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INTRODUCTION TO WOMEN'S STORIES

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Reading the stories in this book will give you a window into the lives of many incredibly courageous women. Their stories are each unique, yet the remarkable device that each now has implanted within her unites them. This device, an implantable cardioverter defibrillator (ICD), is a life-saving, and life-changing medical therapy. It is at once terrifying and life sustaining. Learning about how it works, and why it is needed, will go a long way toward removing the terror and focusing instead on the life-saving aspects of this device.

For generations women have heard that heart disease is more of a threat for men than it is for women. And while it is true that approximately two-thirds of all sudden cardiac death episodes (where the heart stops beating normally, causing loss of consciousness and death if not corrected right away) occur in men, there are heart conditions that actually occur more frequently in women, as well as diseases of the heart which may be more dangerous in women, that may necessitate the implantation of an ICD. The fact is that women's hearts are different than men's hearts in many important ways, so it's critical to learn as much as you can about these differences.

As the stories in this book indicate, there are many different diseases that can affect the heart and cause cardiac arrhythmias (episodes where the heart beats irregularly, or beats abnormally fast or slow). Women can and do develop coronary heart disease, leading to blockages that cause heart attacks and permanent heart damage, and causing the heart to weaken. Heart weakness caused by coronary disease is one of the most common indications for an ICD. Women are less likely than men to develop this kind of heart weakness, but they are statistically more likely to die of sudden cardiac death before reaching the hospital if they do suffer a heart attack, perhaps in part because women tend to have more nonspecific symptoms, which are not recognized as representing heart disease. On the other hand, there are other kinds of heart weakness, or cardiomyopathy, which

are more common in women than in men, or are even unique in women. For example, women can develop temporary or permanent weakening of the heart related to pregnancy, called peripartum or postpartum cardiomyopathy. If this type of heart weakness doesn't resolve after the baby is born, then a defibrillator may be indicated.

Inherited disorders such as long-QT syndrome, a condition where the electrocardiogram, or EKG, becomes abnormal and thus an individual is at risk for life-threatening arrhythmias, occur in both genders, but the risk of having a sudden cardiac death episode varies by age and gender. Before age 16, boys with the condition are at higher risk than girls, but after age 16, the risk ratio reverses, so that older girls and women are at higher risk than older boys and men. Women also more commonly suffer from medication-related long-QT syndrome, a condition where the EKG develops abnormalities because of a medication. Many different medications can cause this disorder, and women's sex hormones seem to have an interaction with the medications. This predisposition can even vary depending on a woman's menstrual cycle and the hormone levels during a particular phase of the cycle.

Whether or not the heart condition treated by ICD implantation manifests differently in men than in women, young women affected by a disease are faced with the unique problem of pregnancy as it affects their particular condition. Having an implanted defibrillator does not in and of itself prevent a woman from having a successful pregnancy and delivering a healthy child, but every situation is unique, and the condition that required implantation of the ICD may itself be associated with risks during pregnancy. Certainly, any woman with an ICD who is contemplating having a child needs to have a thorough discussion of the potential risks to herself and to her baby before becoming pregnant.

As you read these stories, you will learn about many different heart conditions, all of which required the implantation of an ICD as part of their treatment. You may recognize yourself in some of the stories, and you will certainly see your own emotions and fears mirrored in the stories told here. I urge you to learn as much as you can about your condition, about the device that you have received or

are about to receive, and about what you can and cannot do with your condition and device. Recognize most of all that these stories, and your story, are about our amazing capacity for resilience and healing in spite of incredible adversity. In that, they are truly inspiring.



MY SECOND CHANCE

Jenna

Growing up I was always a normal kid. I played every sport in the book, had my tight group of friends, was very involved in school, and was always fit and healthy. I had so many hopes and dreams as I started the beginning stages of planning my life. Little did I know one day when I was 13 my life would change forever.

May 9, 2008—the date that will be in my mind forever, the day that changed my life. I was at track practice and we were running relay sprints. I ran my first and second relays just fine. During my third relay something went wrong. As I was almost to the finish line I became very dizzy, and my head hurt. Because I was so close to the finish I thought I would just finish running, and then I was going to sit down and tell my coach I wasn't feeling well. Unfortunately I didn't make it that far.

While I was running I went into cardiac arrest; I crossed the finish line face first. My teammates and coaches all thought I had just tripped and fallen until I didn't get up right away. My coach, Tom Novak, ran over to me and flipped me over. He realized my coloring had gone gray. I wasn't breathing, and I had no heartbeat. He started calling for help while one of my other coaches called 911. Luckily for me there was a girls' soccer game that night and one of the girls on the team, Emily Kuiper, wanted to be a nurse and was CPR certified. The two of them performed CPR and revived my heart. I don't recall any of this because I was still unconscious until after I arrived at the hospital. When I woke up, the doctors started asking me all sorts of questions to test my memory; everything checked out to be normal. I kept asking my dad why my face hurt. I guess in the fall I had road rash on my face, but didn't know it. He finally took a picture with his phone to show me why my face hurt so I would understand.

After they ran a few more test in the ER, they asked if I had any questions. I said, "Yes, one." I wanted to know when I was going to leave because I had a softball game to get to. When they told me they were keeping me overnight I wasn't too happy, but I decided at least

it was Friday and I wouldn't miss any school. After I had said that, my parents knew I was going to be just fine.

After another battery of tests in Kalamazoo, my doctor made me an appointment with a pediatric cardiologist. Before we made it to that appointment the cardiologist called and said it was her opinion that we should go to the University of Michigan to pediatric cardiologist Dr. David Bradley. Once I got to U-M I had even more tests done. This time the doctor had results for me. He told me I could have one of three conditions. He didn't know which one I had, but his treatment for all of them would be the same. So he started me on a beta-blocker and they scheduled me for surgery to implant an ICD.

On June 25, 2008 I had my ICD surgery. I was super scared with this being my first surgery ever, and I had no clue what to think or how it would change me. My doctor was nice enough though to put my scar on my side under my arm instead of on my chest so I wouldn't have to worry about that the rest of my life. My surgery went as planned and I went home the next day. The hardest part was remembering not to put my arm above my head for a week.

The next step was to figure out what I had. We had the first genetic test done, and it came back negative for long QT syndrome. So they needed to run the test again and find out what it was.

About a year after my life settled down again we finally got a diagnosis. I have CPVT, which is short for catecholaminergic polymorphic ventricular tachycardia. It was nice to know after all this time what was wrong with my heart. After we knew what I had, my parents got tested to see if it came from one of them or if I was just the mutation. The results came back negative for my dad and positive for my mom. Because my mom had the mutation, my two siblings needed to get tested. My sister tested positive for the gene and my brother tested negative.

Once we knew my mom and my sister had the condition I do, they had to go through some of the tests that I had. We found out that my mom and I are affected in a way by the condition, but my

sister was not affected at all. My doctor started to wonder why that was, and because not much is known about CPVT, he asked us to participate in a study on it. Right before my 16th birthday my mom, my sister, and I donated our skin cells for the study. The researchers took our skin cells, made them heart cells, and grew hearts to test on. If that isn't the coolest thing to have done I'm not sure what is.

Before all of this happened I played five sports—softball, basketball, cheerleading, baton twirling, and track. After my surgery I was itching to get back into all of them. Every time I would go in for a check-up I would ask if I could start doing any of them again. I only got back into cheerleading and baton twirling again. I did, however, find new activities like color guard to fill in the time I would have been playing one of my other sports. In fact, I was able to join Legends Drum and Bugle Corps in the color guard and tour the country for two summers competing in competitions for 65 days of the summer while sleeping on gym floors and the bus at night and practicing all day to get ready for competitions.

One of the things that has helped me get through everything so well is Camp Odayin. Camp Odayin is located in Minnesota and is a camp for kids with heart conditions. Through camp I have met some amazing people and made some really good friends. I only went to camp for four years, but in those years I became extremely accepting of my scar and how my ICD and condition changed my life.

I also have not missed the Young at Heart ICD conference since I have gotten my ICD. I enjoy going to see the people who come every year and catch up with them. It is also nice to be there to talk with the ones who are just starting to go through what I have already experienced and be able to tell them everything is going to be okay. It's like getting to see long distance family once a year.

Now, about six years later, I am a “normal” college student. I go to class, participate in college marching band and hang out with my friends. My ICD and my heart condition don't hold me back in anything I do. I have traveled the country doing the things I love to do. Every day I am thankful that I have never been shocked, and even though I've never needed my ICD, it's my safety net that will

catch me just in case I do fall.

To be honest, I'm glad this happened to me. I found a new respect for life, and I choose to live everyday like it's my last because we don't ever know which one will be. Because of my heart I have made so many lifelong friends that I would have never met otherwise. I have always looked at this as a blessing and a curse, but the days that are a blessing far outweigh the days that feel like a curse.



STAY GOLD

Wendy Ellen Wesala-Dwyer

My name is Wendy Ellen. My story is about luck, God, karma—whatever you want to call it. If one thing about my story had been different, I would probably not be here to tell it. I was born with long QT syndrome, type II, which went undiagnosed for 12 years. They didn't discover it until my first episode in June of 1982. I had just returned from a school trip where we had gone on a seventeen mile hike over three days. After dinner my family was enjoying some television. It was a Friday night, *Benson* was on the tube, and I was munching on a bowl of Doritos. There was nothing different about this Friday night except it was the eve of the city track meet. I was going to be in the first lane of the first heat of the 440. I worked my butt off to get that spot, and as a 7th grader it was quite the accomplishment. I never got to race. As a matter of fact, I was never allowed to run competitively again.

It's pretty hard to describe what an episode feels like. For the most part, after I pass out I can't recall a thing. For a few moments after I recover, I can't even recall who I am. This night though what I remember was that I started to feel funny. My head felt weird, like I was in a fish bowl. It started to look like I was in a tunnel. My ears were ringing and my throat was closing up. I thought a glass of water might help, so I walked into the kitchen to get it. When I returned to the living room, I immediately knew I wasn't going to be standing for much longer and told my mom that I felt faint. She told me to sit and put my head between my legs.

That is the last I remember. I was told that I sat up and told my mom that I was just fine. I looked at her, then fell over to my side and I passed out. What I woke to were my two sisters crying, my father in a panic and yelling at my older sister to call 911, my mother with her fingers in my mouth (to keep me from biting my tongue from the seizure I was having), and my brother just staring at me. The look on everyone's face was that of horror, bewilderment and fear. Those looks haunted me for many years. This was the night that started the long journey which I am now on.

Long QT is defined by the Mayo Clinic as, “a rare inherited heart condition in which delayed repolarization of the heart following a heartbeat increases the risk of episodes of torsades de pointes. These episodes may lead to palpitations, fainting and sudden death due to ventricular fibrillation. Episodes may be provoked by various stimuli depending on the subtype of the condition.” This is a rare condition that three of my six family members have.

Living with type II, I need to avoid stress and being startled. I work in the automotive industry, am a single parent to two teenage daughters, and have an extremely challenging ex-husband, so avoiding stress can be next to impossible at times. I take caution and use a light ring on my alarm clock, don't go to scary movies, and I try to get enough sleep and eat the best I can. I still enjoy sports very much and I stay as active as I can, everything approved by my cardiologist.

I lived almost 21 years without an episode. I played volleyball competitively, had two beautiful daughters with no complications, and continued to be active in sports. But that all changed quickly on August 13, 2010. I was dealing with A LOT of stress at work and at home. My ex-husband had dragged me back to court (again) to switch the schools for my children. I was adamantly against it. For six years I had won in this battle, but this year I wasn't so lucky. The judge assigned the case to a mediator. The mediator convinced me my best option and the best option for my kids was to move them to the new school district. The recommendation came down on a Monday and I broke the news to my kids that night. I felt like a total failure. My kids were crying, and I was crying. I didn't want to cause this pain on them but I had no choice. I could keep spending money with a great chance of losing or just take the recommendation and make it work. I couldn't think of how to make it work at the time. All I thought about was how I had failed those two beautiful, innocent girls and how my bully ex-husband had won. I was tired of all the name calling, fighting, and anything to do with him. I was hurt and didn't know how to cope. This was the catalyst that started the most painful part of my journey and the chain of events that brought me to my ICD.

Monday I had broken the news to my daughters, and Wednesday I dropped my children off to their father. I went to play sand volleyball that night, as sports were still my sanctuary where I could get my mind off of things. This particular sporting event was hosted by a bar. What better way to drown my sorrows than with sports and drinks! I proceeded to get hammered and did this again on Thursday night. I would wake up late and race off to work. No breakfast, no good sleep, no hydrating, just racing around. I would recharge with caffeine once I got to work. By the way, if you have heart issues, caffeine is probably one of the WORST things you can introduce to your body, especially when it's run down like mine was. Needless to say, I wasn't taking care of myself at all because I was having the pity party of a lifetime!

Friday August 13th, 2010. Friday the 13th. What could go wrong!? My two-night binger had me dragging into work Friday morning completely burned out and probably still drunk, but I didn't care. Once I got off work I was going out again, as I was miserable and I was determined to drown my sorrows. What I didn't count on was my sorrows had learned to swim. Drinking wasn't the best way to deal with my troubles, but that's another story. In an odd way I was kind of excited about going out again. I just had to make it through the work day. My day started simple enough with caffeine mixed with some hot chocolate. I did this all day along while eating Aleve like M&Ms. Meetings passed, and so did the hours of the day. My 2:30pm meeting was held two desks down. It consisted of me, and three other people. Within fifteen minutes I needed some gum, as my mouth was dry (I'm sure from the drinking the two nights before), and my head felt funny. I got up, went to my desk, put the gum in my mouth, and headed back to the conference. I didn't make it.

One desk away, I looked at my co-worker sitting in his cubicle and told him that something was wrong and I needed help. I saw a chair in his cubicle I could sit in if I was going to faint, but I didn't make it to the chair either. My brain froze and I could feel my heart doing something very very wrong. All I could think of was, "Shit this is it! I have been saying I would be better off dead for days now. My

kids didn't need me, I was a failure." But as my eyes went from the empty chair to my co-worker, I looked at him again and he had that same look on his face as my family did from my first episode. I remember feeling faint, starting to fall backward, grabbing for the filing cabinet drawers to stop my fall, and that was it. I was told I fell straight back and hit my head on the floor. Like a tree most people said. So you can imagine the lump on my head that resulted in this "timber" moment as the floors are essentially concrete covered with a thin layer of carpet. My boss told me he thought someone had thrown a chair. The sound he heard was the sound of me (my head) hitting the ground. I was very lucky I didn't get a hold of those cabinet drawers. I would have pulled the entire cabinet on top of me.

When I woke up, I saw a bunch of people standing around me, and I had no idea where I was or who these people were. Someone was yelling that I had just put this gum in my mouth and they were telling me to spit it out. Then a mystery hand showed up by mouth so I spit it out. I remember saying, "Isn't that kind of gross?" but I still wasn't sure where I was, so maybe that was a normal thing to take other people's gum. There was a tall man trying to keep my dress down while they raised my feet up. The onsite paramedic was taking my pulse, and I was up to 40 now. Up to 40? What the heck *was* I at??? I was starting to figure out that something wasn't right, and I was the one causing all the commotion. Someone was holding my head while someone was yelling to call 911. Then there were the others that just kept looking at me, all with that same look on their faces, bewilderment, fear, and horror. I saw a girl have a seizure once. She had it right next to me. It's not a pleasant thing to see. I'm not sure what is even worse, going through the seizure or watching one.

The paramedics arrived (and were very cute). They asked me my name, which I got right. I couldn't remember what city I lived in, and when asked what year it was I said, "1980." As soon as I said it, I knew I was wrong as no one in the office had big hair. I was placed on the gurney and wheeled off. My senses were in overdrive. The smell of the diesel from the ambulance was strong in the office. The bright lights from the ceiling hurt my eyes as they rolled me to the truck. I knew something was wrong and knew it had to be my heart.

My daughters were gone with their dad, and I had already started to feel as if I would never see them again. Dying was not an option even though I was begging for it only a few days earlier.

My ride to the hospital wasn't a very long one. Just long enough for the handsome paramedics to put an ice pack on the still-growing bump on my head. Also long enough for me to ask for my cell phone so I could cancel my date that night. They laughed at me and said if he was worth it he would understand. At this point I had no reason to believe I wouldn't be home by the following day. Every episode before was always just the one. There were never any back to back. I would get my medicine and I would be fine.

I was checked into the emergency room. I can't say the experience was pleasant. I laid there for several hours with no food or drink. My mom and dad had to keep asking for people to help out. They eventually decided, with the help of my primary care physician, to keep me over night. I was checked in about 11pm and was wheeled to my room, still no medicine given to me even though I had told them I forgot to take it that morning. My nurse was wonderfully patient. I remember telling her I didn't want to die. I remember telling her that I had wished for it the last few days. She told me I would be okay. They tried to give me heparin. It was a shot I would get in my stomach to help prevent clotting. Since I was still pretty confident I was getting out of there in the morning, I turned it down.

Saturday morning around 7am, the blood pressure cuff went off and startled me awake. I started to yell for help, apparently cursing for help. I immediately had all those weird feelings and knew I was going to pass out again. This time was different though. I didn't recover on my own. For a brief moment my wish had come true. I was gone, caput, the end. I was a goner. Thankfully for me the staff was not having that, and the doctors and nurses were able to shock my heart and bring me back.

As they wheeled me to the ICU, I was waking up. My gown was open, and I had a few more patches on my body. I again had no clue of what was going on and had no idea of where I was. I did

recognize the nurse. I asked her if we had met at the bar the night before. She giggled and politely said no. She asked if I remembered coming into the hospital. She reminded me that she was with me all night. I suddenly had remembered what was going on, and I again knew something wasn't right. I also knew I wasn't going home anytime soon.

My stay at the Château St. Mary's was pleasant enough. I call it château because any plans for any vacation I may have had were out the window from the expenses I had incurred with this luxury four-night stay. I had several nurses checking on me. One male nurse I flirted with insanely. I needed something to keep my mind occupied and he was nice enough to take it in stride. I was one of the lucky ones in ICU that didn't have a hose down my throat to keep me breathing. I think the fact that I could talk and laugh made some of the nurses taking care of me feel better too. I can't even imagine the types of patients they must get nor did I want to walk around and find out. I was as happy as I could be in my little suite. I just wanted to talk to my kids.

My heart was monitored 24/7. I could see it from my bed. I couldn't sleep. I just kept watching the blips. Was it going to happen again? I REALLY didn't want to die. I had officially decided that. I just wanted to see my kids or talk to them. They were in Chicago, and they were not going to be brought home for this incident; my ex-husband made that very clear. All my emotions would show up on that monitor—giggling with my nurse friend, my mom talking too much. It was there for all to see, including the very clear, "NO, your kids aren't coming to see you." I hated that monitor, but it was the only way I could tell the difference between a full-fledged event and just plain anxiety. I would watch that monitor intently. My anxiety was out of control. They kept telling me to relax. My mom actual got thrown out of my room once because they thought she was causing my heart rate to escalate (she probably was). I even had to ask the male nurse to leave once because my heart rate jumped when he came into the room.

There isn't much else to tell about this stay. It was uneventful. It was awful. I hated waking up alone. I hated the shots in my

stomach that left bruises. I hated the potassium that burned my hand while being fed through my IV. I hated it all. I hated that the doctors told me that I SHOULD be okay since I hadn't had an episode for so long and they thought this was an isolated incident. Thought??? Should?? What the heck!? I was going out of my mind trying to figure out what to do. They let me leave the hospital without the ICD implanted. My anxiety checked out with me.

The first ten days at home I had a Holter monitor on me. Things were looking okay. I was able to have relations (sex) and I wasn't afraid of anything. I was even playing volleyball. They monitored everything I was doing. If something was going to happen, they would know. That monitor was my safety net. But when they took it away, I lost it. The anxiety started off small attacks, most of them at 3pm, which was the same time as the original incident. The tough part about having LQTS is that there aren't many medications I can take that won't affect my heart. Most doctors were reluctant to give me anything. Trying to overcome what was going on in my head on minimal doses of meds was not working. I was approaching full-blown freak out stage. This was not good and not cool.

I was to a point that it was hard to walk into work. The smell in the office would throw me back to August 13th. I couldn't look at the ceiling. I had to change my shampoo, my perfume, my hand lotion. Anything that smelled like that day made me sick. Panic, anxiety, BOOM!! Back to the ER to make sure I wasn't dying. On good days I would get to work, last till 3pm, then I'd want to go to the ER because panic would strike and I would freak out. I would later learn that anxiety in cardiac patients is the hardest to diagnosis and treat. The symptoms are so much alike, doctors commonly misdiagnose people. I was rapidly losing control and I didn't know what to do. I must have gone to the ER four or five times thinking I was having an episode, only to be told it was just anxiety. I also learned that seeing the EKG with no blips made me feel a lot better, but I couldn't be hooked up 24/7. What was I going to do? I started to suffer from secondary anxiety. I was so afraid of having an anxiety attack I would *HAVE* an anxiety attack. I lost an insane amount of weight, probably one of the only good things that came out of it (except I

gained it all back). My heart wouldn't stop racing. Although I thought I looked good, I felt like crap. I was not living my life. I was scared to do anything anymore. I was alive but wasn't living.

It wasn't long before I checked myself into an outpatient mental facility. I wanted to live, but what I was going through wasn't living. I had become scared of everything. I tried to play volleyball in a league, but would just end up having panic attacks on the court and would have to leave. I was a mess. The guy I was seeing broke up with me. He told me while I was at this outpatient clinic. He was going to wait until I got home, but I told him to do it then. I had group therapy that afternoon, and I could talk about it with them. To be fair to him, what we were going through, what I was going through, wasn't for a couple just starting out. This was the kind of thing a couple that was together for years might survive—might. I hogged group session that afternoon, bawling like I had never cried before. I felt so bad for everyone else who didn't get to speak. I officially lost it. I had no idea how I would, or could, become normal again. I was back to wanting to be dead.

Prior to me checking myself into the clinic, I spoke with as many cardiologists as I could. I was looking for some kind of reassurance that I would be just fine. I never got that. What I got instead was I should probably get the ICD and they were surprised that I left the hospital without one. It was at this time I was introduced to the Young ICD convention. I went to the conference and met so many great people. They accepted me and knew exactly what I was going through. One wonderfully fantastic person said she spotted me in the crowd and knew I didn't have an ICD. She knew by the look on my face that I was confused and hurting. She wanted to help me. I have never felt so much love in my life. I can't say enough about how these angels helped me. At the women's support session, I again hogged it with my story and tears. There wasn't a woman there who didn't commit to standing by my side when I would wake up from my surgery, if I decided to have the ICD implanted. These women are truly fantastic. They let me see their scars, they let me touch their ICDs and let me talk about what was going on. Blouses were opening and I was looking. When I left, I still wasn't 100% sure I wanted the device implanted, but I now knew what it would look

like and feel like to have one put in. I had one more appointment to go.

I met with the third doctor while enrolled at the outpatient mental clinic. He told me something I hadn't expected to hear. He actually said he didn't know *what* to tell me. What he did know is that he had been to a seminar that Dr. Ackerman had spoken at. Dr. Ackerman is a leader in long QT. This third doctor asked me if he could get me in, would I go to Minnesota to speak to Dr. Ackerman. I felt like a kid going to see Santa Claus. I had read many of his articles on LQTS. I was going to see him, and he would tell me what to do. This was my answer. I promised myself whatever he said to do was going to be it.

November 3rd, 2010, my younger sister made the trip with me. I was pretty calm going there. It wasn't until after I saw Dr. Ackerman that I made my final slip into hell. He said I had four out of four things that would cause him to recommend me getting the ICD. As a matter of fact, he recommended that I not leave the hospital without it. My sister claims I went into shock. I don't know. I think in the back of my head I was still holding out that I was going to be just fine and I was going to leave the next morning. The next morning I was already checked into the hospital and on my way to getting my first implant. There were minor complications that kept me there longer than expected. I had lost so much weight from the anxiety, I had no body fat. They nicked my lung during surgery, which caused my lung to collapse. A few extra days in the hospital and they were ready to send me home. I'm not sure how many doctors in total I saw that visit. One was a psychiatrist who prescribed all sorts of prescriptions to calm my nerves. They were a little more lenient on the medications since I now had the ICD that would assist me if any trouble arose. I found out later on that I had called my boss every day to let him know I wasn't going to be in that day. I was on some pretty good meds that were going to help me over the hump, and I was going to start living again. I was excited, and I was scared. Our hope is that I will never need my ICD. The hope is that the medicine, when taken like it is supposed to, will keep me from having an episode. I hope and pray every day this will be the case. I hope and pray I will never feel that donkey kick in the

chest.

When I got home, I had to deal with my lung. There was a tube in my chest that was supposed to be draining something. I can't recall all of the details. Well, it wasn't working. My lung wasn't healing, and the tube needed to go. After they pulled the tube out, I coughed. The hole the tube had left whistled. My aunt looked at me and said, "Did you just whistle???" She wasn't sure if she should laugh or cry. We laughed, and I laughed hard. This had to be the first time in many months that I was able to laugh. I was happy. My life was finally turning around. I was happy to be alive.

I think the hardest part of my journey has been that I am a single woman. I hated waking up alone. That was so absolutely horrible. It was worse than the needles in my stomach or my lung not working. Not only do you know you are physically alone and just want someone's hand to hold, but you are mentally alone. But I got through it. I never thought I would, but I did. I've never been a very confident person either, but somehow this experience has transformed me.

I can do things on my own. I can wake up alone; I can go to appointments alone; I can cry alone. Holy cow, I spoke in front of 150 people and made them laugh at my story. That says a lot about the woman I have become. I now know it will be okay. I have friends and family who love me. I have a phenomenal support group of women who have the same experiences that I do and aren't afraid to cry with me. I truly love those women. I hope they can feel the good vibes I send their way. There are angels here on earth. They take the form of cardiac nurses, ICD recipients, doctors and friends. I cannot thank them enough.

I'm at the point in my journey that I am positive that everything happened to me for a reason in exactly the time it happened. An hour later on August 13th, 2010, and I might have been driving or alone. I was left here to deliver a message and it's this. When you go through this journey, it's okay to cry. You may cry more than you ever have because life is just clearer. You see the beauty in everything. It's okay to mourn the old you, your old lifestyle, it will

be okay. You are turning into a butterfly, and you will get through this. Wear your scars with pride. Tell your story. You never know who is listening. Pay it forward.

I can happily say that as of February 16th, 2014, I have not had a shock. I was a little worried about writing the chapter since my ICD hasn't shocked me and "saved my life." As I wrote though, I realized it did save me. I have the confidence to do things now and not worry about my long QT. So I might not have been shocked yet, but without my ICD I wouldn't have had the courage to start living my life again.

I did have one aborted shock. Upon finding this out, I cried. I'm not sure of all the reasons why I cried. One was out of relief. One was out of fear, and yet another out of knowledge that this thing is working and I did the right thing by having it put in. I still cry whenever I need too. I'm currently off the mental medications. I hated how they made me feel, or lack of feelings. They did their job. I am alive and I want to feel it all, bad or good. I have night terrors now. It is what it is. I'm still scared to sleep alone in my house. I'm fearful that something will happen when I am alone. I still struggle. It's a daily fight. I am depressed. Some days are worse than others.

I am scared for the day this thing does go off and the anxiety it will bring. But the key thing is that I am now alive; I'm no longer a zombie. I have my bad days. I let myself have the pity party (which includes a quart of ice cream sometimes), and I move on. This is my new life. This was the chance I was given and I can't spend the time worrying about it. I still do worry, but I just don't let it eat me alive anymore. I fight back. I prove it wrong. I do things. I play volleyball, softball, flag football, you name it. I wrestle with my kids. I go to their concerts. I go out on dates. I hang out with my friends. I travel. I try new things; I work to improve the old things. I influence my daughters positively. I love. I am loved. *I Am Living*, and that's what matters now.



THE OTHER GIRL

Jasmine Rivera

I've been pondering about what I should write for this chapter while at Atlanta International Airport waiting for my flight home.

Unlike many folks who can only envision the nightmare of ticket-counter headaches and delayed flights, I actually love airports. I have yet to regard them as anything less than romantic settings—crossroads of the earth, gathering places of travelers set to journey to who knows where. I love to sit in the lounges and speculate upon the stories of my fellow passengers—where they're going and where they're coming from. I like reading excitement and elation on the faces of those on their way to vacations and the resignation and exhaustion on the newly tanned faces of return travelers. The roar and rumble of the jet engines outside, the background chatter of CNN screens and the squeak of baggage rollers on the concourse—I love these elements.

I've experienced many airports in my life; a privilege made possible by the grace of parents whose personal philosophy of dragging their children around the world for cultural education purposes has extended the borders of my life. From an early age my folks have taken my sister and me on the road, initially on cross-country road trips in a spectacularly painted converted van to every state in the continental US and then onto jumbo jets to Europe, Asia, South America and various points between.

This restless need to travel was fueled by my family's natural taste for adventure, but it was also no doubt fueled by something a little more immediate: my precarious heart condition. At the age of two I was diagnosed with Marfan syndrome, a congenital disorder of the connective tissue with wide-ranging effects on the muscular, skeletal and cardiovascular systems that leads to severe scoliosis, cardiomyopathy, mitral valve prolapse, and dilation of the aortic valve. A champion of the genetic lottery, at the age of 10 I also developed severe cardiac arrhythmia and chronic heart failure, a

condition that became precarious enough at the age of 18 to necessitate an automatic implantable cardioverter defibrillator to shock my heart back into a proper rhythm should it beat erratically due to dangerous and potentially fatal ventricular tachycardia.

So with no guarantee that healthy year would follow upon healthy year, my mother and father made a pledge that while I was well I should be able to see the world, such as the time when before a major surgery during my sophomore year in high school when my family traveled to Italy.

There we bounced between Rome, Venice and Florence, gazed at the ceiling of the Sistine Chapel, floated down the Grand Canal in a gondola, and my little sister became sorely disappointed to learn that absolutely no one in Italy made Stouffer's Fettuccine Alfredo (her favorite food). The days were heady with adventure and the delight of new discoveries, made all the more poignant by a conscious awareness of the purpose of the trip and the preciousness of time we were experiencing together.

But even without my family I've had their blessings to travel, an astonishing leap of faith on the part of my parents, considering my health. In college I studied abroad in Eastern Europe where I dragged a ridiculously heavy suitcase onto old Soviet trains to study post-communist transition economics in Romania, Hungary and the Czech Republic for an international relations degree. Laden with souvenirs and bottles of Hungarian wine, the weight of the suitcase was enough to kill any healthy grown man, but my parents were hugely supportive in letting their skinny little cardiac patient of a daughter ramble about Europe with classmates. Looking back, I find such a huge allowance of freedom from my parents remarkable, and it has become clear to me the depth of the sacrifice of security my parents made just so I could live a full life of adventure that included seeing the world for myself. As a result, though I have only vague memories of the economics lectures I attended, I do have brilliant memories of eating goulash in Bratislava, walking through a pitch black labyrinth in the dungeons of Buda Castle in Hungary, seeing Dracula's castle in Transylvania, and other much more useful experiences.

And so, over the years I've been lucky enough to collect a rather large store of memories and experiences in different countries that I can play back in my head in less exciting times. This collection has been particularly useful during my many hospitalizations when most patients would understandably struggle with either boredom or anxiety. When I returned from Italy to undergo scoliosis surgery at the University of Michigan, I had to endure months of recovery, and as I lay immobile, encased in a heavy body brace and unable to walk, I was able to entertain myself and transcend the physical pain by recalling details such as the angle of sunlight hitting the sides of the Coliseum in the early morning, the taste of perfectly roasted chicken in a hidden Florentine trattoria café, or the smell of newly worked leather in the carnival mask shops of Venice.

But more important than providing me with a mental cushion of pleasant memories in times of stress, my travels have also served as a reminder of something much more precious and profound—the grand possibilities of life itself. It is an invaluable perspective, especially when one is forced to cope with a health condition that can understandably lead to depression and post-traumatic stress disorder if viewed as a death sentence rather than as an opportunity to live life anew. The memories are an assurance that the human experience of joys and sufferings is universal, not to be borne alone, but in solidarity with people around the world whom we might never even meet.

For I have had many moments of despair and frustration in contending with a life that demands so much careful maneuvering. Unlike other patients who are diagnosed with severe arrhythmia as adults, I grew up as a cardiac patient, making it easier for me to accept the burden of my unique circumstances as a constant feature of my life rather than a new and frightening development. But even an old veteran of pediatric and adult cardiac units can bend under the pressure of repeated hospitalizations and the constant specter of the words such as heart failure and sudden cardiac death hanging overhead.

There have been many days of tears; the day I was told that I

would have to have an AICD implanted I sobbed for a solid two hours over the thought of having an electrical device designed to shock one's heart inserted into my chest. After many gentle talks with doctors and assurances from family that I would be safe, I eventually got over the fear and came through the surgery well enough, but there were a few terrible days after that: the day in college when an inappropriate shock knocked me off the dance floor during a date, and the day in graduate school when I went into the cardiac arrest that disrupted my studies at Columbia University in New York.

Then there was that second time in grad school when traveling back to New York from Michigan I was shocked out of ventricular tachycardia on the drive through New Jersey. My father and mother had to rush me to New York Presbyterian Hospital, and after a few days of observation they ultimately decided to take me back home to again recover in Detroit rather than leave me in New York. Another semester of graduate school ruined.

These dramatic moments of interrupted life eventually took their toll on me, yanking me out of the independent adult life I had fought so hard to build and forcing me back to dependency on family and doctors with a sense of defeat. After a lifetime of trying to avoid the label of 'disability', I was proud of my ability to live in a city and travel far from home, resigned to the fate of being a lifelong cardiac patient, so long as I could at least be a highly functional one.

So as I lay at home, unable to drive or work, my mood would spiral down into despair over a life that would be constantly interrupted by the cursed uncertainty of my intermittent heart condition.

My friends and family were supportive as ever and tried to comfort me, but the uniqueness of my circumstances felt isolating, with no one available to talk to who could possibly even imagine the experience of being a cardiac cyborg given to occasional electrical shocks. Unable to sleep, concentrate on my thesis work, or get up from bed, I finally hit a wall of immobility and concluded that I had no choice but to ask for help.

Swallowing my pride, I admitted to my mother that I had to see a therapist. I took advantage of Columbia's student mental health program, visiting a counselor to address depression and post-traumatic stress. At the beginning there was a bit of push and pull as even then I hated the thought of having to see a mental health professional and shied away from chronic illness support groups that seemed too "touchy-feely" to be of any real use. But the relief of being able to talk out my fears and adjust my perspective on my circumstances was profoundly helpful in getting me back on my feet.

The positive value of mental health care was further confirmed by a visit to a Young ICD Conference at the University of Michigan where I was finally able to meet fellow young cardiac cyborgs who spoke of their own experiences and ways of overcoming the hardships of our shared circumstances. Their strength and courage inspired me, helping me to accept the reality of having to be knocked down on occasion by my heart condition but always ready to stand back up and live life to the fullest. With their help, and with the constant support of my family, my heart and psyche began to heal, as they inevitably would.

One moment that really helped to clinch my healing journey, however, came from my travels. My parents were never ones for shielding their children from the harsh realities of local life beneath tourist gloss, and from an early age they made it a priority to build awareness in my sister and me of the enormous privileges we had just by virtue of being born American with our basic needs met and additionally blessed with the luxury of travel. So every other year they brought us along on numerous medical missions to the provinces of Asia where it is notably hard to take American life for granted and simply lounge by the pool while just over the fence there are mothers and rice farmers standing in line for hours in the hot sun to see a mission doctor.

A couple of years ago I was lucky enough to accompany my parents on one such trip to their homeland of the Philippines. Our destination was a makeshift free surgical clinic serving hundreds of villagers in the western Philippine province of Isabela where my parents had signed up to volunteer.

While my father handled registration and my nurse anesthetist mother worked in the operating room, as a lifelong patient I found myself a useless bystander with few medical skills to offer. I got out of the medical teams' way and observed the numerous babies and children waiting in line to be seen—often for the first time in their lives—by a doctor, and as the lines snaked down the block, the kids were made to wait hours for their turn. Their little faces were either bored or frightened and recalled to me my own fears while waiting to see my doctors at Children's Hospital in Detroit.

Then I had a sudden bolt of inspiration.

I hopped onto a tricycle taxi motorbike and went to the local market where I bought enormous bags of teddy bears and games for only a few dollars. Upon return to the clinic I took some lipstick and painted my cheeks with hearts, made a pink paper crown and wand out of cardboard, and gathered the toys into a garbage bag. I burst through the clinic doors, surprising the doctors, and proceeded to entertain the kids with bubbles, balloons and disastrous attempts at juggling.

The children were shy at first, no doubt wondering what in the world this overly tall and strange lady with the weirdly American-accented Filipino conversational skills was up to, but gradually they were brave enough to leave their mothers' arms to join in the games. Some of the babies, who just minutes before were screaming loudly as doctors examined them, became still as they stared at me, fascinated by my costume and the teddy bears I slipped in their hands. By the end of the day I was out of toys, but several toddlers had glued themselves to my legs, calling me "Doktora Ate Clown": Doctor Big Sister Clown.

The next day I moved my act to the charity pediatric recovery wards at the surgical hospital, where kids lay groggily on bare mattresses in stiflingly hot rooms with no air conditioning. Their families bent over them worriedly, fanning them as best as they could, while the children grimaced with pain. Many of them had undergone surgery for cleft palates, some for goiter removal, others

for leprosy or severe burns, and other more serious procedures. None of them had pain medication—there were none available. My own recovery experiences in comfortable American ICUs were luxury hotel stays compared to these wards.

And so I tried my best to entertain the children who were awake, slipping toys and books into their hands and sitting down for a few hours for story time. If I came upon a child still unconscious from anesthesia, I slipped the teddy bear or coloring book under his or her pillow. I was happy to be of some use, the visiting hospital fairy trying unsuccessfully to bring the comforts of a modern pediatric ward to the children of tenant farmers.

And then I saw her.

She was a young woman, about my age, walking down the hallway of the charity ward. Unlike the other Filipinos passing by, she was noticeably tall and thin, with long limbs and a curved posture. She had all the classic symptoms of Marfan syndrome—my own condition—and other than the ragged clothes and rubber sandals she wore, she looked exactly like me.

I stared at her, distracted from handing out candy to a group of toddlers. She caught my glance and raised a hand in greeting, then smiled as she turned the corner and disappeared from sight. I handed the kids the entire bag of candy and went after the girl, but she was gone. I searched frantically for her, sure that such a tall young woman would be easy to spot. But there was no trace of her.

Later over dinner I asked the doctors about the Other Girl. No one could recall seeing a young woman of my description, and they all shrugged, saying that she was one of hundreds who had come through the medical mission that morning and most likely had disappeared back into the countryside. There would be no way of tracing her. When I insisted that she could possibly need treatment for a severe heart condition, they shook their heads sadly. “There’s nothing we could do,” said one doctor. “We’d have no way to treat her for such a serious longtime chronic illness; she’d have no way to afford it. The best we could do is to tell her and her family that she

should not run or lift or overexert herself physically for the rest of her life.”

I could hardly bear the tragedy of what I was hearing. For no other reason than the circumstance of birth I was lucky enough to have a family and doctors who could provide me with the finest care and the latest technology in cardiac health. I was so lucky in fact that I had twice been saved from episodes of cardiac arrest that otherwise would have killed me. But what of the Other Girl and her family? Were they unaware of the danger that followed their daughter through her life, or did they know that the help she needed existed just beyond their reach? The tears of relief that my family had shed when I awoke from each episode were a privilege that they would likely never know. How could I ever again justify succumbing to depression and despair about my own life in the wake of such circumstances?

For the duration of the free clinic I went back and forth between the hospital and market, noticeably more sober as I shelled out cash for more bags of toys and books and searched the crowds for a glimpse of a tall, girlish figure as I handed the treats out to the children. Though it was, for the most part, happy work and the doctors were thankful for the distraction, I was haunted by the vision of the Other Girl and felt helpless observing the crushing poverty and squalid clinic facilities.

It was hard to see, at times, what difference a plastic bear or picture book could make in the midst of such injustice. But the smiles of joyful relief and gratitude from the parents buoyed me. In spite of whatever circumstances they endured, their children were being cared for and they would grow up with whole palates, intact legs, and hearts undefeated. And as I observed the mothers cradling their stitched-up children in their arms I recalled my own parents' determination to give me, their own sickly child, the world. I could at least offer a moment of happy distraction to these children in return.

During one of the last days at the mission clinic I found myself visiting the children who were being prepped for surgery near the OR, a loud, frightening, busy place filled with masked doctors and

trays of instruments. One little baby with a cleft palate screamed so uncontrollably the doctors were ready to take her off the day's operating schedule. But upon sight of me she became instantly calm, too intrigued by the skinny brown fairy that had suddenly appeared in the room. I gave her a fuzzy blue rabbit, and she fell asleep in her mother's arms.

As I held her tiny hand in mine I wanted to whisper comforts in her ear, comforts that I myself need to hear when faced with my own fears and struggles. "Don't be afraid, you'll be all right, your family loves you. The pain is only momentary, and it's worth getting through because did you know there are double rainbows every day on the black sands of Maui's beaches? That Mount Fuji is shrouded in mist and rises above Tokyo like a part of heaven? That in Vienna there are some of the best cakes you'll ever taste? That the Mediterranean Sea off the island of Capri shines like a sapphire? That there are thousand-year old olive trees in Spain? You'll be all right, because you'll recover here and maybe one day, someday—with all my hope and against the odds—you'll be able to leave this province and see the world because there are misty mountains in California, underground caverns in Kentucky, fireworks over London, brilliant autumn leaves in Michigan, castles in Denmark, jazz festivals in Montreal, lavender farms in France...."

I thought of the Other Girl and wished her the same.



HEART OF A WORLD TRAVELER

Lisa S. Mulcrone

If you had told me seven years ago when I first got my ICD that I was going to travel the world to remote places on an incredible eight-week trip, I would have looked up from the crumpled mess I was on the floor and called you crazy. I might have even thrown something at you. Back then I was scared, mad, sad and felt like I had been handed a life with limits.

Eventually, I got up off that floor, got some counseling, met some incredible people through the Young ICD Connection, got help from my wonderful doctor and nurses and got back to living my life and stopped being so afraid. Don't get me wrong, I still have my moments and I never truly forget I have an ICD, but I decided I wouldn't let it limit my experiences.

A bit of background on how I became a world traveler. I never even had a passport before three years ago. I got one to take my daughter to college in Scotland and found that I loved experiencing new places, people and culture. I discovered a thirst for adventure I hadn't known I had. I was on the lookout for ways to quench it.

I work at Michigan State University in the main communications department. We do a president's report every year that highlights MSU's impact and achievement. Last year, we knew we wanted to highlight the university's global reach, but how? My colleague, who is our video producer said, "How about a trip around the world?" and *Spartans Will. 360* was born.

We decided to take a video crew around the world and highlight researchers and the important work they do tackling some of the world's most challenging problems. We wanted to let the audience follow along through social media, blogs, and a special website that we would create as we went along. This would not be to tourist spots, and this would not be easy.

The producer and a photographer would go to all locations and meet up with video teams of two who would leapfrog each other. The producer and our boss decided they needed one more person to join the small crew at every location to write, coordinate, do social media, and generally help organize. In my daily job behind my desk I do content coordination, editing and writing.

I thought for a few minutes. I thought about my device and what would happen if I had an emergency in some remote area. “Would I be a burden on the team? Maybe I should just stay home near my doctor where it’s safe.” Then I thought, “Why not me? Take a risk. Live life. Remember what you were told—you have the device to LIVE...so go LIVE.”

I volunteered. My bosses thought my skills fit perfectly with what the project needed. The producer questioned my health and whether it would be okay for me to go. When I heard that, I got angry. He was just being kind, but I got mad that anyone would think I couldn’t do it. That’s when I decided I really, really wanted to go and show everyone what I could do, heart problems be damned.

Of course I checked in with my doctor and he gave his blessing and told me not to drink the water and to have a great time. I had just had my device replaced four months before we left and I knew my battery was in good shape.

So I packed my bags—a personal computer bag and one, just one, piece of carry-on luggage. Luckily, my ICD was already packed inside my chest so I didn’t have to worry about taking up any precious space in my bags. We were going to be traveling so fast that we couldn’t take any chances of dealing with lost luggage, as it would never catch up.

And then we were off for almost eight weeks. I went to places I never would have gotten to on my own and saw things I never thought I would see. We traveled to China, Mexico, Costa Rica, Brazil, Malawi, Zambia, Rwanda, Tanzania, Bangladesh and India. We took at least 25 flights and countless bumpy jeep rides into the middle of nowhere, where MSU researchers are doing incredible

things. I look at photos now and sometimes can't believe I was actually there. A trip like that will change you. It was the experience of a lifetime I never would have done had I not gotten up and started to live again.

I mentioned 25 flights. That's a lot of security clearances. On top of that, we were in many places where hotels and other public places had metal detectors. I'm not a doctor and I'm not a manufacturer's expert. I'm just the patient. I've heard and read varying opinions about metal detectors. Don't go through them, they're okay if you move quickly, just don't let a wand get closer than six inches, etc.

But, as the patient it's my choice and I chose to play it as safe as possible. The last thing I wanted was an inappropriate shock or a beeping or faulty ICD when I was in the middle of nowhere in China or Tanzania. So I asked for a hand search each time.

I was pleasantly surprised how readily airport personnel all over the world understood what I needed and quickly shuffled me around the detectors. I did use the word "pacemaker" instead of ICD or defibrillator because I figured it was more widely used. In all those flights, no one really gave me any trouble, and in all but one stop I encountered understanding, polite and very nice people.

When I packed my passport, I made sure to pack my ICD identification card. I think I only got asked to show it twice, but it's always a good idea to have it. Many times, I was asked if I wanted a private area pat down but I didn't bother. Sure, some countries are a bit "friendlier" than others, but it's nothing I minded others seeing.

None of this really slowed us down. We got stopped for many things—nail clippers, pliers, camera equipment, batteries, shampoo and even macadamia nuts—so my searches weren't a problem.

I did end up in an emergency room during the trip, but it wasn't for me. My coworker, and photographer on the trip, dislocated his shoulder on our second stop in China. I took him to the ER in the middle of the night in Guangzhou. No one at the hospital spoke English and no one gave him anything for pain before trying to yank

his arm back into place. When they started saying, “cut,” we got out of their pretty fast. Eventually, we got him to Hong Kong where some great doctors got him fixed up in a sling, and he caught up with us just in time for our next stop in Mexico. He did the whole trip, shooting stunning photos, one-handed. We Spartans are made from pretty tough stock.

During my travels, I saw some pretty horrible things—an area ravaged by a deadly earthquake, people standing in line for days to see a doctor, children with malaria and malnutrition, communities without water, families with only basic shelter, extreme pollution and even people so poor they were selling their organs to pay their debts.

After witnessing the challenges people face every day, I found it pretty hard to feel sorry for myself because of my ICD. I have a heart condition...so what? I should be thankful every night for the access to care and technology that I have when so many people wonder if they or their children will make it through the next day. Had I been born in the places we visited, I would never have been afforded the opportunity to have this lifesaving piece of technology put in my chest.

The trip proved to me that I am stronger than I ever thought I was. It granted me perspective I never would have if I hadn't gotten up off that floor or if I had been too afraid to volunteer. It gave me adventure, wisdom, gratitude, grace, understanding, pride, compassion, lifelong friendships, and the experience of a lifetime.

I know that not everyone will get the opportunity I had. I was extremely lucky to be able to be a part of a project like that—a project I almost let pass me by due to fear and uncertainty. Everyone's health is different and we all have different reasons for having our ICDs. So clearly, travel, especially to the extent I did, is something everyone should discuss with their doctor before packing their bags.

But, don't let the mere fact that you have an ICD stop you from grabbing life by the horns. Don't let the fear of travel make you miss all this world has to offer. Take chances. Take a risk here or there. Be

open to new experiences, and be grateful for all you have. Go live while you have the chance.

To see photos, videos, blogs and more from my trip, visit www.msu.edu/360



AN UNCERTAIN JOURNEY

The devastating impact of hypertrophic cardiomyopathy and how my AICD has helped me reclaim a “normal” life

Asblea Walton

I am a 31-year-old woman. I have been married six years and have two young girls (ages four years and 18 months). I have had an Automatic Implantable Cardio Defibrillator since I was 16 years old. From as far back as I can remember, heart disease has been a part of my life in some way or another. My grandmother died of heart disease before I was born, my uncle got a heart transplant when I was eight and died shortly after from complications. When I was nine, my dad received a heart transplant. I never really knew my dad was sick before that time. In my memories he was energetic, fun, and playful. After he received his new heart, he struggled with liver failure but eventually recovered and came home. Though he was physically on the mend, I knew he wasn't the same.

I was the youngest of three children living in Wisconsin. After my dad recovered, my siblings and I started getting checked every year by a cardiologist at Columbia Hospital in Milwaukee. My sister and I were both diagnosed with a heart murmur. I had no idea what that meant and didn't do anything differently. My sister was put on medication, and we went back every year to be re-evaluated. By this time my dad's disease had a name: idiopathic hypertrophic subaortic stenosis (IHSS), now more commonly referred to as hypertrophic cardiomyopathy (HCM).

Time went on, and everything started to feel normal again. One summer night when I was 12 years old, I was home watching TV when the phone rang. My sister, who had been at a pool party with friends, had fallen down, hit her head and was at the hospital. My dad immediately rushed out the door while my older brother and I waited for what seemed like forever to find out what happened. Hours later my dad came home, and my brother and I went out to the driveway to greet him. I don't know if it was shock or if there was simply no

better way to put it but he blurted out, “Your sister fell down, hit her head and died.” I will never forget that moment. Time stood still, and I can remember the oddest details about my surroundings—how the grass felt on my bare feet and how my dad squeezed my shoulder. A few days later we learned that she had suffered an arrhythmia and that was what caused her death. She was 17 years old.

Being 12, I didn’t fully understand death or what impact it would have on my family. I did not put the pieces together about this heart disease which was tearing through my family and that it could soon be something I would have to deal with.

Two years later I relocated to Ann Arbor, MI. My mom had gotten a job teaching in Ann Arbor. My parents were divorced, and they told me I could decide where I wanted to live. It was a painful process because I didn’t want to hurt anyone’s feelings, but my dad told me that I should give Ann Arbor a try because it would be a fresh start for me. In Ann Arbor, I began to be seen by Dr. John Nicklas at the University of Michigan Hospital. Normally, at age 14 I would be seen in pediatrics, but my cardiologist in Milwaukee knew Dr. Nicklas so I was able to get in to his clinic. I was by far his youngest patient.

After my first annual checkup with Dr. Nicklas, I began to settle into life in Ann Arbor, and I was loving it. I felt reborn. I escaped the sadness and tragedy that I felt back in Wisconsin. Nobody knew me or knew my history, and I could start fresh.

At 16, I went in for a checkup and then went about my life as I always did. I had a great group of friends and loved my school. A few days after my appointment, my mom and I got home from running errands and pressed the answering machine to listen to the messages. There was a message from Dr. Nicklas. He wanted us to come in to discuss the results of my echo. I can’t believe this now, but I really didn’t think anything of it at the time. I don’t know if I was in denial or just naïve, but I wasn’t scared. Now that I’m a parent I can imagine how hard it must have been for my mom to hear that message. I’m sure she feared something was wrong.

A week or so later, we went to see Dr. Nicklas, and he told me that I had developed HCM. The apex of my heart had significant thickening, and I was at risk for life threatening arrhythmias. He recommended that I receive an automatic implantable cardioverter defibrillator as soon as possible. Because of the severity of this disease in my family, they did not want to wait. I felt like I was dreaming. This could not be happening to me. I felt fine, I had no symptoms. I needed time to think about this. Being 16, I immediately turned to my friends for advice and comfort. Though they tried their best to comfort and support me, they had no idea what this meant. I remember sitting in my room one night trying to imagine what my life would be like living with an ICD. At my age, all I ever wanted to be was normal—not the girl whose dad was sick, or the girl whose sister died, and certainly not the girl with a box in her chest. I decided to start writing down questions for the doctor. What is the surgery like? How often will I have to get a new one? What will my scar be like? My thoughts went well into the future. Can I have children with this thing in me? Scary thoughts also came to mind. Will I die without this? Would my sister have lived if she had received an ICD? We scheduled a phone call with Dr. Nicklas to answer all of my questions.

After speaking with Dr. Nicklas about all of my questions, which he patiently answered, he explained the details of moving forward with the procedure. He explained further the risks that come with HCM and that there was a good chance that if my sister had an ICD, she would have lived. When asking him about having children, I remember him laughing a bit and commenting on the maturity of my questions. I knew that having children was always part of my plan. The University of Michigan Hospital connected me with another young girl who had a defibrillator and whom I could speak with and ask any questions I might have. It was helpful, but at that point it was all happening so fast I'm not sure I even knew what to ask.

Shortly after, I decided that I would go forward with the procedure. I was scared and worried about what my life would be like after I woke up, but I didn't want to show my fear. I knew what my family had been through already, and being brave and strong was the only thing left. My parents were there with me as the staff prepped

for the procedure. I remember my dad teasing me about how loopy I would be and how he was going to get all sorts of information from me while I was out of it. I can't even imagine how scared he felt. He had already lost his mother, brother and oldest daughter to this disease and now his baby girl was going in to surgery.

The surgery went smoothly. I woke up sore but feeling okay. I was scared to look at my incision for a long time. I don't know what it was; I have never been squeamish about blood or injuries but this was different. It felt like looking at the incision made it real, and I wasn't ready to accept that. After two days in the hospital I was discharged. The nurses went over everything with me. Don't get the incision wet, wear a sling, don't pick anything up heavier than a gallon of milk, don't raise your arm, etc. The recovery wasn't so bad; showering was a challenge and I had a lot of down time to think, but other than that, I was surrounded by friends and kept myself busy trying to keep up in school. I remember looking at my friends and watching them talk and joke around with one another and thinking "I am different than you." I had started fresh in Michigan and now I felt like I was back to being the girl who was different.

My first visit to the electrophysiology (EP) lab for a device check was interesting. When they were interrogating my ICD and increased my rate to test my sensors, I was not expecting to feel the thumping sensation and it just about sent me into a panic attack. I also remember someone in my family asking me if it was safe for me to use a microwave since I had a pacemaker. I remember feeling panicked, thinking "They didn't tell me anything about not using a microwave!" At my next appointment I asked the EP nurse. She looked at me with a grin and said, "Of course you can use a microwave. You can't get IN a microwave, but you can certainly use one." There are a lot of myths about what you can and can't do when you have a pacemaker or defibrillator. I started experiencing things I had never thought about. Going through airport security was a lot more challenging. We walked up to the gate and told the security guard that I couldn't go through the metal detector or have the wand used on me because I had an ICD. They looked at me wide-eyed and said, "But you are too young to have that!" "Thank you for pointing that out," I thought. Then I got to experience a full frisk and pat

down. I couldn't help laughing as my mom and I looked at each other, taken back by this new experience. About seven months after my ICD was implanted I attended an annual ICD conference sponsored by the hospital. I went with my mom and we met many families going through similar situations as ours. It was nice to see that there were other young people that knew what I was going through. It was bittersweet though. I made new friends, but I didn't want to have to be in that situation at all, and it made me sad that we all had to deal with this. I did come away with a new sense of strength and confidence, and for that, I will forever be thankful.

About a year later I felt back to my old self; I had found my new normal. During a rainy weekend day, a group of friends and I decided to play football outside at a park. Most of my friends were guys so we couldn't just throw the ball around, we had to play tackle football. We were having a blast and it started really raining so we were all covered in mud. My friend was way down the field and I was running in the opposite direction and heard him call my name. I turned around and he threw the ball to me. I jumped up and just as I was catching the ball I felt a hard thump on my back. Everything went black for a split second and I fell to the ground.

I opened my eyes and knew immediately that I had been shocked. I had always wondered what it would feel like and the best way to describe it is like you are getting kicked in the back. I immediately panicked and started crying, "There must be something wrong," I kept saying. We went back to my friend's house where I laid down. I felt fine, just very shaken up. A few days later I went in to the EP lab so they could look at the episode. They found that I had actually not had an arrhythmia, but my ICD shock threshold was set too low. They set it at the general setting that they give to older people who likely don't play sports or get their heart rates up very high. They set my device to a higher threshold and sent me home. It took me a while to get on my feet again and feel comfortable.

A few months after getting shocked playing football, I was playing basketball at a park with some friends, and I thought someone had thrown the ball at my back. I turned around to see who had thrown it, but realized nobody was behind me and that I had

been shocked again. It was not as traumatic as the first time, but again, I was shaken and very upset. I was thinking something must be wrong now because they had just raised my settings so this time couldn't be a mistake. However, they found that again it was an issue where at my last appointment they mistakenly reset my settings too low. So, for the second time, I was shocked by mistake. I felt extreme relief and irritation, from then on I made sure to double-check the settings when I left an appointment. To this day I get anxious when someone is standing behind me. I feel like if someone taps me or bumps into me in the back, it will feel like a shock. I know that sounds strange but it gives me a lot of anxiety.

After my two little mishaps, things were good for a long time. I graduated high school, went to college, and lived in the dorms. It was hard moving to a new place where nobody knew my situation. I didn't want to tell my roommates about my ICD, but I also wanted them to be aware in case anything happened. My dad still lived back in Milwaukee, and I would go back to see him or he would come to see me every chance we got (usually every other month or so). It seemed that every time I went to see my dad he appeared a little bit weaker (both mentally and physically). He had been through so much in his life, and now he lived alone with nothing but time to think about all of the tragedies. Because of his health, he was not working but was very spiritual and involved in his church. I was walking home from my job at the campus rec center one night having a long talk with my dad on the phone. This was not unusual at all. He and I spoke every day and he knew everything going on in my life. He was in the hospital because he had not been feeling very well but assured me he was okay and I should not be worried. We carried on laughing and talking for about an hour, told each other we loved one another, and I hung up the phone.

The next day I stopped by my mom's house and she told me that my dad's good friend had called her the night before and that he said my dad was not doing very well. He said we should think about coming back to Wisconsin to see him. I told my mom that I just spoken to my dad last night and he seemed fine. We decided that the next day we would drive back. My brother was at college in Nebraska and received the same message. He decided to get on a flight that

night and go see my dad. I ended up sleeping at my mom's that night because we were leaving early the next morning. At around 5am I heard the phone ring and heard my mom talking. I jumped out of bed and walked out in to the hallway. I knew something was wrong. My mom informed me that my dad had died during the night. I remember closing my eyes and saying, "no." I was in absolute disbelief. This could not be happening; he could not be gone. At that point I shut down and it was a blur. We got in the car and drove to Milwaukee where we met my brother who told me that he had sat with my dad the night before and he had not let on that anything was really wrong. He said that he told my dad that I was on my way the next day and that made him happy. We were both in shock. My brother and I planned a funeral, we settled his affairs and cleaned out his belongings. I am so glad we didn't have to go through it alone, however, that is an experience no child should have to go through. I was 19 when my dad died.

As the months went on I tried to pick up the pieces. I was so angry that I had lost my dad after everything my family had been through. I didn't understand how this could have happened while he was in the hospital. The more time went on, the more questions I had. I contacted the hospital in Wisconsin where he died and went through a process of filling out paperwork so that I could be sent his full medical records. I wanted to know what had happened. I received a very thick file of all of his records and went to work investigating. I read about his HCM, his heart transplant, the liver failure he suffered as a result of all of the medications he took, and the fact that he did not take care of himself. His ultimate cause of death was liver failure.

Then I came across something I was not expecting. My dad had signed a DNR order when he was admitted to the hospital. I could not believe this and was instantly angry at him. This person that I spoke to on the phone every single day lied to me and told me he was doing okay and would be fine. By signing a DNR, he had to have known that he was dying and lied to me. It took me a long time to get over his decision. As I got older, I was able to see that he was trying to protect me. He knew how much I had suffered already and wanted me to be free of worry for as long as possible.

Shortly after my dad died, I was transferred from seeing Dr. Nicklas, to seeing an HCM specialist at the University of Michigan named Dr. Sharlene Day.

A very uneventful two years went by, and I was happy with my life. I was a junior in college studying communications and working as a part time nanny. One night when I was watching the kids, I was making them dinner and turned around to open the fridge and felt a hard thumping on my chest. I got tunnel vision and began to fall forward. It felt like slow motion and I remember thinking, "This is it...I'm going to die." I caught myself on the counter before I fell and started shaking. I ran to the phone to first call the parents of the children I was watching and told them to come home immediately. I then called my mom. When they got home they drove me to the ER. I met my mom there and they gave me an EKG and interrogated my device. I had not been shocked and nothing was recorded. I felt like they all thought I was making it up. They ended up sending me home with a Holter monitor to record my heart rhythm for a few days and see if they could find anything.

Over the next few days I had two more episodes like that. They were terrifying, and each time I thought I was going to die. When they looked at the recording they saw that I was having episodes of supraventricular tachycardia (SVT). My heart was at a resting rate of 70 bpm and in a split second would jump to over 180 bpm. They informed me that SVT was not life threatening but it was a secondary symptom of HCM. Because I had thickening in my heart muscle, it caused electrical signals to occasionally get crossed and cause my heart rate to jump. I was put on medication and that helped to control it, but nothing could repair the anxiety those episodes gave me. To this day I struggle with anxiety.

The traumatic experiences took a pause for a while, and I was able to pick up the pieces again and move on with my life. I graduated college and met a man who was not afraid of nor intimidated by my past. After dating for two years he asked me to marry him, and a year later we were married. While we dated we discussed our future and the possibility of having children. We met

with Dr. Day to discuss what it would be like for me to carry a child with my condition. We discussed the possibility that our child might have HCM. Dr. Day was always straightforward and told me that if I wanted to have children it would be best do it while I was young and healthy as I would have to be off my medication during the early stages of pregnancy. This fit well with our plans as we knew we didn't want to wait long anyway. Dr. Day recommended that before we proceeded I should look into genetic testing for HCM. There was more and more of that being done, and the more we knew the better it would be for us and our future children.

Because I was the only living person in my family with HCM, we started by getting blood tests for my mom, brother, and me. The lab identified a genetic mutation in my sample that had never been identified with any other HCM patient. My mother's sample did not have the mutation (therefore it had to have been passed down from my dad). My brother's sample also came back normal. (He had never had any symptoms and his echo and EKG were normal.) Not being able to say with 100% certainty, the doctors were very confident that this genetic mutation was to blame for my HCM, and with these results they could test my future children to see if they had HCM.

Knowing there was a 50/50 chance my children could be born with the gene that caused my HCM was scary. With the help of Dr. Day and an HCM geneticist at U-M, I went through all of my options. I could take the 50/50 chance, I could have my eggs tested and implant the gene negative eggs (similar to IVF), I could have the fetus tested in the early stages of pregnancy and terminate if the results showed HCM. None of these options made us completely comfortable. The decision was very difficult, but we decided to go ahead and take a 50/50 chance.

Shortly after our decision I became pregnant. I was scared about being off of my medication and the possibility of being shocked during pregnancy and it hurting the baby, but I was reassured and supported by the hospital staff that it would be okay. I had a good pregnancy, nothing significant happened, and I was so excited to welcome our baby girl. The doctors took cord blood from her after delivery to be tested so we knew if she carried the HCM gene. It took

about six weeks to get the results. Those six weeks were torture. I let every scenario run through my head. What if she had HCM? It was my job to protect her, and I may have passed on this deadly condition. After the long wait, we found out she did not carry the gene mutation. We were overjoyed, and I felt that I could finally enjoy my family and be at peace. After my husband and I went through that waiting period, we knew that if we ever decided to have another child, we would go about it differently. It was relatively easy for us to come up with our plan, but once we held our baby and felt that intense love for her, we also felt immense responsibility to protect her. Ultimately, we were very lucky with our daughter, but understood that the next time would have to be different.

Two wonderful years went by with my beautiful little family, and my husband and I decided to try again and give our daughter a sibling. This time around we looked further into our options. We both agreed that we could not wait until after the baby was born to find out if it carried the HCM gene. We spoke with genetic counselors and doctors and decided to go forward with a chorionic villi sampling (CVS). This procedure would allow us to find out in the first trimester if the HCM gene was present.

My husband and I spent hours discussing what we would do with those test results. If the results were positive we could go forward with the pregnancy and begin HCM care right away. We knew that this child would have a life of tests, ICDs, possible heart transplant, medication, etc. Not all cases of HCM are that severe, and I had to look at my family. It was pure luck that my HCM was in the apex of my heart and not as severe as most cases. We had to also look at the fact that four members of my family had struggled and died before their time. We also had the option of terminating the pregnancy if the gene was present. This would have been extremely painful, but would we have saved this child from a life long struggle?

These are not easy topics to discuss, and unless you are in our situation you cannot possibly grasp the weight of it. It was a lonely road for us. We knew we couldn't share the decision-making process with our friends and family because everyone has their own set of beliefs and adding judgment or disapproval was not something we

could handle.

We went forward with the CVS and waited three to four weeks for the results. Those weeks were a dark time for us. It felt like there was no right answer and waiting was torture. When the test results came back negative for the HCM gene, we were thrilled and so relieved. We were lucky and didn't have to make a difficult decision.

As I look at my beautiful, healthy girls, I feel so content. It was no easy journey and I'm sure I will face challenges in the future. I am on my third ICD and feel very fortunate to be a patient in a hospital where I am surrounded by a community of doctors and nurses who know me and have helped me through some of my toughest times. Having gone through the genetic testing process I feel strongly that we, as a community of heart patients, need to be supportive of one another regardless of the decisions we make. We all have our own journey, and we are the only ones who can truly relate to one another.

If you are in the process of getting an ICD, know that you are not alone, even if it might feel like it. These small life-saving devices allow us to have a hopeful future and move on from our painful pasts. They allow us to feel some peace and safety when so many things in our lives feel out of our control.



OBSTACLES TO OPPORTUNITIES

Michaela Gagne Hetzler

Let me paint you a picture.

Just imagine you are 15 years old and full of energy. Full of life. And there is *nothing* you love more in the world than the thrill of athletic competition. Soccer, basketball, track and field—it is your passion. You love to fly—to run so fast and breathe so hard, that in that moment you can accomplish anything. It is that moment you live for.

After a long and grueling practice one day, your high school coach pulls you aside, looks you in the eye, and says, “You can coach a player to have skills, but not to have heart. *You* are great because you have all the heart in the world.” And you are good at it. Really good. You are a record-breaking, varsity-lettering, three-sport captaining athlete. And all you want is to compete for the rest of your life.

So there you are. It’s an unusually hot Saturday morning in May, and you are standing at the starting line to the biggest track race of your life. The ten hurdles are lined up in front of you, taunting you to conquer them.

On your mark.

You shake out your legs, feeling the presence of the amazing racers on each side of you. But you know in your heart you are the best.

Get set.

You put your feet in the starting blocks, heart racing, blood pumping, energy screaming.

Go!

You are off. As the wind whips in your face, you take that first hurdle by storm.

Hurdles 2, 3, 4.

No one is by your side, you lead the pack. The adrenaline only rocks you harder.

Hurdles 5, 6.

You feel a wave of dizziness; your vision begins to slightly cloud.

Hurdle 7.

You feel yourself slow down, realizing you can barely see ahead of you. Your head is ringing.

Hurdle 8.

You continue to take on the hurdles by memorization only. You have to finish the race. You're going to lose, but you're going to finish. You wish that you could feel your legs. All you can feel in that moment is your heart pounding.

Hurdle 9.

The lightheadedness is overwhelming. You know you are almost there. You can hear your mom screaming up ahead. You have to finish.

Hurdle 10.

You stumble over the last hurdle, catch yourself, and stagger to the finish line. You fall to your knees as you try to overcome the moment, head to the ground. The officials are reading off the results, but all you can hear is your mom shouting for you as she rapidly approaches. She is rubbing your back, asking you if you are okay. You hear the athletic trainer asking you to say something. Your vision is returning. You are okay. You have to be. The dizziness is gone, you can see the gravel near your face, and the bells have gone away. You slowly stand up, trying to push off the hands helping you to your feet. You need to hold your head high. You need to be okay. You just lost the race that should have been yours. You look up at your mom's face. The worry in it is undeniable. "I'm fine, Mom."

This is my story, my experience.

During my senior year of high school, two years after collapsing at that finish line, my world as I knew it came crashing down. A diagnosis of hypoglycemia was followed by randomly detecting a heart murmur never noticed before. Cardiac follow-up led to genetic testing. I'll never forget the day I was officially diagnosed with the potentially life-threatening heart condition known as long QT syndrome. It was Good Friday of the year 2000. My mom turned to me with tears streaming down her face, still on the phone with my electrophysiologist who had just received the genetic results. It broke her heart as much as mine, the woman whose voice always broke through everyone else's as she cheered on the sidelines as my greatest fan.

No more playing basketball until the streetlights came on. No more racing my friends on the track. No more hopes to play Division I soccer. No more dreams coming true, the dreams of the little girl who wanted nothing more than to compete for the rest of her life.

Not only was my true passion taken away from me, I was told I was a ticking time bomb that could go off at any moment. I was confused, angry, sad. At the time in the year 2000 I could barely find any information on my syndrome, and found virtually no support with regard to meeting other young people with heart conditions. Despite the amazing support of my friends and family, it was the most alone I have ever felt in my life. No one truly could understand what it was like to feel as though you were no longer yourself.

But I was alive. I had been given a chance. And with the resiliency that youth are inclined to possess, I decided to concentrate on what I had, not on what I didn't have.

So, I did what anyone would have done. I entered a beauty pageant. And, yes, that is supposed to be funny, especially if you knew me then.

Of course the typical stereotypes generally associated with beauty queens made me laugh at the idea when it was suggested to me by my guidance counselor. "Michaela, you are a very smart young

woman. You are beautiful inside and out with a great personality. I think you should give Miss Fall River a try. I bet it would be a lot of fun.” You should have seen my mouth drop open— me in my torn jeans, t-shirt, and ratty sneakers. I was the least likely beauty contestant ever. Ever since I could walk, I would’ve rolled around in the dirt and tried to beat up the boys rather than wear a dress or brush my hair.

But I saw it as a new form of competition, a way to fill the void left by sports. And I certainly *love* a good challenge.

So I walked into the Miss Fall River 2000 Scholarship Pageant. Now, I had never been nervous a day in my life before a sporting event. This was just a little different. I almost puked before my interview, I couldn’t breathe during my simple but interesting piano talent, and I knew there was no smile plastered across my face while I was strutting around in an evening gown. The most memorable part, though, was walking like a football player in a swimsuit and heels. No grace. No poise. (Mom was so proud.) And the funniest part of it all is that I actually loved it.

Sure, it helped me build up confidence in ways I never thought I’d want to, but believe it or not, it was fun. I took on an unexpected adventure, and I enjoyed the ride. I loved it most though because I was given time to speak to the judges regarding my platform issue. Every contestant competing in the program chooses to speak on an issue that is important to her. Your platform issue is about advocacy and working in the community for your chosen cause. I told them all about lethal heart conditions. None of the judges had ever heard of long QT syndrome. It was an empowering and therapeutic experience to speak about my condition, and I couldn’t believe how great I felt walking out of that experience.

At this time I threw myself harder into my academics, my love for creating art, and community service. I graduated from high school as an active member of student government and various clubs, number eight in my class of 500 students, and I was accepted into the art program and Commonwealth College at the University of Massachusetts at Amherst. It made me feel great to know I could

still accomplish so much and mean something to others, even when I wasn't able to participate in the one thing I had thought most defined me.

One month before entering college, I had my first ICD implanted, and I'm currently approaching eight years into my second. It was a tough time for me then. My self-esteem and self-worth were fragile. I felt normal, but I was a freak. Sometimes I felt a sense of only what I can describe as claustrophobia in having this foreign object inside me that I couldn't take out. I felt like the people surrounding me thought I was delicate, and when someone found out about my condition it seemed like there was a stigma or stereotype attached. At first I found myself telling very few people what I had experienced because they just wouldn't get it, and I just didn't have the energy to explain.

One day early in my first year of college during art class, a classmate came up to me and complimented my painting. We chatted a bit, and then he questioned if it was okay to ask me if I was okay, as he pointed to my chest. Shortly after my surgery, my incision burst open, and I had been left to dress my wound several times every day for months. I wasn't very neat in this process, and more often than not, bandages would stick out the top of my shirt, and I stopped caring. I took a deep breath, gathered some new-found courage, and told him the story.

"That's cool," he told me. I was caught off guard. All the stress and emotions that had been bottled up in me for months came out in a great laugh. "Yeah, it is cool," I told him.

It became easier to share with others what I experienced after that. It was a slow process, but I learned to love me as I am, robotic metal box in my chest and all. I appreciated being different on a whole new level.

So, I didn't go on to play Division I soccer, but I did develop some pageant in my blood. Proudly displaying the scar on my chest that the athlete in me insisted it was a war wound, I returned to the stage during my sophomore year of college. I began to think about

pageants the way I thought about sports. It became about determination, concentration, and personal effort.

And then I started winning. Seriously! I still kind of walked like a jock, and my piano playing remained something left to be desired, but I had the passion to be there. I was continuing to educate the public about my syndrome while the media was reporting frequently about athletes dying from underlying, unknown conditions.

I started being asked to “tell my story.” At first it seemed funny. “You want me to tell my story? What story? There’s no story, it’s just what happened to me in my life.” Why would other people want to hear about that? And then slowly, I got it. I could not believe how much impact I had just by sharing my experience. Through telling my story I became a new face of heart disease. No one would pick the young woman out of the crowd as having a cardiac condition. I stressed the notion that heart disease does not discriminate. And people listened.

I decided it was time to do more, say more, and accomplish more because lives were being lost for no reason. I contacted Massachusetts legislators and went to the Massachusetts State House. Work began being done on bills that would make automated external defibrillators mandatory in schools— a battle that continues today.

In June of 2006, I returned for my final state pageant, shortly after receiving my master’s degree in art therapy and mental health counseling. I walked like a lady (It was hard work!), sang as my new talent, and picked up the swimsuit and interview awards. It was down to the final two, and I held the hands of the other remaining contestant. All I could hear was my mom cheering from the audience, still my greatest fan.

“Miss Massachusetts 2006...Michaela Gagne!”

They told me my heart could race from playing sports, but they apparently have never checked out the heart rate of a girl who just won a pageant. A million thoughts rushed through my mind when the crown was placed on my head, the same girl who once didn’t

know how to walk in high-heeled shoes or put on mascara. Most importantly though, I realized my new role would give me a megaphone for heart disease awareness that could literally save lives.

In January of 2007, in front of a national TV audience, I proudly walked across a Las Vegas stage as a contestant in the Miss America Pageant. I was featured in USA Today and interviewed nationally on CNN, Fox News, and Inside Edition regarding my story and my fight. Backstage, one contestant asked me if I wanted to borrow her make-up to cover my scar for the swimsuit competition. “No, thanks,” I told her. “It’s a badge of honor.”

My best and most memorable Miss America experience, however, wasn’t walking across the stage. It wasn’t having the TV camera in my face, filming a reality show, or the red carpet appearances, and it certainly wasn’t making sure that I had enough butt glue under my swimsuit bottoms to prevent a wedgie. (That’s a bonus secret pageant trick!) I won’t even tell you what I can do with duct tape or Vaseline. Ah, I digress....

My best Miss America experience was an email. Yes, an email. A lady had read about me in the media, and she told me that she had a life-threatening heart condition as well. She was told she needed an ICD, but she had not yet found the courage to go through with the surgery. After reading my story, she decided that if Miss Massachusetts could do it, then she could too, and she made her surgery date. She ended the email with, “Michaela, thank you for saving my life.” She let me know all was successful after she had her device implanted, and I knew, once again, that it was never about the crown or the glamour for me. It was about the impact I could have on others. Well, and of course, world peace.

Through this mission to save lives, I became a national spokesperson for the American Heart Association, and I was able to speak on Capitol Hill several times about my story and the work that has to be done to prevent more lives from being taken unnecessarily by heart disease. I have spoken for the SADS (sudden arrhythmia death syndromes) Foundation, as well as nationally for Parent Heart Watch, the national organization founded by parents who have lost

children to sudden cardiac arrest. In between, I have met so many tremendous individuals and organizations who are part of the fight to save lives.

I love these groups, I love the people I have met, and I certainly love my work.

The best part of my role has been speaking nationally to children and teenagers who are affected by heart disease. I encourage them to view their syndrome with a new sense of hope. It's not every day you get to compare scars with an eight-year old who has had open heart surgery. Or better yet, hear a five-year old who has his own ICD grab your hand and yell, "Wow, that's so cool! Miss Massachusetts has a heart problem too!"

So, it's been a journey, and one that certainly never ends. Now seven years after a whirlwind of pageant adventures and 13 years after diagnosis, I never thought I would be in the position that I am in today. I had my life mapped out in a very different way, most of which included adventures such as volunteering in orphanages around the world, becoming a potter, and playing in the NBA. In the end, however, I would not change any of my history because it has made me into a woman I am proud to be. I have been able to speak nationally and internationally concerning various issues of the heart and overcoming challenges. Currently I am a school counselor and art therapist working with high risk youth, many of whom have a variety of extreme social and emotional issues.

Most importantly, I am a proud wife to Josh and mother of three amazing children—Lorelei, Evan, and Andreas (with baby Gwentyth on the way as #4!). Pregnancy and motherhood certainly brought up a new series of challenges for me. The concern I have over passing on my genetic condition has taken its toll in stress. I am unwavering in having my kids monitored and cared for medically for anything needed, and I have to remind myself constantly that they live in a generation of great medicine and technology to diagnose and treat should they ever have any abnormalities like mine or otherwise. This faith has helped me be strong with accepting I can only take on the challenges presented to me and take sensible precautions, not fixate

with the “what if’s” that can consume us.

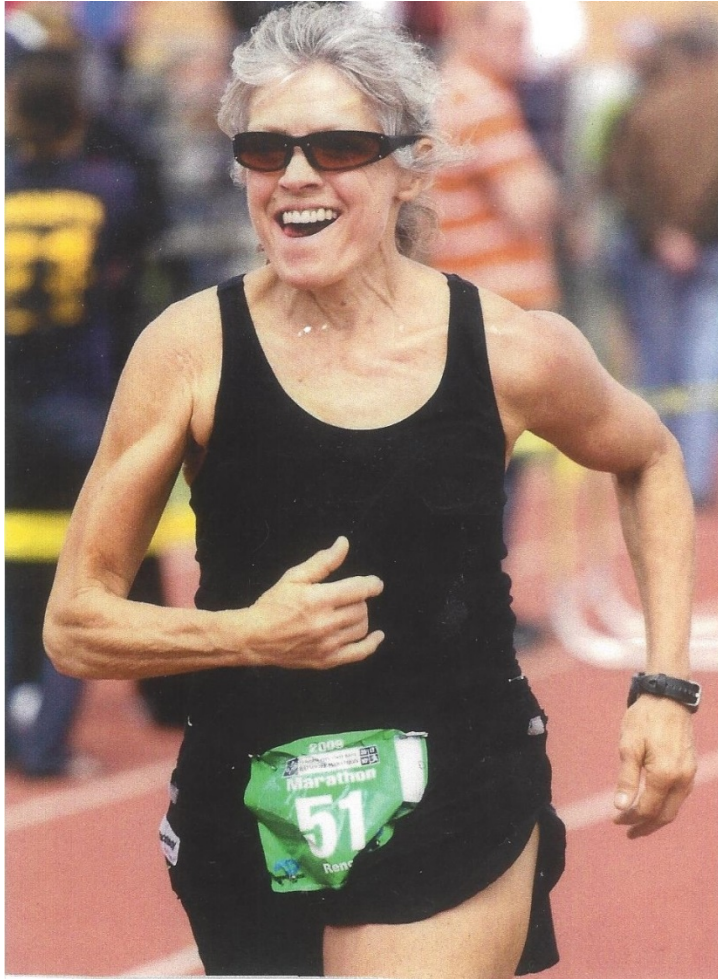
So, for those of you out there who are reading this and are troubled by past and current obstacles, wondering about the experiences to come, dealing with having a device, I can only hope my story has helped just a little. Each of us has a very different story to tell, and sometimes we will relate to one another, and sometimes despite both having a heart condition and device, we will not see eye to eye.

That being said, I say embrace it all. Embrace what you have, and accept it as a part of who you are. I like my scar. I like my box in my chest. I’m proud to say I rock a heart condition. Being a survivor hasn’t been as much about the physical aspects, but the emotional challenges this ordeal has taken. If you can find strength of mind and heart (no pun intended), life can take on a greater meaning for you.

I also believe in finding those important outlets in your life. I have no current restrictions, so I love to exercise, especially kayaking and coaching soccer. I try to find time for creating art. I spend time with my family and take vacations. Life is too short, with or without a medical condition, to not concentrate on what we have and make time for those moments that become great memories.

In closing, I can say I’m lucky—lucky to have a mom and dad who pushed to find answers, lucky to have doctors who cared, and certainly lucky to be healthy. We should all have the chance to be so lucky. I am many things: an artist; an athlete; a singer; an advocate; a “beauty queen.” I am a sister, a daughter, a wife, a mom, a fighter, a dreamer, an optimist, a strong woman.

But most importantly today, I am a survivor. My story is meant for many reasons. It is one to encourage you to appreciate your positive qualities and shortcomings, your successes and challenges, while continuing forward in life no matter the obstacles. I can think of no better cause to fight for than life, and my work is done in the memory of those who could not be saved.



PASSION, PERSEVERANCE, AND THE GIFT OF CHALLENGE

Renee Vettorello

Hi. My name is Renee Vettorello. I'm a 67-year-old, physically active, high-energy woman. I have a career in massage that I love, a life bigger than I could have ever imagined, and an ICD.

At the age of 57, training for the Boston Marathon, I had my first debilitating occurrence, known to me as v-tach. I was on the 17th mile of my last 20 miler. I became lightheaded and had to stop and sit down. A fellow runner flagged a ride for me back to my car. I collapsed. I was put in an emergency vehicle. As I lay there with an oxygen mask on, unable to speak or move in response to their questions, I was observing an altered reality that astonished and humbled me. I had no control and I was helpless. As they were beginning to transfer me to the hospital, I self-corrected and returned to normal functioning. I refused to go to the hospital, signed a release form, and wrote the episode off to dehydration.

I contacted my PCP, and to be on the safe side had an echo stress test and passed. Relieved but not totally convinced, I shared the story with my client and friend who was also a cardiologist. He gave me the name of a colleague who specialized in electrical problems and told me I was at risk to do the Boston Marathon. I did it anyway, cautiously and afraid. I saw Dr. Shinn after I got back, did a month-long Holter monitor and at the very last day of wearing it, it recorded three events of v-tach. It was a good thing that after the monitor dropped in the toilet on the third week I replaced it and finished the study.

I had my first cardiac ablation in April, an atrial ablation, as the meds I tried depressed and fatigued me to the point of almost incapacity. I could barely do my work. I ran a 5K race a week later. It was a disaster. I finished running with a concerned best friend who was a nurse. A good friend of ours was being honored at this *For Women Only* run. I had such a hard time focusing my friend Grace

insisted I go to the medical area. I was at Gallop Park in Ann Arbor, Michigan, and I went inside the canoe livery room and had to lie down on the floor and could not get up. An ambulance was called and I was taken to the nearest cardiac emergency room. I think my heart rate was exceeding 280 bpm, and three drugs later I was defibrillated and admitted to the hospital for a very scary night. As I was being observed by some young doctors during my ER portion, I kept feeling faint but found if I shifted my body a little I didn't pass out. I even quipped when I heard how high my heart rate was that I always knew I had a six-minute mile in me but never thought I would be lying down. I heard someone comment that she was surprised I could still "mentate." I could have hallucinated the word but I've used it ever since.

I was released the following day after a muga stress test and I saw a specialist at the University of Michigan Hospital. I then returned to my doctor at St. Joseph Mercy Hospital. It was determined that I receive an implanted cardioverter defibrillator – or an ICD as it's known. Trying to stay active was the next hurdle. More drugs and three ventricular ablations later, I felt I had come to a dead end of what we could do for help. I was even getting shocked while walking at this point. I was so desperate. My life was grinding to a panic-attack-filled halt. Even my work looked like an impossible long-term option. I then went to the Cleveland Clinic with a letter of referral and the blessings of my wonderful doctor, Dr. Kappler, who also became a great friend.

It was during a three-day hospitalization to try a drug that had a side effect of stopping the heart that I was thrown into despair. I wouldn't let anyone come to see me. My friend Mark came and sat a while anyway. I was so grateful. I was feeling half crazy to go to such extreme measures to keep running. A doctor who came to check on me asked why I couldn't be content with moderate activity like golf or walking.

I began evaluating for the first time how running had changed my life. I stopped smoking. My last cigarette was at the starting line of my first race, the Traverse City Cherry Festival Run. I finished second to last and a new love was born. It was a 6.2 mile run.

My massage career was to begin from a running camp I attended the following spring. I wanted to learn how to run a marathon (26.2 miles). I had only run eight miles, signed up for a 20 miler and then a massage four hours later. I had never had one but all the runners were so excited to have the massage therapist there that I had to try it. Besides, if I made it back in four hours, it would be my reward, if not my loss. I will never forget the amazing feeling and results of that skilled therapist's hands. It was the best twenty-five dollars I'd ever spent on myself, and I knew I had found my new path.

I have never looked back. Running continued to help me grow. It became a catalyst in my life. It centered me in the spirituality of nature, outside in all weather, joyful as a child. It gave me a new extended family. At the time, our group consisted of five women, and we would run before work at 5 or 6 a.m. As the group grew they adopted the name of Dawn Patrol, meeting at coffee shops, running from there, and socializing after. There are now 60 plus runners on e-mail. We all share our lives as a community. On my own and with my friends, we have traveled all over the country (and a few places outside of it) for our races. We have been to Paris, London, Barcelona. I even did my first out-of-the-country marathon for my 45th birthday in Athens, Greece, the original birthplace of the event. What a thrill! My world had expanded exponentially.

I'll never forget the sense of pride and accomplishment after completing my first marathon in 1979 in Detroit. At 33 years old, I ran 4:08, faster than the time I'd hoped for. Every wonderful memory of it is still vivid. So while it would seem the logical choice to stop after my heart challenge appeared, I couldn't accept it. I found the thought simply unbearable. I'd like to think that if the condition of my heart had worsened with this activity, I would have stopped, but I live in the land of idiopathic, the unknown, so I chose to continue to push.

Much of the courage it took to continue on came from the shared experience of the people in the University of Michigan Young ICD Connection Conference. I was surprised to be invited as I

wasn't young, and at the time was a patient at another hospital. The young 16-year-old girl who shared her story of multiple shocks as matter-of-factly as talking about the weather gave me courage during my own. There were so many other people with varying conditions living full lives with the help of their ICDs—the gatekeepers of our lives when called upon. I will always be grateful to the wonderful people at U-M Hospital for the opportunity to experience the gifts of this conference.

The journey to now has been rocky and exhilarating, scary and empowering. After two defibrillators and 16 shocks, I'm still out there. I was getting to the point of giving up, but my sixth ablation has given me the most relief. It was an unusual ablation procedure done by Dr. Tchou at Cleveland Clinic. I've only had one shock since and it was not from an arrhythmia but an inappropriate shock from a setting that needed to be reprogrammed on the ICD device. Dr. Tchou is an amazing friend and human being and he gave me back my life.

I've had the experience of being shocked twice during the London marathon and still getting my medal at the finish line. It was my 60th birthday present to myself. I was with my two dear girlfriends who were turning 70 so it was for their birthdays too. I was determined to finish and not let my ICD shocks ruin our much anticipated celebration.

I have had such severe panic attacks that I actually laid in the mud in the dirt road that I was running on because I was afraid of getting knocked down. I have picked myself up off the pavement when I was in mid-stride and got shocked, lost my balance, and fell flat on my face during a race. My daughter and granddaughter were participating in this race with me. As I was walking to the finish line, complete with road rash, they announced my name and called me a race walker. My family knew then what had happened. It was funny, and I needed a light moment.

So in closing, here is what I've learned through all of the past eleven years. While we are all different and our personalities, diagnoses, and life circumstances are unique, we share the common

desire to experience our lives as fully as possible in our new normal. With our ICDs we are able to be as active as our conditions and courage permit. It's "got our back" as my grandchildren would say, and technology is my friend. I've learned that gratitude brings an appreciation of what you have, not what you lack, that fear is part of being human, and courage is walking through it. When I started having panic attacks, my life became a nightmare. They are so much more debilitating than the actual ICD shock. I accidentally found a way to stop them. As soon as I feel them coming on, I tap two fingers gently on my temple and breathe while saying "this too shall pass." So far so good!

Never give up your quest for answers. If things don't feel clear or right for you, satisfy your own need/right to know and participate in your own health care. I left one physician who did not seem to be a good fit for my style of participation even though he is a gifted, well-regarded expert. Just not for me.

I have so much appreciation for all of the wonderful, caring people whom I have met and become friends with through this challenge. Thanks, thanks, thanks.

As age has pushed back at me, I have gone from running to jogging, to wogging (a word made up for walk-jog), to shwalking (another word made up for shuffle-walk). It's all a gift to just still be out there. My knees hurt, my feet hurt, my breathing sucks, literally, but still I love it!

In 2008 I was invited, as an all-expense-paid guest, to participate in the Medtronic-sponsored event during the Twin Cities Marathon in Minneapolis, and Saint Paul, Minnesota called the Global Hero. It was for people from all over and gave us a chance to meet and spend time with other athletes who have multiple varieties of implants. It was wonderful. About 20 of my running friends who nominated me through a letter to Medtronic came to celebrate and run. It was so touching to have my "family" at this event!

Life is good. I'm signed up to do my last marathon this fall. It will either be New York, if I make the lottery, or Detroit where I

started my first of over 100. My goal is to make it before they close the course.

Just showing up is winning for me. If it turns out that something happens that prevents me from participating, I'll still treasure the gift of now, and even planning it.

Then it's onward to my next adventure—aging joyfully. Grateful for the chance to do that too!



A QUIET COURAGE

Karen Westhead Griffin

Isn't it strange how you can be sailing along through life with just the typical everyday worries and concerns and in one moment your whole life as you know it shatters on the ground before you. You are left asking questions such as, "Where do I go from here?" "What do I do now?" This happened to our family on one beautifully sunny, warm day in 2001. On that day we began a journey along a path that we never had any idea we would be following. It is a path that has tested our strength, our courage, and our resiliency.

My name is Karen and my husband's name is Jerry. We have three children. Ethan is our oldest, Kathryn is our middle child, and Alayna is our youngest. Ethan is 23, Kathryn is 20 and Alayna would be 16. On May 28, 2001, Memorial Day, Alayna collapsed and died after going into sudden cardiac arrest (SCA) while playing at the local pool with her siblings. There were no symptoms that warned us about her unknown heart condition. She appeared to be a healthy and active three year old. An autopsy was performed, and a number of weeks later we discovered that she had myocarditis. Our family was devastated.

It was the beginning of what was to be a long, sad summer as we attempted to try to pick up the pieces of our lives and reassemble them in a new way. I struggled with a multitude of feelings. I was overwhelmed with grief, and angry at life and at God. I was also consumed with guilt. I knew in my head that Alayna had a condition that we had no idea she had, but wasn't it my job as her mom to keep her safe? I felt as if I had failed her. Little did I know how much more we were all going to have to deal with.

Slowly we struggled to rebuild our family. It was hard, extremely hard. We all missed Alayna in so many ways. Her smile, her love of life, her endless questions, even her orneriness. We continued to move forward, however, as we learned to live life without her.

About a month after the third anniversary of Alayna's death, we were again faced with another life-changing moment. Ethan was now almost fourteen and Kathryn was eleven. School had finished for the year and we were looking forward to a summer of swimming, a trip to the beach, and visiting family, staying up late and sleeping in. I decided to take Kathryn and a friend around to all the different places that were offering students rewards for good grades. We had lunch and then headed for Chuck E. Cheese. The girls got their free tokens and headed off to the arcade area. I joined Kathryn at one of the video games, and then it happened.

One moment she was standing next to me and the next she was lying on the floor. What was happening? There had been no warning, no indication of a problem. I quickly knelt down beside her, yelling for help while checking to see if she was breathing. All I could see in my mind was Alayna and all I could think was, "It's happening again." Never in my life had I been so scared. The paramedics arrived and Kathryn regained consciousness before being transported to the hospital. Much later on it was determined that Kathryn's heart went into an arrhythmia but went back to a normal rhythm on its own. At the time, however, we had no idea what had caused her to pass out. After being examined at the hospital, we were told that she had fainted due possibly to locking up her knees or dehydration. She was allowed to leave and we contacted her pediatrician the next day. Although he did not think it was anything serious, to be on the safe side he advised us to set up an appointment with a cardiologist at the local children's hospital because of what had occurred with Alayna.

Before we could make it to that appointment, Kathryn fainted again while playing with her brother. This time we headed straight to the children's hospital where she was admitted. After several cardiac tests, it was determined that she had Long QT Syndrome (She has since been diagnosed with catecholaminergic polymorphic ventricular tachycardia or CPVT). We were told that she would need to start taking a beta blocker and that she needed an implantable cardioverter defibrillator (ICD). We were in shock. We had struggled so hard to put the pieces of our family's shattered lives back together again after losing Alayna. Now I felt as though life had sent us all crashing into the ground again.

Kathryn had her surgery on July 3, 2004 and went home the next day to begin life with a cardiac diagnosis and an ICD. I was also adjusting to the idea that I might have this condition as well. While at the hospital, they had done ECGs on all of us and mine looked very similar to Kathryn's. As a precaution it was advised that I begin taking a beta blocker as well. Physically everything went very well. Kathryn's body healed from the surgery and she had no problems adjusting to the beta blocker. Emotionally, however, it was another story.

For a short time after the surgery, Kathryn wanted me close by at all times. Wherever I was in the house she had to be nearby. I assumed this behavior would eventually disappear as she began to feel more confident that she was going to be okay. She also had to come to terms with the fact that there were certain activities she could no longer participate in. This led to both anger and sadness. So many times over the next several years I would hear, "Why me?" Every time it broke my heart and caused anger to boil up inside of me. Yes...why her? Hadn't she and Ethan been through enough already? It wasn't going to do her any good, however, to see me upset. I tried to encourage her and to point out the many activities that she could still participate in. I realized though I also had to give her time to grieve for those things that she could no longer do.

Although Kathryn continued to do well physically, the next few years were rough. She had three events when her ICD had to shock her multiple times. Each time they were appropriate shocks. I cannot speak to how it was to be there when these events occurred as they all took place when neither Jerry nor I was present. The emotional fall out after these events was the next most life-altering moment along this path we were travelling.

With each event Kathryn would recover physically with just some soreness in her shoulder and chest muscles. Emotionally, she was not doing well at all. Kathryn became more and more afraid to leave my side, to spend time with friends or to go anywhere outside our home. She lived in fear of another event occurring. There was no convincing her that the ICD was keeping her safe. It got to the point

that I was driving her to school and we would sit in the parking lot while I tried to coax her to go in. We would attempt to go to the grocery store and would get 20 feet into the store and she would start to panic and insist that we leave.

Life was extremely difficult. Kathryn was in an emotional tailspin. Anxiety had taken over her life completely, and as anxiety was one of her triggers for cardiac events, this made everything even worse. We were all under a tremendous amount of stress and it was emotionally and physically exhausting. There were times when I felt complete despair as I watched my child go from being happy and active to fearful and anxiety-ridden and as a result confining herself within the four walls of her home. Despite the despair and frustration Jerry and I felt, we never stopped pushing her to move forward. Sometimes it seemed we were making progress. Many times it seemed we were going nowhere. I knew if we ever stopped pushing, however, she might never get back to living a full life again.

We got her into therapy and eventually, although reluctantly at first, started her on an anti-anxiety medication. These both helped tremendously. We were blessed with a therapist whom Kathryn connected with and with whom she felt comfortable and safe. The medication brought the level of anxiety down to where Kathryn did not feel overwhelmed by it. As she began to feel more and more like she, rather than the anxiety, was in control, she began to feel more comfortable being a part of the world outside her front door again.

After her third cardiac event, the doctors reevaluated the medication she was taking. They decided to change it. Since that time, which has been quite a few years, she has not had another event.

She continued in therapy for a long time and we continued to encourage her to try new things and step into new environments. It was tough at times, but we tried to focus on the small steps forward rather than the steps we took back and the occasional walls we ran into.

As we have traveled this path with Kathryn, there are things I

am glad that I did. There are things I would have done differently or not at all. It has been a learning process for all of us. When your child is diagnosed with a cardiac condition, start learning all you can about that condition. It has been my experience that there are quite a few doctors who are not in the cardiology field and who know very little about these heart rhythm conditions. During the time that we thought Kathryn had LQTS there was a long list of drugs that she could not take. I carried this list with me at all times and I could easily let any doctor that we encountered know whether a drug he or she was possibly prescribing was safe for her. Also knowing everything you can about your child's condition just makes you feel more confident in making decisions about drugs or procedures a doctor may suggest with regard to treating them.

At the same time I was learning all I could about her condition, I also began a search for a support group that she could get involved with. From my own experiences with certain situations I was sure that Kathryn would benefit from getting to know others who were dealing with a similar medical situation. Not only realizing that she was not alone, but also having someone who had more experience dealing with all that came along with her condition, would lead to her feeling more in control—something that she needed greatly. I started searching locally and worked out from there.

Unfortunately there were few or no opportunities for support in our local area. I continued to search and found two groups, both out of state but close enough that we could attend their annual conferences. We have been able to attend one or both since then and that has benefitted both of us tremendously. Kathryn got to know others her own age and I got to meet other parents. An added benefit for Kathryn occurred several years after the first conference at which she was one of the speakers. A young girl attending the conference for the first time and who had only recently received her ICD, stated that it had helped her greatly to hear other young people speak about their experiences. This was a very special and empowering moment for Kathryn.

Take full advantage of the Internet and seek out the experts if you still have questions. This is how we made contact with an expert

in the field of LQTS at the Mayo Clinic and were able to get an appointment with him. He answered many of our questions and was eventually the person who determined that Kathryn actually had CPVT through a research study that he was conducting. Genetic testing was initially done on immediate family and we were able to include Alayna as some of her heart tissue had been stored. It was determined that Alayna and I had the gene. Jerry and Ethan do not. From this information it was suggested that the myocarditis that Alayna had aggravated the CPVT, and this probably figured largely in the cause of the SCA that took her life. Genetic testing has recently been performed on extended family members through the same study, and there are several who have been identified with the gene for CPVT.

Advocate for your child and teach them to advocate for themselves. After Kathryn was diagnosed I would meet with all her teachers as a group at the beginning of the school year. I would explain her heart condition, explain about her ICD and how it worked, make sure that they had a plan in place if something should happen at school, and make sure that they each had contact information in order to reach me if they had any questions. It gave both Kathryn and me peace of mind that they were aware and had knowledge about her condition.

I was fortunate that Kathryn was also a natural advocate for herself. She knew what her limitations were and was not hesitant to let school personnel know if she could not participate in an activity. We did have several situations come up where teachers wanted her to participate in something that she could not do. Once she explained to them, they would figure out an alternative. I always told her from the beginning that if this type of situation arose, explain in a polite and respectful way that she could not participate. If the teacher still insisted, I told her she was to ask to go to the office and call me and I would speak with the teacher. Fortunately this situation never came up. Being able to speak for herself built up her confidence and let her feel like she had some control of the situation.

I have not said much about her older brother, Ethan. This is an area where I wish I could go back and do things differently. Siblings

are highly affected by their brother's/sister's diagnosis and subsequent treatment. Speaking for myself only, I became so caught up in Kathryn's situation that I feel I neglected how it was affecting Ethan. I think there were many times when he needed more support than we gave him. It had to have been so scary to first watch your one sister die so suddenly and then a short time later watch your other sister be diagnosed with a life threatening condition. If I could go back I would have spent more time with him individually and done a better job at acknowledging the fact that this was a very frightening time for him as well.

As the parent I wanted to make everything better for everyone. I poured all I had into helping Kathryn to adjust to a new way of life and to overcome the terrible anxiety she dealt with. I worried about Ethan and what affect all of this was having on his life. Time spent doing fun things with Jerry went to the bottom of my priority list. As a consequence I became drained both physically and emotionally. I realized I had to find time for Jerry and me to go out for dinner, go see a movie, or simply go for a walk. I had to find time for myself to read a book, exercise, or just sit and enjoy a moment in the sun. I discovered I could not help anyone else if I did not have anything left to give. I had to give myself time to recharge.

On that same train of thought, do not get so caught up in the diagnosis that you cannot just have a fun time with your child. Go out and find something fun to do where the diagnosis, the ICD and all of it can be put aside for a while. Find time where all members of your family can do something fun together that will strengthen the ties that bind.

Where are we all now? Ethan is attending university and working towards a degree in biology. His plans are to go into trauma medicine, a field he excels in and is passionate about. He will bring much knowledge and dedication to the career he pursues. Kathryn is attending university with plans to become a high school math teacher. She is a warm, caring young lady who has all the characteristics that are needed to become an incredible teacher. Jerry and I found that we were able to relax a little as Kathryn's anxiety became less of an issue. In turn we have been able to focus a little

more on the parts of our lives that had been set aside while dealing with the issues that were a result of Kathryn's diagnosis.

There were many times that I would never have believed that Kathryn would ever get to the point where she would be able to live away from home, let alone attend university. She continues to take anxiety medication and has learned breathing techniques to calm herself as well. Her approach to life has changed. Where she would not even consider an activity that, in her mind, has the potential to bring on a cardiac event, she now refuses to let anxiety get in the way.

I am extremely proud of both of my children and how far they have come. They were forced to grow up much too quickly by the death of their sister and Kathryn's diagnosis. They learned too early that the world is not always a happy place where nothing bad ever happens. Things are definitely not perfect now. Our family continues to struggle with what we have been presented with. What I have learned, however, is that when presented with a crisis, all of us have more strength, more courage, and more resiliency than we ever imagined. These characteristics are buried somewhere deep inside. If we can summon them to the surface, we will survive.

Getting to where we are now would not have been possible without the support of our extended family and friends. They listened to us vent. They gave us shoulders to cry on. They gave us moments of much needed fun and laughter; they were our rope to hang on to when life events became overwhelming. They made this path we were forced to travel a little easier to navigate. I am so very grateful for each and every one of them and what they did for us individually and as a family.

I heard a quote by Mary Anne Radmacher at a medical conference Kathryn and I attended several years ago: "Courage does not always roar. Sometimes courage is the quiet voice at the end of the day saying, 'I will try again tomorrow.'" This rang so true for me. We still have issues ahead of us as a family. I know there will be days when we will all become frustrated, angry, or upset. We always need to remember that tomorrow is a new day where we can try again. That might be searching the Internet for some new bit of

information, discussing with my child's doctor whether a certain procedure or medication is the best way to proceed, or just offering a shoulder to a family member who may be struggling.

To you who are reading this and are just starting this journey, life may feel completely out of control right now. You may be asking as I did, "Why my child? Why my family? Why me?" I have learned that there is no answer for these questions. I have to accept that this is what I have been presented with and just continue on to the best of my ability. It was and still is a matter of choice for me. I try to choose to make the best life I can for my child, for my family and for me. It is all a work in progress and will continue to be so as we are presented with new challenges and new discoveries related to Kathryn's condition

Just keep trying to move forward for your child, your family, and you. Try to look at each new day as an opportunity to find new ways to adjust and to make the best of this new way of life. It is not how any of us wanted things to turn out, but it is what it is. Now we have to figure out what is the best way to go from here. That can be so hard and at times seem almost impossible. When I am feeling that way, I just need to catch a glimpse of my children and something happens within me. I discover that I can dig up that little bit more determination to keep moving forward for them and I know that you will too.

Frequently Asked Questions about Implantable Cardioverter Defibrillators (ICDs) for Women

*Laura Horwood, NP
University of Michigan Hospital*

1. **Can I have routine mammograms?**

Yes. Mammograms are radiology screening tests used for early detection of breast cancer. They are essentially an x-ray of breast tissue and pose no issue for ICD recipients. Depending on your ICD placement, the device may interfere with imaging of breast tissue and may require additional testing for optimal results (possible follow-up ultrasound). Further, the presence of an ICD (typically left or right upper chest area), may make the imaging of the breast more uncomfortable, but be assured it will not cause damage to the device.

2. **Can I wear a bra after my ICD is implanted?**

Yes. Depending on your ICD placement (typically upper left or right chest area), your bra strap may feel uncomfortable on your new incision. It is fine not to wear a bra until healing is complete. However, women with large breasts may feel the weight of their breasts causes discomfort, and a bra or a larger sports bra can be helpful for these women. If the bra strap is an issue, temporary use of a feminine napkin placed along the bra strap can provide a cushion to prevent the strap from rubbing or placing undue pressure on the fresh implant site.

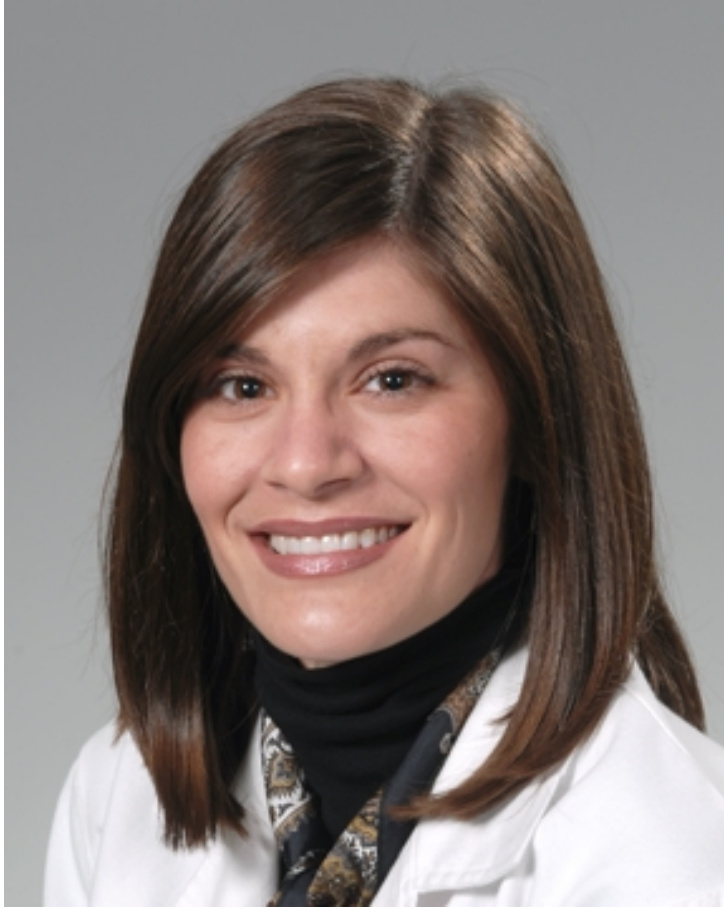
3. **Are there options for ICD placement?**

If you have concerns about the placement of your ICD, this should be discussed with your electrophysiologist prior to device implant or generator replacement. Many times a plastic surgeon will need to be consulted, depending on the

placement options that are considered such as submammary (under the breast), axillary (armpit area), submuscular (in upper chest area or abdominal). Traditionally, devices are placed subcutaneously (under the skin and fat tissue) in the upper left or right chest area. If other placements are considered for cosmetic reasons or due to underlying physical characteristics, there are advantages and disadvantages to these non-traditional placements. Advantages would include a less visible incision line, overall comfort, and a less noticeable device. In addition, possible erosion is less likely to be an issue since the device is placed under the muscle. Disadvantages include increased pain and discomfort initially due to a more invasive procedure. You will likely need to have a plastic surgeon at each replacement procedure and subsequent replacement procedures may be more involved due to increased scar tissue after every procedure.

4. Can I get pregnant with an ICD?

Yes. If you are planning to become pregnant it is recommended that you discuss this with your cardiologist/electrophysiologist. You may require medications that are not recommended during pregnancy, or depending on your underlying health condition, it may or may not be recommended for your safety and well-being. Further, if your condition was inherited, you may want to consider genetic counseling/testing to understand possible risks for your offspring. However, many women have successfully become pregnant and undergone natural childbirth. If you do become pregnant, we recommend that you be under the care of a high-risk OB/GYN. Generally, your ICD is disabled during childbirth to prevent inappropriate ICD shocks due to normal heart rate increase with labor.



Coping with Life as a Woman with an ICD and Proposed Strategies for Success

*Lauren D. Vazquez, PhD
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Living life with an implantable cardioverter defibrillator (ICD) can certainly be considered a challenge. Research has shown that ICD patients face common difficulties after implantation of their device. For women, ICD adjustment needs tend to be unique and very specific to being a female coping with medical treatment. My work as a clinical health psychologist has been focused on identifying female-specific adjustment needs and helping women with ICDs embrace adaptive coping strategies to enhance their quality of life. The purpose of this chapter is to describe the female-specific psychosocial concerns that are common in women with ICDs, and to propose a set of coping skills that can help you to increase your confidence and be more successful in living life to the best of your ability.

Female-Specific Psychosocial Concerns

We know that ICD patients cope with challenging device-specific stressors that may create psychological concerns. Approximately 15% of patients experience significant emotional distress that can include anxiety (often centered on the potential for ICD shock), depression, family concerns, or other adjustment difficulties (Sears et al., 1999). Risk factors for psychological distress include those patients who have limited social support, those with a limited understanding of their heart condition or how their ICD functions, patients who have a previous history of ICD shock, being young (under the age of 50), and being female (Sears & Conti, 2002).

Research suggests that women are at risk for the development of distress after ICD implantation possibly due to a combination of changes in the family, body satisfaction issues, concerns about femininity, and changes in socialization (Sears et al., 2004; Sears et al., 2006). Female gender has also been associated with both anxiety and

depression (Bilge et al., 2006). In one study, researchers found that female ICD recipients were more likely than men to experience anxiety (Spindler et al., 2009). Additional studies have demonstrated that female ICD patients experience higher levels of anxiety and depressive symptoms as well as more ICD-related concerns when compared to male patients (Thomas et al., 2006; Wolbrette, Naccarelli, Curtis, Lehmann, & Kadish, 2002).

About 13 to 38% of all ICD patients experience significant symptoms of anxiety (Sears et al., 1999). Anxiety symptoms most common for ICD patients include thinking fearfully about the device, avoidance of situations, objects, or activities, and bodily hypervigilance (paying excessive attention to one's bodily symptoms). Symptoms of depression may affect between 24 to 33% of all ICD patients (Sears et al., 1999). Depressive symptoms may be related to feeling like the ICD is limiting one's life or a sense of sadness or hopelessness.

Young women (under the age of 50) have been identified as a particularly at-risk subgroup of female ICD patients. An investigation of a multi-site, international sample of female ICD patients showed that young women reported significantly higher shock anxiety, more fears about death, and greater body image concerns than older women (Vazquez et al., 2008).

Living with an ICD often creates changes for patients and their family members. Roles, responsibilities, or expectations are likely challenged when a person is faced with a potentially life-threatening condition. Some female patients feel stressed or guilty because of these changes. They may begin to question their ability to fulfill their roles as wife, mother, sister, or daughter. Experiencing heart disease and living with an ICD may lead women to feel uncertain or fearful about the future. Additionally, any problems patients or families were facing prior to device implantation are unlikely to have gone away. Many women describe having difficulties coping with a stereotypically male-centered disease state, and question whether other women living with an ICD even exist!

The challenges a woman experiences after ICD implantation may also include changing body image. Device implantation leaves physical scars that for some women may represent visible reminders of their experience with heart disease. Many women who receive an ICD deal with a range of body image issues following their surgery, including dissatisfaction with their appearance, a sense of a loss of femininity, reluctance to look at themselves naked, feeling less sexually attractive, or dissatisfaction with their scar. Body image affects our self-esteem and our relationships with others. Many female patients experience concerns about how changes in their bodies will impact intimacy and romantic relationships. After ICD implantation, it is normal and expected to experience changes in romantic relationships, both positive and negative. Partners of ICD patients also face a time of adjustment. Some partners may take on an overly protective role and may try to do everything for their partner to attempt to protect them from further distress. Partners may avoid bringing up certain topics for fear of upsetting the patient. Some partners simply need time to accept what has happened.

Proposed Strategies for Increasing Confidence

As a woman facing unique challenges, it may be easy to find yourself feeling isolated as you struggle to cope with changes since you received an ICD. Many women find themselves frustrated with a sense that they are just not living life the way they want to. Being prepared with effective ways to deal with challenges related to being a woman with an ICD is essential in taking control of living life the way you want to. The following strategies emphasize promoting better quality of life while coping with the stress of living life as a woman with an ICD.

1. Emphasize family adjustment

Adjustment to life with an ICD takes time for both the patient and their family members. Changes within the family need not be negative. Many patients actually describe their families as being stronger after dealing with the challenges of treatment with an ICD. Flexibility of roles and responsibilities can enhance family communication, teamwork, and connectedness. Family adjustment is certainly an ongoing process that requires time and energy by all

members. Open and honest discussion about feelings can help you and your family work out solutions together.

2. Enhance body image

Widen your ideas about beauty. A woman's physical body is much more than just a thing that reflects beauty. Challenge your thinking to include viewing your body as providing specific functions such as walking, moving, carrying your children, or embracing a loved one. Acknowledge and appreciate areas of your body that you consider positive physical attributes, rather than focusing on areas that may cause you to feel self-conscious or ashamed. Name what you like about yourself. Try to see your physical scars as something that tells a powerful story rather than something that reminds you of suffering.

3. Obtain social support

Connect with other women who have an ICD. Discuss how your lives have changed since you received an ICD and identify emotional and physical health promotion strategies that you can embrace together. Focus on sources of friendship and support that help you feel good about yourself. Identify some social activities that you can schedule for yourself and make sure you follow through with participating in these activities despite any fear or discomfort.

4. Assert yourself

Allow yourself the opportunity to express anger, frustration, or sadness over changes in your life. Staying silent only leads to isolation; try to explore ways that you can express yourself appropriately. Try keeping a journal or a blog detailing your emotional journey as you cope with treatment with an ICD. Empower yourself by finding your voice. Never underestimate the impact your story can have on someone else coping with a similar circumstance!

5. Take time to relax

Relaxation is the act of letting go of the stress and worry you may be experiencing. Learning effective ways to relax and let go of tension can lead to a sense of calm and serenity. Learning to control your breathing is a powerful tool for relaxation. By focusing your

attention on taking slow, deep breaths you can take control of allowing your mind and body to relax. Deep breathing is a tool you can utilize in a variety of settings—during doctor’s appointments, lying in bed at night, or in any of the daily situations you find stressful. Identify how you feel after breathing deeply. Make a list of situations in your daily life where breathing deeply may be helpful.

6. Communicate with romantic partners

Discuss issues related to intimacy with your partner as openly and honestly as possible. Remember that a temporary decrease or absence of intimate activity after ICD implant is completely normal. Intimacy is a continuous process not a single event, and reflects any activity that brings you and your partner closer together. Being able to talk openly about your feelings regarding intimacy can help you to work out solutions together. Allow your partner to talk about what attracts him to you. Let him affirm his attraction and what he finds beautiful about you. If you have questions about safety of intimate activity, feel free to discuss this with your healthcare provider.

7. Decide what is really important to you

Women who find themselves living with an ICD are forced to look at life a little differently. Studies suggest that individuals with health issues who are able to adjust appropriately actually report feeling more resilient than before their illness. This is the idea of gaining strength through hardship. If a woman can navigate the stress of coping with treatment with an ICD successfully by continuing to embrace what is really important to her, the quality of her life can be better than ever. Deciding what is truly important to you—family, spirituality, or anything you find intrinsically rewarding—is a vital step in improving your quality of life.

8. Consult a professional

Even if you know strategies to deal with your difficulties, at times stress can become too overwhelming to handle on your own. Despite all of your efforts, there are times when stress cannot be handled by one person any longer. When that occurs, seeking the help of a professional is the best way to gain support in dealing with what you are experiencing. It is not uncommon for people dealing

with health issues to develop psychological symptoms. Many seek help from a mental health professional in order to better manage or cope with their feelings. It is important to be able to recognize when it may be beneficial to enlist the help of a professional.

The process of implementing change in your life is something that requires time and energy. Using the strategies outlined in this chapter should provide you with the building blocks to facilitate the process of enhancing adjustment to living successfully as a woman with an ICD. I hope that this information, in combination with regular follow-up care and support from your healthcare team, will help you begin to take control of creating the life that you want to live. Remember that challenges are normal and expected. But as a woman, you can empower yourself and learn to cope effectively with treatment with an ICD. This is all part of the process in changing your mindset from being a victim of heart disease to celebrating life as a female ICD survivor. I commend you in your ongoing journey and hope that this information helps you advance through the process of adjustment and embrace the quality of life that you deserve.

Dr. Lauren Vazquez is a clinical health psychologist who specializes in the treatment of patients with cardiovascular diseases. She has been involved in a variety of research and has authored over 30 research manuscripts, abstracts, and book chapters spanning topics such as women's health, quality of life, psychosocial functioning, anxiety management, and body image concern. She was the recipient of a National Institutes of Health research fellowship to fund her research on female cardiovascular patients. Her practice is focused on utilizing cognitive behavioral strategies for helping patients gain insight and make changes with regards to how their medical conditions affect their physical and emotional functioning.

Additional Resources:

How to Respond to an Implantable Cardioverter Defibrillator Shock
Samuel F. Sears Jr, PhD, Julie B. Shea, MS, RNCS, and Jamie B. Conti, MD

Available at: <http://circ.ahajournals.org/content/111/23/e380>

How to Respond to an Implantable Cardioverter Defibrillator Recall
Kari B. Kirian, MA, Samuel F. Sears, PhD, and Julie B. Shea, MS,
RNCS, FHRS

Available at: <http://circ.ahajournals.org/content/119/5/e189>

Coping with my Partner's ICD and Cardiac Disease

A. Garrett Hazelton, MA, Samuel F. Sears, PhD, Kari Kirian, MA,
Melissa Matchett, PsyD, and Julie Shea, MS, RNCS, FHRS

Available at: <http://circ.ahajournals.org/content/120/10/e73>

Sexual Health for Patients with an Implantable Cardioverter
Defibrillator

Lauren D. Vazquez, PhD, Samuel F. Sears, PhD, Julie B. Shea, MS,
RNCS, FHRS, and Paul M. Vazquez, DO

Available at: <http://circ.ahajournals.org/content/122/13/e465>

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