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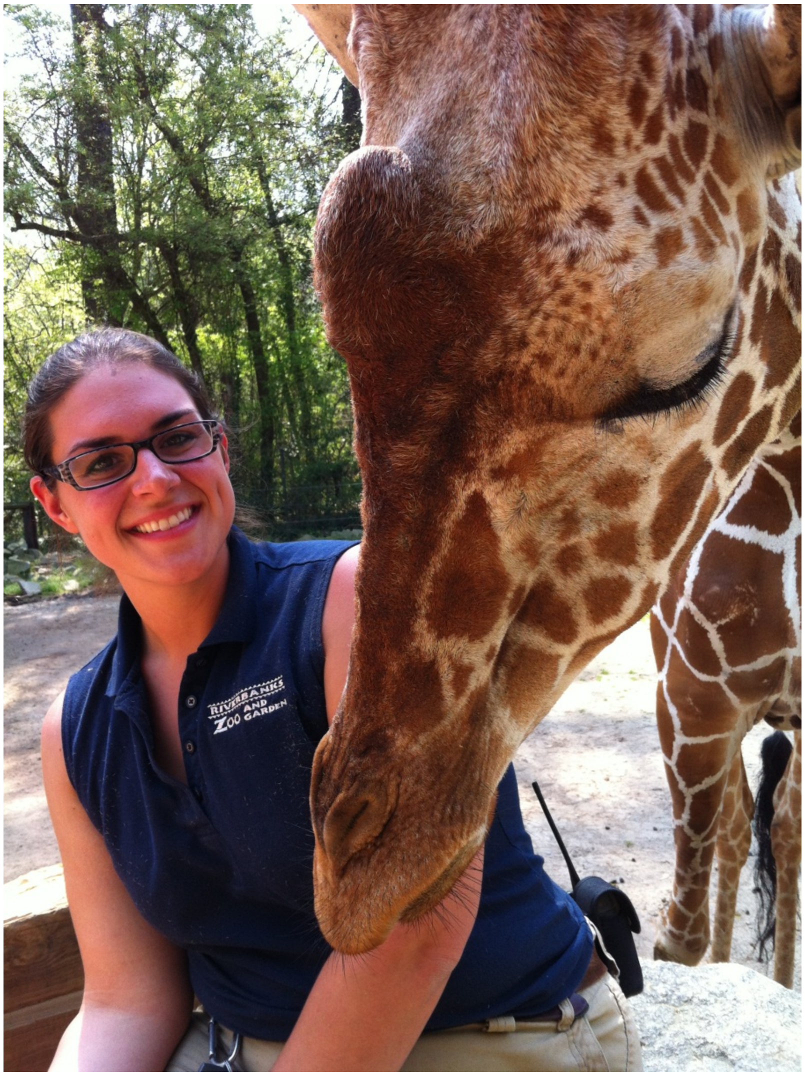
RIVERBANKS
ZOO AND GARDEN

CHAPTER 8: MY JOURNEY WITH LQTS

Renee

I have always been a little different from your 'average' girl. Of course, I appreciate all things that glitter, and heaven help someone that messes up my hair, but I've always had an itch for adventure. So, when my 19th birthday rolled around, I wasn't about to hop the border to Canada like my other friends. Instead, I hopped on a train and headed west.

Philmont is a huge parcel of mountainous land in a remote area of New Mexico owned by the Boy Scouts of America. What many people don't know is that boy scouting is *not* just for boys. There is a branch of the BSA called Venturing, a coed youth-led group of which I was a part in 2007. My Venturing Crew had decided the year before that we wanted to conquer Philmont even though my intuition was telling me to stay home, this would not be an opportunity missed by any of us. After a 32-hour train ride, involving copious amounts of bad train food, card games, and some awkward sleeping positions, we made it to our destination.

On the morning of July 18, we gathered in the mess hall for our breakfast, took a group photo, and headed off for the trails. This was to be a weeklong trek of strenuous backpacking up and down mountains, over streams and rivers, and at the end of the day, into the comfort of our tents. The scenery was breathtaking and the trails, at points, seemed impossible. I joked to the group that if I made it home I would get a pint of Ben and Jerry's Chunky Monkey ice cream and watch the movie *Coyote Ugly*. I didn't realize that going home wasn't a guarantee.

After a few days, we made it to the peak of our first mountain. We took a group photo, sat and enjoyed the view before cooking up dinner. At this point, one of the cell phones had regained service and we all took turns and made a few calls. I called my mother to let her know where we were. I could tell she was worried. To be honest, I was too.

After supper we pitched our tents and hunkered down for the evening. It was the coldest night of the trip.

I woke up the next morning around 7am to the sound of my own voice. I wasn't talking in my sleep, I was screaming. I could hear myself howling and felt my body thrashing. I remember my inner monologue, "Why am I screaming? Just stop, STOP screaming. Just close your mouth. *Why can't I stop?*" Fear consumed me. I felt trapped in my own body. Then I heard the voice of one of the dads in the group. He was saying my name. I listened to him. I finally stopped screaming and lay still.

He was kneeling down beside me, looking scared. I noticed that my sleeping bag was wet. I had urinated on myself - needless to say this hadn't happened in many *many* years. No one knew what had happened. I had been screaming and thrashing for thirty minutes. I was embarrassed and terrified. I had no idea what had just happened or why.

One of the mothers said that her children had experienced night terrors and they looked something like what had just happened to me. The group decided that this was the best explanation.

I knew it was unlikely for a 19 year old to suddenly develop night terrors, but we were at an unstaffed camp on the top of a mountain. There were no other options except to push on 10 miles to the next camp.

When we finally made it to the site I was relieved to see that it was a staffed camp. I could tell everyone else was relieved too. I washed my clothes and aired out my sleeping bag and took a much needed shower. We sat up until about 2am playing card games with our sister crew and then headed off to our tents. I remember waking up the next morning feeling warm and uncomfortable. I am thankful that I don't remember anything else.

According to my crew, around 5am it happened again—but much worse. They ran for help and I was taken by truck back to base camp to see a physician. By this point I was lucid and they asked me if I wanted to talk to my mom. I told them "no." I didn't want her to worry. The doctor told my mom that he thought I would be okay, but he wasn't sure what had happened. He was sending me to the hospital just in case. I was driven by ambulance to the closest hospital—about 80 miles away and as soon as I was admitted into the ER, I crashed. I was defibrillated and diagnosed with Long QT Syndrome (LQTS). This small hospital did not have the equipment to deal with this type of patient, so I was then taken by helicopter to the Heart Hospital of New Mexico in Albuquerque.

While I'm sure I enjoyed the drive and flight, I now try to vacation in slightly more populated areas.

From what I have been told, I was a bit of a difficult patient at the first hospital. Naturally, they pumped me full of drugs to calm me down. This was great for the doctors, but unfortunately the drugs masked my arrhythmia and the doctors at the Heart Hospital could not accept the diagnosis of LQTS since they couldn't see it for themselves. I was then put through what I like to call a real life episode of *House.* I was given multiple CTs, x-rays, blood tests, EKGs, and even a spinal tap. They just couldn't figure out what would make a 19-year-old woman go into ventricular fibrillation for no good reason. Luckily, when a nurse was changing my IV, I provided an answer for the doctors by coding once again. The prolonged interval shined bright as day on my monitor and was my ticket to my very own implantable cardioverter-defibrillator (ICD).

I now love and appreciate this little box that makes me feel just a little bit better than everyone else, but I haven't always felt this way. My implantation didn't exactly make me feel all warm and fuzzy inside.

Leaving the hospital I was very confused. The medications had severely impacted my short-term memory, and every time I looked down I needed to be reminded what happened, where I was, and why the pain was so excruciating. Remembering to take my pain-killers was the only thing that was not difficult.

The confusion lasted for about a week and I am thankful that everyone was so patient with me. The most difficult thing for me to deal with is the fact that there is a week of my life that I cannot remember to this day. Part of me wishes I knew what happened. Maybe I would have some clarity if I did, but the other part of me knows that if I truly had to live with those memories, I would be haunted by them. Instead, I enjoy the stories of mistaking my nurse for a "who" from the movie *The Grinch*. Like I said, they gave me *lots* of medication.

After returning home and once my short-term memory restored itself, I was back to the headstrong woman I had always been. Two weeks after I got my implant, I hopped on a train to Chicago to visit my cousin. This trip was planned before my adventure out west and there was no way I was going to let a "little" cardiac event stop me. I cannot believe my mother actually let me go after everything that had just happened, but I am so thankful she did. Immediately after returning from Chicago, I headed to East Lansing to begin my sophomore year at Michigan State University. I was determined not to let my fears of the unknown control me.

My ICD was just a speed bump, and If you've ever had the misfortune of driving with me, you know I don't slow down for those either.

Some speed bumps were larger than others. I remember the day that it all became real. It was the day I saw my scar. Because I had moved in early at MSU, there were only a few people in my dorm and, thankfully, I was alone in the community bathroom. I had finished my shower and as I toweled off I noticed that the sterile strips had finally loosened and were ready to come off. I stood in front of the mirror. I just stood there. Staring at the loosened strips, terrified to see what lay beneath. I finally worked up the courage to peel them off.

I cried. I stood in front of the mirror and cried. I must have been hoping that there wouldn't be a noticeable scar. Or that maybe the whole thing had been put in through one *very* small pin-hole. Obviously this was not the case.

I now know that my scar looks similar to everyone else's. It is above my left breast, and is about an inch and a half long. I hated it at the time, but I now just accept it as a part of me, just like a mole or a birthmark. And I decided that I would not hide my scar (mostly because this would involve an entirely new wardrobe) and that I would do my best to embrace it. Everyone has battle wounds; ICD patients are the lucky ones who get to show them off every day.

Living with an ICD changes things. Feeling like I lost control over my life was my greatest struggle. Between doctor's visits, random excruciating pain, and the constant fear that I might get shocked, I felt helpless. I had to learn to work through it.

According to state law, I was not allowed to operate a vehicle for six months. To me, this was worse than hearing the news that I nearly died twice. Six months. No driving. It seems silly looking back, but I was heartbroken at the time. A vehicle was freedom. The simple fact that I *could not* drive completely overruled the fact that I didn't really need to. I was in school, there was adequate public transportation, and, if I ever needed to go home for the weekend, my mother was more than happy to pick me up. Sometimes logic escapes an ailing mind.

Living in fear also made me feel like my life was no longer in my own control. I am fortunate enough that I have not had any episodes since my initial cardiac arrests, and I have also not experienced any inappropriate shocks. The most difficult fear to overcome was the device itself. I have no reason to doubt my ICD, but the possibility that it could send 32 Joules through my body at any given moment can be a little nerve wracking.

One of the first weekends back at Michigan State I spent the night on the futon in the room of my two best friends, Mark and Sam. We had previously gone to an orientation event called "Sparticipation" where we collected copious amounts of junk from various student organizations. Most of this junk consisted of organization flyers, chip clips, pens, and the dreaded refrigerator magnet. I know that a magnet must be pretty large to affect an ICD, but 4-weeks-post-surgery

Renee did not fully trust that. I had made sure that all refrigerator magnets were in a bag on the opposite side of the room before I went to bed, but I woke up in the middle of the night and decided that this was not good enough because I had forgotten the ones actually stuck to the refrigerator. I made quite a fuss until both Sam and Mark were both trying to calm me down and remind me that I was going to be just fine. I have since realized that most of my fears regarding my ICD were unwarranted. It is there to keep me safe, and so far it has done exactly that.

After about nine months I was much more comfortable with my ICD. I had accepted my new restrictions and was ready for a new adventure. Less than a year after my implant, I took off to Tampa, Florida, for a four month internship at Busch Gardens.

My implant site was still healing and the drastic change in weather seemed to upset the area a little. I quickly found a heart clinic in the area and went for a checkup. The clinic waiting room was something I had become accustomed to. The ladies at the desk always comment on my age and tell me I'm "too young to have heart problems." Then I take a seat in a room full of people my grandmother's age. I finally saw the doctor and he told me I had "healing pains." Take my word for it: these pains felt remarkably unhealthy. I had experienced pains like this right after my implant and I actually left a Detroit Tigers baseball game and ran out of Comerica Park when the pains hit. I felt like I was dying. No one ever told me that the pain would last for a year and a half, but trust me, it can.

I am now approaching my fifth year with my ICD. I finished a B.S. in Zoology at Michigan State University and was hired shortly after graduation into my dream job working at a zoo with babirusa, elephants, giraffes, kangaroo, ostrich, wallaby, vultures, and zebra. I know it's that little box of technology that made it possible. And I am grateful, even though it can be a bit of a burden at times.

The doctor I saw in Florida said something to me that changed my life. He asked to shake my hand and said, "You are a survivor and I am grateful for meeting you." I had never thought of myself in that way, but he was right. We are all survivors, emergency implant or not. We have defied nature and pulled through life-threatening conditions.

I have learned that every challenge the ICD has and will present, is *much* better than the alternative.

Keep on beating.