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CHAPTER 1: A NEW WAY OF LIFE

Kathryn

If you saw me walking down the street, you would look at me and just think I was any other average teenage girl. I absolutely love to shop, I spend most evenings with my best friend Tyler, my cell phone is always within reach, I constantly check Facebook, and my Yorkshire Terrier Lincoln is my baby. If you stuck me in a group of people nothing would really make me stand out in the crowd, nothing noticeably obvious. One small scar though sets me apart from most people. That one small scar has impacted my life so much and is called an Implantable Cardioverter Defibrillator--such a big name for something that seems so small. It symbolizes what I've gone through and what is yet to come in life. According to Boston Scientific, an ICD or defibrillator, helps stop dangerously fast heart rhythms in the ventricles, the heart's lower chambers. To me, it's my life saver and I couldn't imagine life without it.

My life got flipped upside down over 10 years ago. It was my parents, my older brother, me, and my little sister. We were your average family living a happy life. The summer of 2001 though changed our lives forever. On May 28, 2001, my little sister, Alayna, suddenly and very unexpectedly passed away. The cause of her death was Myocarditis. It is a virus that attacks the heart. Alayna was only a month away from her 4th birthday when she died, I was 8 years old. She was my partner in crime and was my little shadow that followed me everywhere. We would rescue "wormies" in the rain, play in dress up clothes, or build these humongous forts with blankets and the kitchen chairs. Alayna lived every day to the fullest and pointed out the small things that often times go unnoticed. She really taught my family to just slow down and enjoy life as it comes. Even though she is gone, she is never forgotten in our home. As quoted on her tombstone, "Those we hold in our arms for a little while, we hold in our hearts forever" which will always be held true with Little Miss Layna Ladybug. As much as no one wants to move on with life after a significant death, it seems that's the only way life can get any better. I was constantly scared the same thing was going to happen to me even though Myocarditis is neither contagious nor genetic. I remember my mom always reassuring me that nothing was going to happen to me. Much to everyone's surprise though that wouldn't be the case.

The summer after 5th grade was just like any other summer. I was enjoying school, Girl Scout camp, and hanging out with my friends. My mom decided to take me and my friend Kaitlyn out to get rewards from different arcades and food places for getting good grades on our report cards. We were having a good day and had decided to go to Chuck E. Cheese to get free tokens. I remember standing in front of this game, playing it and next thing you know I was waking up on the floor with my mom crying over me and paramedics surrounding me asking me questions like, "What's your name?" and "Do you know where you're at?" I was confused and scared out of my mind as to what just happened to me. I remember thinking on the ambulance ride, "I'm going to die, I'm going to die." All I could think of was what happened to my little sister, Alayna.

The only enjoyable thing about that ambulance ride was when the paramedic decided to play "paper, rock, scissors" with me. They decided at the hospital I had either locked my legs or had become dehydrated and I was released later that day. That week was stressful, but went by as usual and before long I was back to my normal self. Exactly one week from the day I passed out, it happened again while having a water balloon fight outside with my brother on the side of the house. I remember turning around to scream at my brother for hitting me with a balloon in the back and next thing you know I fell face first into the grass. I woke up to the world spinning and feeling my dad carrying me into the house. That night my parents decided it would be best to take me to Children's Mercy Hospital in Kansas City, Missouri. I was checked into a room that night, not exactly knowing what I was getting myself into. I was constantly monitored, poked, and prodded. I felt like 100 different doctors came into my room daily just to stick their cold stethoscopes on me and listen to my heart beat. It was rather annoying and at times I definitely was not happy. I have to admit, I didn't always have the nicest look on my face when doctors came in.

Every couple of hours I would get woken up as well so the nurses could check all my vital signs, not that I was getting that much sleep as it was. All these wires were attached to me to monitor my heart and if one came off, even just a little bit, the machine would start sending off this loud alarm. Also I had an IV going into my hand and I could only sleep a certain direction. I had to do a stress test much to my dismay. No one wants to have all these wires attached to them, and have to keep going faster and faster on this treadmill in fear of possibly passing out again. That was when my diagnosis was discovered, at the time I was diagnosed with Long QT Syndrome. According to the National Heart Institute, a problem with any part of the heart's electrical system can cause irregular heartbeats called arrhythmias. During an arrhythmia, the heart can beat too fast, too slow, or with an irregular rhythm. Faulty electrical signaling in the heart causes arrhythmias. My heart rate was getting up to a dangerously fast rhythm.

It was decided I would need to get an ICD and 2 days later, bright and early in the morning I was getting prepared for surgery. I was given relaxing medicine about 30 minutes before I was taken into surgery. My parents found that very amusing seeing as anything they told me I thought was hilarious, and I was practically falling out of my chair. In a joint effort, one had to prop my head up and the other had to keep me from sliding out of the chair. They were probably very relieved when a bed was finally brought in for me to lie on. On July 2, 2004 I had my first surgery. My last memory was lying in that bed, not being able to see straight. The next thing you know, I was opening my eyes to see both my parents standing there. I slept most of that day after I was out of surgery. The next day, in the afternoon I was released from the hospital, much to my excitement because it was the day before 4th of July and I just wanted to be at home with my family to watch the fireworks. My dad had to make a couple trips from the hospital back to the house because we had about 25 or so of those big balloons, tons of stuffed animals, and a couple vases of flowers. I remember sitting in the wheelchair with this huge bear in my lap spinning around in circles in the hallway waiting on my parents to hurry up. I was so ready to get out of there. That week was full of emotion and a whole new way of life for me. But I was ready to begin my 6th grade year.

Unfortunately that first semester in December, I had my first episode at home alone with my brother. I remember I started getting extremely nervous for no reason besides the fact my dad wasn't at home. I passed out for just a second on my bedroom floor and woke up to a shock, and my dog standing over me with a confused look on his face. I immediately got to my feet and ran into my parents' room where my brother was watching TV. I received 5 appropriate shocks in less than 5 minutes. After that scary event, I had difficulties returning back to school and pretty much stayed at home when I could. I managed to make it through my first year with the support of teachers, friends, and especially my family. It was like I was walking on a tight rope and I was losing my balance, but had managed to catch myself before I fell and I was able to keep moving.

Throughout the rest of middle school, I experienced 2 more episodes; each causing 5-6 shocks. Both of those episodes occurred during the 8th grade year. For those of you who have never received a shock, I can tell you what it's like. It is like someone punching you in the back extremely hard except it goes through your chest and you feel a tingle throughout your entire body. I have been conscious when I received my shocks, and I even have received a shock while hugging someone trying to calm myself down. Even though it's a scary experience that no one should have to go through, you'll be okay afterwards. I was shaken up but glad my ICD did what it was meant to do. Those shocks though emotionally hit me hard. That was where you could say, I completely fell off that tight rope. I couldn't go anywhere without my mom, every time I went on a walk I wanted to immediately turn around because I felt my heart rate was getting too fast. I had a huge fear of ambulances and I refused to stay at home alone. Even with my dad at home with me, I didn't ever want my mom to leave me or go anywhere. I would freak out when it was time for her to head off to work even though she would only be five minutes away. My anxiety pretty much took over and controlled my life. I really didn't know how life was going to go on. I never hung out with friends for fear of getting shocked again. All three times I received my shocks neither of my parents were around. I felt if I stayed at home or was always with my mom that nothing could ever happen to me. I buried myself into a hole, and I was scared to come out. Even though I had lost hope, deep, deep down I never lost determination and I think that is what kept me going. It got to the point where I just wanted to live life like any girl my age. High school was arriving and I wanted to make the best of those 4 years.

I really had a complete turn-around after a lot of hard work and struggle. I learned breathing techniques to relax myself if my anxiety ever started to go up. It helped tremendously. I still use that deep breathing today to calm myself at certain times and I definitely recommend others to use it as well. I was also put on anxiety medication which also helped a lot. But overall, I really had to change my mind frame and realize I couldn't allow my anxiety to live my life for me. It was choosing what I would do each day, and I couldn't let that happen anymore. Besides just coping with the anxiety, I also had to change my outlook on life. I was so angry that I was presented with this situation that a majority of people will never have to go through in their life. I was always looking at the negative side of things. I was upset that I could no longer go on those thrilling amusement park rides, I couldn't play any competitive sports, and I pretty much had absolutely no social life. I blamed my condition for everything and I felt it had completely ruined my life. I had to understand that you can't live in your life in anger. There was so much I could still do and half the things I couldn't do weren't because of my condition, it was because of my anxiety. Things I could still do definitely outweigh the things I could no longer do. Today, when other people start to become negative about something, I notice myself pointing out the positive side of things and I realize what an impact this whole situation has made on me and I'm happy.

I really couldn't have achieved anything without the support of friends and family, especially my parents who never gave up on me. My mom, who is my best friend, never once left my side and was always there for me even when she had to sleep in uncomfortable leather chairs night after night at the hospital and put up with my frustration of having to be stuck in that hospital bed. If you would have asked me five years ago how my life was, I would have said I hated my life and it was just so terrible. But I came to the realization; I was making this whole situation bigger than it needed to be. I am truly lucky. I have loving parents, a roof over my head, I'm well taken care of, and I can pretty much live a normal life, I was just allowing my anxiety to take that privilege away from me. If you asked me now how my life is, I can honestly say, I love it. Could I ever imagine being at this point in my life and be happy? No, but look where I am now. I graduated from high school last year with a 3.6 GPA. I have worked at the burger joint near where I live for close to 2 years. I attended the local community college this past fall. I have now decided to take a break from school and am moving to Raleigh, North Carolina to live with my great aunt. I am excited for this big change in my life and I would have never guessed in a million years this is what I would be doing today.

For those of you who haven't had an ICD very long or are struggling with accepting it, I can tell you things will get better. You may be sitting there thinking, "I don't believe what this girl is saying" because that is exactly what I would have been thinking 5 years ago. You just have to understand that this is an obstacle that life has presented to you. You can choose to go over or around it and continue moving forward or you can choose to stay stuck behind that obstacle and not get anywhere. Having an ICD is quite the learning experience. I had to accept that it is a part of me now and it's not going anywhere. I now enjoy showing it off to people and seeing their facial expressions when they feel my skin where that hard chunk of metal is inside me and I love telling people all about it. It is my life saver and I know that it will never give up on me, it's always going to make sure I continue living a healthy life. I should want to show it off and be happy for what I have. I received my second ICD over a year ago on a Tuesday. I was released the following morning and on Thursday I was back at school. On Friday night, I was back at work taking orders one handed. I didn't let my surgery slow me down or set me back at all. I have such strong determination after all that I've gone through.

This year will be coming up on 8 years since I first received my ICD. In total I have received 16 shocks, but the last shock was 5 years ago. This past year, my diagnosis was changed to CPVT after discovering the gene I had. It is a very similar condition to Long QT. It explained though why I had been shocked so many times because CPVT is a more aggressive condition. It is nice to know the gene I have, especially since I was the first person in my family to show signs of this heart condition. It was discovered that my mom also has the gene, but has not had any outstanding symptoms like me, and it was also discovered that my little sister had the gene as well. As of right now, my mom's side of the family is getting tested to make sure others don't have the gene. I am relieved to know that in the future when I have children, I will be able to know if they have the gene as well. I wouldn't change a thing about my life though because I believe that all I've experienced has made me a stronger, more grateful person. I have a more positive outlook on life now and look to the future with excitement, not fear.

To be completely honest, I'm happy life presented me with this situation because it made me realize you should always enjoy life. You never know when one day things may completely change for you. Life is hard. Every day can be a challenge. Getting up in the morning can be a challenge. Getting out of bed and putting that smile on your face during tough times is a huge challenge. But you need to remember, even through tough times, you can do it. There were so many times I wanted to give up, but I didn't and look at my life now.