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Doctors, Hospitals, Surgeries, Oh My!

Forward: Early August 2014

I'm lying flat on a table, surrounded by the lights, sounds, and doctors in the Doernbecher Children's Hospital operating room. "You're going to sleep now" a doctor said, turning on the machine which will keep me asleep for the next seven hours or so. While I'm anesthetized, doctors are attempting to fix, or rather remove, a part of my brain which has been wreaking havoc on me for the previous six years–the part which was causing what seemed like medication–immune seizures.

My seizures started in the first, grade almost 12 years ago. Telling my entire medical journey over the past six years would be way too complex, so rather, I'm going to take you through a two and a half year span from March of 2012 through August of 2014. This is a long and complex few years, so I'm only going to point out key moments. It'll start when, after an unsettling appointment at another hospital (I'm not going to say which one), and per my pediatrician's recommendation, my family and I got a second opinion at Doernbecher Children's Hospital.

Rewind to March 2012

I took a deep breath as I walked through the doors of what is said to be one of the best hospitals in Oregon. We knew that my doctor was located on the seventh floor, in the office known as the “Purple Chipmunk.” All of the offices on that floor had colorful animal names, which I found to be quite funny. My next job was to wait patiently while my parents filled out A LOT of paperwork. After all was said and done, a nurse called us back to an exam room. My Doernbecher journey had begun.

After giving my height, weight, and other standard vitals, the nurse left, and we waited in suspense a bit longer. When my new neurologist, Dr. Roberts was his name, came into the room, he immediately extended a warm welcome, and I knew things were going to be good. After quickly reviewing my medical history and getting to know us, he cut right to the chase (no pun intended). This was to pick up where we left off with my previous neurologist, which was the plan for me to have a video electroencephalogram, or V-EEG. Dr. Roberts described the procedure in a way that didn’t sound scary, and therefore a way that I could understand.

Spring Break, 2012: A vacation of wires

While most kids my age would be off enjoying their break from school, I would have wires stuck to my head and be confined to a hospital room for 48 hours. Okay, okay, I may have exaggerated a bit. What will be happening is wires, known as electrodes, will be attached to my head with glue that stunk like fingernail polish remover (one of the parts I still remember), to monitor my brain activity when I have a seizure, as well as when I don’t. There’s a camera in the room to capture video of what my seizure looks like. This information will help my doctors understand more about the inner workings of my brain.

But it wasn’t all work and no play, and I wasn’t confined to a bed the whole time either. I was free to move about my room as far as the cord hooked up to the computers could reach, which was pretty long, and as long as I was within sight of the security-style camera. The one exception to this was the bathroom, thankfully! I also got daily visits from Dr. Roberts, nurses, and medical students. I could also watch TV and play games. I could choose my food from a menu; the food was delicious. I'll eventually miss this, as I've heard it's nothing like what adults get. Not to get too far off track, but the next year for spring break, my family and I took a trip to Disneyland!

About a year or so later: Meeting Dr. Selden

After Dr. Roberts began to get a clear understanding of how my brain works, and how the seizures were affecting me, it became apparent that more drastic measures, other than medication, should be considered. One of the options was to implant a device called a Vagus Nerve Stimulator, which has wires which emit small electric pulses when a seizure is detected, ending it before it was started. But I would still have to be on medication, and there's always the possibility that the machine would malfunction. The other option was to have surgery to remove the troublesome part of my brain all together. It was a risky operation, but Dr. Roberts said with confidence that Doernbecher Children's Hospital was the right place to be, as it is home to some top-notch neurosurgeons. One of which was Dr. Nathan Selden, who also happened to be the chairman of OHSU Neurosurgery. Having already established trust with Dr. Roberts, my family and I opted for the riskier, but hopefully more permanent option of brain surgery. It wasn't as scary as it may sound, as I've had five previous brain surgeries pertaining to my hydrocephalus (a whole other story in itself).

After waiting several months for my appointment, we arrived bright and early to Doernbecher Children's Hospital on the morning of my intake appointment with Dr. Selden. But Doernbecher's wasn't our final destination. We needed to get to the OHSU Center for Health and Healing on the waterfront of the Willamette River. My family had been told that parking down there was slim to none, and they suggested taking the tram down the hill. My dad and I were all into it, but my mom was quite skeptical. Also, knowing how hectic traffic can be in that part of the city, she overcame her fears, and we boarded the tram. When we arrived at Dr. Selden's office, my parents checked me in, and we waited a LONG time. Fortunately, my dad and I were kept occupied by watching a barge be built next door in a large shipyard. Finally, we were called back to the exam rooms.

After getting all the standard vitals, the nurse left, and we waited a bit longer (I've since heard this is typical for world-class surgeons). When Dr. Selden entered the room, we once more were greeted with a warm welcome. Prior to the appointment, Dr. Selden had reviewed Dr. Roberts' notes, as well as data from the numerous tests I've had, and agreed that I would be a good candidate for the brain resection surgery. I had another world-class neurosurgeon, Dr. Webby, who'd helped manage my hydrocephalus since I was a baby, so out of curiosity, we asked Dr. Selden why she couldn't perform the surgery. At this time, Dr. Webby was planning on retiring from the medical field, and running for U.S. Senate. Dr. Selden's response to our question was: "We'll let Dr. Webby fix Washington, and we'll fix you!" This was a quote that I still remember to this day.

Sometime between then and August 2014: Discovery of Claustrophobia

As we moved forward with the plan for the resection surgery, more tests were needed to further pinpoint the troublesome part of my brain. One of which was known as a Functional MRI. I've had MRIs in the past, but I've always been sedated, as I (probably) couldn't stay perfectly still for an hour, so they were a piece of cake. Unlike those ones, with this particular scan, I would have to be awake, stuck in a noisy tube, and respond to both verbal and video cues presented on a small screen right above me. To make it even more complicated, I couldn't move, and I had to respond by just THINKING about the answers. I'm pretty sure this was the first time that I was severely claustrophobic. If anything good did come out of it, I had a seizure while in there, so the radiologists could see with greater accuracy where they were coming from.

Fast Forward to August 2014

The time has finally come for me to bring this story to an end – well, for the most part! Literally days after showing my champion breeding gilt (a female pig) at the county fair, I was on a bed in the pre-op area, my parents alongside me, as we wait for me to be wheeled off to the O.R. "We're ready for you" a nurse came in and said. They then rolled me off to the operating room, where, once inside, I saw at least a dozen doctors, all with one goal – to bring these seizures to an end! I was then slowly put to sleep, so the doctors could get to work.

Removing the troublesome part of my brain will actually take two surgeries, a week apart. During the seven or so hours while I was under anesthesia, the doctors placed EEG electrodes, similar to what I had back in March of 2012, and a couple other times, DIRECTLY ONTO MY BRAIN! While this may seem straight out of sci-fi, it is probably the most accurate way to pinpoint exactly where my seizures were coming from, so when they open me up in a week, Dr. Selden and his team will know what part of my brain to extract. The brain is a vey complex machine with many components, and therefore they don't want to take out any more than they have to. Fortunately, prior tests revealed that the part of my brain causing the seizures was doing little to nothing else, which made me an even better candidate.

I woke up later that day in the Doernbecher Children's Hospital Pediatric Intensive Care Unit with my parents by my side. I would stay in bed for the next several days, while doctors monitor me closely. I got daily visits by Dr. Roberts, Dr. Selden, and numerous other doctors, nurses, and medical students. Most of my time was enjoyable, given the circumstances, except for a few parts, the worst of which being the liquid oral steroids that I was given several times a day. They had to have been the grossest things ever. My parents told me at first to push through it, but it began to get hard. Finally, I mentioned something to one of the doctors, and he too admitted it was gross. Not knowing why I was prescribed the stuff, he got me changed over to tablet form. Everything was better from then on.

Having the electrodes placed directly onto my brain revealed something shocking to the doctors: I was having many more seizures a day than what I could even sense. This gave them even more drive to get that part taken out. As the week ended, and the neurologists collected all the information they needed, Dr. Selden and his team called my parents into a meeting to ask them the critical question as to whether or not to proceed with part two of the procedure, which was to remove the part all together. We'd built such strong trust with Dr. Roberts and Dr. Selden that I'm pretty sure it was close to a no-brainer for them. So, the next morning, (it was August 10th or something like that) I was once again sound asleep under anesthesia as the doctors removed the troublesome part of my brain. In the end, it too was a success.

Fast Forward to Today: Conclusion

Today, almost seven years later, my life has changed tremendously. Rather than having multiple seizures a day, I was having a "cluster" of three or so a month, up until about a year ago. Things have further improved since transitioning from pediatric to adult care and a change in medication regiment, as I can go several months without having one. This additional change has helped me gain more independence as I'm now leaving home next month to attend college at

Western Oregon University. Overall, I’m doing great, and can’t thank my amazing doctors enough for helping me get this far.