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INTRODUCTION TO MEN'S STORIES

*Aman Chugh, MD
University of Michigan*

Most electrophysiologists care for patients with arrhythmias and ICDs in the hospital or office setting. Although critical decisions are made regarding medical management in this realm, one really does not get to know the patient on a personal level. Therefore, I consider myself very lucky to have been able to fill this gap through my participation in the ICD Connection event that is held every fall.

Through my involvement in the men's program, I have learned so much from these guys who just happen to have an ICD. I have learned about the challenges and the sacrifices these men have made in coming to terms with their ICDs. As they told their stories, they described the process it took to move from considering the ICD as a hindrance to using it as a prism, allowing them to gain a unique perspective and charter a new course toward self-realization and betterment.

Yes, men may approach the challenge of living with an ICD differently than women do. But as you read through the men's stories, you will be moved by the disappointments, plateaus, and triumphs along each journey, not because this process is unique to one gender, but because it is wholly human.



MY JOURNEY

Brian Hereza

Wow, where do I even begin? Senior year was my best year yet in high school. I made it on our school's twenty-fifth anniversary homecoming court. I was the treasurer of the class of 2013 for my third consecutive year. Everything was going really well. I couldn't believe how fast the year was going! In January of 2013, my twin brother Andrew and I went down to Naples, Florida to visit our grandparents because of a long break that we had from school. Andrew, by the way, doesn't have any heart issues. Lucky him! It was nice to be away for a week and spend some time with family. A few days after we got back from Florida is when my journey began with my heart condition— nonsustained ventricular tachycardia.

First off, ever since fifth grade I have had a couple of heart-related issues. My heart would speed up and slow down for no apparent reason. I was in the hospital a couple of times because it was very uncomfortable. I took atenolol for a few years to slow down my heart rate. I was diagnosed with inappropriate sinus tachycardia. It is exactly as it sounds—inappropriate. It came and went when I would be sitting, not exerting myself or playing any sports. In ninth grade I went off the medicine because I was doing really well. I didn't really have any other issues except for a few premature ventricular contractions (PVCs), or skipped heart beats every once in a while. I noticed one or two times that I felt several PVC's in a row. I was concerned and was put on my fourth 30-day heart monitor. Of course, nothing showed up. Otherwise, I felt fine and I learned to deal with the PVCs.

Fast forward to 2013. On January 26, 2013, the day started just like any other day. It was a typical Saturday morning. I woke up, ate, showered, and watched TV. I went on my mom and dad's bed to pet my dog. All of a sudden, I felt the PVCs, but they were not stopping. It was like I couldn't catch my breath. I called out for my mom and then passed out. The next thing I remember was my mom and dad hovering over me scared out of their minds. I knew it wasn't good.

My mother, who is a nurse, called my doctor who told us to go to the hospital right away. Once I was at the hospital I was fine. I felt back to normal and my heart rhythm was fine. I was in the hospital for almost four days with numerous tests ordered by my cardiologist, who is a family friend. I had a stress test, a tilt table study, a CT scan of my heart and brain, and many other things. He also referred me to the electrophysiologist in Saginaw. That doctor thought I had just passed out from not eating enough. He did not think it was my heart that had caused me to pass out. We were very upset because I knew with 100% certainty that it was my heart. He reluctantly ordered for me to go on another heart monitor. I was also started back on the atenolol.

Fast forward to February 8. I was sitting in a restaurant having lunch with a group of friends. Once again, I felt fine, and it was a normal day. I then had the same feeling that I had before I passed out back in January. I pressed the button on the heart monitor. Luckily I did not pass out this time. I was obviously scared about it though. After I got home, I told my mom and we called in the recording to a company that reads the rhythm of your heart when you record it. My cardiologist called right away. I had a nine-beat run of nonsustained ventricular tachycardia. I didn't realize how bad this was at the time. My mother was petrified. I did not realize that people sometimes die from this condition because it can lead into ventricular fibrillation. That is where your heart quivers before it stops. My mom started to call both of my grandfathers who are retired physicians. Everyone was just really worried, and I was not even that scared because I didn't know how bad it could have been.

I had to go back to see the electrophysiologist in Saginaw after this happened. He told me that it can happen to people for no reason and that we shouldn't be worried. All he said was to double the dose of my atenolol and go about my life. We went to U-M to get a second opinion. I am so glad we did.

We got an appointment with Dr. Morady in March. We were very nervous about what he had to say because my doctor said that he might want to do an electrophysiology (EP) study. After we met, Dr. Morady was really concerned and wanted to hear all of my

history. He took a lot of time talking to my parents, as well as me. After looking at my charts and the rhythm strip of the v-tach, he said it quite simply, “You need an EP Study and an implantable cardioverter defibrillator (ICD).” I was literally shocked when he said that I needed an ICD. I couldn’t believe it, but the doctor said that if it were his child, he would do the same thing. I already knew what this device was and how they worked. My one grandfather has an ICD, and the other one has a pacemaker. They needed them for reasons other than v-tach. Heart disease runs in my family. Even though it was hard to take at first, we knew this had to be done to get down to the bottom of it. Dr. Morady referred me to Dr. Bogun, another electrophysiologist at U- M who specializes in arrhythmias in the ventricles of the heart.

Reality started to set in before the surgery which was scheduled for April 17. I realized that I would be missing a crucial time in school. My teachers were great during the entire process. I started to ask myself, “Why me?” I was way too young for this. Only old people have ICDs, or so I thought. I was scared for the surgery itself—especially since I knew I was going to have two surgeries at once: the EP study and the ICD implantation. I was just ready to get this surgery done and over with so I could move on with my life.

April 17, 6:00 a.m. — surgery day. I wasn’t as nervous as I thought I was going to be. I checked in to the U- M Cardiovascular Center, and I got all prepped before Dr. Bogun came in to meet my parents and me. He said that the EP study, if all went well, would map an area out in my heart where the arrhythmia was coming from. If he could find it, he would be able to ablate it, or burn that tiny piece of tissue in the heart to stop the arrhythmia. He warned us that the EP study could take many hours. He then told us that if they couldn’t find any areas of the heart that could be ablated, he would put in the ICD. He told us that he thought he wouldn’t be able to ablate any areas because they are very tricky and sometimes can’t be found. So I went into the surgery knowing that I would probably come out with an ICD.

After being wheeled into the operating room, I was hooked up to many IVs and monitors. Before I was put under, I was warned that

they might wake me up during the surgery to see if that would induce any arrhythmias because of the drugs given or my own nervousness. They told me that because of the drugs they would give me, I would feel comfortable if they woke me up. At 8:00 a.m., I saw them pump the IV in, and then the easy part for me—I got to take a nap! The doctor and nurses had the hard job. At around 12:30 p.m., I think (I am not so sure because of the drugs they were giving me), they woke me up during the EP study. I remember pretty much everything they were doing after they woke me up. I remember talking to the nurse and asking questions. I couldn't believe that I had three wires inside my heart at that very moment! Not many people can say that they have had that experience. Then I realized how uncomfortable I was because of the guide wires that they put through the groin. They told me they were going to start to speed up my heart with medicine and the electrodes inside my heart. It was very uncomfortable. I remember seeing my heart rate on the screen going up over 200 beats per minute. I'm glad I wasn't fully with it at the time. Dr. Bogun then came from the room where they controlled the wires in my heart. He explained to me that he was not able to find any areas to ablate, as expected. He told me that he would tell my parents and not to worry. The nurse then told me that it was time to go back to sleep, and I would wake up in the recovery room.

Around 5:30 p.m. is when the surgery was over with. I remember being very tired and asking how it went. I was on the operating table for eight and one-half, almost nine, hours. I couldn't believe I had an ICD in me now. The pain was surprisingly not bad at my incision. The next morning after my surgery they did an ultrasound and an x-ray to make sure everything was going well. Then I had the first interrogation of my ICD while being awake. It was the weirdest feeling when they press a button on the screen and you can feel your heart beating faster. After that, they gave me a lot of literature on everything, and medicine. I went home only one day after the surgery.

I was feeling really good. The pain was manageable with the medication that they gave me. I had my friends come and visit and it was nice to be able to see them. That Saturday I went out to dinner with some friends. It is amazing how good I was feeling after what I

had done. I was very careful not to move my left arm and couldn't have any sudden movements.

I went back to school on that Monday, which was a huge mistake. I was feeling really well and wanted to see my friends. Remember, I had this surgery on a Wednesday and went back to school the following Monday. That decision was definitely not the best. That was the scariest day of my entire life.

During fourth hour of school, I started to get short of breath with pain in my back and neck. I thought it was just my pain medicine wearing off at first. Then it got to the point where I could not function. I called my dad and had him pick me up after lunch. I got home and called U-M and asked them what I should do. They said to go to my local emergency room right away. When I got to the ER, I was taken back right away. The moment I was signing the papers I felt an electric jolt on my skin on the left side of my chest. I knew something was very wrong.

The pain was so excruciating that they had to give me a lot of medicine to calm me down and for the pain. They got a CT scan of my heart and found out that the lead had punctured through every layer of my heart. This happens to only less than one percent of people who have ICDs implanted. Leave it to me to be in the one percent. What I was feeling was the tip of the lead on my skin. My cardiologist came in and told us that I would have to be transported back to U-M by ambulance.

Once I got back to U-M later that night, they said that I would have to have the ICD surgery all over again to reposition the lead. I was stable by that point, so they waited for Dr. Bogun to do the surgery the next afternoon. The scariest part of this for me was that they had to prep my chest for open heart surgery in case there was bleeding in the heart. I am glad that I don't remember much of this because of the medicine they were giving me to keep the pain at a level that I could withstand. I asked the nurse before they put me out to please make sure that I didn't have to have open heart surgery. She assured me that everything was going to be okay. Here we go. Round two.

I remember waking up from surgery and the first thing I asked was if I had open heart surgery. Thankfully, they did not have to do that. They reopened my incision where the ICD was and repositioned the lead in my heart. I was very lucky! The incision pain was a lot worse than the week prior because of the scar tissue that was forming there already. That surgery took three hours because they had to put a catheter ultrasound in my groin that was led up to my heart to make sure there wasn't any bleeding. Fortunately the tiny hole closed up on its own. I went home the next day with no other complications.

The first few days after surgery were the toughest. It took a while longer for my incision to heal up because of the scar tissue. I felt so much better after everything was done. I went back to U-M a week later for a check-up. Everything was all clear! I could finally move on with my life again! I went to prom on May 4, 2013, only 11 days after the second surgery! I could not move around as much because of the limitations after surgery. I was so happy that I was able to be with my friends and have a good time. Things were definitely starting to look up!

Living with my ICD has been very easy. I go in every six months for device checks and have an at-home monitoring station that automatically sends information about my device to the clinic. I have not been shocked, thankfully! The only thing I have to do differently is just to show my device card at the airport so they can manually check me so I don't have to go through the machines. Otherwise, I don't even know that I have an ICD. I am so thankful to all of the doctors and nurses down at U-M for the exceptional care that I was given. Living with the ICD is not the hard part for me. It was the process that I went through to get it that was the toughest. It makes me feel so good knowing that in case my heart goes into a dangerous ventricular rhythm, that I will be protected with a life-saving shock!



RYAN'S STORY – FROM CHAOS TO GROWTH

Ryan and Peter

RYAN'S ICD STORY

The only way to describe both my son Ryan's experience and my experience in this ICD story is to say that it was surreal. Sort of like a Salvador Dali painting that mixes both dream and reality. Moreover, it was an experience that to us "only happened to other people you see on TV and TV shows," but not one that happens to our own family.

Ryan is a fun loving, social, sport enthusiast who currently attends Bowling Green University and is in his junior year. He belongs to a fraternity, shares an apartment with two other guys, and has a rather pretty and talkative girlfriend. And, yes, he actually has been visited at his apartment by the local constables for holding a big party and later for playing video games too loudly at midnight! He is majoring in sports management and one day hopes to run a professional sports team. Normal in most every way, except that like most in this book, he has an ICD implanted in his upper chest.

ICD DIAGNOSIS AND IMPLANTATION

It all started out in late summer when Ryan was 16 years old. He was soon to head back to school in September, so he had been out playing baseball with the other guys in the neighborhood. That day he entered the house mildly complaining of a racing heart, noting that he nearly fainted a number of times while playing ball that day and over the previous several months. While he did mention that the racing often stopped after a few minutes to an hour, Ryan always did have an active imagination, so I didn't really think much of it at that time since heart disease did not in any way run in our family tree. He did ask me to check out his heart rate once later when his heart was racing, but being the amateur I was, I didn't know how to take a pulse rate correctly, and by the time I was able to figure it out his heart rate was down. Additionally, he was clearly not in any physical

distress, so I just dismissed the symptoms. I even briefly discussed it with my wife, but she felt it was likely his imagination and possibly his nerves as well since the beginning of school was soon to arrive.

Well, when school started up in September, Ryan started taking his medication to treat his attention deficit disorder (ADD). During the end of the first week, I had taken the day off and was at home when Ryan arrived with his book pack in hand. He had a big smile on his face and a lot to talk about. However, he did note that his heart had been racing for the last few hours. I could feel his heart lightly beating, but couldn't really gauge the rate. I called my wife at work, and we both agreed that it couldn't hurt to take him to our family doctor for a quick checkup that day.

At the physician's office, a young nurse dropped into the room to ask the usual questions and take Ryan's blood pressure. After a few failed attempts, she left and brought in an experienced nurse to take his blood pressure. The experienced nurse took his pressure three times just to be sure and then promptly left the room and within a very short period of time our family doctor popped in. Calmly, he checked Ryan's pulse and heart beat and asked Ryan how he felt and what brought us here today. Ryan said that he felt fine, but that his heart was beating faster than normal. Our doctor noted that Ryan was right about his racing heart and that his heart rate was 166 beats per minute. While Ryan insisted that he felt fine, our doctor noted that while kids can tolerate a fast heart beat for a fair amount of time, it was critical that we head straight to the emergency room at the hospital since they had the means to right his heartbeat.

So, we headed down to the hospital and into the ER. The ER doctor who greeted us asked Ryan the same sorts of questions that our family doctor asked. He quickly checked Ryan's vitals and noted that Ryan's heart rate was 166 beats per minute which was the same reading we had 20 minutes earlier. While he wasn't concerned at that point, he did have Ryan try a few maneuvers (forgot the specifics) to see if any would slow down his heart rate. When none had worked, a pediatric cardiologist was called. The cardiologist suggested the ER doctor try a few intravenous medications to see whether any would slow down Ryan's heart rate. After none appeared to have any effect

on his heart rate, Ryan and I were then routed to the cardiac intensive care unit of this hospital.

Given all the futuristic monitors and white coats in this ultra-modern glassed in unit, both Ryan and I felt as if we had just stepped into the future. Considering that Ryan had good vital signs, it was decided by the pediatric electrophysiologist (EP), who was consulted by phone, that Ryan would be cardio-converted in the morning to reset his heart rate back to normal, assuming that he remained stable. Well, in roughly three hours, his vitals went from good to not so good. The cardiologist spoke with me and noted that Ryan needed to be cardio-converted STAT. The thought of hitting my son with two paddles to shock his heart back to normal seemed unbelievable. Given the alternative, there was really no other choice, so they put Ryan under and cardio-converted him. Ryan's heart rate was now back to normal. Still no diagnosis of Ryan's condition, but at least his heart was back to normal and he was resting comfortably.

In the morning, they performed an ultrasound of Ryan's heart. My wife and I were guided into a room whereupon the EP noted that there were potential issues with Ryan's heart and that he suspected Ryan might have arrhythmogenic right ventricular dysplasia (ARVD). Neither my wife nor I could even pronounce the diagnosis let alone comprehend what that meant at this point in time. They would be sending him in for a heart MRI for further analysis to determine whether it was, in fact, ARVD.

After reviewing the MRI and running the gold-standard tests for ARVD, it was determined that Ryan had ARVD. Dr. Hugh Calkins from Johns Hopkins University, one the foremost experts in the ARVD field, remotely reviewed the lab results and also confirmed the findings. We were soon told that Ryan would need to have an implantable cardioverter defibrillator (ICD) inserted in his chest to protect him moving forward. The idea of implanting anything in ones chest seemed extreme. It was explained that we were actually pretty lucky since the device would allow Ryan to live a largely normal life. So, once again, we consented and a day later Ryan was sent to the EP lab and had the ICD implanted. Two days later, Ryan was discharged. Unfortunately, there was no ARVD discharge

package to help us understand the condition or the limits placed on Ryan. It was, however, suggested that Ryan take it easy and avoid competitive sports for at least the near term. And Ryan was put on a beta blocker and ACE inhibitor.

For the next several months, we were a bit on pins and needles while we learned more about the condition. I can remember taking Ryan to a University of Michigan football game shortly after he was discharged from the hospital and watching him hoot and holler throughout the game and me worrying about that, or the long walk down and up a hill back to the car, potentially setting off his ICD. Ryan, of course, also had those concerns but bravely never mentioned them. We just didn't know what his limitations and boundaries were and what would set off the ICD at that time. We simply did not know much of anything including whether he could safely take a flight, what he could eat and not eat, whether he could take cough formula, amongst many other things. Still, that first simple step of going to the football game gave us both the confidence to begin testing the bounds. So our journey of testing the bounds and learning what we could had begun.

THE FIRST EXPERIENCE WITH THE ICD FIRING OFF

While I worked to research all we could on ARVD and living with ARVD and ICDs, Ryan moved ahead with his life, although at a much more measured pace than before lest he accidentally set off the ICD. Roughly speaking, we were told by his EP that the ICD would go off either when it detected several really bad heart beats in a row or when his heart rate exceeded 180 beats per minute. Not knowing what that would feel like, Ryan, like most kids his age, let his imagination run a bit wild assuming the worst. Nothing we could say could change his mind. So he set his goal to never have it fire off ... not knowing what was in store for him moving forward.

In light of that goal, my brother suggested we seek a second opinion from a well-known pediatric electrophysiologist at another hospital, especially since we still really had no idea on what physical limitations Ryan had other than no competitive sports. The answer to that was very important to Ryan since life prior to the ICD

consisted of playing baseball, football, hockey, roller blading, basketball, skiing, you name it!

When we arrived at the hospital, the doctor checked Ryan out carefully and asked many questions. When he asked what brought us here, both Ryan and I answered that we needed to understand what Ryan's physical limitations were with ARVD and the ICD. The doctor said that he could answer that best through testing Ryan in his lab. That would be best accomplished by having Ryan walk on a treadmill for a stress test. Although my gut feeling was that this was not a good idea, we deferred to his expertise and experience in the field. In hindsight, this was not exactly one of the better decisions my wife and I made, but it was one to learn by.

We then walked over to the treadmill room and Ryan received instructions on the test about to begin and what he should do should he feel faint. The EP was not present, but two nurses were there to provide instruction, hook him up to some monitoring electrodes, and watch his readings as he walked. No special instructions were provided as to when he should stop other than to stop when it became too hard. Ryan stepped onto the treadmill and the test began. Initially, the treadmill went at a very slow pace with Ryan pointing out how he was going to easily beat the 14 minutes I had earlier reached in my stress test two months ago. How he remembered, I don't really know, but he had always been competitive and was still in good shape physically. So as the clock ticked by and the treadmill became harder, he kept pace. At fifteen minutes, just after he proudly boasted of beating his old dad, he started to stagger a bit and noted that he was feeling faint. At that moment, his heart readings went wild on the machine and his ICD fired off. You could visibly see Ryan's chest jump at that time, so it was clear it fired off. The nurse quickly guided Ryan to the gurney next to the machine. Then both nurses ran to get help. At this point, Ryan was clearly starting to panic. Having never been in a circumstance like that before, he grabbed my hand tight and I told him to take slow deep breaths, which he worked to do. Unfortunately, within another 10 seconds his ICD fired off again. As a father and son, we both felt powerless, especially since neither of us had any idea on whether the ICD would fire off again. I did try to keep him as calm as possible.

Fortunately, it did not go off again, but based on Ryan's massive anxiety that day and in the following days, he clearly picked up post-traumatic stress disorder.

So, for the next several months Ryan really was walking on eggshells, afraid that at any moment his ICD could fire off. At school I met with the school nurse and his teachers to walk them through how to handle a situation should it ever occur. We also purchased a stethoscope, oximeter, and heart monitor to ensure we could quickly gauge his heart. During this period, Ryan said many times, that he wanted the ICD taken out and further noted that when he turned 21, he would have it taken out. No doubt this was a tough four months.

Fortunate for us, my sister-in-law, a psychiatrist, had attended a conference where she met a world-renowned psychologist who specialized in EMDR. EMDR is a psychotherapy that alleviates or eliminates the symptoms of post-traumatic stress disorder (PTSD). We were referred to a local psychologist who had many years of experience treating PTSD in firefighters and policemen and knew EMDR treatment well. I had never heard of EMDR, but figured it couldn't hurt, so we met with her the following week. Needless to say, Ryan and I were both very skeptical about this relieving his PTSD but figured what the heck, let's give it a shot. We were both very surprised when after a single two-hour session, Ryan noted that he no longer had any emotional attachment to the earlier ICD events and felt relaxed for the first time in months. He stepped back into becoming the confident Ryan I had always known. This was definitely a new beginning.

GROWTH WITH THE ICD

Since that event, Ryan and our family have gone through a strong period of growth in all respects. There is much we learned and Ryan has consistently tested the boundaries across many different dimensions. My wife and I now attend the annual ARVD weekend medical conferences held each year for families to learn about new research in the field, share experiences with others, and learn more about living with ICDs. We've also spent countless hours

on the Internet reading up on newsgroups that focus on ICD recipients and people with ARVD. Ryan, on the other hand, has lived it first hand and learned to deal with it better than we ever imagined. Still, there were a number of compromises that he had to make to move forward. With that, I would like to cover some candid remarks from Ryan based on an earlier interview with him.

How Did the ICD Change Your Life?

Ryan's Overall View of the ICD: I know that the ICD holds me back from fully living the way I'd like— from doing the activities that I want to do. But I know that it's protecting me 24 hours a day, 365 days a year. Sort of like having my own personal EP walking with me year 'round with lifesaving gear. While initially it was hard to view it that way, I now know that this device is a lifesaver. I might not be here today without it. Once I accepted that, I moved on with my life.

Ryan on ICD Shocks: I've found that it gets easier to handle the idea of an ICD shock over time. After getting the ICD, I was afraid of getting shocked. And my first shock was traumatic. However, after a few more shocks, the fear is off your shoulders. You get to know your body better. You become more aware and ready. You can ease off if you're pushing too hard or prepare for the shock if you've overdone it. In the two cases where I used less-than-good judgment and knew it was coming, I laid down and took slow deep breaths, and it's over fast. Really, not that big of a deal. From personal experience, I would strongly advise anyone with an ICD to avoid wrestling matches with your frat brothers or challenging an elite hockey player to a one-on-one "first to score wins" game of hockey!

Ryan on Sports: The main way my life changed with the ICD was through sports. With the device, I can no longer play high-intensity sports. While that may not impact some people much, sports has always been my passion, so this change has had a big impact on my life. I grew up playing sports on a daily basis with my friends. But now I can't play sports at the same intensity as before. Admittedly, I am sometimes sad when I watch my friends playing sports and I can't join in. I've learned to live with the limitations and enjoy sports in a

different way. I still ski, swim, and play tennis and basketball. I also play golf a lot—that has become my main sport. Except for golf, I do play sports at a lower intensity and pay attention to my heart rate and stop when needed. I also love to watch sports and play online sports video games with my friends.

Ryan on Exercise: I think as a younger guy it's also hard because you want to look good, but the ICD holds you back from that. While in the past I worked out a lot and had six-pack abs, I've had to back off quite a bit. So, I've accepted that I'm not going to be big and muscular. Still, I do work to stay active as much as I can and eat healthier meals than before.

Ryan on the ICD Chest Bump: For the first several years with the ICD, I was very self-conscious on how the device looked. At that time, when my family and I headed to Mexico for a vacation, I wouldn't take off my shirt in public. No problem around my family, but not in public. I also didn't want my first girlfriend to see the way my chest looked. However, since then I've found that most of my doubts were in my head and nobody really cared or noticed my ICD. However, when I got my second ICD it helped that my EP placed the unit partially under my chest muscles which helps hide the unit.

Ryan on Telling Others of His ICD: At first I was nervous about letting people know about my ICD, but I found that people are really supportive. I think that it's far better to tell your friends about it, than keeping it to yourself. Not only does that eliminate the need to make excuses on why you can't do certain things, but it also eliminates the stress of keeping "a secret" by putting it out into the open. People are more understanding than you think. Your friends will better understand you and your limitations.

Ryan on his Support System: I have a lot of support from family and friends. My frat brothers are all aware of my condition and they all would help out if I need them. My parents are really supportive and helpful, especially my dad. My dad became my main source of support and he's the first person I go to when I have a question. He has done enough research on my condition and ICDs to answer most questions I have. When he doesn't know, he talks to the doctor for

me.

Ryan on his Hopes for the Future: I live a normal life now and focus on what I can do instead of what I cannot. I'm a college student doing just about everything that other college students do. I play golf, and I'm more interested in school than before I had the ICD. I have an active social life, drink beer, take classes that I enjoy, and am having a great time overall! I am also hopeful for the future, especially with all the new research being done on ICDs, the heart itself, and my condition. While I can't go after some careers that require great physical stamina, most careers are wide open to me. Since my passion is sports, the way I've been able to keep my dreams alive is by pursuing a career in sports management.

A FATHER'S ADVICE TO OTHER PARENTS

As with any challenge of this type, there's a big growth curve you'll go through before really understanding how to deal with the variety of situations your son or daughter with an ICD will encounter. It's no doubt a life changing event for both your child, your family and yourself. That being said, after working through the issues for the past six years, I'd like to share some of the lessons learned that we've picked up along the way. Some may be relevant to your situation, while others may not.

Lesson Learned #1 – Establish a Safety Net

To ensure you can effectively deal with situations that pop up due to the ICD, it's really critical that as parents, we develop a workable safety net for our affected child. It definitely gives my son, me, and my family better peace of mind vs. needing to "wing" every situation. Some examples of our safety net include:

- *Cell Phone Rules* – Answering Ryan's calls have always been given high priority, even when it's inconvenient to answer them. Also, heart clinic numbers are programmed into our phones.
- *High School Update* – When Ryan attended high school, we developed and presented a documented ICD event protocol to the HS Staff, including nurses, teachers, and

administrators. Additionally, although against school policy, we secured permission for Ryan to use his cell phone anywhere and at any time at the school to allow him to call my wife, me, or the clinic.

- *Friends and Family Update* – We immediately and openly updated our friends and relatives on Ryan’s condition so that they would know and so that Ryan would feel comfortable around them without the need to explain anything.
- *Heart Rate Monitoring Equipment* – We purchased heart monitoring electronics and showed everyone in the family how to use them. This included an oximeter, pulsometer, heart rate monitor, and even a stethoscope.
- *Maintain Good Relationships with Your Medical Providers* – We’ve worked to build good relationships with Ryan’s EP, device clinician, and family doctor.

Lesson Learned #2 – Teach Your Son or Daughter Medical Self-Sufficiency

We found it especially useful to teach Ryan to deal with his condition to provide us with some peace of mind, but also to give Ryan self-confidence in dealing with his condition and ICD.

- *Medicines* – Since he needs to take meds, he uses a seven-day dispenser so that he regularly takes his medicines. Taking his meds substantially reduces the chances of the ICD going off.
- *Special Meds for Special Occasions* – Ryan’s EP gave Ryan a fast-acting beta blocker to take as a precautionary measure before taking part in an activity that might raise his heart rate. Additionally, although likely a taboo topic, we secured a Xanax prescription for Ryan to take before events that could cause his heart rate to accelerate, such as an assignment requiring Ryan to speak in front of the class. This has worked out very well.
- *Monitoring Equipment* – We taught Ryan how to use basic heart monitoring equipment (e.g., combined oximeter-pulsometer) so that he could check his heart rate at any time to largely give him peace of mind that all was okay.

Lesson Learned #3 – Help Them Learn Their New Limits

As a parent, I didn't want Ryan to become a "cardiac cripple," so I worked with Ryan to understand his new limits (the "new rules").

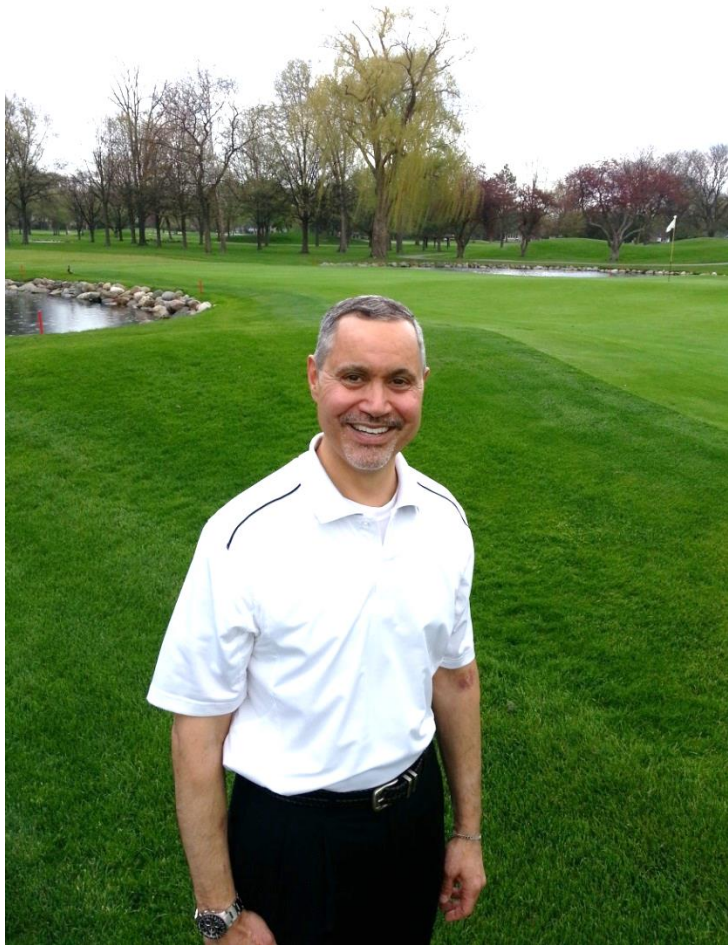
- *Start Out Slowly* – We initially worked him into low-stress activities such as easy walking, golf with an electric cart, picnicking and spectator sports. We also kept simple heart monitoring gear nearby so that we could easily check him out in cases where he felt his heart rate was abnormal. In virtually all those cases, his heart rate and beat was normal giving us good peace of mind.
- *Safely Explore Boundaries* – Generally, the challenge with Ryan was not pushing him forward, but holding him back a bit. For example, while he wanted to head out west to ski at 12,000 feet for a week, we instead headed to easier terrain in Vermont to ski at 3,000 feet for 4 days. As another example, instead of a river rafting trip, we took a trip to Mexico. As time went on, he gradually expanded his boundaries to where they are today.

Lesson Learned #4 – Manage the ICD for the Long Term

Since Ryan was only 16 when his first ICD was implanted, it was important to think long term and, very importantly, ensure that his EP was thinking long term related to the ICD. It's no secret that the lion's share of ICDs are implanted into people much older, so issues related to long term ICD management don't really apply to them. For example, the size of the ICD scar in an older person and the chest protrusion that the ICD makes doesn't matter much, whereas with Ryan it makes a big difference in "body aesthetics" which are important at his age. Scar minimization is especially important since he'll need a number of additional ICD replacements in the upcoming years. Additionally, where a five-year battery may work for someone who's 80 years old, there are now ICDs with nine-year batteries that may be better suited for a younger person.

Lesson Learned #5 – Be Optimistic, Level Headed, Strong

As a parent, I recognized that how I acted when things weren't going well would directly impact how Ryan reacted to a situation. So it was critical for me to stay strong, level headed, and optimistic even through the trying times—no exceptions allowed! While earlier on Ryan was down at times, I'm an optimist by nature and have spent a fair amount of time with Ryan discussing all the positive advances that are occurring in the field today related to both his condition and the ICD. I have also raised a fair amount of money to help research in the field. We've also talked much about his future, including his upcoming sports management career and the fun parts of life in general.



TO 50 . . . AND BEYOND

Kevin I. Green

Men in my family tend to die before they reach age 50:

September 7, 1936: My grandfather (my dad's father) was murdered. He was 46 years old, my dad was three.

November 13, 1949: My other grandfather (my mom's father) died of a heart attack. He was one month shy of his 49th birthday. My mom was 13.

October 14, 1982: My dad died of a heart attack/aneurysm (we didn't do an autopsy, although in hindsight we probably should have done one). He was 49 years, seven months and two days old. I was 24.

March 19, 2008: I turned 49 years, seven months and three days old. I owned the record.

Three men, my only direct blood male relatives, all dead before the age of 50. I'm now 55 years old and almost didn't make it this far, but I'm getting ahead of myself.

Even before my dad died, in fact ever since high school, I had been a dedicated workout person, running (my all-time favorite type of exercise), lifting weights, bike riding—anything to stay in shape. I never smoked or did drugs and my drinking was limited and occasional. As far as I knew, I was doing everything possible to ensure that I would live well past 50. Apparently, it wasn't enough.

Let me take you back to when my (what we now know to be) heart problems began. I was 40 years old, an avid, semi-competitive bicyclist (1600-2000+ miles per year at average speeds of 18-22+ mph) and a runner. In March of 1999, my best friend and I went to a cycling camp in Florida to learn how to get faster. Most of the trip was fun and uneventful until the final team time trial, which is a race

against the clock (I think this one was 20 miles) that you ride as a team and your team's time is determined by the time of the last person to cross the finish line; it requires teamwork, endurance, speed and determination. To keep up your speed, you ride in a single file, with one person going as hard as they can at the front and then peeling off and going to the back of the line until their next turn or "pull." I made a few pulls but, after one of them, I got dropped by the group and fell so far back that our instructor, a young woman, had to come back to me, plant her hand on my butt and push me back up to the group. Normally, I would enjoy having a young woman touching my rear end but not under these circumstances. After that, I was able to take my pull when my turn came around but I got blown out the back every time. Being as competitive as I am, or at least was, I was pretty embarrassed but I explained it away by blaming it on what I had eaten and drunk before the ride and then just forgot about it, at least for a while. Looking back, this was the first time (that I can remember) that I almost died, but it wasn't to be the last.

Throughout the summer of 1999, I continued to ride but couldn't seem to keep up like I used to. As had happened in Florida, I would take a pull at the front of a group ride, get spit out the back and then have to recover before I could catch up. I'd try to climb a hill and I'd be completely out of breath by the time I got to the top. The problems were primarily severe shortness of breath and/or a feeling that my legs were dead. At the time, I attributed it to being out of shape and needing to work harder, although I knew that wasn't really the case since I rode more miles in 1999 (including indoor training all winter) than I had ever ridden before. I also got out of breath going up stairs or doing heavy lifting or exertion, resulting in a need to bend over and suck wind for a few minutes. However, these episodes were always short and I could always return to what I had been doing. By the end of the summer, I started to think that something was really wrong, but nobody believed me. Over Labor Day weekend, my wife Margaret and I were planning to do a 400-mile ride on a tandem (yes, a bicycle built for two), and I told her that we needed to work out signals so that if I passed out or was about to lose control, she could protect herself. Margaret would have none of it and, essentially, told me to stop acting like a baby.

We survived the ride but I knew something was wrong and arranged to see a cardiologist, who concluded that I had a strong heart and no obvious cardiac problems or arterial blockage based on a stress test, echocardiogram and asthma-related breathing test. The breathing test did reveal reduced lung capacity (with which I concurred) and possible occult asthma (a conclusion I rejected).

Despite this relatively clean bill of health, I knew otherwise. Despite six months of problems that were very obvious to me, why wouldn't anyone believe me? After the cardiologist, I went to see a nephrologist (kidney specialist) to investigate some slightly elevated creatinine levels in one of my many blood and urine tests. This doctor took a fresh look at my case and decided to investigate pulmonary sarcoidosis (see below for explanation). My thoracic surgeon had noted this condition after a 1998 biopsy of enlarged lymph nodes in my chest, although at that time I had no symptoms and I received no treatment. After additional blood tests and chest x-rays, my nephrologist informed me that he was 99% certain that I had sarcoidosis and he wanted me to take an additional breathing test (CO₂ lung diffusion study) to confirm his diagnosis.

In February, I started seeing a sarcoidosis specialist, who confirmed that I had inactive sarcoidosis and further concluded that I had exercise-induced asthma. I disagreed with her diagnosis but agreed to follow her suggestion to use an albuterol inhaler before exercise. I was given permission to resume exercise, which I did immediately (cycling classes and weightlifting). I returned in April for a CAT scan, which confirmed the inactive sarcoidosis, and I told the doctor that the inhaler did not help. I was then put on a daily regimen steroid inhaler and told that it would take two to three months before it had any demonstrable effect. In fact, it had no effect whatsoever that I could tell.

On Thursday, May 25, 2000, I got up early, ate a bagel and went to the gym. After cycling class, I worked on my abs and started to feel weak and lightheaded. At 7:00, I started lifting weights although lighter than normal. I finished my full weightlifting workout but was still weak and lightheaded and didn't feel very good. At the office, I continued to feel weak and lightheaded; it felt like my heart was

racing, sometimes up in my throat. I ate a large donut (for the sugar), had my usual half-decaf/half-regular cup of coffee, and drank a lot of water (as usual). I continued to feel weak until around noon, when I had lunch and slowly started feeling better.

On Saturday, May 27, I got up around 6:30, fed and walked the dog, and had a bagel. We left our house around 7:20 and drove to Monroe for a bike ride with some members of my cycling club. It was cold and damp but we decided to ride anyway and left the parking lot around 8:45. I rode a tandem with our older daughter on the back and our younger son behind her on the third wheel. The rain stayed with us off and on for the entire ride. I took the lead for the first 20 minutes at around a 16-17 mph pace. I didn't feel particularly strong but not terrible either. We stopped in Dundee (around 17.5 miles) for a potty break and a cookie and decided to push on back toward Monroe. I tried to take the lead again but ran out of energy very quickly. First one bike, then many, passed us. I had no energy or strength and gave up any hope of staying with that group. As we went along, my legs got even weaker and at some points we were doing less than 10 mph, but usually more like 11-13 mph into a fairly strong headwind. With much difficulty, we finished the 33.5 miles, albeit at a very slow pace. I felt extremely weak but was able to help load the bikes and drive home. I tried to take a shower when we got home but felt even weaker, needing to lie on the floor, with my heart racing and my chest tight. I used the albuterol inhaler but didn't feel any improvement. It was difficult to stand up in the shower, and I had to lie down again after I dried off. I then drove our kids to the bowling alley for my son Alex's fifth birthday party. I was barely able to make it to the alley and I was very irritable. The kids went inside while I tried to rest in the van, without success. After eventually going inside, I sat in a chair watching everyone else bowl, had a Sprite (again for the sugar), and felt even weaker. We moved into the party room and I continued to feel weak, with my heart racing, even after pizza and cake. When we moved to the game room, I had to sit on the floor because I felt so poorly. I helped Margaret move the presents into the van and went home. I immediately went to bed but couldn't find a comfortable position, particularly on my side because my chest continued to feel tight and my heart was still racing. Eventually I fell asleep for around 2 ½

hours. When I woke up, I felt much better and was able to eat dinner. I felt fine on Sunday and Monday although I got a little lightheaded while doing some relatively easy household chores.

On Thursday, June 1, I did another cycling class. I warned the instructor that I hadn't been feeling well and I took it a little easier in the class and with the abdominal exercises afterward. Class was okay although I didn't have the leg speed and strength that I had earlier in the spring. I then did three sets of weights. I felt weak but okay and drove home where I felt much weaker and more lightheaded and had to sit down while I fed our dog. I continued to feel lightheaded and weak while walking the dog. I made it home and laid down in the bathroom. My heart was pounding hard and fast and I still felt weak after I took a shower. Margaret commented that I looked pale. Nevertheless, I drove to work but kept my tie off because I felt hot, sweaty and lightheaded. At 10:00, I could feel my heart pounding quickly and I was somewhat shaky, but most of the sweating had stopped.

While trying to continue with my normal morning routine, I felt my heart pounding and my throat was a little tight. I was sweating a bit and my heart was still pounding, to the point that my whole body shook. Thinking back over the past months, I could remember my heart pounding so fast or hard that I could see the left side of my chest bounce with each beat. I also sometimes felt a pounding in my upper chest/lower neck (near my clavicle) or at my sternum. Occasionally, I got sharp pains in my chest (left or right side) that lasted for only a second or so. I tried to take my pulse but the only good place was the left side of my neck near the chest. My heart seemed to have a weird rhythm, like one beat followed by two fast beats on top of each other. I couldn't get a count, but it seemed fast.

I finally decided to call my sarcoidosis doctor and spoke with her nurse. I described my symptoms and she said they sounded cardiac-related. She suggested that I contact my primary care physician to get a Holter monitor to try to capture what was going on.

I followed her advice and called my primary physician's office and asked if I could come right over to have someone listen to my

heart and tell me whether I was imagining things. I drove over and arrived at 11:00, spoke to a nurse in the exam room around 11:20, and spoke with my doctor at 11:30, still without anyone listening to my heart. At 11:45, I had an EKG and was told I could get dressed. Shortly thereafter, my doctor returned and told me, "I won't kid you, your EKG looks terrible. You need to go see a cardiologist immediately." I then drove to my cardiologist's office and checked in around noon. The nurses were surprised when I told them that I was alone since they had already seen the EKG that was faxed over and expected someone to be wheeled in or brought in with assistance. I told them that I drove myself and they told me that it wasn't safe for me to drive in that condition. I was hooked up to another EKG, which continued to show a heart rate near 300 BPM. The cardiologist told me that I needed to go to the hospital but that I would have to go by ambulance since they wouldn't let me drive. One of the nurses started an IV and then I was loaded onto the gurney. Shortly afterward, my heart returned to a normal rhythm and I was fine all the way to the hospital.

After a number of tests at the hospital, it was determined that I had two heart-related problems. First, the arrhythmia that I had experienced (ventricular tachycardia or VT) was electrical in nature and I would need to have an automated implantable cardioverter defibrillator (AICD or ICD) implanted permanently in my chest (that operation was performed successfully on 6/5 and I was discharged 6/6). The second problem was that my heart was functioning at only 30-40% efficiency (ejection fraction [EF] of 20-25) due to damage to the heart muscle (probably caused by a virus or sarcoidosis), a condition known as cardiomyopathy. On the positive side, other tests confirmed that I had no arterial blockage or valve problems and my blood pressure was fine.

I returned to work and everything seemed fine, I had my ICD and life was good. However, within four months after my first ICD was implanted, I received a series of five shocks, which led to an ambulance ride back to the hospital. Having never received a shock of this type before, I wasn't sure that the first shock came from my device and I actually turned around to see who or what had punched me in the back. I quickly realized what had happened and

immediately sat down and explained to my wife and two younger children what had just happened and why I had let out a small screech. The second shock followed shortly thereafter, at which time I laid down and told my wife that if I got a third shock, she should call 911, which she had to do within a minute. Two more shocks followed, all while my family watched helplessly. At the hospital, the doctors confirmed that the shocks had been "appropriate," meaning that my heart had been in VT and the shocks were required in order to restore a normal rhythm. My medications were adjusted and I was sent home within a couple of days, not knowing when (or if) I would receive another shock.

As it has turned out, my ICD (actually ICDs, since I'm now on my third one) has functioned well these past 14 years, delivering a total of 11 shocks during that time, all but one appropriate. While I don't enjoy being shocked, the pain lasts only a fraction of a second and then I remember how lucky I am to have this constant companion watching over me.

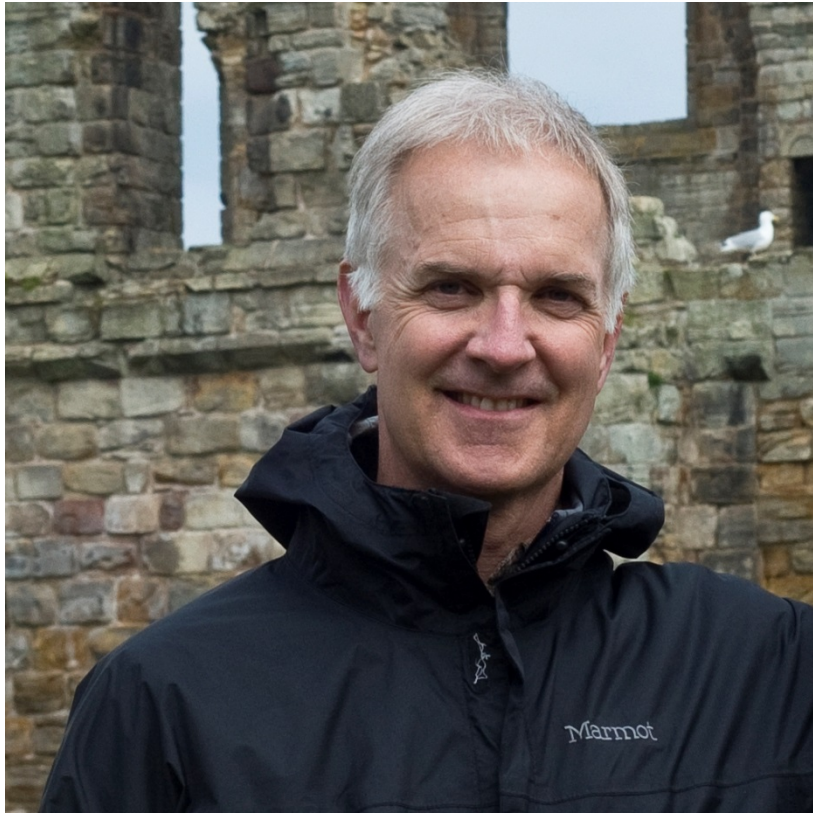
I still experience periodic episodes of VT but am happy to report that my heart function has improved. I continue to work out 4-7 times per week (although I can't run or do any other type of intense cardio exercise), don't drink or smoke, and try to eat right. In fact, last year I worked out even more and dropped 15 pounds to get back to my college weight. All in all, not bad for someone who wasn't expected to see 50!

POSTLUDE: Since completing this chapter (of the book and my life), things have recently taken an unexpected turn. Since approximately May 2013, my sarcoidosis flared again in my already seriously dilated right ventricle and I was experiencing over 1,000 episodes of non-sustained VT (NSVT) every three months or so. [This might be a good time to define *sarcoidosis*: An autoimmune disease that can affect any or multiple organs, predominantly the lungs (90%), and is caused by small areas of inflammation, which can cause the affected organ to become stiff, or in more serious cases, scar tissue to develop. In my case, my sarcoidosis began in my lungs but ultimately affected my heart.]

I began treatment with prednisone and eventually Cellcept, both intended to control the sarcoidosis. Despite occasional issues, things were generally okay (other than continued NSVT) and I continued to work out, though cautiously. On April 30, 2014, I was admitted to the hospital after my home-monitoring revealed that I had moved from NSVT (which continued) to VT that had required repeated pacing therapy, though no shocks. After five days in the hospital and heavy doses of steroids, things appeared to be under control and I was discharged although I soon thereafter developed atrial fibrillation (A-fib) for the first time, which was treated and went away. After receiving a single shock on May 15 but not seeking treatment, I woke from a sound sleep on May 17 to six consecutive shocks while my wife called 911. The VT (but not the shocks) continued during the ambulance ride but subsided after I received a heavy dose of steroids, at which time I appeared stable and was transported via ambulance from my local hospital to my treating hospital. Unfortunately, I experienced five additional shocks during the ambulance ride before reaching the hospital. Fortunately, those were my last shocks but I now had my first experience with post-traumatic stress disorder (PTSD), resulting in my inability to go to sleep for fear of being shocked and also panicking whenever I felt the slightest change in my heart rhythm. With the help of Benadryl and Ativan, I was able to move past the PTSD but the adventure was only beginning. After extensive testing (PET Scans, CT, cardiac MRI, echocardiogram, etc.), it was determined that the sarcoidosis scarring had become even worse and that the arrhythmias were not responding to drug therapy alone. As a result, the decision was made to attempt an ablation, which was expected to take at least nine hours due to the extensive scarring. The surgery actually lasted 12 ½ hours and during it, I went into VT at least twice, the last time resulting in a perforation of the pericardium and the need to stop the surgery, repair the hole and insert a chest tube. Again, I seemed to be stable but then my blood pressure plummeted and it took 10 hours (of excruciating pain) and 16 liters of fluids before the medical team was able to get my blood pressure stabilized above 70/50. I ultimately spent 24 days in the hospital and ended up on Amiodarone, prednisone, Cellcept, Coumadin and a variety of other medications. I am also now on the heart transplant list. The good news is that I have few issues since my discharge, am now nearing the end of my disability and plan to

return to work. The future may entail additional ablations (atrium for A-fib/A-flutter, and right ventricle, both inside and out), possibly a new ICD that can treat the atrial arrhythmias, and at some point, a new heart.

I guess the purpose of this postlude is simply to remind us (you and me) that our issues may appear be controlled and fade into distant memories but don't necessarily go away completely. As a result, now is the time to enjoy life, not wait until sometime in the future that may never come.



THE HEART

Rob Pulcifer

At the emergency room, cars were lined-up around the entrance. It was a busy Tuesday evening, September 11, 2007. A valet came over and assessed the situation. We got out, my wife Connie gave him the keys, and she and my daughter Lauren helped me out of the car. We walked into the emergency room. We joined another long line. When Connie mentioned I had chest pain, the line shifted aside and the registrar's chair rolled directly to us. She ordered a wheelchair for me and I was pushed straight back to the assessment room filled with the bustle of orderlies, technicians, nurses, and doctors. It looked like a busy night, but I was quickly the center of a lot of attention. I now know what to do to get good service in an emergency room. Mention chest pain and you're the show until determined otherwise.

The preliminary round of tests didn't show much. I was temporarily relieved. I still felt pain, but it was nice to have all these professionals around me. Then they did an EKG and there it was. A blip out of place. "It looks like you've had a heart attack," the doctor said. "We'll run some more tests to verify. But in the meantime, we'll call in the coronary surgeons."

"A what?" I said. I couldn't have had a heart attack. I'd spent the past few years taking my physical fitness seriously. I was an athlete. My dad had a fatal heart attack thirty years earlier because he was overweight and he had a bad diet. I was careful to counteract that with a very active lifestyle and good eating habits. I'd worked so hard to stay healthy.

I biked. That's how I stayed in shape. It had become a major emphasis in my life. It gave me fitness, a community, a way to enjoy the outdoors, and a way to explore my own ability level. I'd taken up racing bikes a few years earlier and it was exciting. I instantly flashed back to all I loved about biking. All the friends, the joking, the teasing and bravado, the times when my legs just soared, the ability to hold

on and sometimes pick up the pace against all odds.

And now it was over. All of it. I'd had a heart attack. My dad had died of a heart attack when he was only 57. He was overweight and out of shape. I was now 51 and extremely fit. When I was young, the words heart attack meant that life slowed way down and physical activity was metered out in small doses. I turned to Connie and let her in on my fears. Did this mean that I would no longer be active? Would I now be only a spectator? Tears started to sting my cheeks.

One of the doctors asked what was wrong. Connie told her. "Not a problem," the doctor said, "you'll be racing again." She said it so casually, like, what was I thinking? I wanted to believe it, but I didn't yet know if I could.

This all started earlier that evening during a ride, a very challenging one with about 15 other riders. It's affectionately called the Dirt Hammer, a weekly ride that covers hilly terrain on area dirt roads. It's a hard, fast 25 miles, where the goal is to keep the pace high and then take it a little higher. It's a way to train the legs for the intense exertion of cyclocross racing, a type of non-stop autumnal bike racing that lasts an hour or so over rough, grassy terrain. It's like turning the heat on high under a pan of water and leaving it there to boil furiously for an hour. There's no let-up. So the training has to be equally intense.

This evening I found myself off the back on the first climb. I loved to climb and I was usually near the front so it was a bit odd, but I told myself that it was just fatigue. I tried to get into my usual groove and take on the challenges to come, but at every effort I felt like I was working awfully hard just to hang on. It was a cooler evening than usual. I thought maybe my muscles were fighting the chill.

After about 10 miles of this punishment I let the last wheel pull away and I waved goodbye. It wasn't my night. I was breathing awfully hard. Then I felt a pain fill my chest and run down my left arm. Had I pulled some chest muscle that affected my lung capacity? Was it the cooler temperatures that my body had not adjusted to? I

looked ahead and there was the group turning left and climbing the next rise. That was my favorite place to attack on the whole ride. I loved those hills.

I had no idea what was going on, but I pulled over and called my wife on my cell phone and asked her to pick me up. A couple of stragglers from the ride pulled up to me and we all waited for her to come. The pain got worse as I scuffed around in the road, kicking stones, moving to keep the pain at bay. My stomach felt awful. I learned later that I should have called an ambulance, but at the time I thought I just had some major bout of indigestion, or overworked muscles in rebellion. After what seemed like hours, but was probably about a half hour, Connie and Lauren showed up. We packed the bike into the back of the car and we all agreed that I was headed to emergency at U-M hospital.

After the preliminary tests in the emergency room they gave me a nitroglycerin tab under my tongue. Then my blood pressure plummeted. Athletes often have low resting heart rates and their vessels are so dilated that any further opening can drop the blood pressure into the danger zone. The nitro was supposed to ease the pain by getting the blood to flow into my heart again, but any further tabs were out of the question. "Get the morphine," said one of the doctors. Option B. I was put on a morphine drip. It made me drowsy and it eased the pain somewhat, but it took a while. In the meantime I was wheeled to the cardiovascular building and into the chilly operating room. Three nurses were prepping the area furiously. This was the first time I realized, through my addled stupor, that time was important. Within minutes this amazing new room that looked like the Starship Enterprise control room was shifted into place for my operation.

They'd decided to put a catheter into an artery in my groin and work through it to access the left lower coronary artery where the blockage took place. Apparently I'd had a crack in my artery that was seeping blood and filling it with a clot. This cut off oxygen to that part of my heart. Once that happens and no oxygen is reaching the heart muscle, it begins to die. That's why getting to the hospital quickly is essential. Actually, that's why you want to call an

ambulance, since they can start the process of reopening the blood supply on the way to the hospital, as well as handle any other issues that arise.

They did an angioplasty to open the vessel, then inserted a metal stent to keep it open. That stent is now a part of me and will be for the rest of my life. The operation itself took just over an hour. Then I was taken to another part of the hospital and put in the cardiac ICU. There, a nurse watched over me for the night. She took my pulse and blood pressure constantly. She sat and talked with me the whole night. Another fellow came in and removed the catheter, then stood over me for nearly an hour holding pressure on the area to prevent the artery from leeching blood and causing a hematoma, and waiting for it to clot enough to plug the hole on its own. He was a good natured, patient man. I fell asleep and he startled me awake. "Talk to me," he said. "That's your part of the deal."

Throughout the day, friends dropped by. Many were surprised by two things. First, that I looked and acted fine. Physically, it looked as if nothing big had occurred. I was actually kind of spunky and cheerful most of the day. (I was happy to be alive and from all the doctors' reports my prognosis was a good one.) Second, that I'd had a heart attack. These people knew me and knew my fitness level. I'd raced and ridden with most of them for years. I was not their first choice for someone with a heart condition. I wasn't even on their list.

I was sent home the next afternoon. That was it. My job for a few weeks was to take it easy. I could still get out and take walks, but I wasn't supposed to push myself physically. After a month I was allowed to get back to my usual fitness routine. In fact, I was encouraged, though the cardiologist thought that racing should be on hold until the next year.

I worked on my fitness all winter and by spring I was ready to take on the world again. It was one of the best race seasons of my whole life. I was finishing in podium spots, winning races every now and then, placing highly in most races I entered. The spectator I'd prepared to be after the initial moments of my heart attack would have to wait.

Though I felt fine, at each subsequent heart check-up the results of the echocardiogram showed a lowering of my ejection fraction. The ejection fraction measures the volume of blood flowing out of the ventricle with each beat. Mine was fine months after the heart attack, but each subsequent year it dropped. By the second year it was in a danger zone. I was told this meant that I was at high risk for a ventricular fibrillation, or potential heart attack with more serious ramifications than previously, and that an ICD would respond immediately if such an event occurred. I didn't even know what an ICD was until my cardiologist said it was something I should think about.

I was lined up to talk with a surgeon who had implanted these devices in patients for a number of years. He and I had a long talk about the procedure and my prognosis, with some honest talk about what it meant if I didn't have one and another heart attack occurred. He wasn't necessarily pressuring me to get one implanted, but he was definitely a proponent on the side of caution. He said there's actually a higher likelihood that I wouldn't have another heart attack than that I would, but if I did, I'd have my own built in device that would pace and/or shock my heart back to a normal rhythm. The decision was ultimately up to me. It was another surgical procedure and because I'm thin it meant that it would have to be tucked in between my left shoulder muscle rather than merely slipped under the skin. I was asked to go home and think about it.

It didn't take much persuasion. I trusted what they were telling me. These were highly respected cardiologists and I liked the idea of living a good healthy life. I didn't want to worry about a lack of resources should another heart attack occur. ICDs have come a long way from their earlier models. They were now small, the batteries lasted for a decade or so, and the problems that arose early on with false shocks were becoming much less likely. I said yes.

That also included an invitation to a yearly day-long banquet held for all those with ICDs put on by the nurses at the U-M. It was held in October of that year, which was handy because it was shortly after my device had been implanted and I welcomed the chance to

get a deeper understanding of what this new part of me would mean in my life.

It was a wonderful experience. There were speeches by a few ICD recipients, many of them far younger than I am. There were breakout roundtable discussion sessions with peers where we had a chance to tell our stories if we wanted to, listen to others who'd had experience with the devices, and talk to the representatives from the device companies, and, in my case, have the doctor who implanted my device there to explain his experience as a surgeon specializing in ICD implantation.

The most fascinating part to me was listening to men who'd lived for years with heart conditions, some since childhood, many with some of the earliest iterations of ICDs. I truly realized I was not alone and that these men were living constructive lives even with all of the challenges and adversity they've had to contend with. Each man's story was filled with life's challenges, but each had found a way to carry on with meaning. One man was once told he wouldn't live past his twenties and he was now in his sixties. Another still raced triathlons, not to win, but to finish. That was important. To finish. I realized then I could live a good life with my own achievable goals. In essence, to finish is to win. To be here each day is to win. I felt proud to be in the room with them. Since then, any time I fall into self-pity I think of them and realize that they've had to deal with far more than I have, and they've confronted it with humor, resolve and dignity.

My passion for bike racing has waned, but my love of biking hasn't, nor has my enjoyment of good physical fitness, getting outdoors, or riding with family and friends. I ride nearly every day, and when I don't, I get out and take a nice long walk. I feel that these amazing advances in health care are giving me the chance to carry on with a good, full, healthy life. It's a wonderful thing. Every day is a win.

Rob is a writer, photographer and publisher. He focuses on outdoor recreation, and bicycling in particular. He has two books, *Best Bike Rides Detroit and Ann Arbor* (Falcon Press), and *Dirt Road*

Washtenaw (Clay House Publications, LLC). He also publishes a website that focuses on bicycle travel, pedalgood.com.



COUNT YOUR BLESSINGS

Alan

Our medical professionals quite correctly recommend that we adopt healthy lifestyles. This, of course, is aimed at reducing the risk of becoming afflicted with any number of illnesses or conditions, including a heart attack. Back in the spring of 1962 at the age of thirty, I decided to heed this advice. I changed my diet quite substantially, stopped eating bacon and eggs, hamburgers, cheeseburgers, hotdogs, processed meats, steaks, pizza and several other naughty foods. I also embarked on a regular exercise program. On top of this, I have never been a smoker. We are also reminded that adopting a healthy lifestyle is not an ironclad guarantee that health problems will not occur. Oh, how true that is!

My “surprise” happened on 9th March 1989. At that time, I had a 48 mile commute between my home in Ann Arbor and Highland Park. As I climbed the staircase to my third floor workstation, I felt some mild chest pain, but when I sat down it immediately receded and I thought no more about it. At lunch time the pain returned at about the same intensity, but again quickly receded. Later on in the hospital, I realized that these were warning signals that I did not recognize at the time. Then, on my drive home, I was almost at journey’s end when the chest pain returned but this time at greater intensity. Upon arrival at home I decided to lie down. The pain, however, was spreading to my shoulders and upper arms, and that convinced me that I should go to the hospital. I phoned my former spouse (with whom I have a cordial relationship), and she arrived within a few minutes and drove me to the emergency room at U-M Hospital. The ER staff very quickly determined that I was indeed suffering a heart attack, gave me a nitroglycerin tablet under the tongue, an EKG, and administered heparin via an IV. (Not necessarily in that order.) I was then transferred to the catheter lab, where they informed me that they would determine which artery was blocked and then open it up with a tiny balloon. To the lab staff this is obviously routine, but their explanation of entering a vein in the groin area and threading a tube and balloon up into the coronary

arteries left me both astonished and full of admiration. Following this procedure, I was finally transferred to the intensive care unit. The nurse told me that since I had acted promptly, the damage to the heart muscle was minimal and that it should heal quite well. This news came as a surprise to me given that I had failed to recognize the warning signals earlier in the day.

Finally alone, it was time to gather my thoughts together. What a day! As I drove to work that morning I was expecting a routine day of course, and not one that ended in the ICU. Plans have to change. Tomorrow my elder daughter was due to arrive from college on her spring break, and I was going to meet her at Detroit Metro airport on my way home from work. Fortunately her mother was able to fulfill that role. Needless to say, my daughter Michele was not expecting to spend part of her spring break visiting Dad in the hospital. The thought that was uppermost in my mind, however, was a business trip to Germany I had made just a few weeks earlier. It occurred to me that the heart attack did not miss that trip by much. At that time I was 57 years old, and so we are talking about an interval of 30 days in a lifespan of 20,856 days. Whew, that's not much, is it? I could not help thinking, "What if the heart attack had occurred over the Atlantic on the flight home, several hours from medical attention?" The outcome might have been quite different. However, my actual situation was that I was in my home town at U-M Hospital receiving expert care.

Alan, it's time to count your blessings!

After a few days I was encouraged to start having occasional walks along the corridors, and I did this accompanied by my constant companion-a pole on wheels on which hung a bottle of heparin! I was not alone however; there were several patients engaged in the same activity. On my third day in the ICU, my attending physician informed me that the monitors were indicating an occasional long interval between heart beats. He recommended that I consider a pacemaker and that it would be beneficial if I received it during this stay in the hospital. I readily concurred. The implant took place on the 16th March. This event is easy for me to remember because of the remarkable young woman who performed it. I received a local

anesthetic and then a small curtain was drawn in front of my face. She and I could therefore converse quite easily, and she told me that she would occasionally explain what she was doing during the procedure. But that was not all she could do. Quite casually, she enquired as to my career and if I was facing any major challenges. We started to discuss these topics in detail, but remember that she is also delicately implanting a pacemaker and its leads into my chest and keeping me updated regarding her progress. I had to marvel at her capability and wished that I had such an agile brain! (I could not find her name on my hospital discharge documents.)

My experience is that pacemakers do their work quietly and unobtrusively. If mine performed any pacing during the active part of the day, I was usually unaware of it. When lying in bed, I would occasionally feel the gentle vibration, and it would normally run for about thirty seconds. The device clinic had informed me that mine had a normal setting of 70 beats per minute (bpm), but also included a “sleep down” mode of 50 bpm which was programmed for 11pm – 6am. I had assumed that if I planned a trip to Europe, it would be advisable for that timing to be temporarily reprogrammed. This unit did not have any operational issues, and from my perspective it was very satisfactory. Far less convenient than today, the procedure for remote monitoring from home initially resulted in my being late for work on the appointment days. The transmitter included a cavity which was designed to accept the traditional telephone handset, and it was also equipped with two ring-style electrodes that had to be placed on your forefingers. In 1989, the pacemaker technician was Dan Biladeau. At the appointed time Dan would phone, I would then push the electrodes onto my fingers and place the handset into the cavity. Dan would record the pulses transmitted by the handset for a given period of time. Then it was necessary to place a magnet over the pacemaker, and the procedure was repeated. Finally, there was a second run without the magnet. During my first face-to-face appointment with Dan in the device clinic, he enquired about how the remote transmissions were working out for me. I informed him that they usually made me late for work, which by itself was acceptable, but their timing usually resulted in me missing most of a department staff meeting. I have mentioned all of this because it is now appropriate for me to pay tribute to Dan and his work ethic. On

my remote transmission days, he volunteered to arrive at work earlier than normal, thus permitting me to attend the staff meetings. Here was a device clinic employee willing to go the extra mile in order to accommodate a patient. Dan knows that this was appreciated, but I want to put it in writing – thank you Dan!

That's a good reason to count your blessings!

This first pacemaker had a long life – just two months short of ten years. It did finally reach end of life for its battery, and on 14th January 1999 my generator was replaced. This surgery was also performed with a local anesthetic, and I was again able to converse with the surgeon. The weather was cold at this time of course, and I immediately began to experience a feeling of tightness in the chest (but not pain) when walking outside. I felt fine when walking inside the hospital or in a shopping mall. On the 27th January 1999, Dr. Walton, my cardiologist at that time, recommended that I admit myself into U-M hospital, and he would arrange for me to undergo angioplasty. This took place almost immediately, and I was kept at the hospital overnight, mostly because I live alone. The angioplasty was quite effective in alleviating the chest tightness, but as a precaution Dr. Walton gave me a prescription for nitroglycerin tablets. These are usually dispensed in a tiny bottle which is easy to carry in a pocket. Dr. Walton scheduled me for an exercise stress test on the 5th February 1999. I don't have any notes regarding this procedure, but my recollection is that the results were positive. Eventually this pacemaker also proved to be a very satisfactory device. It served me for eight years and 10 months, and was replaced only because of the necessity for me to receive an ICD.

In mid-September 2006 I underwent an echocardiogram procedure at the device clinic. Shortly thereafter, Dr. Pelosi phoned me to explain that my cardiac ejection fraction had been observed to vary between 35% and 42%. The lower value was of concern as it indicated a potential for insufficient blood to be returned to the heart. Accordingly, he was recommending that I receive an ICD implant. Once again I concurred. The implant occurred on 28th November 2006, and for this procedure I was sedated. Dr. Pelosi informed me that one of the existing pacemaker leads had become

encased in muscle, and that tugging on it raised the risk of it breaking. Therefore he had capped it and left it in place. So I have an extra lead! Following discharge I was dismayed to find that the chest tightness while walking outside had returned. This proved to be a perplexing situation which persisted for the entire time that this ICD was implanted. Just consider the following:

- The condition occurred only at the beginning of outside walking, always in cold temperatures, and sometimes when it was warm.
- It could usually be relieved by a nitroglycerin tablet under the tongue.
- I could walk inside, such as in the hospital or a shopping mall, without any discomfort.
- Engaging in my regular exercise routines at home presented no problems. This included weight training and walking on my glider.
- I could carry three bags of groceries up to my third floor apartment without any discomfort or distress.
- When at the cardiovascular center (CVC), I was able to climb the main staircase between the second and third levels without experiencing any discomfort.

I have been a patient of my present cardiologist, Dr. Shea, for many years. He has worked diligently in search of a solution, but none has materialized. Under his direction I underwent a stress test, another angioplasty and a double procedure to check for iron deficiency anemia. All of these yielded favorable results, but the chest tightness persisted. Eventually Dr. Shea explained that the next step he would take would be very invasive with no guarantee that it would be successful. He recommended that if I was comfortable with the relief provided by the nitroglycerin tablets, then we should not proceed any further. I readily concurred, and I am confident that we made the correct decision.

In October of 2007, I received letters from both Medtronic and the device clinic, informing me that one of my leads was subject to a possible recall and that it would be monitored regularly in the future. It is now six plus years later and that lead had always shown

satisfactory data and performance. In common with most ICD recipients, I had two questions uppermost in my mind: “Will my ICD function as it should?” and “What will it feel like?” I received my answers simultaneously on 14th April 2011. I was standing in the bedroom, suddenly felt lightheaded, the therapy shock came, and I immediately felt normal. I did not even have time to react – it was all over in an instant. I would describe the shock as “uncomfortable.” Had I received multiple shocks I would probably elevate that to “highly uncomfortable.” I phoned the device clinic, and it was Helen who answered the phone. After checking how I was, she asked me to upload the data to the clinic then she would review it and call me back within an hour. She confirmed that I did experience an erratic heartbeat and that it was encouraging that only one shock was required. It may sound strange, but I was both glad and relieved to finally have the answer to those two questions.

So it worked! Time to count my blessings again.

In late June 2011 I was contacted by Jacqueline Fortino RN, in Cardiac Electrophysiology Services. This contact was made on behalf of Dr. Chugh and was an invitation to participate in an investigational study designed for patients with an ICD. At this point it is appropriate for me to explain that since retirement in 1997 I have been a regular volunteer in U-M research studies. This has involved not only the Health System but the Institute for Social Research and the Transportation Research Institute. This work has enhanced my retirement and has also been enjoyable. It has kept my mind active, I have learned many things, and I have found the university environment quite stimulating. I hope that I have been making a small contribution to improve the lives of future generations. Most research studies involve one or two appointments, but this study from Jackie was very, very different. It required visiting the CVC for two hours per day, three times per week for 12 weeks. There would be two additional visits for PET scans, at the beginning and at completion of the study. The objective was to find out if the beneficial effects of regular exercise could be duplicated by inducing an implanted device to increase the heart rate for an hour. The aim was to improve the lives of patients who are unable to exercise, such as those with low or no mobility, and those with respiratory

problems.

I signed up, and commenced my participation in early September 2011. Jackie would establish a wireless connection between my device and the Medtronic monitor which was next to us. She would then commence to gradually increase my heart rate over a 30-minute period, up to a maximum of 125bpm. She would keep me at that level for an hour. Finally, she would gradually reduce my heart rate back down to its “at rest” level over a 30-minute period. Throughout this procedure she would frequently monitor my blood pressure. I should point out that occasionally I could not resist telling her that she would never convince me that it was that silly monitor which was raising my heart rate! The PET scans at each end of the 12-week long study were used to measure blood flow to the heart. Early on in the study it occurred to me that I had no knowledge of my heart rates during my daily activities. How did they correlate with the 125 bpm I was experiencing during the study sessions? This train of thought prompted me to purchase a new watch with an integral heart rate monitor. I recorded data for approximately four weeks, but it will suffice for me to provide the maximums:

Regular exercises

92 bpm after 15 pushups.

Weight training – 10 lbs. hand, 16 lbs. ankle: 20 repetitions

84 bpm after horizontal leg raises

Walking on glider at home

92 bpm after 35 minutes

Fitness walking

114 bpm during uphill section

Stair climbing

105 bpm, CVC main staircase – 2nd to 3rd floor, 66 steps, 59 seconds

This last activity is something that I do during every visit to CVC, and I use it as a yardstick. The interesting aspect of this is that my limit is not my cardiovascular system, but my legs. I was quite surprised to realize that my activities never did require my heart to reach the 125 bpm level of the study. I passed all of the data on to Jackie just in case it would be useful. One observation of the study so

far is that inducing a device to operate using a wireless connection drains the battery more quickly than placing an antenna directly over it.

Jackie and I were occasionally joined by Suzanne Benloucif-Moore, nurse practitioner, fellow and lecturer at the School of Nursing. Interestingly it would be Suzanne who replaced my ICD generator during the following April. Despite the chest tightness issue surrounding the first ICD, I regard it as a satisfactory device. During clinic checks and remote checks from home, it always generated positive data. More importantly, it delivered a therapy shock when I needed it. It finally started to show “end of battery life” data, and on 18th April 2012 the generator was replaced by Suzanne. While I was in the recovery room, Jackie came in to visit me. Lovely surprise! I was not her patient, my participation in the research study had ended four months earlier, but she took the time from her work schedule to see me. Thank you, Jackie. That was not the only pleasant surprise I received on that day – the chest tightness when walking outside was gone! I have not had to take a nitroglycerin tablet since. When I see Suzanne, I cannot resist asking her about her “magic touch.” But on a more serious note, I have to wonder if the shape and dimensions of my chest cavity contributed to the situation, or if the cavity was only compatible with two of my four devices.

At the ICD Connection lunch meetings we occasionally heard from patients who had suffered unpleasant experiences when passing through the heightened airport security which unfortunately is necessary today. Consequently, it was with mixed feelings that I was facing a trip to Tampa in November 2012, for my elder daughter’s wedding. Looking forward to the wedding, but not to the flights. Fortunately on 29th October, I had a regular device clinic appointment with Dan Bochinski RN, and he informed me that many major airports had installed “enhanced body scanners,” which had eliminated the need to pass through a magnetic field or a pat down. Thankfully, both Detroit Metro and Tampa International had these scanners, my ID card was quickly recognized, and the whole procedure was routine. Count your blessings!

If you have been keeping count, the device now implanted is my

fourth—two pacemakers, two ICDs. It is now 20 months old and has been flawless. Since I have not experienced any “events,” it has not been called upon to deliver any therapy shocks. It has always recorded positive results when checked at the clinic and from home. Finally, it has not been accompanied with chest tightness when walking outside. As I look back today, I feel that I have much to be thankful for. Yes, I suffered a heart attack in 1989, and yes, I have an implanted device. However, many important events and activities were unaffected. Here’s a good example: Elder daughter Michele entered Bryn Mawr College just seven months before the heart attack. Bryn Mawr is just outside Philadelphia, but I was able to undertake eight 1,176 mile round trips without any problems, including all of the loading and unloading of the minivan. Then two years later, I repeated this kind of activity with younger daughter Teri, who entered Stephens College in Columbia, MO. Once again, six 1,344 mile round trips, with more loading and unloading, were accomplished without incident. Add to that a summer theater round trip of 1,640 miles to Spirit Lake in Iowa. Today, I can joke about my daughters conspiring to ensure that I had the opportunity to see more of the country. But the point I am making is that it was all accomplished without any “events” intervening. It could have been much different, and then I would have had to make other arrangements. As I approach 82 years of age, I am also thankful that I can still exercise regularly, can maintain a walking program, and can ascend the CVC main staircase without difficulty.

At one of the ICD Connection lunch meetings, we were introduced to the “My Heart – Your Heart” program. This permits someone who has an implanted heart device to donate it upon their death. If the device indicates useful battery life, it would be re-sterilized and transferred to someone who needs one but who would otherwise have no hope to receive one. This program has much appeal to me. It makes no sense for such an expensive device to be discarded if it can extend the life of some deserving person. Michele is the executor of my will, and she is aware that I want my device to be donated if its battery life permits. I have often thought about the subject of batteries. There is so much technology inside the modern bedside monitors; surely it must be feasible to have rechargeable batteries. How much more preferable it would be to occasionally

recharge the battery at home or at the clinic rather than to undergo surgery to replace the generator.

It is now approaching 25 years since the heart attack. That's a long time, and one could reasonably conclude that the angioplasties, pacemakers, ICDs, medications and the CVC caregivers have all combined to provide assurance that it won't happen again. Yet, I have not visited the family members in England and Switzerland since the attack, and that reluctance continues today. There's not much logic behind that is there? But the thought of receiving several therapy shocks during a transatlantic flight is not very appealing. How would I be feeling for the remainder of the flight? Would the delay in receiving care be important? This is probably the only issue that I find bothersome.

This essay enables me to say "thank you" in writing. First to the device clinic team. Ideally, I should mention each of you individually, but old fogey that I am, I run the risk of missing someone, and that is unacceptable. During regular appointments, I usually see one or two of you. One reason why the ICD Connection meetings are so enjoyable is that I see so many of you all together, and that's a treat. So, thank you all. Thank you Dr. Pelosi, Dr. Good and Suzanne for implanting my devices. Many thanks to my cardiologist Dr. Shea, for several years of care. Must include Dr. Shea's nurse, Diane Lack for being so helpful and supportive. Thank you to research nurse Jackie, for what turned out to be a most enjoyable project, and for staying in touch after my participation was completed.

Count my blessings one more time.

I would like to end with a little side story. During that period of 38 appointments with Jackie on the research project, I would arrive early at CVC and purchase a coffee and muffin at the café at the foot of the main staircase. One of the servers was a young Asian girl who was a bundle of energy. She would treat every customer with a warm greeting and a great big smile. Her stature was quite small, but her sunny demeanor was much larger. Eventually, I was referring to her as "Little Miss Sunshine," and the first time I mentioned this to Jackie she knew exactly about whom I was speaking. This young lady

had nothing to do with my ICD, or with the research project of course, but she did become an integral part of my CVC experience. She never failed to brighten up my day.



MY MIRACLE ON ICE

George Stefureac

On Friday, January 14, 2011, I, George Stefureac, was playing hockey at Kensington Valley Ice House (KVIH) with my usual Friday evening hockey teammates. After my second session on the ice, while I sat on the bench between my teammates, I collapsed. My teammates, John Springhetti and Steve Thome assessed that I was not breathing and had no pulse, and they immediately began CPR. Steve Davidson, who had prior experience giving CPR, quickly took over the chest compressions. Other teammates called 911, and summoned to get the automated external defibrillator (AED).

Stephanie Williams, who was working at the front desk of the Ice House and happened to be a student nurse, properly applied the AED pads to my chest, and initiated the shock as indicated by the monitor. Immediately after the AED shock was given, I had a pulse and took a breath. While CPR and AED were being given, the rink attendants went outside the ice arena to guide the EMS ambulance to the door closest to where I was.

The Livingston County EMS personnel, who were on this emergency call, told my wife that their arrival time to the scene was about two minutes after they had received the 911 call. They stated that the hockey team's quick response with CPR and the AED had saved my life. The hockey group had worked so well together. They did everything right. The EMS personnel gave my teammates scissors and they cut off my uniform and removed my skates. Six teammates quickly lifted me onto the stretcher. Due to my critical condition and unconscious state, another teammate, Ron Pastor, accompanied me in the EMS ambulance to U of M hospital to provide information on me. The EMS personnel told my wife that the quick response with CPR and the AED, and the teamwork involved, enabled them to have me on the way to U of M hospital within minutes.

When my wife arrived at U of M hospital and spoke with the

doctors, they told her that the quick actions of the hockey group with CPR and the AED saved my life. I was in critical condition, but with treatment and the InnerCool therapy that I was receiving in the cardiac intensive care unit, my family was told that they could be “cautiously optimistic” that I would recover. While I was at U of M hospital, other doctors who were caring for me also commented how the hockey group’s quick response with CPR and the AED saved my life.

When I regained consciousness after four days in CICU, my first words were “What happened?” My family told me about my cardiac arrest at the hockey game and that the hockey group did CPR and used the AED. My next very emotional words were “They saved my life.”

I have recovered very well and am alive today because of the immediate CPR and AED given by John Springhetti, Steve Thome, Steve Davidson, and Stephanie Williams. They are truly “Everyday Heroes” who, without any hesitation, sprang into action and saved a life. My family, my friends, and I are eternally grateful.

While I was still in the hospital recovering from my cardiac arrest, the doctors at U of M advised me to have an ICD implanted. The doctors told me that because of my unexpected and sudden cardiac arrest, the ICD would offer me protection in case the life threatening arrhythmia that caused my cardiac arrest would occur again. I have adapted to the ICD well, and I am thankful for the protection it provides.

I told some friends the story about my cardiac arrest. Most of them responded saying “You don’t know how lucky you are.” I responded by saying “I do” along with “fortunate and blessed.” One of my more religious friends to whom I told my story responded by saying “You were saved for a reason, and when you figure it out, I would like to know what is.” That thought started me thinking. I began thinking that since my life was saved I would like to give back to society in some way.

One day, John Springhetti, one of the persons involved in saving

my life, approached me about playing the Detroit Red Wings Alumni in a hockey game at our home ice rink. He told me that if the game were to be a charitable event, we would have a better chance of scheduling with the Red Wings Alumni Team. We came up with the idea of taking the proceeds of the game and purchasing defibrillators for organizations that cannot afford them. We then produced a short video telling the Red Wings Alumni Team about our goal. Shortly after we submitted the video, we received a call from the Red Wings Alumni organization. They were interested in scheduling a game because they thought our cause was very worthwhile.

Soon after hearing the news about scheduling the game with the Red Wings Alumni, we formed our organization, the “Sparky Defibrillator Challenge.” We then formed a committee of eight people, John Springhetti, Joe and Robin Fry, Ron Pastor, Mike Crawford, Tom Kinczkowski, Jim Munof, and me, George Stefureac. All the members are very dedicated to the cause.

During the planning stage for the Red Wings Alumni game, I contacted Jeff Boyd, the director for the Livingston County EMS. I asked him if he would like to help with our organization. After explaining what we are about, he said that he would. I had initially met Jeff at a Red Cross fund raiser breakfast where we both were speakers. After the breakfast, I spoke with him about cardiac arrest and we became friends.

Our game against the Red Wings Alumni was a great success. Our organization made enough money to purchase two AEDs. One was donated to the Pregnancy Help Line, a not-for-profit organization dedicated to helping teenage mothers and fathers in need of assistance with their babies. The second went to the American Legion Post in Howell, MI, another not-for-profit group dedicated to helping others.

Our summer fund raiser was a golf outing. I must say that due to the dedication and hard work of our Sparky Defibrillator Challenge group, the golf outing turned out to be a success. It turned out so well that it enabled us to donate two more AEDs. One for the Salvation Army Chapter of Livingston County, and the other for

the Special Olympics of Livingston County.

As of this writing, we are in the process of arranging our second annual hockey game with the Detroit Red Wings Alumni Team. We are committed to surpassing last year's goal and to selecting even more organizations that would benefit from AED donation.

We are a small group with big goals. We hope that we are setting an example for other groups to learn more about CPR and using AEDs to help save lives.

For further information on our organization and our mission, please visit our website

www.sparkydefibrillator.org



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

Siddharth Mukerji, MD

When can I resume sexual intimacy with my partner?

For most patients, being sexually intimate does not pose a medical risk. The heart rate increase that naturally occurs during sex is the same as the heart rate increase that occurs during any physical activity. Sometimes exercise testing at the hospital will help in programming your defibrillator so you do not get a shock during sex. Though there are no specific guidelines regarding this issue yet, general recommendations suggest waiting two to four weeks after implantation prior to resuming sexual activity. The time frame also depends on the individual patient and associated medical problems.

What if I get a shock during sex?

If you do get a shock, your partner may feel a tingling sensation. The sensation is not harmful to your partner. Be sure to let your doctor know if you get a shock during sex, since programming changes may be indicated.

What types of activity are considered safe after implantation of a cardiac device?

There are few activities that are considered off limits. However, for the first six to eight weeks any activity that involves heavy or strenuous upper body movements should be avoided. Some of these include swimming, lifting heavy weights, tennis, golfing, racquetball, or any other sport/activity that involves physical contact. Avoiding such activities helps to ensure that your lead or leads have time to attach firmly to your heart tissue. After this period, you should discuss with your healthcare provider the resumption of prior activity. Also, always talk with your healthcare provider if you have any concerns about any kind of physical activity.

Will an ICD cure my heart rhythm problem?

Unfortunately, it will not. An ICD is like having 9-1-1 in your heart. It monitors the heart rhythm constantly, 24/7. In the event that an abnormal heart rhythm occurs, the device detects this and delivers therapy as appropriate. It treats the problem each time it occurs. Sometimes physicians use rhythm control medications called antiarrhythmics to help with abnormal heart rhythms. The goal is to protect you if your heart rate increases dangerously despite the medication. Thus, the ICD is a back-up in such situations.

Can people with defibrillators go near microwave ovens?

Yes. The newer ICDs do not demonstrate any interaction. In fact, the FDA has also approved this. Smaller hand-held power tools, small magnets (like those on the refrigerator), and cellular phones have no significant effect, per the FDA. We do recommend that calls on cell phones should be answered on the side opposite to the device. Very powerful magnets, such as those you might find in a junkyard to lift discarded automobiles or contained within the cases of a powerful stereo speaker, the electromagnetic field near an automobile ignition system, or arc welding should definitely be avoided. The main concern is that a very strong electromagnetic field temporarily deactivates the ICD. This effect persists only as long as the patient is in the field, returning the ICD to full function as soon as you move away from the magnet.



A CHAPTER FOR MEN: TAKING THE CHALLENGE OF SEEKING HELP

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At this point in the book, you have read about the personal experiences of a handful of ICD recipients as they managed the challenges of their cardiac health and ICD. One thing they have in common is that they developed a healthy perspective. For some of them, developing this perspective was not immediate or easy, but happened over time and with help from others. Research on ICD patients indicates that all too often they experience clinical levels of psychosocial distress (Dunbar et al. 2012). In other words, they struggle with things like anxiety, depression, relationship problems, health worries, and so on. That is certainly understandable. The situation that brings people to the point of needing an ICD is often unexpected and upsetting. This chapter will discuss some reasons why men may experience psychosocial distress, why we are often so reticent to seek help, and why seeking help is the smart, commonsense decision that men should make.

Psychosocial Distress in ICD patients

Research has found that rates of anxiety and depression in ICD patients range from 10-46% (Dunbar et al. 2012). Rates of post-traumatic stress disorder were reported at 21% of patients in one recent study (Kapa et al. 2010). These figures are much higher than for the general population and are not surprising given that getting an ICD is accompanied with troubling health news and may also have come after experiencing a life-threatening cardiac event. In our clinical practice working with cardiac patients with psychosocial distress, we encounter patients who experience many concerns including fear of heart disease, fear of the unknown, fear of death, fear of living with an ICD, fear of exertion, fear of ICD shock, fear of overall health, fear for their families, financial worries, sexual worries, occupational concerns, and so on. What is also of concern is

that of the high number of ICD patients who experience psychosocial distress—*over half of them do not seek assistance for it* (Hoogwegt et al. 2012).

The Challenge of Seeking Help for Psychosocial Distress

Numerous studies have shown that men are not nearly as quick to seek help for psychosocial distress as women (Addiss & Mahalik, 2003; Oliffe & Phillips, 2008). Addiss and Mahalik (2003) identify one contributing factor to why men do not seek help as something they term “masculine role socialization.” Men are socialized to embody qualities such as toughness, independence, aggression, and emotional control. In keeping with these values, men are more likely to be risk takers with their health rather than health promoters. Asking for help is often associated with perceived feminine values such as fragility, gentleness, and nurturing—all opposites of traditional male values. A study by Robertson and Fitzgerald (1992) found that the men who most strongly endorsed those values also had the most negative attitudes about seeking psychological help. Not only do men not seek help, they often actively *resist* help. There are costs involved in not seeking help in resolving depression and anxiety. Irritability, lack of energy, inability to concentrate, inability to enjoy the things you once enjoyed, problems in relationships, and lack of sexual interest are among the symptoms and consequences of untreated psychosocial distress. Heightened levels of psychosocial distress in ICD patients may also place patients at higher risk for ICD shock (Whang et al. 2005).

No one wants you to be alone in dealing with depression and anxiety, but all too often that is the way men decide to overcome this kind of distress. While values that men commonly esteem, like being independent and self-sufficient, are useful in some realms, they can be detrimental in trying to overcome depression or anxiety because men are more likely to try and “push through” or “work it out,” becoming even more distressed when their efforts do not seem to help. Men may choose behaviors that ultimately exacerbate the underlying depression or anxiety such as turning to drugs or alcohol or trying to escape their problems by over involvement in work or hobbies.

One of the best things you can do is to recognize that you are not alone. The stories of the men and women in this book help ICD patients know that they are not alone in their experience of living with an ICD. We have all heard about famous people in history who struggled with psychosocial distress. Abraham Lincoln suffered with severe bouts of anxiety and depression, including suicidal thoughts. The playwright Tennessee Williams, the scientist Isaac Newton, writers Charles Dickens and Ernest Hemingway all battled anxiety and/or depression. Winston Churchill, the Prime Minister of Great Britain during WW II, nicknamed his reoccurring depression “the black dog.” More recently, hall of fame quarterback and sports analyst, Terry Bradshaw, described the battles he has had with depression. In his words, “It's hard for me to put into words the horrific feeling of being depressed. It is the most sickening feeling in the world when you believe you are miserable and you're all alone.” (Morgan & Shoop, 2004) He has also been transparent in describing steps he has taken to get help.

Many segments of society are working to rewrite the norms for male behavior to make seeking help for psychosocial distress the smart, commonsense choice instead of a last resort. The National Institute of Mental Health [NIMH] instituted a campaign entitled *Real Men, Real Depression* (RMRD) that detailed the experiences and journeys of five men who suffered depression. You can view their stories and other good information at

<http://www.nimh.nih.gov/health/topics/depression/men-and-depression/>

Helpful information concerning anxiety can be found at

<http://www.nimh.nih.gov/health/topics/anxiety-disorders/>

Important steps ICD patients can take to reduce stress, regain a sense of balance, and improve psychosocial health include doing such things as educating yourself about your ICD and health condition, communicating concerns to your family and healthcare team, and re-engaging in enjoyable activities. Activities that can specifically help

reduce stress include meditation, yoga, exercise, hot baths, reading a good book, immersing yourself in a hobby, listening to peaceful music, or any other activity that you find relaxing. Resources that include more detailed information include:

<http://open.umich.edu/education/med/resources/icd-connection/2012>

and

<https://circ.ahajournals.org/content/127/4/e426.full>

If recommendations described by these resources are not working to resolve your psychosocial distress, then the smart thing to do is take action and seek a consultation with a professional mental health care provider. If you don't know who to approach, your primary care physician knows of such professionals and can help.

How do you know if that is a good step for you? Symptoms of anxiety or depression include:

- lack of interest in life
- poor appetite (or eating too much)
- sleep problems
- difficulty concentrating or memory problems
- fatigue or loss of energy
- irritability
- feelings of guilt, worthlessness, or helplessness
- sadness
- thoughts of suicide
- excessive worry
- restlessness or feeling on edge
- physical problems like muscle tension, headaches, sweating, or nausea
- being easily startled

While most of us have experienced many or all of these symptoms at some point in our lives, if these symptoms are persistent (occur for more than two weeks) and disrupt your normal

functioning, then that is a good sign that it is time to seek a consultation.

What can you expect when you visit a mental health provider

While providers may differ in style, the following are common procedures that you can expect. First, he or she will ask you to describe the most pressing concerns that you have. Just use whatever language you have to describe what you are experiencing. This can be a challenge in and of itself. Some men are not very adept at describing what they are feeling, perceiving that something simply is not right, but not really able to use many adjectives. There is even a term for that called “alexithymia” that literally means “without words for emotions.” Just do the best you can in describing how you are feeling. Your provider will help by asking you follow-up questions about your concerns that will help in getting a fuller understanding of what you are experiencing.

After this, your provider will likely ask a series of questions that may not seem to have anything to do with the problem at hand. He will get a brief personal history that will cover areas like relationships with family and friends, education, occupation, personal interests, health, use of alcohol or drugs, and current living situation. This information helps the provider to better understand your background and identify less obvious factors that may be contributing to your distress. While in some cases there is nothing pertinent in a patient’s history that is related to the current distress, there is often information that helps inform the clinician about additional ongoing stressors besides one’s ICD and cardiac condition. Based on this information and your needs and goals, the provider will work with you to develop a plan to decrease your anxiety or depression and to increase your life satisfaction.

The Case of Stephen

For example, one patient (we will call him Stephen) came to our clinic reporting a high level of anxiety that began after experiencing two post-implantation shocks several months prior to our first visit. These shocks were “inappropriate,” meaning that they occurred as a

result of non-life-threatening arrhythmias. His device was reprogrammed to reduce the likelihood of this happening again. Sometime after these two shocks, Stephen began experiencing “phantom shocks” up to several times a week. Phantom shocks are patient-reported shocks that never actually occurred. The patient perceives a defibrillating shock when in fact, upon interrogating his device, it is revealed that there has not been one. Understandably, this was very troubling and distressing for Stephen as it was very hard for him to believe that he had not been shocked.

Upon getting his personal history, several important events came to light. He had recently retired from an extremely stressful job and moved to a new location several hours away. After years of working long hours, he now had lots of free time on his hands. A typical day consisted of sleeping late, surfing the Internet, and drinking alcohol.

Stephen initially stated that he was satisfied (although not necessarily happy) with both “doing nothing” and consuming large amounts of alcohol daily. Stephen was bright, engaging, and affable, yet he was burned out from so many years of work. He had not developed a network of friends in the new area, nor had he developed many hobbies or pursuits since retirement. Research has shown that one of the best things cardiac patients can do to restore peace of mind and contentment with life is to re-engage in meaningful, enjoyable activities and relationships after their cardiac event. We encouraged Stephen to pursue a few activities with which he had been minimally involved like singing in a barbershop chorus and joining a local civic organization. It is also important to work on reducing anxiety, so we taught Stephen anxiety-reduction techniques like deep breathing and progressive muscle relaxation.

We also explored Stephen’s drinking habits. Stephen had established drinking patterns during his employment days as a way to cope with stress. During retirement he had maintained those patterns as a way to cope with boredom and general dissatisfaction with his life and longstanding bitterness over previous life events. We discussed research with Stephen that indicated that the physiological effects of cocaine were associated with increased phantom shocks in ICD patients (Jacob et al. 2010). While the physiological effects of

cocaine are different than that of alcohol, we suggested that it was possible that his excessive drinking could have an influence on his shock experiences. While Stephen had been willing to socialize more, he was not yet ready to alter his drinking behavior.

During our initial few sessions, Stephen experienced phantom shocks that had been “so real” that he had contacted his physician to have his device interrogated. In all cases, no shock had occurred. On a subsequent visit Stephen announced that he had not had a single phantom shock over the previous two weeks. He also revealed that he had decided to stop drinking after our last session because he was concerned that alcohol consumption might be related to his phantom shocks.

We saw Stephen several more times over the course of the next two months and he continued to limit his alcohol consumption and remained free of phantom shocks. He also reported feeling much less anxious and more at ease. During this period, Stephen began volunteering at the local hospital and started a fitness program at a nearby gym. We ended treatment with Stephen after eight sessions as his anxiety had markedly diminished, he had become excited and re-energized about his life and his health, and he no longer had concerns about his ICD or phantom shocks.

Stephen had the benefit of seeking consultation at a site that specializes in providing mental health care to patients with cardiac concerns. You may not know where to find specialists in the field of cardiac psychology. However, your physician will be able to recommend a mental health provider who has a background in providing psychosocial care for patients who also have health/cardiac concerns. In the event that is not the case (e.g., you live in a rural location with few providers) then it would still be beneficial to seek general mental health support. In Stephen’s case, any qualified professional provider would be able to ascertain the existence of problematic anxiety and the negative effects that his drinking behavior and lack of engagement in life were having on his anxiety. In your case, a qualified mental health provider can be a great step toward eliminating depression and/or anxiety and regaining hope and excitement about your future.

In Conclusion

Every case is unique, and yours certainly is as well. Dealing with cardiac concerns and an ICD can be stressful and overwhelming. Unfortunately, there are many erroneous messages in our society that lead men to think that seeking help for navigating these issues is a sign of failure. Hopefully, you agree with us that those messages are misguided and detrimental to your future health. We want you to view seeking help as the smart, common sense approach to improving your health, and we encourage you to take the challenge of seeking help if warranted. The benefits are great. The decision and your future are yours.

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