

## Comments

Prayers...and more prayers

*—Barbara Skipper, May 20, 2019*

Hugs and more hugs. And I judge Momo not you guys! Sorry, had to be said. Puhlease, who gets offended when a small child tells you to sit down. Issues, much? I hope everyone gets some sleep and rest.

*—Marci Roth, May 20, 2019*

# hospital-ity

*May 22, 2019*

Just to save everyone the stress: Things today turned out about as good as they could today, but it was a rough road getting there.

So, when I went to bed last night, the plan was that we were going to go to the hospital today, get the pre-op meetings out of the way and then get Colin admitted to the hospital so that he was in the system and there was no chance that everything would fall apart if there was suddenly no bed free on Thursday.  I was especially partial to this plan since, now that Momo has cancelled out of so many shifts, it gets Christina and Colin in the hospital where they have people watching them and gives the nursing agency time to figure out a coverage plan for when we're all back home.  I went to bed last night with a sense of ease and actually got some good sleep, in no small part thanks to Emin, who knows how to handle Colin and even kept him busy from 2 a.m. (when he woke up ... sigh) to 5:30 a.m.

We had ordered a medical transport for 8:30 a.m.  Neither of us is sure why we did this. Even though our car is in the shop, we have a loaner.  True, his wheelchair is in the car at the shop, but we pulled out his old buggy.  We should have been able to drive ourselves.  But, at the time, it seemed like a goo idea to order a medical transport.

Except 8:30 a.m. came and they were not there.  Christina started making calls, to find out if we should just drive ourselves after all.  In the course of this, we learned that there was no bed free for Colin today and unlikely to be one tomorrow.  The best they could offer was that we would just call the hospital every day for the coming days to see if this would be the day we should head out.  Who knows how long that would have taken?

I fell apart a little bit at this point, because I saw us never getting him to the hospital for this surgery and sitting around the house for the next few days with no nurse.  Then the hospital called and said we should at least get the pre-op talks done today.  And then the medical transport showed up.  And we figured, we might as well get this done and, if we go to the hospital, we're at least surrounded by medical professionals, unlike here in our home.  In a brief swell of optimism, I still told Christina to take the overnight bag for her and Colin.

The transport team got us up to the ear, nose and throat division and Christina disappeared with some administrators.  Colin and I hung out in the lobby, him sleeping, me trying to figure out what awful procedures had been performed on all the other patients' noses, when odd rumors began to trickle up from the administrative side. Maybe there was a bed after all.  Maybe the surgery would happen tomorrow.

And indeed, that is the plan now.  There was even an MRI cancellation, so they're going to squeeze Colin in there.  As of this moment, Mrs. Hansen in the ear, nose, throat division is our new hero and, honestly, we're trying to talk her into taking over at the nursing agency to get that place running properly.

Now, bear in mind, this is the hospital, so they're quite resourceful at screwing up things, but the plan right now is that, tomorrow morning, Colin will get an MRI, he will have his tracheotomy incision cleaned up, and he will have a full test of his upper breathing passages.  I've lost track of what order that will all be in.  And then they'll have to stay in the hospital through at least Saturday.

Honestly, I am so happy with the outcome.  I'm not much of a praying person, at least not the kind who prays for specific things from God.  But I was praying so hard during the entire ambulance ride and wait in the lobby that this might just work out because, come on, we need things to go our way for once.  it's a small something, but having a medical procedure scheduled as planned and having nursing care for Colin feels like a major victory at this point.

Of course, I had long written off the chance that the MRI would happen during this visit.  Now we've got that to face, so there's a possibility that, in the next 24 hours, we'll know if we're playing a long game or an endgame.  There's also a decent chance we'll just get another murky outcome.  I'm not sure which scares me most.  Endgame means Colin is going to die soon.  Long game means we have to figure out how we're going to get Colin through all his health problems amid our nightmare of a nursing care plan.  Just trying to manage his day-to-day issues feels overwhelming still.  I don't know how Christina and I will ever have a life that is not dominated by Colin and his needs right now.  I don't know how we're ever going to have time for more than a few passing moments with Emma and Noah at this point.

And murky means we keep muddling on as we've been doing.  Except now Christina and I both have our prescribed anti-depressants.  And we just found out that we're not supposed to drive when we are on them, which will further complicate our lives.

Other bits and pieces:

- Katia seems to think she can get Momo back on our team. I'm not sure why she thinks she can do this, since she only met him Saturday, but I'm curious.

- The insurance doctor approved my long-term sick leave. It was an exhausting process, showing up for an 11 a.m. appointment and then not seeing a doctor until 1 p.m., at which point I got to lay out the whole tableau of awful that is my life.  I did not expect the doctor to go full Oprah on me, but let's just say the most sympathetic she got during the session was to say "Yes, that must be exhausting."  Whatever, she stamped the form.

- It's been a few weeks, but the pool where I broke my nose responded to my letter of complaint and basically said that they did everything right and, come on, they had 8,800 customers that day, so how could they be expected to take care of the guy bleeding into their water?

- Also a few days old: The court system wrote me that they are ending the traffic court procedure against me for my accident and I'll only have to pay relevant court costs. I'm not really sure what happened here.  I got a letter saying I had to pay a fine.  My lawyer asked for more information.  I got a letter with more information and a second announcement of the fine. After some urging, my lawyer sent a letter saying we object. Now the case seems to be closed. I really wish I had the energy to figure these things out.

- We have managed to get Colin's melatonin intake halved in the last few weeks. We might have to see about doubling his melatonin though, since his sleep has been off-the-charts awful. That said, now that the doctors have adjusted his breathing machine, he barely needs oxygen any more (still a horrible sentence to write about a kindergartener) and is suddenly a lot more social and able to play by himself for longer periods of time, with significant concentration. He'll even stay in the room with Katia and Emin and play with them for short spells, instead of demanding that Christina and I be around full time.

## Comments

Prayer works!

*—Barbara Skipper, May 22, 2019*

Resiliency! You guys are the photo next to the definition of that.

*—Jeremy Cook, May 22, 2019*

# So far, so good

*May 23, 2019*

It was a morning of back and forths. We were told they would start all the medical procedures around 11. Then they took him away around 9. But, as near as we can tell, nothing really started until 11 anyways. And then, when they brought him back to the room, no one had warned the team at intensive care, so they weren't at all ready for him.

Meanwhile, I didn't get there until he was gone thanks to an extended adventure with Google Maps.

Anyways, all the procedures went fine. They're optimistic that it will at least be easier to control the hypergranulation around his tracheotomy incision in the future. They saw nothing in their tests of his lungs, ears, throat, etc. that caused too much worry.  I don't know when we'll get the MRI results, but no one has called us in a panic yet to say they've found something terrible, so that's something.

## Comments

Yay for a smooth day...despite Google Maps!

*—Jeremy Cook, May 24, 2019*

## End of the affair

*May 24, 2019*

Everybody, I think we're about to embark on a spectacular break-up with the nursing agency. Like a Mia Farrow/Woody Allen-level bad break-up.

The short version is that there is no medical reason Colin can't leave the hospital tomorrow after his surgeries. But, since the service can't get a nurse lined up for tomorrow night or Sunday morning, the doctors feel it would be irresponsible to send a child with breathing problems who is fresh from surgery home for a 28-hour stretch with no medical supervision.

I hate everything about this.  I hate that the service can't get its act together.  I hate that Christina and Colin are stuck there one extra day.  I hate that I'm happy that they're stuck there, because as miserable as it is for them, at least they have medical care there.  I hate that, when they come back, the service will be able to cover night shifts, but won't have any day nurse there again until Saturday at the earliest. The only glass half-full way I can look at this is that I'm so angry that it might be overriding my depression issues. And, if I'm facing anger issues again, it puts me back on familiar psychotherapeutic terrain with my doctor, which could also be a real time-saver. Otherwise, I'm just so annoyed.

I'm willing to believe that, back in March, when Nick and Stephanie introduced themselves, that they had a team of people together who would be good for Colin. But then they lost half a dozen team members in the weeks that followed and, in hindsight, probably did not have a team on hand April 1 that was good for Colin. Instead, they pulled together a team of second-stringers and people on the verge of quitting because of some dispute about overtime pay and tried to sell that to us as a care team. And we all know how well that worked out: We asked for help and they sent us Eryan and his Medical Instrument Techno Party.

Then they hired Momo and told us all of our problems were solved. But Momo ran, and I don't think it was because his shift was particularly bad or because Colin told him to sit down, but because he saw how incomplete our medical files were and realized that he faced serious liability issues if he were to work under these circumstances. These are the files that were supposed to be put together by Nick, but he disappeared. And when Katia raised her voice and said these needed to be fixed, nothing happened. And then Katia had to go to Slovakia for half a month to deal with her son's broken foot, so everyone forgot about it. And now Manuela (the new Nick) is going through the files and telling us how awful they are, like it was our job to handle this, and one can't escape the impression that this company is very interested in getting the paperwork together so they can rake in the cash from the insurance agencies, but not so interested in finding a replacement worker almost a week after their promised star nurse quit a job because they didn't have the documentation done up to standards.

In the end, we'll probably keep some kind of cooperation with this company, just because we want to keep Katia and Emin on our team. But we're going to start looking around for other agencies that might be able to work with them or services that can supplement the care. And if that means our company gets less of the financial pie, well then, they should have done their job right.

I know several of you have probably been screaming at your screens these last few weeks, essentially yelling at us to dump this team and end this abusive relationship. So I get any frustration that we're keeping them somewhat in the picture, but having some minders Colin halfway knows is huge. And the truth of the matter is that we've been wandering around dazed since the start of April, just hoping it would all get better and that we might get some sleep at some point as well. We haven't had it in us to kick up a fuss, until they just made things so awful we have no other choice.

To any of my German friends reading this, if you're into the medical or legal professions, I would love to know your take on this. It's not like I want to sue the company: i don't have the energy. But I feel someone should know how uncaring they've been about this whole situation. How willing they are to just leave us high and dry. How incapable they are of putting together a team and then making sure that team works. I mean, Christina calls to say we'll be out of the hospital Saturday afternoon and their response is "We'll have someone there Sunday night"? And then they try to make it better by pointing out that new people are starting on June 1. Like, first of all, the first few days of a new nurse are exhausting, because you have to show them everything. And, honestly, I have so little faith at this point that someone who shows up for a shift or two will actually return for a third one, that I can't treat June 1 like it's going to be a major breakthrough date for us.

And through this all, Colin remains in the hospital, glued to his tablet, because that's almost all he will do when he's trapped in bed.  Christina is losing her mind because he sleeps so badly there, meaning she's chained to his side.  And I'm shuttling back and forth between the house and the hospital, feeling like I'm not really doing anyone any good.  Christina is still frazzled and the kids are still feeling abandoned.  It's like we're breaking down slowly as a family unit.

Not only is the hospital miserable, but it continues to irritate.  Remember how they won't bring parents food to the room?  It gets worse.  Christina can't get a room this time, meaning she's not officially admitted, meaning she's technically a visitor.  That means she doesn't even get coupons for food.  They do have a knack for adding insult to injury there.

As for me, I thought I had bottomed out on my weight loss, but I checked myself on the scale and am now pretty sure I'm the lightest I've been in my adult life.  Like, in the last few weeks, I've metabolized calories I laid on during the Clinton administration. Depressingly, only after losing this much weight, am I no longer considered overweight in terms of BMI.

We're going to have a tough week ahead, with only night shifts starting on Sunday.  I won't lie: I briefly pushed today to put him in a kind of hospice, just so we had a place for him with medical care.  I'm getting desperate for ways to keep him safe, because I don't think we can do it.  But Christina is right, we'll pull it off, even if we don't sleep for a week.  That said, if you're nearby in Berlin, I'm officially calling for help.  Is anyone going to IKEA soon?  Is anyone going to a hardware store soon?  Does anyone know of a teenager willing to mow our lawn for the going rate?  I'm not even sure how we're going to swing grocery shopping for the next few days.  We'll take any and all help.

## Comments

I am so so sorry, my friend. And trust me, I have never thought for a second about yelling at my screen. There's simply no simple solution to what you're facing, and in the midst of a terribly complicated decision, you're making the best decisions you know how to make on little sleep and no margin. Oh, may you know peace and, dare I say, even some justice at some point soon!

*—Jeremy Cook, May 24, 2019*

I am speechless! Are there other agencies that provide such services in your area? Can you hire, and insurance pay , for a 2 free agent nurses to pull 12 hour shifts? We have friends here with a severely disabled child who do just that. A third nurse handles the weekends. Hmm...you have every right to be angry.

*—Barbara Skipper, May 24, 2019*

I wish I was in Berlin.

*—Kathryn LaPointe, May 25, 2019*

## sanctuary

*May 25, 2019*

There was a brief rumor this morning when I got to the hospital that they were going to send Colin home after all.  That turned my stomach into knots nicely, but five minutes later, a doctor showed up and assured us that we weren't going anywhere tonight.  I must learn to arrive at the hospital later.

Colin is doing fine, though he's pretty much permanently plugged into the tablet while he's in the hospital.  It's going to be ugly weaning him off that thing once he's back home tomorrow, but that's part of the deal.  And here's hoping his sleeping patterns aren't as much of a mess as they were when he got back from the other hospital stay last week.  It's hard enough caring for a sick child.  It's hard enough caring for a sick child who doesn't cooperate with his care.  It's that much harder when you're not getting enough sleep.

The only other excitement was that they did the monthly replacement of his trach tube today.  They were supposed to do it Thursday during the surgery, but the doctors got confused.

No one has said much about the MRI.  I would hope someone has looked at it by now, but no word.  The panel of experts probably won't look at it together until Tuesday.  I don't know when they'll call us in to tell us what they found.  Given that we have no nurse and the kids come home around 2 p.m. most days (when, if we're lucky, the doctors are just showing up for their 11 a.m. appointments), they're either going to have to talk to us by phone or wait until June.

I keep being annoyed by the nurses.  I did the math last night and realized that, by the end of this month, out of a possible 62 shifts, they will have not filled 26. That's a 58% fulfillment rate.  And still, they seem confused about why we're so annoyed.  Let's hope some of our meetings next week with other health care teams yield some useful results.

## Comments

Here’s to a great week next week! May all that you need to happen actually happens. May there be an actual break in the bureaucratic anarchy that you have been experiencing! I can wish can’t I? Prayers. Barbara 8-)

*—Barbara Skipper, May 25, 2019*

If they were playing baseball they'd be millionaires with that batting average! But as students? Muy mal!! Caring for a sick child? Geesh!

*—Jeremy Cook, May 26, 2019*

# pill poppin’

*May 30, 2019*

I’ve taken my first antidepressant, proving I’m more motivated by loved ones telling me to take my pills than I am by fears of potential side effects.

So far, I can report a great sense of calm, bordering on just not caring about anything. It’s kind of a nice feeling, though I’m not sure how helpful it is, given our lack of a daytime nurse until Saturday.

Sent from CaringBridge iPhone app

## Comments

Hope any side effects will be mild and need a lot time to show...

*—Sofia Gueorgieva, May 30, 2019*

And I will add a wish that any side effects be transient! And remember that if you have intolerable side effects, you can change to a different medication.

*—Cynthia Meyersburg, May 30, 2019*

I've tried a few, and my reaction has varied a lot to them. Don't be afraid to try a different one if you don't like how this one is working. I hope they help because — jeesh — can't think of anyone who deserves a little peace more than you and yours.

*—Kerri Kennedy, May 30, 2019*

Like floating on clouds with a brain full of cotton. Lol Prayers

*—Barbara Skipper, May 30, 2019*

I took something like that for a while after a family tragedy. Numbness was a nice break.

*—Kathryn LaPointe, May 30, 2019*

## Prayers please (2019)

*June 7, 2019*

I'm afraid we have bad news. The MRI results are back and the tumor is active again. There is no treatment the doctors can recommend: Anything they have left in their arsenal would degrade his quality of life incredibly, with next to no chance of success. They cannot tell us if he has days, weeks or months left.

We've actually known for almost two weeks now, but didn't want to spread the word until we had a chance our options and to tell Emma and Noah ... and we wanted them to get through the worst of the academic year before we laid this on them.  We had the talk this afternoon.  They're taking it as well as can be expected.

We are considering a hospice option, one with a family apartment that would let us all be near him. It's here in Berlin and it seems very nice, but we have not yet made the decision if this is the right step for us.

There is other news from this or that front, but none of it seems appropriate at this point. There will be other blog posts. I started this cycle of communication in March 2016 with an email titled 'prayers please'. It's the only appropriate title I have today. Please think of us.

## Comments

I’m so very sorry. Thinking of you. .

*—Boris Babic, June 7, 2019*

So sorry to learn this is the case!

*—Sofia Gueorgieva, June 7, 2019*

Sending love to him, to you, to Christina, to all your family.

*—Cynthia Meyersburg, June 7, 2019*

I’m so deeply sorry.

*—Maddie Sheesley, June 7, 2019*

I just can not imagine! Donna shared this with me earlier, and you all are the only thing I have been thinking about and praying for. We pray Colin will not suffer great discomfort, and you can all be together to laugh and cry . Get those Legos out and make a mess!! May the time you all have together be a time you will always treasure, and if I could take some of your pain, truly I would!! Praying you can feel the Presence of our Lord to lead and guide you in the coming days/weeks/months!! Feel our hugs!!

*—martha stanley, June 7, 2019*

I am so sad....many prayers for the entire family.

*—Barbara Skipper, June 7, 2019*

Niels - you are all in my prayers. I wish there was something else I could do.

*—Lisa Caasko, June 7, 2019*

Prayers, hugs, wishes, and thoughts.

*—Lynda Schmitz, June 7, 2019*

Oh Niels, I am so very sorry to read this and send you and your family all the strength in the world for this unimaginably difficult moment.

*—Alexandra Mayer-Hohdahl, June 7, 2019*

I’m so sorry Niels. I’m thinking of you and your family. I truly wish this was not the case and I always hoped I’d never read an entry like this from you. Please give Colin extra hugs from us here, and know that we love you and are thinking of you, Christina and the kids, dear friend ❤

*—GF Santos, June 7, 2019*

I am so very sorry, Niels. We will continue to pray for Colin, Christina, Noah, Emma, and you during this extremely difficult time. Thinking of your family and you!

*—Lisa M, June 7, 2019*

I am so deeply sorry. Sending you much love and prayers and the strength to get through the challenges ahead. Thinking of you all daily.

*—Marci Roth, June 7, 2019*

Many, many hugs and much love and strength to you all.

*—Kerri Kennedy, June 7, 2019*

I'm so sorry. We will continue to send prayers for all of you.

*—Jennifer Covington, June 7, 2019*

Praying for hope, strength and peace for your family.

*—Erin Rotter Mayer, June 7, 2019*

Holding you in prayer tonight from Nashville...
Kymberlee

*—Kymberlee Stanley, June 7, 2019*

Much love to all. You are all in our thoughts.

*—Todd Rosenberg, June 7, 2019*

We are so sorry about this news of Colin. I will pray for your family and for Colin. Wishing comfort and strength to you all.

*—Dan Wooldridge, June 7, 2019*

I’m heartbroken for you. I’m so sorry.

*—L Smith, June 7, 2019*

Oh Niels. I was worried about the silence. You, Cristina, Emma, Noah and Colin are in our hearts and we will keep you in our prayers. Our love to all of you.

*—Claudine LoMonaco, June 8, 2019*

I'm so sorry to hear this Niels, it's devastating. I'll be thinking of you, much love to you all.

*—Helen Livingstone, June 8, 2019*

I'm so very, very sorry to hear this news, we had such hope for all of you. My heart is breaking for you, please know we are praying for you guys.

*—Jeanne Clayton, June 11, 2019*

Hey brother. This sucks. We'll keep praying for your little boy and the rest of you, as well.
Give me a call any time if you're up for talking or venting.
Love you, man.

*—Rich Daly, June 13, 2019*

Oh Niels, I'm so incredibly sorry for you and your family. Continuing to pray and hope you can find some comfort during this time.

*—Anne Custer, June 21, 2019*

# vigil

*June 8, 2019*

Thank you all for the outpouring of hearts and comments.  It really does help.

We persevere.  Colin's sleeping medications seemed to work a little better than normal last night, so he stayed in bed until about 4 a.m.  Then he got the tablet around 5 a.m. and played until I took it away from him around 9 a.m.  Then he threw me out of the room and, within the hour, was down for a nap.

He's as well as can be, though I find his horizons are becoming more limited.  Mostly, all he wants in the world is Christina nearby and his tablet in his hand, and I'm no longer even sure which of those comes out in first place.  We can still get him downstairs to the coffee table to play with his new Lego set (no other Legos are allowed on the table), but he doesn't wander very far from the table when he plays.  I don't know if this is a sign of the tumor causing weakness or him being under the weather from this fever he's been suffering.  Furthermore, we don't know if the fever is linked to the tumor or infections he's suffering from the incisions for his tracheostomy and feeding tube port.  He's on antibiotics, which could also leave a mark on him.

The rest of us cope.  There were a lot of tears yesterday as we finally broke the news, but I feel I'm already multiple steps along in the grieving process.  Maybe I went through it all back in March when we had the seizure scare.  Maybe I'm just tired after all the nursing drama of April and May.  Maybe the news about the tumor's return just confirmed what I've already known and feared since March.

The news about the tumor came on May 26.  Christina and Colin had stayed in the hospital an extra night, as we had no nursing service lined up for the night of the 25th.  May 26 was a Sunday and we had long ago agreed that I was going to take Emma and her friends out for a belated 11th birthday party.  Christina had already agreed to take a cab or medical transport home, where her mother was waiting for them.  The doctor came in sometime before noon and broke the news.  Christina kept the news to herself all day, because she didn't want to hit me with it at a birthday party and she didn't want to tell her Mom before she told me.  I got the news around 9 p.m. that night, after returning home from the party and having several conversations with Christina about how well I thought Colin was doing, which must have been hell for her.

We talked to the oncologist that Tuesday and she confirmed then that we were out of options.

The first three days after the news came went pretty well.  There were whole stretches of time I could forget about the diagnosis.  He woke up, he got his tablet and then around 10 a.m. I would break him away from it so we could play superheroes for a while. Then we came downstairs in the afternoon to play at the coffee table for a while before watching some Curious George before bedtime.  It felt strangely normal.

It got a little dicier starting on the 30th. He no longer wanted to play with the superheroes and I began taking my anti-depressants, which did not work well for me.  I only last four days.  I spent most of Sunday, June 2, in bed, essentially having a series of panic attacks.  I haven't taken a tablet since then and, honestly, feel I'm functioning much better without than with.

We're not sure about his condition.  I see decreasing coordination and strength in his arms and legs (though he still managed to kick me in the face today when I took the tablet from him).  After two weeks of getting along with just the breathing machine, it looks like we might have to start adding oxygen again, which could be a sign the lungs are weakening.  But the doctor could not give us any idea how this would play out.  Will it be a lingering decline?  Will he just shut down from one moment to the next?  Will he experience pain?  We just don't know.

The hospice decision still looms.  In general, we're agreed that we will go for a two-week-long Entlastungspflege, which I can only translate into English as a 'care break.'  The question is, once those two weeks are up, do we choose to stay for the duration or do we go back home?  On the one hand, it would probably do Christina, me and the kids well to have a house full of people who can help look after us and a life where we don't have to worry about whether we have fresh sheets for Colin's bed or where we have to spend our down time sorting through the medical waste to separate the recyclables from the non-recyclables.  We would be freed to focus on each other and Colin.  On the other hand, Colin seems to do better at home and will probably only see a move to a hospice as a transfer to another medical facility.  It will be stressful and traumatic for all of us.  We also have to ask the kids if they're prepared to up sticks with us for this move.  It will not go well for any of us if Emma and Noah are being, effectively, held against their will in this hospice.

Marvelously, the nursing agency is unhappy that we're considering this move, especially since it would probably come as soon as next week, disrupting their work roster.  Given the disruptions we experienced in April and May, my sympathy is limited.  Then again, in their defense, now that they've added Silvia and Thien to the team, we've had uninterrupted service for more than a week now.  Were the diagnosis different and had we not endured two months of hell at their hands, I might feel very differently about our ability to pull this off at home.

I think Emma and Noah are holding up as OK as they can.  They've definitely gotten cuddlier with Colin.  But Noah has already asked if we can get another baby brother to take Colin's place, so you can tell they don't quite grasp the complexity of the situation.

Otherwise, there's not much to report.  My traffic court case was dropped in regards to my February accident, so I guess that's a small victory.  After two months of fighting, the insurance agencies have finally agreed to fund a medical bed and wheelchair for Colin here at home.  Whether they'll show up in time to get used is a completely different question.

## Comments

I‘m so sorry Niels. My thoughts are with all of you. I wished I could help you to make things easier for you. I pray for Colin. I hope Emma and Noah are as fine as possible in this situation. Best wishes from Katja, Simon, Max und Felix

*—Katja Reif, June 8, 2019*

If all of you are at the hospice, would it be possible to tell Collin that you all are moving to a nursing house to live there together, that he won’t be going back to the hospital? Sending prayers and love

*—Cynthia Meyersburg, June 8, 2019*

I'm so grieved for you guys. No good words, just love for you all.

*—Jeremy Cook, June 8, 2019*

I continue to pray for all of you.

*—Lisa Caasko, June 8, 2019*

I don’t have any words to describe how heartbroken I am for you Niels and your beautiful family. Sending you all our prayers from Florida.

*—Michelle Vaughan, June 8, 2019*

Just know that we are heartbroken, that we care about you and your family, that we send prayers your way. “I can do all things through Christ who strengthens me.” Philippians 4:13

*—Barbara Skipper, June 8, 2019*

So very sorry! Words which are usually feeble at other times feel completely useless now. Any comfort or help I can provide emotionally or physically, please don't hesitate to ask.

*—Marc Galmoud, June 9, 2019*

## hook'ed

*June 10, 2019*

We still have small victories.

Due to the last three years of so, so many doctor's visits and time sitting still for medicine, Colin has had way too much screen time in his life.  Since he came home in April, it's been a struggle to get him away from the tablet, though we were usually able to interest him in toys for the first two months.  Since he came home from the hospital, it's gotten harder and, since Thursday, nearly impossible.  All he wants is his tablet.

About the only thing we could reliably use to lure him away from the tablet until Thursday were Legos, specifically a new Cars set he got about a week ago.  Understand, one is not allowed to touch these Legos and they are kept segregated from the Cars Legos he had beforehand.  Usually, I play with him by sitting near him and playing with other Legos.  About a week or so ago, I started trying to find the pieces to build Mater (they call him Hook in Germany).  It took forever, since the pieces are so small, our Lego is spread across three rooms and, honestly, I don't think we even have some of the necessary pieces.

But, by bending a few rules, I finally got Mater finished yesterday.  And, when I showed it to him, I not only got a smile, but got him to put the tablet down for about an hour without fuss.  True, he then sent Mater back to the old Cars while he played with the new ones, but it felt like a win of sorts.

Otherwise, we keep going through the motions.  He's sleeping a bit more and playing tablet when he's awake.  We just try to keep things moving.  We've contacted the hospice about coming for a two-week stay, but it's a holiday in Germany, so we probably won't get any answer for a day or two.  He has a fever he can't shake and we don't know if that's a side effect of the tumor or his hypergranulation or something else.

At least, as I keep saying, he's mercifully unaware of what's going on.  The rest of us have our good and bad moments. We see another kid in the neighborhood having a birthday, and we realize there probably are no more for Colin. We sit next to him playing tablet and wish we could make his final days a bit more meaningful. We just wonder how much time we have left and how vigorously we should pursue things like therapy and getting him medical equipment that's been recommended. We just don't know.

## Comments

Cheers to small victories. Take 'em.

*—Jeremy Cook, June 10, 2019*

I am glad Mater/Hook got you an hour of play. That is a victory.
He is with his family, all of whom love him. I think that is meaningful for him, even if he spends a lot of time on his tablet.

*—Cynthia Meyersburg, June 10, 2019*

Thinking of you guys.

*—Daphne Retter, June 10, 2019*

Live in the moment. Celebrate the small successes. I cannot even imagine your pain. Love and prayers.

*—Barbara Skipper, June 10, 2019*

Thinking of you all - my heart goes out to you.

*—Molly Land, June 10, 2019*

Colin is cherished, he is cared for and he is with the people and things he loves most in this world (whether it's the tablet or his dad wielding a hand-crafted Lego Mater). You understandably want to make his final days more meaningful, but it sounds like he is surrounded by meaning with all of you.

*—Jennifer Dlouhy, June 10, 2019*

I am so sorry. Life has really kicked you when you were already down. You have to keep on keeping on for everyone's sake. A lot of prayers are being sent to God on Colin's behalf. Stay strong and know that you are loved.

*—Phylles Lagarde, June 10, 2019*

Sending you all of my prayers, love and positive thoughts. Hang in there.

*—Erin Taylor, June 10, 2019*

Dear Niels, I've been reading your journal entries sporadically and am amazed at your ability to keep everything going, to see the humour and light in these moments and to share the beautifully disarming humdrum humanity of these unimaginably difficult times. It made me infinitely sad to hear of the new diagnosis, which just does not seem fair. I wish you all peace and love and togetherness and the space you need as a family, in this mad entanglement of medical needs and healthcare professionals and the daily demands of three different children (not to mention you and Christina!). You're superheroes for making it through each and every day. Thank you for sharing, and please do say if there is anything we can give back in return. You are all very much in my thoughts.

*—Helen Maguire, June 11, 2019*

## Tally ho

*June 11, 2019*

It looks like we'll be moving into the hospice on Thursday for our initial, two-week stay. The timetable is moving a lot faster than we'd anticipated, so Christina is having to scramble a bit to work out a medical transport while we all have to figure out what to pack.  Clothes, obviously.  But will we have a TV?  Can we hook up our DVD player to it so Colin can watch his US DVDs?  We bring his medical devices, obviously, but do we need to bring our own bandages, etc?  It's a bit of a leap into the unknown.

We'll have to see.

In today's main excitement, Katia couldn't arrange a dog sitter, so she showed up with Bullitt, a Pomeranian, whose name apparently means "wolf" in Turkish.  He apparently spends most days lounging around inside.  Today he was chased around outside by Emma and Noah pretty much all day. The anticipation is that he is now going to sleep until Friday.

Colin continues to grow more listless.  I got him to let me read to him for a bit yesterday.  Today he played cars for a while.  He was a bit off because his vaporizer attachment for the breathing machine never got turned on last night, which meant his air passages were dry, which meant it was harder for him to clear his breathing passages.

Let's see what Thursday brings.

## Comments

Really glad to hear you're going to the hospice facility.

*—Jeremy Cook, June 11, 2019*

After I put my mom in Hospice, I wished it had been sooner. They met her every need, provided everything she and us needed. Provided snacks and soft drinks for us and visitors. Answered our every question honestly. I hope they are similar in Germany.

*—Barbara Skipper, June 11, 2019*

# The nursing news

*June 12, 2019*

Another day, another nurse's resignation.

This one, at least, is understandable and, shockingly, is being handled professionally.

Silvia started on May 31 and has been one of the reasons we've actually had 24-hour nursing care all this month.  She's straightforward, conscientious and professional: Kind of like Katia without all the drama.  When she interviewed with us way back in April, she told us she was currently with an agency that had her in a home with two sick little boys, one of whom had just died after she'd cared for him for three years.  She was, understandably, finding it hard to keep working in the same household, but had her reservations about coming to us, given Colin's then uncertain prognosis.  I remember almost saying in a fit of bravado that our plan was for Colin to live.  Thank God I refrained, alone because of the sheer sensitivity of it.

Nonetheless, she started with our agency.  We made sure that they told her before her starting date that Colin now had a terminal diagnosis, but she came anyways.  And she really did the job well.  But she says she's falling apart taking care of another dying boy.  She says she barely sleeps.  However, in a real show of professionalism, she says she's prepared to finish her June shifts in the hopes that this buys the agency time to get a replacement lined up.

Meanwhile, everything continues to fall apart at the agency.  I forgot to include yesterday's silliest news.  Ricardo - who took over as deputy head of the nursing staff in May and even spent a day with us that month - failed to show up for five days at work and got fired.  This prompted his girlfriend Manuela, who started work at the agency at the same time as the head of the nursing staff, to leave in solidarity.  So, the administration is once again reduced to Stephanie, who by all accounts is a half step from a nervous breakdown, and Layla, whom Katia continues to insist has quit, despite the fact that Layla keeps picking up the phones at the office.  All the best to Ricardo and Manuela, wherever they go.  I only met Ricardo the one time and found Manuela more interested in the bookkeeping than keeping actual nurses on staff, but I did love the fact that, if even for a month, the agency was run by a couple of people who looked as if they'd just left an Aerosmith concert.

## Comments

Glad you seem to have retained your sense of humour despite all the stress and upset this must be causing you - I hope the agency comes good sooner rather than later...

*—Helen Livingstone, June 12, 2019*

# countdown

*June 13, 2019*

It's getting harder the closer we get to the time we depart for the hospice.  We're at about 3-4 hours until departure now and I can't think of a time when I was sadder.  I had a little conversation with myself while I was stowing our bikes in the shed.  Conversations with myself these days always lead to dark places.  But I just kept thinking that I was going through the exact same motions I go through every time we go on vacation, except this time we're packing up the car for an outing that, in all likelihood, is going to end with the funeral of a 5-year-old, and there is simply nothing understandable or acceptable about this situation.  So, I thought, maybe we just forget it and go somewhere actually fun, but that's dumb, because the setting doesn't matter.  Here, the North Sea, Legoland or Vegas, we're facing death and we don't know if it's coming in an hour, a day or a week or longer.

The crying jags are coming more regularly.  Silvia had her final shift and I sobbed as she left.  I knew her for two weeks.  I read a passage from Winnie the Pooh, where Christopher Robin departs, and that was a waterworks.  And then I apparently don't think I'm crying enough, so I start running through songs in my head to trigger being sad.  Phil Collins' "Against All Odds" is embarrassingly effective.  It is hell, wishing more than anything that a certain situation will end, only to realize that, for your wish to come true, a child has to die.  If I could make the wish that we have a miracle cure, I would.  I do.  I do every day.  But I'm running a little short of hope in miracles right now.

Colin is actually a bit peppier today than yesterday.  Yesterday we could barely get him to move, until almost 4 p.m., when he started playing with his cars and even had a fun half hour or so with Noah.  Today he woke up at 2:30 a.m. (the doctors cannot tell us if this is just the way he rolls or if some aspect of the tumor has messed up his sleep functions) and we could not get him down for a nap until almost noon.  Yes, he played tablet for a good long time, but he also sat down and played with his Legos for a good chunk.  The only problem there being that he has a very specific set of rules in his mind about how to play with the Legos, most of which involves me not touching any of them unless he starts asking for one, at which point I'm allowed to try to start guessing AND DEAR GOD NOT TOUCH THAT ONE. It's stressful.

But we're mostly packed.  A medical transport will come sometime in the next three hours to take Christina and Colin to the hospice.  I'll take a moment to make sure all the windows are locked and all the trash is out and then I'll follow with Emma and Noah.  Emma heard the doctors tell me yesterday that there is a Playstation at the hospice, so her weekend is planned.  I also saw on Facebook that one of the other families from our rehab in 2017 came there at some point, I assume when he died last year, and spoke highly of it.

We assume that this is the final phase of this journey.  Then again, who knows?  We're not doctors.  Maybe he'll bounce back and surprise us all.  Maybe the nursing agency will have a realistic plan for staffing July and maybe we'll pull together enough trust in them to give them a shot.  I do know that Katia gave Christina a form to sign a day or so ago, which Christina did without thinking.  Only afterward did she realize that she had signed off on a form saying Katia had worked multiple shifts in May which she had not, in fact, done.  We contacted the agency asking if we could have a new, corrected form to sign.  They said they'd just sort it out in the office.  One can't help but think that there's a money laundering aspect to this whole venture.

Updates from the hospice as possible.  We neglected to ask if they have wi-fi, but I kind of assume they have to.  If you're in Berlin, we'll take any and all visitors, just call ahead beforehand to make sure we're not in the middle of something.

## Comments

All I can off is prayers for you and your family with what your about to do. I can't begin to even imagine how you're feeling. Good luck with this part of the journey, and I hope that you can feel the support of friends and family, even if they're far away.

*—Dan Wooldridge, June 13, 2019*

Many prayers for you and your family my friend. Many prayers.

*—Lisa Caasko, June 13, 2019*

Thinking long and hard, trying to think up something that doesn't bring up the thought: "You're making it worse." Nothing comes up. But I do want to say, from the bottom of my heart: I think of you all every day.

*—Boris Babic, June 13, 2019*

Thinking very often of you. Words fail me to say more than "bon courage".

*—Sofia Gueorgieva, June 13, 2019*

Niels, I feel like I’ve been with you on this journey. Thank you for sharing your updates, thoughts, challenges and small victories with us throughout. I hope that you find comfort in knowing how we all think of you and care so much. Love to Colin, Christina, Emma and Noah.

*—GF Santos, June 13, 2019*

Oh Niels, I'm thinking of you and your family every day. I can not begin to imagine how this must feel, just going through the motions of this path you are on. It is just terrible. Please know you and your family are in our thoughts and prayers, my heart is breaking.

*—Jeanne Clayton, June 13, 2019*

I'm thinking about you every day. Words don't do justice to the heartbreak, so I just want to say that I am sending good thoughts and wishes your way and I hope that the hospice is as supportive and caring as possible, and I will keep praying for good days and moments for all of you.

*—Molly Land, June 13, 2019*

You're doing fine, Niels. Keep writing, and keep using this forum to tell us what's going on, and how you're feeling and coping. Wish we could be there.
Don and Dan

*—Don Summers, June 13, 2019*

I know this is a journey that you never wanted to take...but God must have His reasons for bringing you to this point.
Perhaps one day He will let you know what the reason is and bring you to full understanding of His purpose. Yet we all question with you WHY? WHY COLIN? WHY OUR FAMILY?

Please know that all of you are in our thoughts and prayers.

*—Phylles Lagarde, June 14, 2019*

## arrival

*June 13, 2019*

It's a strange business, checking into a facility, a main purpose of which is to support you as your child dies.

We made it. It's very pleasant. It's not a luxury resort, but they provide food every day and decent rooms. There's staff to interact with the kids and they seem to have something going on most days. The garden is beautiful.

Colin's also perked up. He napped until almost the time the medical transport showed up and then had a really grouchy spell before a very frightened spell when he clearly thought we were going to another hospital. The transport had a 20-minute head start on me and the kids and Christina said they drove like maniacs. Meanwhile, the GPS in our borrowed car seemed to take us on an ... unorthodox route. So, Christina and Colin were settled into his room by the time we got there.  Granted, he was plugged into the tablet, but his mood was still great.  I haven't seen him smile so much in days.  Let's see how the trend continues when there are days where it's not all tablet all the time.

Everyone seems very nice.  There's been a lot of eye-rolling on their part as we tell them about the home nursing service.  We all had tours of the facility.  Emma and Noah are already playing with the staff and checking out the chill-out room.  The only drawback might be that they are the only kids their age here right now.  Then again, we might get to know the staff well.  It seems we're going to spend a lot of time with them, meals and all.

There was no real program today other than seeing the place and finding out the basic rules (clean up after yourself, never leave after 7 p.m. without a key).  We'll see what the program is.  There is apparently pizza-making, which will go down well with Emma and Noah.  It's also clown day, which I don't see going well with Colin.

They're a little overstretched staff-wise, so it means Christina and I (and let's be honest, mostly Christina) will have to do a lot of the diaper changing and feeding and suctioning.  But we have doctors and nurses here we can call if things get really out of hand and they will always be here, so, to me, that's already an upgrade from home health.

In short, Colin is happy.  The kids are into it.  I'm exhausted, which I'm taking as a sign that I'm mentally relaxing.  I haven't had a chance to ask Christina what she thinks of it (we had to take separate tours and separate meals, etc, so we're not seeing each other much more than usual), but she seemed OK.

## Comments

Sounds weird to say, but I'm glad you guys are there, all things considered. Really hoping there is some good bonding time and an uncanny sense of connection as you approach each day of unknowns.

*—Jeremy Cook, June 13, 2019*

This all sounds good, Niels, long may it stay that way!

*—Helen Maguire, June 14, 2019*

Thank God you are no longer in the clutches of that circus otherwise known as the "home health care agency." This sounds like a safe place right now. Plan on a visit from me, and maybe Raffi if you think that would work, next week before we head off to the States. We'll coordinate with you via email. Prayers to all of you.

*—Claudine LoMonaco, June 14, 2019*

## On the first day

*June 14, 2019*

We're almost 24 hours into the hospice experience and it's going as well as such a thing can. Perhaps I'll eat my words and, in a few days, this blog will be full of rants about that awful nurse and 'I can't believe that one therapist said this,' but, for now, it seems to work. My first impression is that we've moved in with an extremely large family and they're just all taking care of us. Obviously, it's not a family: They're employees of this foundation. But they give a sense of belonging and working together and extending that feeling to us. And though Colin is the main focus, he's not the only focus. I don't want to bad mouth the home care nurses (much), but their job was to make sure Colin was fed, clean, etc. If he wasn't in need of care, they were often staring at their smartphones. Here, as often as not, people are asking me if I'm OK with the food, if I need a drink, if the bed is comfortable enough, etc. etc.

Colin's have a bit of a rough time, though it's mostly due to exhaustion. As near as I can tell, he slept from 11 p.m. to 1 a.m., then a little between 4-6 a.m. and again from 9:15-10:45 a.m. He's so far just walked off the melatonin and the hydrochlorat they've given him as sleep assistance, so tonight they might try to start something based on cannabis. We'll see. Something has to work. For right now, we at least managed to keep him off the tablet most of the morning, so he's now plugged into that.

Noah and Emma found the Playstation, so all is right in their world. I don't think they're particularly good at it. They found some Harry Potter game and, as near as I can tell, they spend most of their time watching Harry fall to his death. But if they get two weeks at this, maybe we'll see some improvement.

Today we're going to see if we can get him out into the garden, even if we have to roll his bed out there. Later we'll be making pizza together and then one of the therapists is going to make slime with the kids, so it seems like it will be a full day.

We had one of our last meetings at home with the visiting doctors this week (we will still see them, as they work in cooperation with the hospice). Depressingly, they talked about getting a morphine preparation ready for Colin, should he begin to be in pain. I know being put on morphine doesn't mean you're instantly in a coma or anything, but it still feels like the start of a slippery slope.  I hope we can hold off on that as long as possible.  The doctor also said a very interesting thing.  She noted that children don't die like the elderly, because "children have different reasons for wanting to stick around." Maybe that's the point of being here for whatever time we have: Seeing what he's sticking around for and then giving him as much of that as we can.  Here's hoping it's not homemade slime.

## always something there to remind me

*June 14, 2019*

As nice as it is here, it is hard at times dealing with the fact that death is such a key part of the program.

We were told before we got here that some people who were planning a visit here for their own mental health break got bumped for us, because we're acute.  There's no way to make it feel like a win when you know you made it because your kid's health status is that much worse than those of others.  Since we've been here, we've been told that, once a year, all the families of children who died here are invited back for a memory day.  I just found out there's something similar at the hospital.

And then it sneaks up on you.  There's a beautiful pond in the garden.  I walked up to it with Colin and realized that it was full of rocks painted with the names of, I can only assume, dead children.  Also, each family makes a little lantern to hang in front of the patient's door.  We haven't made ours yet.  But I see them on the other doors and today I wandered into a gallery full of old lanterns.  I should know it's coming, but I'm floored each time knowing I'm going to be adding to this sometime in the near future.  it's good here, but it's a head trip.

## Comments

Be strong, my friend. And in moments where you can't be strong, let yourself be weak. That may make no sense at all, but I'm trusting that even a sliver of truth in it will help you in this situation that no human being should have to go through.

*—Jeremy Cook, June 15, 2019*

## Snoozeln

*June 15, 2019*

It was a bit of an uneven day. I started the day with either a panic attack or food poisoning.  Sometimes it's hard to tell the difference. I suspect it was a panic attack, as I knew Christina was taking the kids (eventually, only Emma) to a late-night science open house, meaning she would pretty much be gone from 2 p.m. until well past Colin's bedtime.  And even though there's a nurse here to help me and I know the drill, I think I went into a panic.  So, until about 9:30 a.m., I was forcing myself up every time I had to do something, the rest of the time I was a wee bit catatonic on a beanbag in Colin's room.

Understandably, Christina needed none of this.  She deserves a night out with the kids (well, kid, Noah refused to go) and she's been moving heaven and earth to make this stay happen, so she certainly doesn't need me passed out.  But we got through it, even if Colin was in a spectacularly bad mood in the late morning after we took his tablet away from him after five uninterrupted hours.

Interestingly, he then crashed into a nap and woke up in the most relaxed mood I've seen him in ages.  He didn't ask for his tablet any more.  He didn't care about watching TV before bedtime.  About the only thing he seemed to feel strongly about was having stories read to him.  But, left to his own devices, he was more likely than not to stare at the ceiling smiling, seemingly talking to himself.

The nurse said it might just be the heat getting to him.  But I can't help but wonder if this is another stage in his progression.  Heaven knows, he didn't seem to have much strength at all today (unless he was trying to resist getting his teeth brushed. There's always strength to resist tooth brushing).

We did also get him outside in the garden in the ridiculously large rolling chair. Honestly, it's like a La-z-boy on wheels.  But he went without a fight, which is a nice change.  He used to love going outside, but the last few weeks has developed a real aversion to it.  We've now gotten him in the garden here without too much drama two days in a row, which is nice.  As a bonus, it also gets the other kids outside too.

And then, before bedtime, we hit the Snoozelroom, which is, essentially, a room with a waterbed, a disco ball, various other lights and lots of ambient noise.  I can see scenarios where this is relaxing. One where you try to chill out on the waterbed accompanied by

Noah and Colin is not one of them.  Nonetheless, Colin seemed to have a good time, I learned not to fear spending time with him and Noah finished his new nanoblock set, one of many gifts showered upon us by my co-workers.  It is still hard being here on many levels, but I think I'm learning to make the most of it

## Comments

I know that pushing yourself past your limits is your new normal, but I still feel the need to say that I think you're amazing and a wonderful dad. To make some decent memories while you're in this situation and feeling how you are takes incredible strength of will.

*—Kerri Kennedy, June 15, 2019*

That scene with the watered is hilarious! Hoping for some good memories, despite the difficulty of being in that place.

*—Jeremy Cook, June 15, 2019*

Happy Father's Day to the best dad ever. You and Christine have given everything that Colin has needed. You have exemplified love, courage, and unimaginable strength in the most difficult of times. Know we love you and are thinking about you today. Barbara & Family

*—Barbara Skipper, June 16, 2019*

## marking the days

*June 16, 2019*

We don't think he has a lot of time left.

We can't put it in terms of hours, day or weeks.  I mean, even the doctors can't do that.  But he's grown so noticeably weak in the last 48 hours.  It's as if we have the body of a 5-year-old here in the hospice with us, but there's not enough Colin left to fill it up.  Left to his own devices, he'll lie fairly flat on the bed, either playing tablet or listening to us read.  He worked up the energy to play a little Lego today, but 10-minute stretches seemed to leave him wiped out.  To my eye, the left side of his body is significantly weaker than the right side, which I'm sure has a lot to do with where the tumor lies and where it's pressing.  Mostly he gives the impression of being exhausted.

That said, he doesn't seem to be in pain or distress.  We'll even catch him smiling for no reason at all.  Maybe he's seeing things?  Maybe he's just going into a happier place in his head?  It's hard to say.  It's so hard for him to communicate and it's so hard for him to get what he wants.

It wasn't as good a day as yesterday, though it was far from awful.  As he gets weaker, it becomes far easier to care for him on a day-to-day basis, physically.  Emotionally, I'm not saying I'm numb, but I've worked through so much fear and terror since the March seizure that now I'm just trying to focus on keeping him happy and the other two occupied and just willing my stomach to stop seizing up and for me to wake up without a sense of panic on a daily basis.

The low point came for me when we talked to Emma and Noah over coffee, discussing the last three days of school this week and whether they wanted to attend.  We told them we don't know how much time Colin has left and that it doesn't look good, and they might have to think about how far they might want to be from Colin in these days.  They both responded, really without blinking, "we know."  Children their age shouldn't know these things.

We'll see how tomorrow goes.  The hospice has a skeleton staff at the weekend and there are not a lot of patients here.  There will be a ton more staff around tomorrow, so we'll have an easier time keeping the kids busy (not that the Playstation isn't doing that job admirably) and we can ask some questions.  Can anyone tell us what will come (probably not)? How should we contact a funeral home?  Is it even worth taking him for his doctor's appointment on Thursday?  It's all a lot to take in.  We're no longer sure if we want visitors any more.  We had a visit yesterday that was pretty awful, due to no fault of the visitor, but due to us being complete basket cases at the time.  Every minute is different.  Every hour is different.  I have moments where I feel the depression weighing down on me like a stack of bricks.  I have moments where I can laugh with the kids. Noah and I watched Mr. Bean last night and we laughed.  Yesterday, I was reading to Colin and his feeding tube became unclipped, spilling stomach contents on him and the bed.  I handled it without blinking (OK, I also sent Noah to get a nurse).  Then I have moments where I can barely get out of bed and my stomach feels like it's going to go into knots.  I just don't know.  If you're thinking about coming, check with us before you leave.  Make sure we're up for it.  I can't promise anything.

## Comments

Colin - and you all - deserve an immensely better hand in life than has been dealt. Colin, though, has the most loving and amazing parents one could possibly hope for, especially given the situation. I know it is a really difficult Father's Day, Niels, but know that you and Christina are the love that Colin needs. Sending you all hugs.

*—Michelle Lee, June 16, 2019*

Niels, I love you, Brother. Please hug that beautiful family of yours for me.

*—Keena Graham, June 16, 2019*

Thinking of you on this Father's Day, Niels, and I echo Michelle's comment that this must be so difficult for you. It is indeed so awful what Emma and Noah have to face. But here's to more Colin smiles and Mr. Bean laughs.

*—Jeremy Cook, June 16, 2019*

Neils
I'm following this with the heart of a mother and the heart of an art therapist/social worker. I am thinking about activities and memories you guys could share now. One idea would be to take some clay and make hand prints to save together and date them to save. Another is to take a food tray or cookie sheet and put a bunch of shaving cream on it. Drop a few drops of food coloring or paint and let Colin swirl is around with his fingers to mix colors. Then he can take his meds at fingers and make a handprint on a piece of white paper or co struction paper. The whole family and kids can do this together too. This takes little actually energy but can make memories to keep. Also, giving the kids a piece of large paper and have them write their "things love about Colin" inside a heart or a drawing of a jar. Reading them together. Making a memory book together where the kids get to draw favorite funny or fun memories and share them with Colin. Having the two older kids (separate from Colin) write or draw with pens or crayons/paint what they are feeling, questions or fears they are having, or some ideas about how they would like to say goodbye. Most children like to think of some way to express their feelings and make it do something as a way of giving to their sibling. Could they build a Lego tower and have Colin add to the top? Call it a Lego memory tree? Make or paint a shoe box and have it be a box of feelings...and have them write little post it notes of how they are feeling, good bad or different, with acceptance, and put the post it notes in the feelings treasure box to hold them for them? They can be private or shared. Just a few ideas to help everyone express nonverbally what may be going inside. Exhaustion, fear, sadness, anger, relief... all normal and Ok. Modeling this may help you too. Is there a social worker or therapist working with the family? Maybe they can help. These times are precious.
My heart is with you. This is brutal. You are a dad who is also human with a breaking heart.
You are not alone,
Kymnerlee Stanley

*—Kymberlee Stanley, June 16, 2019*

Sending thoughts of strength and peace to you and Christina. You and she are the best parents Colin could have, even if it was for too short a time. What you are going through is immeasurably painful and wrenching. All you can do is try to enjoy time with him now.

*—Dan Wooldridge, June 16, 2019*

Sending you love and strength for the days ahead. It has already been too much, and I am so sorry. I hope you can hold on to the small moments of peace as they come.

*—Marci Roth, June 16, 2019*

Niels, Happy Father’s Day to you and much love. You are doing an incredible job and always have, from the beginning. Never doubt that Colin feels all the love you have for him, and that he is comforted by it. When he smiles sometimes, maybe it is God whispering to him and calling him home.

*—GF Santos, June 16, 2019*

The Hospice staff (including one that we selected to be Mom’s primary doctor, while in Hospice) answered the type of questions you are now asking. On Monday, hopefully you can get your questions answered. It was our decision to eliminate any painful procedures and add anything that would make Mom more comfortable, She no longer left the facility for appointments, etc. She slowly began sleeping more and eating less. We took turns staying with her. It was not a good time for visitors, other than the immediate family. There was usually a Hospice worker with us. They notified us when they thought we were 48 hours out so that we could notify family. Emotions...yes...all over the place! Denial, Fear, Understanding, Acceptance. I could not believe this was where we were. They did feel that she was in some pain based on her sounds so we agreed on morphine to be administered. I never regretted our decision to put her in Hospice. We found Hospice staff willing to honestly answer our questions, including the ones we didn’t know to ask. Their answers were on point as well. Mom passed peacefully during her afternoon nap, while Martha and a Hospice worker were with her. Hard to believe that was two years ago. You are in our daily prayers. Love you guys. Barbara

*—Barbara Skipper, June 16, 2019*

This is just too much. You guys are wonderful, Colin can feel the love for sure and what a beautiful example you are for the other two kids. They look to you for guidance and they will remember. You are a great, loving family, my heart breaks for you. Love to all of you. Jeanne

*—Jeanne Clayton, June 18, 2019*

## Decisions and time management

*June 18, 2019*

The thing is, when dealing with a situation like this, it's far from being all tears and thinking about the last moments. There's a lot of parenting that still needs to be done, leading to things like the last two hours of bedtime which involved me saying, among other things "I don't care how sick you are, but you need to stop kicking me" and "If you think we're watching Curious George without brushing teeth, you are sadly mistaken." Life trundles on like normal in many ways.

The main news is that Christina and I took a longish walk on Sunday night and got kind of lost in a gardening colony. During the time, we talked more about Colin's burial - which is oddly helpful to my mood - and agreed that we are staying at the hospice until the end, no matter how long that takes. We checked with them on Monday and they basically told us they never expected we would limit ourselves to this two-week break. So, that's that. We'll be breaking the news to the nursing agency soon, but I suspect even they have figured this out by now.

Otherwise, we do our things. I'm finding life in the hospice a little difficult - mind you, it's far better than the alternative - just because organization is all over the place and I like things to run sort of on a schedule. We'll start the day with minimal plans. Then hours will pass during which nothing happens. Then, just as the plans are to start, a guest shows up, so does a doctor, as well as the behavioral therapist and everything is supposed to happen at once. In the end, nothing happens. I mean, I've been trying to get laundry done all day and we only managed to get it started about an hour ago. Nor, to my knowledge, have we made the call to the funeral home. There's always tomorrow.

We did talk to the chef, so we at least have food lined up for Noah. Do not believe whatever Christina tells you. He's a mean man and, I'm certain, actually Tom Skerritt. But he cooks well. I don't know what it says about my mental processes, but my appetite is back. I ate more today than I probably ate during a week back at the start of April.

We did most of the work on the lantern yesterday (though that almost got derailed when every therapist in the place showed up just as we were to start). Emma did 80% of the work, but we still have a few things to do on it. It didn't get done today, because we were surprised by plans to take the kids to a lake that came out of nowhere and then took half the day to organize. But at least one little project is sort of done. Tomorrow: I start the quest to make plaster casts of all the kids hands. I predict tears. Likely mine.

## Comments

Let it out, man. Cry away, during plaster casts or whenever. Really glad to hear your appetite is back.

*—Jeremy Cook, June 18, 2019*

Don’t bottle it up and don’t apologize for tears!

*—Barbara Skipper, June 18, 2019*

Love!!!

*—Lynda Schmitz, June 18, 2019*

I have to tell you, your updates are responsible for a fair few tears here, too. Hope today‘s a little less chaotic, a little more productive (and not just in the tears department).

*—Helen Maguire, June 19, 2019*

Trying to keep life as normal as you possibly can is good for all of you. I'm sure that Colin sort of expects (and maybe appreciates) a little normalcy in his routine. Also, tears are good. Never hold them back. Prayers

*—Phylles Lagarde, June 19, 2019*

# anniversaries

*June 20, 2019*

I learned this week that, when a child dies in the hospice, they close the room and put a teddy bear in front of the door as a sign that someone has died.  So, of course, now I'm terrified that I'll show up to Colin's room one day and find a teddy bear lying there.  I'm sure they would tell us first.  I really am.  But, irrationally, this is my new phobia.

Christina and I can't agree on how well or poorly he's doing.  It doesn't help that he has a fever that won't break, which we believe is related to an infection from his tracheostomy incision.  Christina and Colin headed to the hospital this morning - along with a doctor and a nurse from the hospice - for a planned replacement of his trach tube.  Apparently the hospice doctor is not happy with the antibiotic that the ear, nose and throat doctor picked out, so hopefully they'll hash things out and maybe we can get the fever out of the way.  The appointment was at 6:45 a.m. today (because, that's the time of day everyone wants to go to the hospital!) and there's been no word yet, but 2-3 hours wait at a hospital doesn't surprise me any more.

We started the footprint project yesterday.  Only with paint, not plaster (though I think that's in our future).  Colin was tired and out of it, so we didn't try with him, but we have footprints for all the rest of us.

When we do get our act together and participate in these group events, they are nice.  But the getting there is hard.  And there are strange moments too.  I don't know how many of the other kids here are in end-of-life situations.  Several of them have severe disabilities and seem to be here for a week or two while their families get a break and take a vacation.  On some levels, Colin is one of the most active and aware children here.  And then they pull us all together Monday morning for a group song and it's hard, because most of the group is barely aware of their surroundings.  The theme was the beach and one of the songs they picked was "Yellow Submarine" and I was asked to lead the song, since I'm the native English speaker and, for a variety of reasons, it's a song I associate with farewells, so it wasn't long until i was more sobbing than singing.  So, it's a lot of ups and downs.

In a side note - and only because I'm a bad person - I then went through the rest of their song book and noted that it included "Total Eclipse of the Heart" and "The Time Warp."  Neither are songs I see being performed strongly by a group of disabled children, their grieving families and a nurse on an acoustic guitar.  They asked me if I wanted to request another song and, I must admit, the awful part of me almost asked for "Zombie," just to see what would happen.  I'm sorry, but sometimes dark humor is all I've got left in me.

We're meeting with a funeral director tomorrow, not because of any urgency that's recently come to light, but because we'd like to make some of these decisions with a clear head.  We haven't yet told the kids yet that we're here for the duration, not just the initial two-week stay as planned.  We'll have to figure out how to tell them.  Then again, they're generally thriving here.  They keep finding new Playstation games and we pull out a new Lego set every day or so (though Colin seems to be losing interest in new Lego sets unless they're Cars ones, and I think we have every Cars Lego set there is).

We still haven't told the home nursing agency that we're done.  I really don't mind stringing them along though.  We do have to cancel the medical bed we ordered just before coming here, because we're unlikely to need that.  We finally got a slightly better wheelchair (and even that is not the one that's prescribed for him), but don't think he has the energy to sit up in that, so we might be sending it back.  I continue to fear the chef and Christina has found a nurse she doesn't think she wants to work with any more.  Otherwise, we're muddling through.

We've been here a week today.  It's also been four weeks since the MRI that revealed the horrible news.  I don't know what to do with these anniversaries, but I can't ignore them.

## Comments

I can't believe it's been 4 weeks, and indeed you must feel like you're in a time warp. Blessings on you guys as you muddle through as best you can. And hey, can't they do any Elvis songs?

*—Jeremy Cook, June 20, 2019*

# 7:30 p.m. at the hospice

*June 20, 2019*

This is such a strange place.

Down the hall, one of the staff is sweeping the dining room while listening to Depeche Mode's "Personal Jesus" on the radio.  She's a sweet lady, but looks like Klinger from M*A*S*H and has a deeper voice.  That is not meant to be judgemental, but to complete the image.

Stefan, one of the teachers here, has Noah and the sister of a patient wandering through the garden, setting up a treasure hunt for tomorrow, they seem like they're having fun.  When he's done, we're going to seek out birthday gifts for him, because my son is going to celebrate his 9th birthday at a hospice, which also seems like something that could potentially come up in therapy for decades.

The couple from northern Africa that keeps to itself just left the hospice for a walk, their baby swaddled in sunglasses.  I have no idea what the child's problem is or what his diagnosis is.  I'm not even sure of the baby's gender.

Christina is upstairs putting our youngest child to bed, while we try to keep whatever normalcy we can around his cancer.

Emma went to her room after dinner to watch TV.  I found her watching Navy CIS.  I asked her if she didn't think the show was too scary for her.  She said the scary part had already happened.

And downstairs, some people are unloading party benches from a truck, I guess because there's going to be a party here soon.

Down the hall, the guy who is here every night is doing the bookkeeping.

It's a strange place.  I'm both glad it exists, but sad that a place like it has to be.  I noticed today that it's slogan is "Ein Zeit voller Leben."  A time full of life.  Maybe I'm pessimistic, but I can't help but noticing what would happen if we reversed that sentence and how that just doesn't apply to Colin any more.

It's a strange place.  I'm both happy to be here, and infinitely sad at the same time.

## Comments

When my husband was diagnosed with Stage 4 cancer and given less than a year to live, I found myself screaming inside all day that this cannot be happening and at night when I knew he was asleep, I let the tears go. I didn’t want him to see me crying. I wanted to be strong for him, which made it all that much harder. Fortunately the Stage 4 Cancer turned out to be Stage 3 and the ending, so far, is different. But I will never forget the terror and grief that was in my head for several months. I pray peace for your family because I got a glimpse of what you must be feeling. Peace, love, prayers, and concern from our family to yours, Barbara

*—Barbara Skipper, June 20, 2019*

Niels - I wish I had something to offer, something to say. You and your family are in my thoughts and prayers.

*—Lisa Caasko, June 20, 2019*

Hang in there!

*—Jeremy Cook, June 20, 2019*

## Who knows?

*June 22, 2019*

We met yesterday with a funeral director to plan our 5-year-old's burial.

God, I hope I never have to write another sentence half so depressing.

We got some good ideas. He's from a home that works often with the hospice. And then one of the nurses pulled Christina aside and told her to check with other homes, because this guy is apparently pricey. I appreciate the sentiment, but man, about the last thing I want to do these days is price comparisons on children's funerals.

Colin, at least, seems to be doing a little better. We don't know why or how, because he remains a medical mystery, but, just an hour ago, he actually played Lego with me (as opposed to playing Lego while refusing to even let me look at the bricks).

Thursday's procedure seems to have gone OK. It took half a day, but they got him back here in one piece. The only annoying part was that the hospital refused to let either the doctor or nurse who accompanied Christina from the hospice into the wake-up room, which greatly complicated the coordination of getting everyone back to the Sonnenhof halfway on time. We'll see how it heals.

That night, the hospice doctor told us that they were going to start a round of antibiotics, but that the bloodwork showed no sign of infection. That would indicate the fever he's had the last few days might be caused by the tumor, which would be a very bad sign indeed. Then Friday, after a day of the antibiotics, his fever started to sink. No one really knows why.

Friday morning, he worried me, because he acted so sluggish and disoriented. I had to head back to the house for a little bit to finally pick up our car (Five weeks in the shop! A big thank you to Stephan and Sabine for loaning us theirs for the last few weeks) and really wondered if I should make the trip, given how he looked to be on his last legs. Then I got back around 6 p.m. and found him lounging in the garden in his special chair, looking reasonably content. He even played with me and engaged in some arm wrestling with Florian, who is turning into one of our favorite nurses here.

Then this morning he slept until 8 a.m., which hasn't happened in months, which once again got me worried that something awful was happening. But since then, he's been perky. Honestly, every hour is an adventure.

I have good and bad moments. Driving home and back, I've reached the conclusion that I maybe just ought not to listen to music for a while. I mean, Fleetwood Mac's "Go Your Own Way" had me in tears, and I like the song, but I don't know what possible emotional resonance it could have with me.

Mostly I think I just want to go to a bar. I don't even really want a drink. I just kind of want to be among people who are drinking and just talking about life. But we're here instead. I've got my family, so that's nice, but I'm not quite at the point where I'm taking the kids to a bar yet. The rest of the guests aren't the most talkative. Many are ill. The Eritrean couple keeps to themselves, though I realized last night they've been here since October. I can't even imagine what living this half life for more than a half year would do to a person. There's another woman here with her daughter and two grandchildren, all watching her other son. But they're heading home in a day or so and, honestly, we're getting tired of them, since they keep leaving their 1-year-old grandson in the car of Emma and Noah and disappearing. Mind you, I have no problem with my kids babysitting. I'd just like to be asked first. And I'd like the parents to be somewhere in shouting distance just in case. We have our own things we need to keep an eye on here.

## Comments

Sending you a virtual hug and a wish that we could sit and just talk about life with you and play Legos too.

*—Tamara Cook, June 23, 2019*

It just keeps getting harder. You feel so helpless. But you are doing the most important thing by just being there for Colin and the rest of your little family. Christina and your presence is vital to them right now. With God's help, stay strong. Prayers,

*—Phylles Lagarde, June 23, 2019*

Niels - I cannot fathom what you and your family are going through. Yet, somehow from somewhere you and your wife are finding the strength to persevere. My husband Donnie & I are praying for you & your family. You are in our thoughts daily. ❤

*—Heidi Sprow-Knaub, June 23, 2019*

When my friend died all I wanted to do was go dancing and play “Groove Is In The Heart” on repeat. I get what you mean about the bar.

*—Keena Graham, June 24, 2019*

## little nuggets of hope

*June 25, 2019*

Every day is different here.  A few days ago, I thought we only had hours or days.  Then he perked up and suddenly we're wondering what we're going to do if the end of summer vacation shows up and we're juggling hospice care and school.  It's so hard to find your bearings here.  Do I have a little breakdown because it's all too much?  Do I enjoy a moment 10 times over because I got a smile out of him?  There really is no right and no wrong.

We have lots of good moments.  Yesterday we played a "get your nose" game that seemed to genuinely engage him for several minutes.  He's ear-to-ear smiles if you let him watch his tablet on endless repeat.  Some things that he wouldn't look at a few weeks ago spark interest for a few minutes.  I'd say, more often than not, he's comfortable and happy.

But it's still frustrating.  He can barely speak, often because we have to block his windpipe to make sure he doesn't aspirate.  Even if it is unblocked, he doesn't seem able to say a lot of the things he used to be able to say.  It's a lot of guesswork figuring out what he wants sometimes, elevating stress levels for all.

Moods are also strained because of the temperatures in Berlin right now.  We're scraping 90 Fahrenheit right now and it could hit 100 on Sunday.  And I know all my DC friends are thinking "Yeah, but you've got no humidity," and I'll grant you that, but I assure you, we're not used to these temperatures in Germany, the buildings aren't constructed for it, and we're living in a hospice with about 10 children who can't understand why they're so hot and miserable and can't sleep properly.  It can suck at times.

That said, if you can get past the awful reasons why we're here, it does restore your faith in humanity here sometimes.  I see staff - from the nurses to the custodians - putting on smiles and finding depths of patience with these kids that I'm not sure I could match to get them through their day-to-day existence.  I've seen therapists trying to interest Noah in activities, getting essentially grunts in response, and diving back in with a smile on their face to see if something else will pique his interest.  I saw one of the girls yesterday do a little dance during the morning session.  I don't know what this girl's diagnosis is - as Christina points out, it doesn't really matter - but I doubt she dances much on an everyday basis.  Here, she got to dance for a moment.  Neither she nor her brother seem able to speak, but he seems so happy most of the time.  I wish I could be like that.  Even the children who are barely responsive get spoken to like they're fully aware, asked what they prefer, etc. etc.  I can't imagine there's a way the staff at this facility are paid anywhere near enough.  And it does restore your faith in humanity a bit that there are people who can make these kids feel a little normal for whatever time they've got here.

I wake up every day not knowing if this is the last day.  If the last time I played with him before I went to bed was the last time I'll ever see him.  It messes with your head.  But I'm glad that, at least, he's getting some time here before it's all over.

In other news, we celebrated Noah's 9th birthday here yesterday and it was very nice. Even the grouchy cook lent Christina some items so she could pull the cake together (of course, he then took some of them back before she got a chance to use them because he "missed" them).

We told the kids yesterday that Colin is set to be here through the end of the summer break (School starts in early August).  Emma was cool with it.  Noah less so.  We'll have to see if we can send them off on some visits to relatives, just so they get a little break. We'll have to look into what's possible.  If one of us escorts the kids elsewhere, that means the other parent is stuck with Colin for a day or two: I wouldn't want to put Christina through that and I'm not sure what I can handle on my own, so we'll have to see what options are at our disposal.  Otherwise, we spend a lot of time with Colin, Christina still has ridiculous amounts of bureaucracy to sort through and Noah is obsessed with the women's world soccer tournament, which at least gives us a distraction from the heat at nights, when they bother to show it on German TV.

## Comments

If women's soccer - pardon me, football - is what it takes, glad it's on. Breakdowns and multiply enjoyed moments are all totally fine. Chuck and Liisa

*—Chuck McCutcheon, June 25, 2019*

It is all about small victories and “tender mercies.” as they say here in the South. You are still making family memories. I cannot imagine existing in those temps! Prayers and love. Barbara

*—Barbara Skipper, June 25, 2019*

Somehow you will dig deep within yourself and discover the strength to carry on...for Colin's sake, for Christina's sake, and most importantly, for yourself. You can and will do it for all of the reasons listed. You are much stronger than you have ever imagined. If the little girl can dance and Colin finds fleeting enjoyment in simple things, then you will continue to love and cherish the small moments of joy strewn among the hours of despair. Prayers,

*—Phylles Lagarde, June 26, 2019*

## heat wave

*June 26, 2019*

We're having another rough day.  His fever is up, despite multiple doses of medicine.  I don't know if the doctors have any idea if it's linked to some lingering infection or tied in to the tumor disrupting the body's ability to regulate its temperature.  The first option is bad enough.  The second means we're really starting to enter the end phase.

He's weak.  He's listless.  He's apathetic about a lot of things.  He's clearly tired, but won't sleep.  He's having more trouble than usual coordinating use of his limbs.  I wish he would sleep a little bit, but he just won't, perhaps because it's so ridiculously hot in here.

I keep finding myself thinking "I don't know how much longer I can do this."  That is, of course, nonsense.  I can do this as long as it takes.  As emotionally challenging as it becomes caring for him in this state, it's physically not particularly hard.  I think the real question is "how much longer can I do this and not emerge at the end as a complete basket case?"  I met with my therapist yesterday and, like everyone else, he told me that I'm doing the best I can with a miserable situation.  It sounds nice, but it doesn't help a lot.

Strangely, what does help are the walks with Christina where we talk about funeral plans, how we're coping, how he's doing, etc.  The talks are depressing as hell.  But I guess, at this point, Christina is the only person in the world who has an inkling of how I'm doing, so talking to her is probably the best therapy on tap right now.

Speaking of people with mental disorders, we have not yet cut ties to the idiot nursing agency.  The social worker here advised us to keep them in the back pocket, just in case something strange happens and we return home.  That is not the plan.  We have worked it out to stay here through at least the end of the summer break (all this depending on Colin's status, of course), which goes through August 2.  We're also sending the agency an e-mail telling them this.  We'll see how they responded.

Christina anticipates they'll be childish.  Already, Layla - who has gone a long way down in my esteem since her speech about how a good head of a nursing agency always jumps in to make sure the patient has coverage - called Christina on Monday to check if we were still in the hospice and then chewed her out for not keeping the agency up to date with our schedule, since they "need to plan."

I mean, if you can put aside the complete hypocrisy of them thinking it's unacceptable not to know whether someone will be available at a certain time, there is the point that Christina emailed them two weeks ago to let them know we wouldn't be home until Thursday at the earliest.  She also told them this on the phone at least twice.  Faced with that, Layla had to admit that we probably had given them enough advance notice.

And then they sent Thien to our house for a night shift on Tuesday.  Poor Thien.  She had to call Christina to find out that we were in the hospice, as we'd told her boss just 24 hours earlier.  She seems like a nice person and a competent nurse.  I hope she quits that company and soon.

The picture is from Friday, when he was having a pretty good afternoon.

## Comments

Here's to more of the good stuff on tap!

*—Jeremy Cook, June 26, 2019*

# Comings and goings

*June 28, 2019*

Suddenly there's a lot going on and I'm finding it a bit much to handle.

The current plan is that Emma and Noah will catch a ride down to Bavaria with Christina's sister this weekend and then spend a week or so with Oma & Opa.  I think it's a really good idea for them to get out of here for a while.  But, being the current emotional basket case that I am, I'm a wreck about not having them around.

Meanwhile, the drama with the nursing agency continues.  Essentially, the hospice wants us to keep them in the background just in case something miraculous happens and Colin could go home, because it would be awful if we got into such a situation and then had no care service around.  But they do also plan to keep us here until the end.  So, we've told the nursing agency, for now, that we're under medical advice to stick around here until July.  They don't like that, because they get no money but have to keep their nurses busy, so they've suggested they might drop us, especially since they argue that they have a whole roster ready for July, and with only one day not filled.  This glosses over the fact that some of those shifts are filled by Eryan, whom we never want in the house again; some of them are filled by a nurse we've never met; and none of the nurses, to our knowledge, are certified in palliative care, let alone palliative care with a child.  When I see how professional and regular the care here is for Colin and then think to the chaos we had at home, I have a hard time imagining ever taking him home again, much less trying to work through his death while one of those nurses makes things worse in the background.

The agency is still going to let us dangle for a while and the chief doctor plans to have a sit down with them soon to make sure they actually have properly trained staff for the eventuality that they would care for Colin and perhaps to explain to them why he needs to be here for now. I like the head doctor here and she's pretty cool: I think she'll take the nursing agency apart. However, as much as I would like to see that, it seems like such an academic exercise creating more stress when we have a child who is dying here.

It's all kind of coalescing to put me on edge. I feel the depression tap, tap, tapping at my door again. My appetite is withering. I just want to get through this with some dignity. Instead, we're fussing with the head of a nursing agency who suggested to Christina that we take Colin to some temple in Sri Lanka because, were she in our shoes, she'd be grasping at straws right now. Thanks lady. Thanks for implying we haven't done everything we can for our dying child. It's a nice dab of icing on the cake.

In good news, I managed to get a footprint off of him last night after he fell asleep. In bad news, I then had two beers while watching the Women's World Cup with Noah and have spent the morning regretting that. I think I'll have to put beer aside until we have some stability again.

Colin does as Colin does. Yesterday morning was a little dicey. Yesterday afternoon he was all smiles and fairly active. This morning we were back to dicey. We'll see what happens when he wakes from his nap later. Overall I see a bit of decline every day: Like I think he's having problems rolling over as of this morning. But it's going slow. And then he perks up, so I really have no idea what's going on.

## Comments

Temple in Sri Lanka - good grief! So sorry for the lame stuff you've got to deal with on top of having a very sick child.

*—Jeremy Cook, June 28, 2019*

Ditch the nurses and the agency...they have never truly been there when you needed them and never will be. So sad for you and Christine having to deal with such craziness in the middle of your lives. Depression...I pray for you daily for the strength to keep it away knowing that when I have experienced it I had little control. Love you guys

*—Barbara Skipper, June 28, 2019*

I have to agree with the other comments. Drop the agency like a hot rock! If somebody had given me lip about my son after having given that same son lousy care, I'd be in court and/or jail after slapping that somebody silly! The fact that you haven't shows you're doing better than you think.

*—Marc Galmoud, June 28, 2019*

## thoughts and prayers

*June 29, 2019*

I imagine it goes without saying, but I'd really prefer that he lived.  I pray to God every day for a miracle cure.  Every time there's an uptick in his condition, I wonder if I dare hope that this is some kind of sign that the doctors are wrong and the tumor is miraculously dissolving or something.

I don't really believe that though.  Which is why the second part of the prayer is always "if he has to die, please do it soon."

Because I'm doing what I can to enjoy my final time with my son - and there are precious moments - but it gets harder and harder each day.  This unnecessary drama with the nursing agency is prying open the door on my depression, with the return of the lack of appetite and the leaden arms and the desire to do nothing but lay down and stare.  It makes it hard to focus on the tiny, good moments.  It makes it hard to do my job as a father at a time like this.

Then there is his deterioration. It's just a little bit each day, but I see it.  If annoyed or if he's trying to stop someone from doing something he doesn't want (hello teeth brushing), he can work up the energy to sit up and flail out at someone disturbing him.  But, absent a panic reaction, he's spending most of his time lying flat, usually on one side so he can play with whatever is in front of him with minimal effort.  He barely sits up.  To my eye, rolling over is becoming hard.  Even moving about in the bed requires him to do a kind of improvised military crawl on his back: I'm not sure if it's because he lacks the strength or the coordination or the full us of his limbs.  Whichever, it's heartbreaking to watch.  I can't quite decide if it's better that he doesn't understand what's happening to him or if it would help if I could make things clear to him.  So far, he seems to be taking it all in stride with no sign of obvious pain.  But he primarily interacts with the world right now by using his right arm - the other limbs have become far less active.  I shudder to think how he will react if he's still conscious and the time comes when he can't even use that last arm.

He's already lasted far longer than I ever anticipated.  We still don't know how long this can last.  It would almost be a mercy if he started showing signs of pain and they started him on his morphine and he just drifted away.  I think about this all the time.  Every interaction we have that isn't the tablet sees me thinking "I must read this story better than ever before" or "I must play Cars the best ever," because this might be the last time he knows me and it might be the last good memory I have of him.

And then it comes down to it, I still have to push those tiny moments of good aside and I find myself, in effect, praying for his death.  And I know it's not a "Please let him die so I can live a life of ease on the Riviera" prayer.  It's a prayer to end his suffering and to let me return to focusing on Emma and Noah, because they are so getting lost in the shuffle of all this.  But I still feel like a ghoul for even thinking it.

## Comments

You’re a great dad, and your honesty about what you’re feeling make you an even better dad. I’m so sorry this is happening to your little boy and your family.

*—Daphne Retter, June 29, 2019*

Sending love and prayers your way.

*—Molly Land, June 29, 2019*

You are in my thoughts and I agree that a you feel is a proof you are a fantastic dad.

*—Sofia Gueorgieva, June 29, 2019*

Niels, I’m so so sorry about all that you and your family are going through. I hope that Colin feels no pain throughout and that you keep your strength to endure this. You will always have my thoughts and prayers and hope that, if no miracle happens, God will be merciful and spare you and Colin anymore suffering. Much love, dear friend.

*—GF Santos, June 29, 2019*

Niels you and your family all remain in our prayets. Much love to all.

*—Lisa Caasko, June 29, 2019*

You sound like the most loving and caring Dad ever. I pray for you continued strength and understanding and please know that you are loved!

*—Barbara Skipper, June 29, 2019*

Hoping and praying for the end of suffering for your loved one is not ghoulish or anything to feel bad about - it comes from a place of love that can't be described. It's the same place where the hope and prayer for a miracle turnaround come from. Thinking of you all every day, and glad that Emma and Noah are in the care of extended family.

*—Michelle Lee, June 29, 2019*

Erika and I are thinking of you, Christina and your kids often. I have no brilliant words or insights (though your posts have that covered). I just wish you all strength and hope it helps to know how many of us are sending caring thoughts.

*—Todd Rosenberg, June 29, 2019*

Erika and I are thinking of you, Christina and your kids often. I have no brilliant words or insights (though your posts have that covered). I just wish you all strength and hope it helps to know how many of us are sending caring thoughts.

*—Todd Rosenberg, June 29, 2019*

Dear Niels, we only met once (in autumn 2014 in Paderborn) but you are all -Colin in particular- in my thoughts and prayers.

*—Anja Jörg, June 29, 2019*

This is a sad yet beautiful post to read, Niels. Beautiful, because, like others have commented, it shows what a great dad you are. You've always been one of my favorite writers, and I'm grateful you're allowing us to walk even just a bit of the path with you.

*—Jeremy Cook, June 29, 2019*

It’s loving to want this to end for him before his losses might become truly distressing for him. Of course we all want a miracle— but if one cannot be had, time worrying about what could happen next is no gift.

((((Sending much love to all of your family))))

*—Cynthia Meyersburg, June 29, 2019*

P.S. I second what everyone else is saying about what a wonderful parent you are. (And also Christina.!!)

*—Cynthia Meyersburg, June 29, 2019*

Sending you courage and strength, as you weather this unimaginable time in your lives. Sitting in the messy middle of all these emotions makes sense.

*—Maddie Sheesley, June 30, 2019*

I admire your courage and strength in sharing your true feelings and emotions in this journey, seemingly without end. Please know that we are all with you in thought, spirit and prayer.

*—Phylles Lagarde, June 30, 2019*

You’re far from a ghoul, Brother. You and Christina are human, beautifully human. I love you both.

*—Keena Graham, June 30, 2019*

You’re far from a ghoul, Brother. You and Christina are human, beautifully human. I love you both.

*—Keena Graham, June 30, 2019*

You are handling everything with so much grace and sanity in the midst of an impossible situation. I’m praying for peace for Colin, and for all of you.

*—Marci Roth, June 30, 2019*

## field trips and head trips

*July 2, 2019*

Today, a guy from my health insurance called and asked if my sick leave would be continuing, seeing as I haven't worked since March.  When I told him I was about to mail my new sick note in, he asked what steps I was taking to ensure my return to health and work.  It took a lot of self control not to tell him that, as soon as my son dies, I'm sure I'll be back at my desk in good time.

There's always some little thing to set you off.  Emma asked me from Bavaria today how Colin is doing and I couldn't think of one answer I could give her that didn't feel like a lie.  Christina went to a cemetery near our house to check out gravesites and says she was in a state most of the time.  I don't know how many people I've explained Colin's condition to, but it never gets easier.  Explaining it to my family doctor today prompted another round of waterworks.

Colin, meanwhile, remains largely status quo. He doesn't have a whole lot of mobility, but he does move quite a bit.  His right arm remains dominant.  He can flop himself into different positions in his bed.  He even sat up for a little bit today.  But I continue to see him having problems with little things like rolling over.  He doesn't use his legs much.  We wonder if he's losing a little control of the muscles in the left side of his face.  Last night when he fell asleep, he had a five-minute spell of waking up with a start, eyes bugged out and lips pulled back.  We couldn't tell if it was a look of horror or pain or panic.

In many ways, it's like watching a child regress.  All the skills he learned in his first few years of life are disappearing: walking, standing, sitting, rolling over, eating, etc.  I have no idea how much longer he can hold on, but it doesn't feel like there's a whole lot left to take away.

They started him on morphine today - or plan to start him, I haven't had a chance to talk to anyome about the status of this plan - even though he doesn't seem to be in obvious pain.  It was a bit of a rush this morning, so I didn't hear the explanation, but we suspect it's because they want to help him calm down so he doesn't resist every time the doctors and nurses try to do something with him.  But I know this about hospices and morphine: It's usually the start of the beginning of the end.

He also had a field trip today to a hospital where they hoped to finally undo the bandages from the surgery for his trach opening and fit him up with a trach that would allow him to speak while getting air.  But the doctors at this hospital - not the one where he had the surgery - took one look at the incision site and said that it wasn't healing right and that the doctors at the hospital where he got the surgery will have to be the ones to do that work.  When that happens, we don't know, but it means another field trip in the near future unless Christina and I just put our foot down and tell them to leave the kid alone, a step we're very close to considering.

## Comments

Geez! Realize that you can put your foot down to ensure what is best for Colin. Continue on that path and know we have not been in your shoes but know we care deeply!

*—Barbara Skipper, July 2, 2019*

Niels, you have incredible strength. I continue to pray for all of you.

*—Anne Custer, July 2, 2019*

Love and prayers to all of you.

*—Phylles Lagarde, July 3, 2019*

## The hospital we hate

*July 4, 2019*

If nothing else from this experience, Christina and I essentially pinky sweared to each other last night that, no matter what, no matter how sick the other gets, we will never check the other in to Charite's Virchow Clinic. Because, honestly, I don't care if I have a coronary right outside their main entrance, I do not ever want to be admitted to this meal-denying, blackout-plagued, chemotherapy-losing facility in my life.

To backtrack: Colin got his initial tracheotomy here back in December. During the spring, problems developed with it. They tried one fix in May, it didn't quite work. So, two weeks ago, the doctors pulled out the lasers and tried to really fix it.

Then the staff here at the hospice decided to go to a different hospital to take off the wound dressings and try a different kind of trach attachment for Colin. Except the people at the Lichtenberg clinic said they had no idea what the doctors at Charite did and they weren't going to touch that trach. That was Tuesday.

Yesterday, Christina, Colin and a nurse bundled off to Charite to get the wound dressings removed and the trachs swapped. Except, when they got there, no one had bothered to schedule an anesthesiologist. Because they thought Colin would lie still while they took out one trach, put in the other, and popped in an endoscopy to see how things looked. So, the mission was scrubbed. Now they're going to try again on Monday. Except Christina had to go and spend the morning there today just to fill out the paperwork and hear from a doctor about the risks of anesthesia.  Because we've never heard that speech before.  Lord, Charite, we can do it by heart at this point.  And this is for a little boy who's dying.  Can you spare us one day of paperwork?

No.  Apparently they cannot.  So, we'll see what Monday holds.

Let me be clear.  I'm willing to believe they have absolutely brilliant doctors and dedicated staff at this place.  But they are so disorganized.  Check that.  To call them "disorganized" is to imply they have some, if poor, level of organization.  Here, it feels to me like an improv theater troupe took over a hospital at some point.  "You're here for your scheduled surgery?  Well, let's see what we can wing on the fly."  You never know what will happen next, but you can assume your records will be lost and the doctor you need will be far from where you need him or her to be.

Back at the hospice, Colin's mostly stable.  After I felt I saw nearly daily deterioration in June, it's like he's plateaued since Monday (can you plateau when your trajectory is downward? I kind of always thought it was an uphill thing, but I can think of no better word).  I'm not seeing him get worse, but I don't see any real improvement either.  He's weak.  He's tired.  He's so grouchy.  I haven't really noticed the morphine drops changing his mood or his capabilities.  I don't know what to make of it.

And I still get a smile out of him from time to time.

That said, there were moments today when he seemed to be suffering pain, or at least severe frustration.  I'm making a pitch for more pain medication, but the doctor has to make the decision.  Colin is also prone to just sitting and staring, in a way that is not normal for a 5-year-old.  I'm told his vision could start to go, and I have to say, it sometimes doesn't feel as if he's looking at anything.  I wish I had some clue, but I think it's our fate to just roll with it for now.

## Comments

So sorry about that hospital! Especially maddening that during this time you want to be with your kid(s) that you have to deal with this stuff.

*—Jeremy Cook, July 4, 2019*

# mutual feelings

*July 8, 2019*

Well, it seems the hospital hates us as much as we hate it. Colin's trach procedure was scheduled for 8 a.m., meaning he had to be at the hospital by 6:45 a.m. At 8 a.m. - and only after Christina asked - were they told that he had been bumped back to noon. So, this means Colin has been kept without food/water for longer than necessary, the nurse who came in on his day off to help out is being kept for an extra-long shift and, it's now past noon and they're still waiting.

I stayed at the hospice because it seemed like I would just be an extra body hanging around the hospital and I wanted to see my brother off, who flew in for the weekend to visit us (thanks Markus!). There was also some logic to the idea that, since Christina went off with him on the dawn patrol, I could rest up and maybe take over this evening. But now things are stretching out far longer than we envisioned and, honestly, I'm turning into even more of a nervous mess than normal waiting for news. I'll update when I can.

Colin continues to remain very status quo. He doesn't move very much, but he can kick out and flail with his arms when he feels a need to. He does manage to sit up every now and then too, but it's a major effort for him. I wish I could make sense of this: How the tumor takes him apart little by little all through June and, now that July has started, seems to be doing nothing. It is making me wonder how long we'll remain in the hospice. Not in a bad way. I believe we're better off here than at home, where we might be having to navigate this with no nurse or an idiot nurse, but being here does start messing with your head after a while. And the mind does start turning to logistics, like, how are we going to handle this in a few weeks, when school starts and the kids ought to be back in the house?

On Thursday and Friday I was convinced his pain levels were rising, because he kept complaining about his leg, abdomen and head. That has subsided. We speculate about whether he could benefit from some kind of sedative, just so he doesn't freak out when we suggest a movie he doesn't like or try to read a book that he doesn't want (even if he just indicated it was OK). He should sit up more often to help his breathing, but has kittens if we try to prop him up. Maybe life would be easier if he was a little more out of it. Or maybe we would lose the little bit of him we have left that much more quickly. It seems like there are no good choices these days and half the choices leave me asking if I'm trying to think of ways to help him, or just to make this easier for myself.

## Comments

Powerful sentence: "It seems like there are no good choices these days and half the choices leave me asking if I'm trying to think of ways to help him, or just to make this easier for myself."

I think any parent in your situation would be facing the same dilemma -- so don't beat yourself up about action, let alone even the thought, of doing some things to make this difficult process easier for yourself. All of us readers on this blog know that overall you and Christina are making choices that benefit Colin, and sacrificing a lot as parents.

*—Jeremy Cook, July 8, 2019*

All I can think to say is that I am praying for and thinking of your family every day.

*—Cynthia Meyersburg, July 8, 2019*

Glad to hear Markus came to see you. Prayers of peace and comfort for all of you.

*—Barbara Skipper, July 8, 2019*

Just be there for him. Don't dissect your reasons.

I wish that I could help to lift some of your burden, but know that my thoughts and prayers are with all of you.

*—Phylles Lagarde, July 8, 2019*

## inpatient

*July 8, 2019*

He’s going to end up staying in the hospital tonight. It’s a longish story. I’ll write it out when I have time and my laptop. But everything is as well as can be. We should be back at the hospice tomorrow.

Sent from CaringBridge iPhone app

# hospital daze

*July 9, 2019*

The good news is that we made it out of the hospital and are back at the hospice. The even better news is that Christina isn't facing jail time for assaulting anyone on the hospital staff.

So, the point of the exercise was to clean up Colin's tracheotomy incision and see if he could tolerate this new trach tube the doctors thought would help him out. We set the appointment for 8 a.m. Monday so it could be done quickly.  That meant leaving the hospice around 6 a.m.

That part went fine. But when Christina, Colin and the nurse got to their assigned room, 8 a.m. came and went and no one came to get them.  That's when Christina went asking and found that they had rejigged the schedule and Colin was down for noon.  And no one had thought to tell them this.  And the noon appointment became a 1:30 p.m. appointment.

Second problem: After they moved him into surgery prep, they kept him on his breathing machine, but no one thought to hook the machine up to an oxygen unit. He needs oxygen to keep his saturation levels up, so by the time they got going, the anesthesiologist had to give him oxygen to keep him at acceptable levels through the procedure.

They cleaned up the wound with no problem and put in the new tube.  But then his oxygen levels really plummeted.  They were having to give him 4-6 liters of oxygen to keep his levels up.  In the past, we've made do with 0.2 or 0.3 liters to keep him steady. They decided the problem might be the new trach tube, so they pulled it out and put in a fresh version of the old one.

And then they decided to keep him overnight, because there was some concern about this drop in his oxygen levels.  In hindsight, it seems like a lot of bad decisions and then an overreaction, but it seemed the safest thing at the time.

It was already clear last night that he would go back to the hospice today.  We were told the transport would take him at 11 a.m.  That soon turned into "sometime between 11 a.m. and 1 p.m."  It wasn't until about 12:30 p.m. that they took off.  And then we got to the hospice to find that two nurses had called in sick, so Christina and I had to do most of the work of getting him set up here again on our own.

At least it's been calm since.  And the hospice staff even baked a cake for Christina's birthday, which is good, since I'm such a distracted mess I haven't been able to do one thing for her day.  I've already told her that, some time down the road, when our heads are screwed on straight, we'll pick a day, call it her birthday and then we'll do stuff.  For now, thanks to the hospice staff for making the day seem a little special.

Colin's doing fine. The new incision needs a little extra care and a lot of secretion comes out, so we're changing bandages and T-shirts at fairly regular intervals.  As always, it's hard to tell how his overall health picture is doing.  Earlier today, I could have sworn he was having problems rolling over.  Now I'm not so sure.  He was definitely wiped out for most of the day, but he also just had a surgery.  He also didn't have a lot of interest in anything for large parts of the day, but again: post-surgery.  We are also having to use more oxygen than we used to to keep his levels up.  Why?  It's anyone's guess.

In short, we don't know.  We're just trying to take it one day at a time and enjoy it as much as we can.  It's not as easy as it sounds (if it even sounds easy), but it is doable if you just strip things down to the basics.

## Comments

It doesn't sound easy, just so you know. You're not doing it wrong: it just really isn't that easy. None of it. xoxo, Kerri

*—Kerri Kennedy, July 9, 2019*

A friend of mine whose husband died of ALS, reminded me that during such times, you are still making memories. Prayers that you will have sweet times with Colin rather than what you had for the last 24 hours. Glad Christine is not facing jail time! Love you all!

*—Barbara Skipper, July 9, 2019*

# weeks and weeks

*July 11, 2019*

In early June, when I was desperate to get into the hospice, I wasn't sure Colin would live long enough for us to get in here.  As of today, we've been in here four weeks.  I never thought we'd make it this long.

It's also been seven weeks since the awful MRI that confirmed his fate.

His status is little changed.  He routinely complains about pain in his head and his right leg.  There are as many guesses as to the specific reason for the pain as there are medical professionals on hand.  I see continued degeneration in the use of his legs.  It also seems to be taking more energy for him to prop himself up on his elbow.  Then again, every time I write something like this, he has a fit of energy and performs precisely the movement I just said he was having a hard time doing.

We can generally keep him occupied with tablet, TV and stories, but there are also long spells where he either cannot be consoled or simply stares into space.  Those might be the morphine working (or not working).  Mostly, we have no idea what's going on.  He doesn't seem to sleep nearly enough, which means one of us is always up far too late getting him to bed, while the other one is up way too early when he starts his dawn patrol.  It's not particularly challenging, physically, to care for him, but it does take it out of you on an emotional level.  Especially when he lashes out and can't explain to anyone what it is he really wants.

We hope to talk to the doctor today about his pain levels and whether there is anything we can give him that will simply calm him down, as many of the things we could do for him to make him more comfortable would require a degree of cooperation he is not able to give right now.  But we also don't want to shut him all the way down.  Nor are we even in agreement about whether we want to do this.  With one another or with ourselves.  It's just another awful decision in a long line of those we've had to make of late.

Emma and Noah should be returning from their Bavarian vacation later today.  I never really imagined they'd come back to the hospice for another round, but this is where our family is set up for the next three weeks, at least.  Then we'll have to see what happens when school resumes in August.

## Comments

Prayers and love. Thanks for the update!

*—Barbara Skipper, July 11, 2019*

You are all in my prayers. Stay strong.

*—Phylles Lagarde, July 12, 2019*

I’m thinking about you.

*—Tanya Jones, July 12, 2019*

## rules of the road

*July 16, 2019*

There's been little to report. Colin's status has remained more or less unchanged for the last few days.  He's weak.  He doesn't move unless he feels he has to do so.  He's mostly only interested in playing on his tablet or watching some TV.  There are rules to it all.  He's more likely to let Christina read a book to him or cuddle with him.  He's more likely to let me put pants on him or brush his teeth.  Who knows what the logic might be?  He's angry and easily upset and none of us know how long this might last.

I've had several talks with doctors and chaplains here at the hospice about the end of a child's life. They've all been helpful, in their own way, but none of them have been fun.

Sometimes he seems to complain about more pain.  Sometimes we wonder if his complaints are to distract us from doing something he doesn't want (ending his tablet time; putting him to bed; brushing teeth; etc).  We had a long talk with the doctor today and will probably boost some of his medication.

Emma, Noah, Christina and I headed out for a few hours today to check out, of all things, a place where kids can learn the rules of the road.  Who would have thought my kids could so enthusiastically spend so long practicing parallel parking in go-carts?  It didn't feel right leaving Colin alone in the hospice (with nurses watching him and the tablet running at full blast), but it was good for us to get out and, painfully honestly, we're going to have to learn how to do it.

## Comments

I'm sure that time for Emma and Noah was really meaningful!

*—Jeremy Cook, July 16, 2019*

## Home run

*July 19, 2019*

The kids wanted to see the house, so here we are in Karlshorst for a few hours.  I don't know what they planned to do while we were here, but they promptly parked themselves on the sofa with some library books ... something they couldn't possibly have done at the hospice.  But I guess the idea was to feel something familiar for a few hours before we head back.  There's a barbecue tonight, so we at least have some good motivation.

I had nothing I really needed to do here, so I'm just puttering. And blogging.

To my eye, Colin has gotten noticeably weaker in the last two days.  But, bear in mind, this is to my eye.  Ask Christina or a nurse and you could get a different viewpoint.  But his right arm, the one that still worked pretty well, seems to be growing increasingly shaky.  He can still use it, but it seems to require more force of will than it did just 48 hours ago, and it doesn't look at all steady any more.  He also just looks wiped out.

Now, there are other possible explanations for this.  It's getting hotter.  He has a fever.  He slept poorly.  But this could also be an indication of the tumor getting stronger.  Then again, I've been worrying about the tumor finishing its work since the start of June, and we're still here, so what do I know?  We all agree he doesn't seem to be in any pain or distress.  But it also doesn't look like he's interested in much the world has to offer right now.

### Comments

Ugh, that uncertainty must be really tough. So sorry.

*—Jeremy Cook, July 19, 2019*

## hate mail

*July 21, 2019*

The surreal moment of the day came when one of the nurses pulled me aside to tell me how some Jehovah's Witnesses had recently come to his house. He wanted to tell me how he'd made a point to listen to their story and thought it was good to keep an open mind to other people's belief systems. It went on for quite a while, until I told him he was better at dealing with them than I was.

At this point he said "But aren't you a Jehovah's Witness?"  I said no.  "Is your wife?"  Again I said no.  And then the conversation ended, with him clearly a little sad he'd been nice to some religious solicitators for no good reason.

In other news, we finally cancelled our contract with the nursing agency.  It was a formality, but it had to be done.  They responded right away with a fairly nice email about how they were sure the hospice could probably take care of us better than they could.  I took issue with the word "probably," but let it slide.

Then came the matter of the bill.  They only just got us the bill for April and, shockingly, we could only find three mistakes, where they claimed they had provided us service when, no, they hadn't.  Impressively, they tried to sell the story that Hannah - who quite on Day 2 after precisely one night shift - had worked a second shift later in the week, after not only leaving our team, but also quitting the company.  So, Christina pointed that all out to them in a separate email.  And then the calls started coming.  The social worker in the hospice had advised her not to speak to them any more, but instead to have all communications by writing.  And, after Christina refused to pick up two calls, she got an email saying "We know you're busy, but we have to talk."  I suspect Christina is going to have quite an email exchange with these people when she finally finds time to get to her email.

In other charming correspondence, the department of youth services is after us because we haven't gotten Colin in for an annual checkup.  They seem to have been alerted to this by the hospital, which doesn't seem to be able to keep track of the fact that Colin both hasn't been in for a checkup and that he is also a palliative case.  Christina pointed this out in an email, to which an apparently particularly kind-hearted worker responded that, given our state, it would be nice if we could then formally cancel his contract for a space in day care.

Honestly, it does seem like some days that the world is out to make this as difficult as possible.

Colin seems to get a little worse every day.  Today was hard to gauge, since they tried to change the bandage on his trach at 2 a.m., which woke him up.  Usually, he sleeps through this, but he would not go back to sleep last night, which had him in a state pretty much all day.  He finally crashed at 6 p.m.  Let's hope he sleeps through the night tonight.

Nonetheless, his control of his right arm seems to be getting a bit worse each day. There were 15 minutes yesterday where it didn't seem to respond at all the way he wanted, and he understandably panicked. It's been better since, but it is still getting noticeably feeble. He also complains about headaches more regularly. We have now put him up to four drops of morphine every four hours, double the amount he started on less than three weeks ago. I'm told this is still a pretty small dose, but let's hope it works to ease his pain, calm him down and maybe get him to sleep a bit better.

It remains impossible to say how long this will go on. The doctor says it could go fast. At the same time, school starts in two weeks and we have to start making contingency plans for running our household and getting the kids to school while keeping one of us here at all times and making sure neither of us gets stuck here for too long.

## Comments

What the (expletive deleted) is wrong with the people at the nursing agency??!! I am so angry at them!!! (And I am not the one enduring their shameful cruel incompetence — I can only get a glimpse at the horrendousness that is the dread nursing agency.) Sending love and prayers.

*—Cynthia Meyersburg, July 21, 2019*

Man, you couldn't make this stuff up! Ugh, what a pain. So sorry about that lame nursing agency.

*—Jeremy Cook, July 21, 2019*

Oh guys, it must seem like you are trapped with Alice in Wonderland right now. Y'all are really being put through a wringer and then some. My prayer for each of you is faith, love and peace.

*—Phylles Lagarde, July 21, 2019*

I would be glad to send a tactfully worded message on your behalf to this nursing agency, the hospital, and department of youth services. Just sayin...! I am myself a bureaucrat by job title definition, but I'm a human being first.

*—Michelle Lee, July 22, 2019*

# gone to pot

*July 22, 2019*

After months of debating it - sometimes with one of us rejecting it, sometimes with a doctor rejecting it - we finally started him today on a cannabis derivative designed to calm him down and take the edge off things.  He got his first dose around 2 p.m. and he does seem pretty chill.  That said, he could just be exhausted, after two terrible nights. Or he could just feel awful and not want to move.  Or all three.

Sunday started poorly since he was up at 2 a.m. after the unwelcome bandage change. He stayed awake all day and only drifted off at 6 p.m.  But then, strangely, he woke up at 8 p.m. and had a series of panic attacks, again because he seemingly had little control of his right arm.  It took until about 11 p.m. to calm him down and get him to sleep.  And then he was up at 4:30 a.m.  Here's hoping things work a little better with this new combo.

I won't lie.  I went to bed last night dreading that this was the final phase.  The nurses asked Christina to sleep in his room (and I think Christina would have done it even if they hadn't asked) and they set her up with an emergency ringer.  It felt more real than many of our more recent incidents.  Yet here we are again today.

My feelings on the hospice come and go.  Some days I'm convinced I'm going to go out of my mind here.  Other days I finish the day feeling I almost had a fun day here.

Medical madness continues. We got a giant delivery from our supplier in the last few days, including a refill of his oxygen tank and a new, backup tank.  Except the backup tank seems to be leaking gas like a deflating tire.  We've parked it in the bathroom, which is now probably the most oxygen-rich lavatory in the country.

After being told that it looked like I lost more weight, I checked and confirmed that this whole ordeal has taken about 11 kilograms off me (24 pounds?).  I am eating better, but the grouchy chef her measures out the portions very precisely, so I guess that's why I'm keeping it off.  All I know is that I had to run for a tram today and, after making it, sat down to question why I wasn't about to die after the sprint.  It took me several moments before I realized: "Oh, massive stress-induced weight loss."

## Comments

So sad for your family. Prayers and Love. Barbara

*—Barbara Skipper, July 22, 2019*

So sad for your family. Prayers and Love. Barbara

*—Barbara Skipper, July 22, 2019*

Words are inadequate for circumstances like these. Sending comfort and peace to all of you.

*—Maddie Sheesley, July 22, 2019*

Danke für diesen blog, Niels und dass du uns auf dem Laufenden hälst.
Wir wünschen dir und Christina, Emma und Noah ganz viel Kraft, innere Stärke und Mut.
Die besten Gedanken und Gottes Liebe
für euch!

*—Dagmar Menta, July 22, 2019*

May the boy sleep! And may you eat and also get your rest! Thanks for the update.

*—Jeremy Cook, July 23, 2019*

## The hospital strikes back

*July 25, 2019*

Well, it wasn't our worst visit to the hospital ever.

Sometimes, that's just the best praise you can give.

Today started out with what should have been an easy hospital run.  We had to go and get the stitches removed from his July 8 operation. And they were going to finally check and see if they could get this new trach tube put in.  No nurse could come with us, since they're having staffing shortages at the hospice, so we left Emma and Noah in the care of one of the non-nursing staff and Christina, Colin and I got picked up at 6 a.m. for an 8 a.m. procedure.

Well, we got there and they had lost Colin's file.  Also, they didn't have a room ready for him, even though they had scheduled this procedure more than two weeks ago.  So, we went right down to the room for operation prep.  That's when Christina mentioned that Colin has a fever.  He might have an infection.  It might just be because we're having the hottest day Berlin has suffered for a few weeks.  Or it could be caused by the tumor.  We just don't know.  The point is, the anesthesiology team got worried when they heard about this, which lead to what felt like an hour-long discussion between the hospice doctor and the ear, nose and throat doctor on one side and anesthesiology on the other about whether to proceed.  They finally agreed to do so, but slowly, meaning Colin's 8 a.m. procedure didn't start until about 10:30 a.m.  The only upside was that the prep room was air conditioned, and it was very hot outside, though even that thrill lessened as the time dragged on and I realized I had left my fleece back at the hospice.

He slept for a long time after the surgery.  He did not get the new trach because someone had told the supplier that there would be no surgery.  Apparently this happened shortly after anesthesiology initially expressed concerns.  But no one ever made a decision to stop the surgery, so who knows what information was conveyed to the supplier.  But he left the hospital grounds and then stopped picking up his phone, so we were left with no choice but to put in a new version of the old model.

Once awake, we went back upstairs for another hour, so they could be sure he was fine after the surgery.  We were told there would be a medical transport to take us back to the hospice at around 3:30 p.m.

And then, shortly before 3:30 p.m., the band that holds the trach tube in place came undone.  Once it came undone, the trach tube slipped out.  Christina caught it, but couldn't get it back in.  Ricardo (I'd happened to run into him on the hospital campus) and I went off to find a nurse, after realizing that no one was responding to the emergency signal.  The first nurse's station was empty.  When we reached the second one, neither nurse there even stood up.  They just told us to go back to the first one, insisting someone had to be there.  We ran into another nurse on the way, who said he had to find someone else to help us.  Somehow in all that, a doctor showed up at the room and go the trach back in.  Then there was a long discussion about whether this really was the best trach for Colin after all, which led to a rushed round of new procedure that ended up with Colin with a new trach tube.

All during this, we were wondering at our luck that the ride back home hadn't shown up in the midst of all this only to get stuck waiting for us to sort things out.  Silly us.  No one had ever arranged a transport for us.  And now it was 5 p.m. and they couldn't organize one until 7 p.m.  Except we called the hospice and they got someone to arrive within 45 minutes.  Oh, I hate that hospital.

And now we're back at the hospice, all of us suitably exhausted (in Noah's case, because he discovered badminton today and spent the day apparently forcing one of the minders to play with him in this ridiculous heat). Colin is growing visibly weaker. I have to keep pointing out that he isn't paralyzed, but he doesn't move his arms and legs any more unless he has to. And his control of his right arm is growing feebler, to the point where I think playing on the tablet is growing too strenuous for him. Worse, he seems content to go long stretches of time just doing nothing, laying on his back and staring at the ceiling. I've never seen a 5-year-old do that willingly before, and it worries me.

The doctor is going to up his sleeping medication and his morphine tonight, so we'll see what that does for his mood. I realize it might mean more staring into space, but maybe that will spare him the frustration of not being able to move like he wants to be able to. I just don't know. All of our options are miserable right now.

## Comments

All your options are indeed miserable. My heart is hurts for you. Putting one foot in front of the other in this situation is truly heroic.

*—Kathryn LaPointe, July 26, 2019*

It sounds like that hospital is being run by Larry, Curly and Moe! Do they ever communicate on a case? Especially a child's care? Shame on them! I am glad that he finally got the new equipment but sorry that y'all had to go through so much. Prayers...

*—Phylles Lagarde, July 26, 2019*

# the trach again

*July 26, 2019*

You have to understand, a lot of this happens very quickly and in German, so even though I'm in the room when it happens, I usually don't understand exactly what happens until Christina gets a chance to break it down for me. And, since Christina and I get so few chances to speak, time can pass until I am on top of what happened just in front of me.

So, yesterday, when they decided to put in the second new trach tube of the day, it seems the doctor discussed a larger size tube.  I remember that part.  What apparently then happened - and Christina noticed it right there - was that he went up about three sizes, as opposed to the half size they had discussed, and outfitted Colin with an adult-sized trach tube.  It apparently fits quite well, but none of the people in the hospice are thrilled about it.  Especially since his incision is healing badly and there's now some chance the tissue could tear and ...

Honestly, I don't want to get into all the details.  It sounds horrific and it's only a possibility, not a given, so I'm just not going to get into it.  But there's a chance all is not right with the tube or the incision.  But to find out how all right or not all right it is, we'll have to go back to the hospital and get an X-ray and maybe some other procedures.  And no one wants to anesthetize Colin again, but you tell me how you're going to get him to sit still for an X-ray without at least juicing him up a little bit.  And I don't know how much time this kid has left on the Earth, and I hate the idea of him spending any more of it at this stupid hospital.

I guess we'll find out Monday when and if this is happening.

He continues to be wiped out.  Today is the first day in ages he didn't play tablet.  He asked for it once, but he simply no longer has the motor skills to play.  The nurses and the doctors point out that he's tired and it's hot and it's been an exhausting few days, all of which are plausible.  Maybe he'll pick up the tablet just like always.  But I don't buy it.  The tumor is supposed to move this way, slowly leaving him unable to move.  He's almost there.  All he can do is thrash around, really.  And he's so tired, but he won't sleep without lots of pharmaceutical assistance.  Is that because he's in pain?  Because the tumor has screwed up his sleep center?  Because he's gotten so many drugs in the last few years that he shrugs off the sleep aids?  We just don't know.  Generally, he's calm and content to listen to us read or to kind of listen to his Curious George shows, but he's pretty out of it.  For now, the general consensus is that he's not in enough pain or in a bad enough state to put him under sedation.  But that option remains in the back pocket should things degenerate.

## Comments

I understand Europe may be getting some relief this weekend from those soaring temperatures. Hang in there, may you get some other relief, and we'll be hoping for good news on Monday.

*—Jeremy Cook, July 26, 2019*

Prayers for all of you and may God Bless You!

*—Phylles Lagarde, July 29, 2019*

## rush job

*July 29, 2019*

So, remember how on Friday the hospice doctor, Dr. Lieber, was working on a plan to get us to the hospital so Colin could get a new trach tube, among other things?

Well, at about 1:30 p.m. today she wandered into our room and told us that there was a bed waiting for Colin at the hospital and that the transport was, essentially, on the way. Usually, Christina packs for an overnight hospital stay the night before. She pulled it off in an hour today, with help from one of the nurses. As luck would have it, Christina's parents are in Berlin and were on their way to the hospice to visit us when this all went down, so we at least had someone to watch Emma and Noah while we all dashed off to the hospital.

Surprisingly, things are running more or less efficiently at the hospital. By 5 p.m., they had him outfitted with a new trach tube and by 6 p.m. he had an X-ray. He's going to get an even better trach tube tomorrow morning, but the upshot is that the tube he got on Thursday was too long, which was leading to parts of his lung not getting enough oxygen, which might explain why we've had to pump so much extra oxygen into him the last few days just to sustain a basic saturation level.

We'll see what happens tomorrow. They're going to do another X-ray to see what one night of the new tube does for his levels. They also have to do a blood test to check his levels. And then we'll hopefully have him back at the hospice as soon as possible on Tuesday.

As for Colin, they upped his morphine levels this weekend and switched him to a version that is time-released over 12 hours. I think we've finally gotten ahead of his pain levels. At least I don't think he's complaining about pain. But he's very weak, moving ever less and with less coordination. He's also tired all the time (though that could be the morphine). He's even starting to care less about which TV shows we watch, which is something that could always get him worked up in the past. We'll just have to see.

## Comments

Yay, hospital, way to go. Finally!

*—Jeremy Cook, July 29, 2019*

## And on the second day...

*July 30, 2019*

So, the plan was to have a series of fairly straightforward procedures today: some physical therapy, an X-ray and then a bronchoscopy. I'm not saying these are everyday procedures - I certainly couldn't perform them - but they were described to us as fairly basic operations that could have all been performed within an hour or two this morning were they organized properly.

But we're at the hospital, so they didn't finish up until about 4 p.m. And he had to be sedated for the bronchoscopy, so he didn't wake up until 7 p.m. And that was deemed too late for a transfer back to the hospice. So, it's another night in the hospital for Christina and Colin.

The upshot is that, even after a night with the new trach tube and the physical therapy, there was still a lot of gunk accumulated in the left lung from the few days that the tube put in last week blocked it. The bronchoscopy pulled a lot of if it out. They showed it to us and it looked like a test tube of snot. Hopefully, with that clear, he can breathe easier and we won't have to keep using the really high levels of oxygen we've had to employ the last few days.

Aside from all this, the other hiccup was that the trach tube supplier didn't show up today as planned to bring the newest model of tube Colin is supposed to get. So, he'll get that tomorrow, implying that, even if everything had been well organized, he wouldn't have gotten out of heading to the hospital again. Let's just all hope all this work and effort was worth all the trouble.

## Comments

Geez! I’ve personally not seen that sort of thing happen here; however, I’m sure others perhaps have. It leaves me speechless. So sorry for your and Christine’s ongoing pain. ...and also Colin! Prayers and more prayers. We think about you every day! Love, Barbara

*—Barbara Skipper, July 30, 2019*

Man kann es kaum glauben, wenn es nicht so wahr wäre, was ihr da erleben müsst! Weiterhin großes Durchhaltevermögen, Geduld und Kraft für Christina und dich und ganz liebe Grüße, wie auch immer er das verstehen mag ,an den kleinen Colin!!! Auch von Rainer! Möge dieser Trach jetzt ordentlich sitzen und gut funktionieren, die Wundränder heilen, so dass Colin mehr Ruhe bekommen kann.

*—Dagmar Menta, July 31, 2019*

## and another thing

*July 31, 2019*

So, we did not get back to hospice today.

This morning, the doctor explained to us that - following the four days with the bad trach tube, which blocked the left lung and left it filled with mucus - they were able to clear it out with the bronchoscopy. However, now the lung is weakened and, because Colin doesn't cough any more, the lung fills right back up.  That left us with three choices.

1) Stay in the hospital for a few more days so he can get regular bronchoscopies.

2) Head straight back to the hospice and hope to treat it with physical therapy and inhalation.

3) Stay in the hospital one more night while they organize something called a Cough Assist machine for Colin at the hospice, which will essentially cough for him and hopefully clear out the gunk.

We picked option #3.  The first option just seems like too much stress and too many sedatives for someone in Colin's condition.  Plus, as the doctor described it, we got a vibe from her that she was trying to tell us we really don't want to put Colin through all that.  Option #2 just seems too risky.  So, we have to hope this coughing machine does the trick, otherwise he runs the risk of yet another round of pneumonia. He had two rounds with the coughing machine today and seemed to tolerate it OK.  Only time will tell if it's doing the trick.

He's wiped out.  They had to sedate him for the bronchoscopy yesterday, meaning he slept until almost 7 p.m.  Then Christina didn't get him to sleep until 1:30 a.m.  He woke up at 5:30 a.m., but then nodded off around 9 a.m. and slept until 4 a.m. when I had a nurse shine a light into his eyes because I couldn't wake him up any other way.  The lung might be wearing him down.  He might just be exhausted from the hospital.  This could be the next step of the tumor unfolding.  We just don't know.  Time will tell.

## Comments

Praying for family comfort and peace!

*—Barbara Skipper, July 31, 2019*

So much for Colin and all of you to endure. My prayers for you are for strength, courage, patience and most of all, love. This is a long, hard journey, but God is beside you.

*—Phylles Lagarde, August 1, 2019*

## the return

*August 1, 2019*

We've made it back to the hospice, with our very own coughing machine.  The new trach tube is causing some questions, but things are as well as they can be.

We're going to have to figure out how to integrate all of the extra inhalations and coughing machine treatments and physical therapy into our daily routine, but one thing at a time.  Right now, it's not home, but being in the hospice is a hell of a lot better than being in the hospital.

Colin remains pretty exhausted.  He's definitely trying to sleep more than is usual for him.  One can hardly blame him.

## Comments

thinking of you all... hope you are able to get some sleep in the midst of all of this.

*—Kathryn LaPointe, August 1, 2019*

Have no idea how to respond to your recent hospital stay except that I’m really glad you made it back to Hospice. Many prayers and love your way! Barbara

*—Barbara Skipper, August 1, 2019*

You and your whole family are in heart, in my prayers.

*—Cynthia Meyersburg, August 1, 2019*

Glad you're all back together again. Another machine - sorry, my friend. I do hope it provides relief.

*—Jeremy Cook, August 1, 2019*

# long or short division?

*August 5, 2019*

Yesterday, I took Emma and Noah back to the house so they could return to school today. We got used to the house, found some stuff we hadn't seen in weeks, cleaned (OK, that was me all on my own), commented on all the things belonging to Colin we found and then had a very serious discussion about death, cancer and life choices over pizza.

Christina remains in the hospice with Colin. Logistically, I can't get there today.  I'll help out for a few hours on Tuesday and then take over for a day or two starting on Wednesday.  I am not looking forward to this phase, juggling schedules and shuttling back and forth just so we can make sure all of our kids have at least one parent around. It will be exhausting, and neither of us has a lot of reserves to fall back on right now. And there is the real issue that I'm getting sick of being separated from my wife.  We already did this from December through March.  Even from April through July, between the home health care and the hospice, we've been in the same place, but often so preoccupied with Colin or paperwork that we barely have time for one another.  Eight months we've been doing this hell.  I just never imagined it could keep on going like this.

Colin remains weak.  His movements remain curtailed, but we can't tell if that is due to pain or exhaustion or lack of control or something else.  He will still thrash out if he doesn't like what you're trying to do to him.  But, mostly, he lies on his back and stares. He's happy if you put on his show (and will let you know if you put one on he doesn't like), but he doesn't even look at the TV half the time.  Ditto with books.  He'll let me read sometimes, but he's usually staring into the distance.  Then again, he knows these books and shows by heart.

He acts tired all the time, almost to the point of nodding off, but he doesn't fall asleep during the day. We'll just have to see how much longer this phase lasts.

## Comments

Kudos to you for having the strength and love to have that conversation with Emma and Noah, with all the uncertainty and dread of getting to this phase, all running in the background.

*—Jeremy Cook, August 5, 2019*

In the States hospice can also be provided in the home, but then you have to depend on your favorite nursing providers. It might work out better where Colin remains around everyone and vice versa, but these are part of the decisions you have to make, and they are not easy emotionally or logistically. Daily prayers of comfort and love come your way!

*—Barbara Skipper, August 5, 2019*

I agree with Jeremy Cook. Emma and Noah are smart and know that something is going on, so they should be informed on the situation so they can better cope as it progresses. Stay strong, Niels. God will give you the strength. Praying for your family as always.

*—Phylles Lagarde, August 5, 2019*

Glad for Emma and Noah to have some routine back in their lives. Hopefully very helpful for them.

*—Todd Rosenberg, August 6, 2019*

## update

*August 11, 2019*

There is little to say. He gets weaker regularly. Movement has become very difficult for him. We’ve had to up his morphine dosage. He generally seems aware of, but also, for long stretches of time, uninterested about the world around him. Every now and then we see a flash of the old Colin, but it’s becoming rarer. The nurses are generally positive, but you can see little things in their behavior - an increased willingness to offer extra morphine, routinely asking us if we know where the emergency call button is, even asking permission to be notified should he die while one of them is away on vacation - that make you think they are getting worried too.

## Comments

My heart breaks for you all. I am thinking of you.

*—Molly Land, August 12, 2019*

Niels my thoughts and prayers are with you everyday. Lisa

*—Lisa Caasko, August 12, 2019*

Thinking of you all every day. Your love for Colin is evident in every word you write and all the things you are doing. Prayers and love to you all.

*—Marci Roth, August 12, 2019*

Continue to think and give prayers for your family. Even though you know this is coming, it is impossible to be emotionally prepared for the end. I am sending thoughts for strength and comfort to all of you.

*—Dan Wooldridge, August 12, 2019*

I am thinking of you every single day. My thoughts and prayers are with you guys, let strength be with you all.

*—Jeanne Clayton, August 12, 2019*

Praying for comfort & peace.

*—Erin Rotter Mayer, August 12, 2019*

So very sad to hear this, dear friend. Thinking of you and Colin and the family and praying for your strength to endure this. I hope he remains comfortable and without pain. All our love to you.

*—GF Santos, August 12, 2019*

Niels, I cannot imagine a more difficult time than what you and your familiy are going through. I read strength and courage and a huge amount of love in your words - and support for each other. My thoughts are with Colin and all of you. Big hugs ...

*—Katja R, August 13, 2019*

I've been reading your posts and know there is nothing to be said, but I'm so sorry Niels, for this hell your family is living through.

*—L Smith, August 13, 2019*

I pray that God will give you the strength to accept His will.

*—Phylles Lagarde, August 18, 2019*

## August 20

*August 19, 2019*

He's moving even less than before. This is part of the progression of the disease and we were told to expect it.

He does not seem to be in any pain or obvious distress.  That is about the best we can do right now.

### Comments

You have been in our thoughts. Sending you all lots of love.

*—Sofia Gueorgieva, August 20, 2019*

Thinking about your family all the time.
Again, I wish I could do anything to help.

*—Boris Babic, August 20, 2019*

Much love and strength to you and your family.

*—GF Santos, August 20, 2019*

Sending prayers and thoughts of strength and comfort for your family.

*—Dan Wooldridge, August 20, 2019*

Grace and peace to you guys as you do your best in this situation.

*—Jeremy Cook, August 20, 2019*

Thinking about you and your family, prayers to all of you.

*—Jeanne Clayton, August 20, 2019*

Our thoughts, prayers, and love are with you today and always.

*—Barbara Skipper, August 20, 2019*

You are in our thoughts.

*—Lynda Schmitz, August 20, 2019*

Our hearts, thoughts and prayers are with you, Christina, Noah, Emma, and Colin.

*—Claudine LoMonaco, August 21, 2019*

Sending our hugs and thoughts with all of you.

*—Carol Hamilton, August 21, 2019*

Sending our hugs and thoughts with all of you.

*—Carol Hamilton, August 21, 2019*

May God grant you the gifts of Faith, Love and Patience as He shepherds you through this valley of tears.
The Lord is my shepherd ...

*—Phylles Lagarde, August 21, 2019*

Wir denken an euch und senden Kraft und Liebe für diesen Weg. Ihr seid da für Colin, das ist das beste was ihr tun könnt, begleiten, begleiten, begleiten und stützen, er spürt eure Gegenwärtigkeit. Ihr macht das großartig!

*—Dagmar Menta, August 21, 2019*

## sleep

*August 25, 2019*

He's awake ever less. But he's also not sleeping so well.  Even when he's conscious, he seems to often be in a daze with his eyes half closed. He can still request some things, but mostly he only reacts when we try to do something to him that he doesn't want.

We still don't think he's in pain or distress, so that's something. Mostly, we just try to be near him, which we think is comforting.

### Comments

Thinking of you guys, sending lots of love.

*—Molly Land, August 25, 2019*

Sending you all love, prayers and strength.

*—Erin Taylor, August 25, 2019*

We are with you and continue praying!

*—Claudia Busch, August 25, 2019*

Sending prayers and healing thoughts.

*—Dan Wooldridge, August 25, 2019*

Thinking of you and the family regularly, Niels.

*—amy mitchell, August 25, 2019*

Wir denken immer an euch und senden euch Kraft, Liebe, Geduld und Durchhaltevermögen. Können wir euch bei den großen Kindern irgendwie behilflich sein?

*—Dagmar Menta, August 25, 2019*

I am so sorry and think of you all often. You have given Colin comfort and love beyond words.

*—Michelle Lee, August 25, 2019*

I am so glad that he has you all around him right now. Even if he can't show it, it must be comforting to have such love and caring surrounding him.

*—Kerri Kennedy, August 26, 2019*

It is so comforting, he knows you are there, he can feel the love. I send you love and strength.

*—Jeanne Clayton, August 26, 2019*

Niels -- he knows you're with him always and it is helping him. Thinking of you and your family and sending lot of love.

*—Sarah Bender Reilly, August 27, 2019*

Please know you are all in my prayers.

*—Lisa Caasko, August 28, 2019*

Thinking of you and your sweet family...

*—Kathryn LaPointe, August 30, 2019*

# Bereaved Dads Grouchy

*September 1, 2019*

Well, that's what appears in your phone's calendar when auto-correct does a number on your attempt to schedule a meeting of the 'Bereaved Dads Group.'

They contacted me a few weeks ago, after one of the doctors contacted them, probably after I'd behaved particularly manically one day.  I had always meant to check out the group, but I thought one could not do so until after the death of one's child.  But they're flexible.  Also, of the six guys there, three of them spoke with heavy Berlin accents, so I only understood about 50% of what was said.  One guy might have told a story about dropping something on his head, but don't hold me to that.

Whichever, it's nice to have another form of support. The guy who leads the group, Jens, lost his son to a very similar brain tumor as Colin's 15 years ago, so he's been particularly helpful to talk to.

Colin is doing the best he can. We're having a heat wave in Berlin, so that's prompted a fever for him, which has him even more wiped out than usual. He's sleeping more all the time and, even when awake, it's hard to tell how much he understands when we speak to him and if he's capable of responding the way he would like.  Honestly, there's very little we can do for him other than being around and trying to read to him or put on a TV show, in the hopes that the one or the other will distract him.

## Comments

<3

*—Maddie Sheesley, September 1, 2019*

Your family is in our thoughts.

*—Dan Wooldridge, September 1, 2019*

Sending lots of love to all of you!

*—Sofia Gueorgieva, September 1, 2019*

Glad to hear about Jens...and glad each of you have the ability to just be there with Colin.

*—Jeremy Cook, September 1, 2019*

Bereaved Dads Grouchy - take the humor where you can get it! And its probably kinda true?

*—Carol Hamilton, September 1, 2019*

Just sending y'all a lot of love and prayers.

*—Phylles Lagarde, September 2, 2019*

## Beginnings of endings

*September 5, 2019*

We've moved back as a family into the hospice, on the advice of the staff here.  His condition is deteriorating generally, but, mainly, the nurse said that his gut instinct told him it would be a good idea for us all to be here today, not tomorrow, if we wanted a family farewell.  So, we're here for the time being.  But no one can tell us if we're working on a timeline of hours, days or weeks.  We simply have to follow this journey until its end.

He is sleeping a lot.  Even when he's not asleep, he tends to lie with his eyes closed.  We don't think he is in significant pain or distress, and the doctor has medication on standby should we think he is experiencing problems.

### Comments

Strength and love to you and your family. Thinking of you always.

*—Jeanne Clayton, September 5, 2019*

I’m so sorry, Niels. Much love and comfort to you, Christina and the kids.

*—GF Santos, September 5, 2019*

Many prayers and much love to the entire family during this difficult time. I cannot even imagine how difficult this must be. May you feel God’s presence and love. Your cousin, Barbara (and Steve)

*—Barbara Skipper, September 5, 2019*

This so painfully sad. Prayers and healing thoughts to you and your family.

*—Dan Wooldridge, September 5, 2019*

I'm so sorry. The only blessing is that he doesn't seem to be in pain. You guys are in my thoughts daily. Much love.

*—Marci Roth, September 5, 2019*

Words are so feeble at a time like this. Just know I have been thinking of you and am here for you and your family.

*—Marc Galmoud, September 5, 2019*

I'm so very sorry, Niels. I have been following, and echo the sentiments of others here. I think and pray for your family and you every day and if there's anything that I can do at all, I am here.

*—Lisa M, September 5, 2019*

I wish I could take some of your pain! Donna shared some of your situation with me the other day, and we just cried together and hugged one another! You are all in that hug! Know you are loved!! Martha

*—martha stanley, September 6, 2019*

Ihr seid nicht alleine, wir denken an euch und senden euch die herzlichsten Wünsche und Grüße, seid alle behütet und beschützt, seid gesegnet von eine höheren, übergeordneten Kraft, die weiß, wann der Weg für Colin auf der anderen Seite weiter geht. Viel Kraft für Christine, dich Nils, Emma und Noah und für Colin.

*—Dagmar Menta, September 7, 2019*

Sending love

*—Todd Rosenberg, September 7, 2019*

## then again

*September 10, 2019*

Whatever the nurse saw on Thursday did not happen that day. Colin is still with us, though he lacks energy and is getting a lot of painkillers to keep him stable.

I am taking the kids back home tonight so we can return them to school and something like a normal life for as long as that is an option.

### Comments

wish I had any words at all to ease this difficulty ...

*—Kathryn LaPointe, September 10, 2019*

I've been thinking of you and your family often, Niels.

*—Kerri Kennedy, September 11, 2019*

Niels - my heart is with you and Christina and the children. Praying Colin has a peaceful journey to heaven. He’s been through so much. I know my Dave will take care of him and spoil him when he gets there. I’m not really religious but that thought brings me comfort.

*—Mary Gonzalez, September 12, 2019*

Niels, a lot of love to your Family

*—Ewa Wronska, September 12, 2019*

## Journey's End

*September 17, 2019*

Colin died a little before 5 p.m. today.  Christina, Emma, Noah and I were all with him at the end.

There will likely be a memorial in the hospice in a few days and then a burial with a commemoration ceremony in a few weeks.  I'll post here as I have more details.

## Comments

I am so, so very sorry for your loss, Niels. I don't know that there is anything we can say to bring you comfort, but you and your family are in my thoughts and I send you lots of strength and courage for the difficult days ahead.

*—Alexandra Mayer-Hohdahl, September 17, 2019*

I have nothing to offer but my prayers and thoughts. My heart breaks for you.

*—Lisa Caasko, September 17, 2019*

Sending you, Christina, Emma and Noah all my love.

*—Erin Taylor, September 17, 2019*

Sincerest condolences Niels to you and your family. Much love to you all. Rest In Peace beautiful boy.

*—GF Santos, September 17, 2019*

I am so sorry, Niels and Christina. He was and is so loved. May you yourselves know deep love, and somehow peace, in the coming weeks and months.

*—Jeremy Cook, September 17, 2019*

I am so very sorry Niels and family. Sending love and prayers to you.

*—Leah Jones, September 17, 2019*

Sending you and Christina and Noah and Emma all the love and strength. I'm so sorry.

*—Viktoria Johnson, September 17, 2019*

Oh. Neils. My heart is unexpectedly breaking for you and your family.

I saw the title of this post and had a sinking feeling. I haven't read them all consistently because, to be honest, they are deep and heavy and I haven't always been in a strong enough place myself to read them. Don't misunderstand - I am *grateful* you write them; for yourself, everyone who wants to follow and know progress and is hesitant to ask, and for our world as your courage and openness only advances it, in my opinion.

Anyway, I write to say. I'm thinking of you all and sending warm hugs, and crying with you. You will get through this. But in the meantime, I feel I can show honour to him with tears and sadness. I can relate and it's healthy to get this low and let it out. I wish I'd had the chance to meet your son - he sounded wonderful, as do your other children.

also. Damn it all.

Here if and when you need an ear, along with the rest of the caring community I sense you have cultivated. Love you.

*—PJ Smith, September 17, 2019*

I'm so, so sorry, Niels. Thinking of all of you.

*—Daphne Retter, September 17, 2019*

I’m so sorry, Niels.

*—amy mitchell, September 17, 2019*

Niels, I'm so, so, so sorry. I've thought about what I would say when this happens, and I find I can't recall any of those things right now. Nothing is right, especially not now, about any of this. You all have my tears and my deepest sorrows, my love and my family's prayers. It's not fair, and my heart is breaking for you.

*—Jennifer Dlouhy, September 17, 2019*

Donna shared with me the news a couple hours ago. As much as I knew his ultimate healing was at hand, there are just no words to describe and completely understand what you are all dealing with. Just praying you are finding comfort with one another as those tears flow! Know that you are loved and we shall continue our prayers for you all as you start a new Chapter in your lives!!❤

*—martha stanley, September 17, 2019*

We love you guys. Rest in peace, big guy.

*—Rich Daly, September 17, 2019*

I'm so sorry, your loss is unimaginable.

*—L Smith, September 17, 2019*

Oh Niels. I am so, so sorry. It is hard to write and words are not enough, but I believe that to the end Colin felt your and Christina's extraordinary love. I am glad only that we had a chance to meet Colin so that we may now hold him, and all of you, closer to our hearts. Our deepest condolences.

*—Claudine LoMonaco, September 17, 2019*

Words are inadequate. I hope God will hold him in the palm of his hand until you someday are reunited. Sending love to you, Christina, Emma, and Noah.

*—Cynthia Meyersburg, September 17, 2019*

All our love. I'm so sorry.

*—Kathryn LaPointe, September 17, 2019*

I am so, so sorry. Love and prayers to your family.

*—Jeanne Clayton, September 17, 2019*

I am so very sorry.

*—Mary Gonzalez, September 17, 2019*

So sorry you have had to go on this journey. Sending you all the love we can.

*—Vikki Killips, September 17, 2019*

Niels, I'm so sorry for your families loss.

*—John Killips, September 17, 2019*

Dear family, so sorry to hear about your loss! Please accept our condolences. Love from us

*—Sofia Gueorgieva, September 17, 2019*

Though nothing we can say can do anything to comfort you, please know each one of you is in our hearts. Lifting you up in prayer.

*—Anne Custer, September 17, 2019*

May peace permeate your hearts as you mourn. Love from Kenya

*—Tamara Cook, September 17, 2019*

Find peace, dear Colin

*—Boris Babic, September 17, 2019*

Alles, alles Liebe und unser herzlichstes Beileid! Weiterhin viel Kraft für einen neuen Lebensabschnitt. Colin wird immer bei euch sein. Danke Niels, dass du so zeitnah berichtet hast. Wir denken an euch. Rainer und Dagmar

*—Dagmar Menta, September 17, 2019*

Thinking about your family and holding you close. Colin was so deeply loved by all of you.

*—Maddie Sheesley, September 17, 2019*

Es tut mir unbeschreiblich leid. Ich wünsche euch viel Kraft. Er wird immer bei euch sein.

*—Anja Jörg, September 17, 2019*

Dear Niels, I feel terribly sad for you and your family and wish you all the strength, peace, and faith you need now to cope with your loss. Colin was blessed with wonderful, caring parents who fought for him with all the power they could possibly find in themselves. I admire you for how you took on this incredible hard journey these last years and pray for you for what‘s to come.

*—Marco Mierke, September 17, 2019*

I’m so very sorry, Niels. I hope the outpouring of love and support you have near and far brings you some comfort.

*—Erin Rotter Mayer, September 17, 2019*

Niels & Christina, I am so incredibly sorry to hear this news. I hope that Colin has found peace. Please know you are in my thoughts, and have my deepest condolences. -Marci

*—Marci Roth, September 17, 2019*

Prayers, hugs, and love coming your way. You are amazing parents. Nothing could be more difficult for parents and siblings to experience. Colin is at peace. Barbara and Steve

*—Barbara Skipper, September 17, 2019*

Our deepest condolences to all of you. We have you in our thoughts and prayers.

*—Lynda Schmitz, September 17, 2019*

Niels, I am so very very sorry -- words just fail us at times like this. I am in absolute awe of how you and your wife have cared so beautifully for Colin (and Emma and Noah) under these most challenging of conditions. I will continue to keep your entire family in my thoughts.

*—Sarah Bender Reilly, September 17, 2019*

I am so sorry, Niels. My heart goes out to you, Christina, Emma and Noah.

*—Molly Land, September 17, 2019*

Niels and Christina, words cannot express how sorry I am. May God hold all of you in the palm of His hand and give you comfort and solace.

*—Phylles Lagarde, September 17, 2019*

Niels and Christina, words cannot express how sorry I am. May God hold all of you in the palm of His hand and give you comfort and solace.

*—Phylles Lagarde, September 17, 2019*

Niels, I am so very sorry. Praying for peace for you & your family.

*—Heidi Sprow-Knaub, September 17, 2019*

Our deepest condolences to all of you. We are very sad and pray for you. May the dear God, whose ways often leave us at a loss, be deeply with you.

*—Mario Czaja, September 18, 2019*

I‘m so sorry Niels. I wish I could take some pain from your family. We are with you. We pray for Colin.

*—Katja Reif, September 18, 2019*

I'm so sorry. May your heart and soul find peace.

*—Helle Ruusing, September 18, 2019*

Dear Niels and Christina, I’m so sorry to hear this and am sending you lots of love. You were amazing parents to Colin. I’m thinking of you xxx

*—Helen Livingstone, September 18, 2019*

I can't tell you how sorry I am to hear this news. My thoughts are with you all. You all gave Colin everything you could. Wishing you what comfort I can for the days and weeks to come.

*—Helen Maguire, September 18, 2019*

Dear Niels, Christina, Emma and Noah, my thoughts are with all of you - it is good to know that you are together at this difficult time. I am sure that Collin lives on in all of you and in the memory of all who knew him. Please let me know if I can help in any way.

*—Katja R, September 18, 2019*

Loving you all and sweet Colin. Susie

*—Carol Hamilton, September 18, 2019*

I have insufficient words - I'm so sorry for your loss. This has been a searing journey on a one-way path, but you gave Colin a loving, comforting, and dignified end of life. May that, and memories of your happier times with Colin, carry you through this time.

*—Michelle Lee, September 18, 2019*

Dear all, when words are not enough...
We are deeply sorry for your loss. Rest in peace, little Colin!

*—Claudia Busch, September 18, 2019*

Niels and Christina, our deepest condolences from Russia. We are very very sorry to hear that...

Eugen, his spouse Lara and their daughters Anna and Lisa.

*—Evgeny Zakablukovskiy, September 18, 2019*

## Hospice farewell

*September 18, 2019*

We want to give those who want to say goodbye to Colin a chance to do so here at the hospice. We'll be around from 4-7 p.m. Thursday (Sept. 19) at the Sonnenhof hospice, which is at Wilhelm-Wolff-Str. 38, in Berlin's Pankow neighborhood.

It's going to be very casual.  Please don't dress up in a suit (Colin is wearing his Superman Halloween outfit, by way of reference) or bring flowers.  Our priest might swing by to say a prayer, but mostly this is a chance to say goodbye.

If you think you're coming, please text or email or call Christina or me (or leave a response to this blog), so we can give the hospice an idea of how many people are coming.

We also met today with the funeral director about the burial.  That's at least a few weeks away.  We'll provide details when we have them.

### Comments

Sorry that we can't make it. Have been thinking even more about him and you. Lots of love

*—Sofia Gueorgieva, September 18, 2019*

I'm so sorry I cannot be there. Sending you all heartfelt strength and love at this difficult and sad time.

*—Michelle Lee, September 18, 2019*

I wish I could be there with you and your family. Much love to you

*—GF Santos, September 18, 2019*

Wir kommen mit 3 Personen: Petra, Ludwig und ich, Jochen

*—Jochen Hofstede, September 18, 2019*

So wish I could be there. Love you guys.

*—Jeremy Cook, September 18, 2019*

Oh, Niels and Christina! That’s all I can say.

*—Keena Graham, September 18, 2019*

## Ark

*September 19, 2019*

It’s hard to use the word “fun” right now, but we made a Noah’s Ark-themed casket for him and it turned out pretty well.

## Photos

Sent from CaringBridge iPhone app

## Comments

So beautiful!

*—Tamara Cook, September 19, 2019*

Such a gorgeous tribute, Niels--both that it turned out so beautiful and the fact that you so lovingly spent time as a family working on it. Such a loving act.

*—Kerri Kennedy, September 19, 2019*

Beautiful

*—Todd Rosenberg, September 19, 2019*

Oh how special!! And a memorable tribute!!❤❤□□

*—martha stanley, September 19, 2019*

So glad the kids can 'have fun' with their brother one last time, processing this hard part of life's journey while doing what children naturally do - try to find the joy in every corner. Susie

*—Carol Hamilton, September 19, 2019*

This is so special, you guys are awesome parents.

*—Jeanne Clayton, September 19, 2019*

Heart-rending, yet so beautiful.

*—Jeremy Cook, September 19, 2019*

Tuesday morning, Jim and I saw the most magnificent rainbow in the sky back of our home. Perhaps it was a welcome sign for Colin. I like it that your little family is decorating his casket. What a loving thing to do. Stay strong. Love and prayers...

*—Phylles Lagarde, September 19, 2019*

## postscripts

*September 20, 2019*

My life feels a bit like the tail end of the last episode of a long-running TV show.  In the next few hours, we're going to put Colin's body into the casket and then the undertaker will take him away in preparation for the final service.  There's apparently a ritual send-off here at the hospice that involves confetti and a bubble machine.

After that, we'll head home and try to feel our way back into our lives.  I'll post separately as soon as I know the details of the burial.  Some details are still not worked out.

Right now, we're saying goodbye to all the staff who kept our heads above water the last few months.  About 20 people came out for the little memorial here at the hospice yesterday and, as has been my experience with every funeral so far, it turned out to be a pleasant event. Thanks to everyone who could make it.

Because it feels a bit like the end of a TV show, I feel the need to do the part where you start relaying the fate of some of the minor characters in the story. To wit:

**- The home health care agency.** They had been told to get us a correct bill by Sunday otherwise we would consider a lawyer. The social worker called them yesterday to find out that ... the company had been sold.

People, somewhere out there, there is an investor nursing a very stiff drink of whiskey as he/she realizes they've just purchased a nursing agency that doesn't provide nurses half the time and, when it does, forgets to bill for the services. The former owner said she'd completely forgotten about the bills to us amid the buyout. Then she emailed Christina to say she hadn't billed us because she wanted to be sensitive to our situation. I can only assume we're not done with these people.

**- The medical provider.** We had assumed that, once Colin died, all the medical devices would become the property of the insurance companies, since they paid for them. No, it all belongs to us now, to do with as we please. Yet the provider company did not get this memo and volunteered, about half a day after Colin died, to come through and take away all these items that did not belong to them. The nurses here have been keeping them at bay and we'll sort it all out, but it's one more nuisance. Especially when you consider that they took his old breathing machine (and backup) a few weeks ago and gave us new ones. We never got reimbursed for the old ones and we paid for the new ones and they cost 9,000 euros a pop, so we have questions.

**- The hospice.** Gets a better ending. Thanks to Facebook, I got to put together a birthday fundraiser for them that has already exceeded 2,000 euros, and it's hard to think of a worthier group. We'll still be regulars here, as they have a variety of groups for grieving parents and children. Also, I've volunteered to translate their website into English. I cannot say I'll miss this place. I cannot say it will ever be my favorite place in the world. But, despite the awful backdrop to the last three months, I've had days where I thought to myself "I had a good day today in the hospice" and I've seen things so touching - minders caring for my child and making sure he had some modicum of comfort long after I think most health care workers would have given up on him; minders caring for other children whose health problems I can't even grasp; workers who manage to be cheerful in spite of the horrible conditions their patients face - that I cannot help but think this might be one of the most beautiful places I've ever been in my life. And yet I am looking forward to being away from it.

## Comments

Big hugs to you and the entire family as you place his body in the coffin. Thinking of you!!

*—Jeremy Cook, September 20, 2019*

Colin's final resting 'home' is beautiful and the pictures you shared of preparing it as a family were very moving. Big hugs to you all...

*—Michelle Lee, September 20, 2019*

Such a painful experience for anyone to go through. Don and I wish you and your family peace and comfort.

*—Dan Wooldridge, September 20, 2019*

## back home

*September 20, 2019*

The funeral will be October 11. We'll email details later, but consider yourself invited if you read this blog.

The four of us made it back home today.  We now have to start rebuilding our lives as they are.

This morning we met before breakfast to put him in the casket.  Physically, it wasn't very hard.  Mentally ... well, I put my son's body in a casket.  This will take a while for all of us to sort through.

After breakfast, the undertaker came.  All the staff at the hospice who could be spared helped us carry the casket to the hearse and then blew bubbles and waved with us as they drove off.  We then walked to the memorial pond where we put down his rock (painted with a Superman S) and set candles in wax paper roses onto the water.  It was a beautiful ceremony, but infinitely depressing.

And now we're home, unpacking and muddling our way through. There isn't much more to say than that.

## Comments

Another hard part begins for Christina and you. Just take each step slowly and together. Many thoughts and prayers accompany you.

*—Phylles Lagarde, September 20, 2019*

Es gibt wohl nichts Traurigeres und Tiefgreifenderes als solch eine Situation! Wir wünschen euch einen guten und harmonischen Neustart, undendlich viel gegenseitige Liebe, Geduld und Verständnis füreinander. Seid so viel wie möglich füreinander da, um euch gleichzeitig Raum und Zeit für alles zu geben was da kommt.
Colin wird immer und ewig in euren Herzen sein. Möge er gesegnet sein, sowie ihr gesegnet seid.
Alles Liebe
Dagmar und Rainer

*—Dagmar Menta, September 21, 2019*

Nothing could be more sad and jolting! I cannot even imagine. Your words about family really resonated with me since we nearly lost Steve last year ...but I cannot even compare that to the loss of a child. Steve and I will not be making the trip for the funeral due to our own age and health issues. Also, I personally feel you need time to grieve and rebuild as a family without distractions. Some of your first cousins,....me, Martha, Scott, Susie, Lisa, and Phylles so far (we didn’t bother your brothers who I know have made trips or sent children to help you already) have decided to put a memorial bench honoring Colin’s life in our family cemetery here in Bandera. It will include a picture of Colin and be placed by your Mom and Dad’s headstone. We wanted to honor his life in a tangible way. We pray for you and your family daily. Love you. Barbara

*—Barbara Skipper, September 21, 2019*

# funeral details

*September 23, 2019*

Colin's funeral will be at 1 p.m. on October 11 in the Waldfriedhof Oberschöneweide.  It's about a five-minute bike ride from our house.

The ceremony will be short. Afterwards, anyone who wants to come is welcome to join us back at the house (Frieda-Rosenthal-Str. 20) for drinks, food and memories. Colin never cared much for uniforms (he'd had enough of lab coats in his life), so please don't come in dark suits and mourning garb. Please, instead of bringing flowers and wreaths, consider a donation to the Björn-Schulz Stiftung (the parent organization to the Sonnenhof hospice).

Friends in the States, we know that the logistics are against anyone making the trip. Please feel no pressure to do so.

Friends in Germany, we are not sending out proper funeral notices. If you're reading this, you are more than welcome on October 11. If there is anyone you can think of who might not be reading this blog, please pass the information on to them.

We are doing as well as we can back at the house. Some moments are tough, some seem almost normal. We can only do this step by step.

## Comments

Yep, step by step, you're gonna make it.

*—Jeremy Cook, September 23, 2019*

# funeral addendum

*September 23, 2019*

If you intend to come to the ceremony, please let me or Christina know, just so we can keep track of how many people to expect. Thanks.

## Comments

I'll be coming.

*—Marc Galmoud, September 23, 2019*

## outages and ashes

*September 27, 2019*

Colin's run of bad luck with Berlin's infrastructure continues. The cremation was supposed to be today. Instead, the crematorium had a blackout. We'll try again on Monday.

I swear, sometimes it feels like we're trapped in an exceptionally dark comedy here.

Otherwise, we're planning the funeral and trying to keep the kids afloat. We sent them back to school this week, but there was only one day where they both managed a full day.  This is as hard for them as for anyone else.

### Comments

Sending love to them, Christina, and you!!

*—Cynthia Meyersburg, September 27, 2019*

Man, give those precious kids as much time as they need! You guys are amazing parents. So sorry about the crematorium.

*—Jeremy Cook, September 27, 2019*

"Run of Bad Luck" could title all the posts. Love to you and your family.

*—Kathryn LaPointe, October 1, 2019*

Please please please contact me when you’re ready.

*—Keena Graham, October 3, 2019*

## funeral plans

*October 7, 2019*

The reality of the impending funeral is hitting us, with the first guests due to arrive tomorrow.  It's like planning a depressing wedding, with all the flowers and music, etc. But we're getting there.  The urn is ready and we're fighting through a ridiculously complicated system to pick the gravesite. Now we can only hope for good weather on Friday.

The funeral is at 1 p.m. Friday, at the Waldfriedhof Oberschöneweide, Verlängerte Rathenaustrasse 131a, 12459 Berlin.  The ceremony will start at the chapel and last about an hour, after which everyone is invited back to our home (Frieda-Rosenthal-Str. 20) for coffee.  It is possible to walk to the house from the cemetery, but it would be a 20-30 minute trek, parts of it on unpaved paths.

There will be a mass for Colin at the Friedrichsfelde Catholic church at 7 p.m. that night for family.

Please don't feel the need to wear full mourning garb to the ceremony. We don't think Colin would have like people showing up in dark suits and veils. We've asked for everyone to donate to the Björn-Schulz Stiftung in lieu of flowers, but please bring flowers if you want to.

## Getting there

*October 8, 2019*

We had our final check-in with the graveyard today. We're going to get our second choice of gravesite, which seems like such a hollow victory, but might be just about the best we get these days. Otherwise, it looks like we're largely set there.

The closest tram stop to the cemetery is Rathenaustr/HTW, which is served by the lines 27, 60, 61 and 67. It's a couple of blocks away.  We don't have the wherewithal right now to help organize spaces in cars to the cemetery. However, once the ceremony is done, here's hoping we'll be able to find spare seats in the cars that are there so no one has to take public transportation back to the house. At the very least on Friday, check with us about whether there's a seat somewhere before you try to make the trek back to our house, especially if it's raining.

# Getting there

*October 9, 2019*

It dawned on me, I should probably include some special instructions for people coming by car, since our corner of Berlin is kind of in the throes of a never-ending construction nightmare at the moment.

The only way to access our neighborhood is via the street Am Carlsgarten. The only way to get to Am Carlsgarten is by turning off of Treskowallee.  Right now, Treskowallee is a street you only drive on if you absolutely must, thanks to the construction.

If, for some reason, you're coming to our house from the north, remember that you are not allowed to make a left turn onto Am Carlsgarten at this point. I'm not saying you won't see people make this turn, but it is indeed illegal at this point in time.

If you're driving from the cemetery to our house after the funeral, you will be coming from the south.

- Leave the cemetery and turn right onto An der Wühlheide.
- Then turn right at the next major intersection onto Treskowallee.
- The construction starts a good 100 meters before you reach Am Carlsgarten. Traffic is usually backed up for most of this stretch.  You'll know you are approaching Am Carlsgarten because you will see a Döner to your right, a Bio Company to your left and the S-Bahn tracks straight ahead.  It is hard to see the right turn because of all the construction and there is a sign saying that you are only allowed to go straight, unless you have business to conduct in the neighborhood (Anlieger Frei).  It is a very sharp right turn. Make sure that there are no trams coming before you attempt it, because the traffic is not quite coordinated enough to make sure the trams have a red light when people are attempting this turn, as I can attest from a recent near-death experience.

If you miss the turn, I am sad to report you will have to fight through about another 100 meters of construction traffic before you have a chance to turn around.  Then you will have to fight your way back south through a different 100 meters of construction traffic before deciding whether you will make an illegal left turn or overshoot our neighborhood by a block and then fighting your way back to the entrance through the traffic you just experienced.

Assuming you manage all this, once you're on Am Carlsgarten, take the second right onto Fritz-Kortner Strasse, a left onto Georg-Stern Strasse and then a left onto Frieda-Rosenthal Strasse. We're number 20.  Good luck.

## Comments

you are such a dear heart. even your directions are dear. xoxo

*—PJ Smith, October 9, 2019*

## The end

*October 12, 2019*

It might just be my personality.  Or it could be my years of training in journalism.  But I have a hard time with adjectives these days.  We buried him yesterday.  Several people told me it was "nice" and "beautiful."  Objectively, I see their point.  It was a beautiful day.  The ceremony was nice.  The priest gave a touching sermon.  I was bowled over by the number of people who came out: people from the hospital; people from the hospice; his pediatrician; people from my office; people from Christina's office; people from his first day care; people from his second day care; our old cleaning lady; one of the nurses who worked here in the house; neighbors; friends (some we hadn't seen in years); and, of course, family.  It was good to see so many people take a moment to stop at the grave and have their final moment with Colin.

But it's hard for me to use words like "good" or "beautiful" in relation to any part of this phase in our lives.  At least for now.  Maybe that will change with time.  For now, I think we remain in flux.

We still have a little time to spend with relatives before they head home. We have our trip as a family of four planned for next week. When we return, we have about 10 days before I'll return to work, time we need to spend learning to live in this new normal, but also shutting down his bank accounts, bickering with the health care providers, paying the final bills and sorting things out.

I expect this will be my last post here.  This started out as a way to update people on Colin's health and it clearly turned into psychotherapy for me at some point.  It might not have been the right place for such a look inside my head, but I didn't have a lot of other places to go with it for the last three years.  I'm toying with the idea of starting a new blog somewhere else, but I have to decide if I have the energy for it and - more importantly - how to write about my path without Colin in a way that lets me share what I want to, but without prying open the parts of my family's life that should and deserve to remain private.  I have to think about it.

## Comments

If this is the last post, thank you for allowing us this space to care for Colin and all of you, to pray, to fear, to agonize, and to mourn. I am so glad it has been helpful to you, but hopefully take some comfort in knowing that it was helpful to those behind you as well. Wishing you strength for the tough road ahead. Confident that you will all find the new normal.

*—Todd Rosenberg, October 12, 2019*

I wish we could have been there - thanks to your frequent posts I feel like we been there all along the way with you and Christina and the kids. I am glad there were so many people and professionals in attendance for the memorial, and that it was a nice day.
By all means, continue blogging - good for therapy, and good to keep us in touch with your lives.

*—Don Summers, October 12, 2019*

He was not my child, not my baby. I hadn’t met him, and have yet to have the pleasure to meet Christina and your children.

However, and please ditch my comment if it’s not helpful, I would use different words. I believe in being allowed to say, and have heard, things like Angry. Desperately Sad. Pissed Off. Questioning.

Theses are good words too. Though I can also see that your loved ones are trying hard to bolster and hold you with ‘beautiful’. It’s a lovely thing to do, especially when it’s all so bloody confusing and heartbreaking.

I appreciated your therapy, and shall look forward to you hopefully sharing more. While retaining essential privacy, of course.

Thank you for your process. You’re in a safe space here, but it still takes courage to honour yourselves and Colin the way you have been doing through this process.

Big hug. Xoxox

*—PJ Smith, October 12, 2019*

I am hoping you will continue blogging. (((((Hug)))))

*—Cynthia Meyersburg, October 12, 2019*

Thank you for letting us walk this road with you.

*—Jeremy Cook, October 12, 2019*

Beautifully written. I always look forward to your posts and will continue to do so if you choose to keep writing. I hope you will.

*—Maddie Sheesley, October 12, 2019*

Beautifully written. I always look forward to your posts and will continue to do so if you choose to keep writing. I hope you will.

*—Maddie Sheesley, October 12, 2019*

I wish I could have been there with a hug. Thanks allowing us to go through this with you and your family, you will always be in our hearts. You should publish all that you have written these past years, what a journey.

*—Jeanne Clayton, October 17, 2019*

## Really the end (here)

*December 1, 2019*

If it wasn't a clear sign that it was time to finally, finally put an end to this blog, I had just finished my entry saying this was the end when my computer did something and I lost the entire entry. That's a sign if I ever saw one.

But yes, I am closing up shop here.  This started three and a half years ago as a blog to update people about Colin and his health and very quickly turned into a blog about how I was coping with his life and death.  But now that he's dead, it doesn't feel right to keep blogging here under his name.  But I've found the blogging helps me, so I'm taking my thoughts and going to start writing them all down at my new blog: www.five-minus-one.com

It's pretty bare bones right now, but I hope to expand it as I learn more about organizing a site. I'm happy for any tips anyone has.

I also haven't decided what direction I'm going with it, but I imagine it will become clear to me as I move on with the project. Perhaps it will end up being nothing more than an electric diary. Perhaps I'll be able to use it to actually help other people. The only thing I can say with certainty is that I know the writing has helped me immeasurably over the years, so I'm going to keep at it for a while longer. And, even though I'm shutting this down, it won't be gone forever. Apparently, I can take everything from this site and export it as a PDF. Perhaps something miraculous will happen and I'll even figure out how to post the PDF on the new website. Stranger things have happened.

For now, thank you to everyone for taking the time to read here. Thank you for your thoughts and comments and all the hearts. Thank you to those who kept our heads above water the last three and a half years and thank you to those who couldn't be here with us, but still kept us in your thoughts. It was all important beyond words to us.

And thank you Caringbridge and your gremlins: Caringbridge for letting me post here and the gremlins because, looking back, this version of this final entry is significantly better than the one that just got smoked.

## Comments

Keep wondering how you four are holding up, and looking forward to the new blog. You are never more than a thought away!!

*—martha stanley, December 1, 2019*

I have loved reading your writing. You are gifted and offer so much to others as you share your story. Keep writing please....
Kymberlee

*—Kymberlee Stanley, December 1, 2019*

Keep writing! You have a gift. I will follow to the new site! Take care!

*—Barbara Skipper, December 1, 2019*

Glad to know about the new blog site!

*—Jeremy Cook, December 1, 2019*

See you in the new place.
❤

*—Boris Babic, December 2, 2019*

Glad you have found a new outlet - we'll be following you there. Liisa and Chuck

*—Chuck McCutcheon, December 7, 2019*

Thank you, Niels, for opening your heart to us all. I had forgotten how gifted you are and have felt in awe many times over while reading this at how you have captured the indescribable.

*—Kerri Kennedy, December 7, 2019*