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CHAPTER 5: YES, I'D LIKE TO USE ONE OF MY LIFELINES!

Phyllis

I imagine it was like a scene out of the TV show, *ER* with bells sounding and buzzers chirping, nurses and doctors running down the hall, holding their stethoscopes, white coats flapping. As I lay watching Saturday Night Live, I heard the loud slapping of their feet pounding the hallway floor and wondered who they were running to attend to. When they burst into my room, I realized it was me!

It was a Saturday night in March and I was in the cardiac ward of the University of Michigan hospital. At 36, I was probably the youngest patient on the floor. I was into the second weekend of my stay and figured I must be pretty sick because I had been there for almost two weeks and they still didn't know what was wrong with me. Lying in my bed, watching some silly comedy skit, I was unaware that my heart rate had skyrocketed within a matter of seconds. But the monitors had seen it and that's what sent those docs and nurses bearing down on my room.

John, the resident, burst in first and snapped on the light, his eyes wide and wild as he ran to my bed. He was followed by two or three other nurses and they all surrounded me. First they looked up at the monitors and then down at me. Up then down. Up then down again. Something wasn't right. Then finally John said, "Hey, how are you doing?" Although I answered fine, it was obvious something wasn't fine since the cavalry was in my room. The monitors at the nurse's station had said my pulse was somewhere around 280, which had sent them racing to my room. They checked my pulse manually, first at my wrist, then at my neck. But just like that, my heart rate was back to normal.

Before that night in 2006, I really hadn't given too much thought to my heart rate. Like others, I would stop and check my pulse when my step aerobics instructor told us to. Often mine would be on the high end of the scale he suggested, but since I didn't feel bad or sick, I just chalked it up to my joy of exercising.

Years earlier I had started working out, mainly as a way to escape from my job as a college residence hall director. At first I just liked being off campus and hanging out with "grownups." But after a while, I found I really enjoyed exercising. Step aerobic classes, kickboxing, balance boards, Pilates—if it was new and different, I wanted to try it. After six years being active, I had lost about 50 pounds, three dress sizes and countless inches. I was in the best shape of my life. Then in 2005, that all changed.

Due to a condition unrelated to my heart, I had a surgery that kept me bed-bound in the hospital for over a month. After a two month recovery to get myself back to walking again, I resumed my usual exercise activities. However, I found myself getting more winded earlier in my workouts and at night, I could hear a "gurgling" in my chest when I laid down to sleep. At a normal follow-up appointment with my surgeon, I shared my concerns. He noticed my heart rate was fast

and abnormal, but didn't believe it had anything to do with the surgery they had recently performed. He suggested that I follow-up with my primary care physician.

My PCP arranged for me to see a cardiologist who specialized in ICDs. After running some tests, he saw that I had an arrhythmia but he didn't know why. He then noted that it was very likely that I would eventually need an ICD to protect myself from a sudden arrhythmia that might be fatal. I may have heard about arrhythmias before, but this was certainly the first time I ever heard of ICDs. I questioned why I should get this device, if he didn't know why I had arrhythmias. Although he did explain the procedure, the device, what it could do and why I needed it, I didn't get the impression that getting one was something I immediately needed to do. I could decide to get an ICD or not.

I left that appointment not ever expecting to have to make that decision. I fell back into my normal routine and began seeing Dr. Dyke, who would become my primary cardiologist. He put me on a regimen of anti-arrhythmia drugs and took a "wait and see" approach, monitoring me for about 6 months while he tried to figure out what was wrong with my heart. During this time, I had an opportunity to go with my sister to Orlando for her company's annual conference. With Disney World and Universal Studios just down the road, I was excited to go, as both of us are amusement park and roller coaster junkies. I asked for Dr. Dyke's blessing. He gave it, but instructed me to stick to land-based rides and forego the roller coasters.

Not ride rollers coasters! Was he insane?! I had been riding coasters since my head first cleared the height limit. Visiting the amusement park Cedar Point in Sandusky, Ohio was a hallowed family tradition each summer, sometimes twice. Forget the merry-go-rounds and ferris wheels, we were roller coaster girls. So much so, that my sister and I would joke that we'd be two old ladies with grey hair, in line for the latest and greatest coaster. We'd never stop.

July 19, 2005. That was the day I rode my last roller coaster—twice. We had stayed two extra days after the conference and giddily strapped ourselves into the Spiderman ride at Universal Studios Island of Adventures. Technically it was not a roller coaster, since it doesn't leave the ground. It does, however, include a virtual 400 foot freefall experience. I did not know this.

Normally, I could vividly recall the details of almost any ride. This one is a blur. Sitting next to my sister, who kept pointing out little things for me to see, I had started sweating. I'm not a big sweater, so I knew something was a little off. My heart pounded quicker and it began to get hot in the ride. Even with the scant four minute length, I was ready for it to be over. When it came time for the freefall, I closed my eyes. This was the first time—ever—I had closed my eyes on the descent, the best part of the ride. Afterwards, we'd normally chat excitedly about what we liked best and replay the experience in our minds. This time, I just wanted to sit down and feel the breeze (in Orlando?!) on my face. I felt jittery and it was hard to breathe in the stifling humidity.

Unaware of the distress I was concealing, my sister went off to ride the Incredible Hulk roller coaster. While she was gone, I calmed myself down and talked myself out of thinking I just had an arrhythmia. Of course, now I know I did. Even so, I sat with jealousy watching my sister scream her lungs out as she experienced weightless zero g's and barrel rolls on the Incredible Hulk coaster. I wanted to again feel the rush and excitement and lamented the fact that I probably never would. After her coaster ride, my sister was on a high and eagerly asked if I wanted to ride the Spiderman again. I think she sensed my sadness and wanted to cheer me up.

Part of me didn't want to go through that dizzy feeling again. But not wanting to show any weakness—after all this was my comrade in coasters—I said yes. This time, I closed my eyes through the whole ride. I knew then that this part of my life was over. No more Cedar Point, which held countless memories of family fun. No more dreams of riding roller coasters well into my 50's. No more “sisters only” vacations centered around amusement parks. I spent the next day and a half riding grandma friendly things like “Dumbo” and “Cat in the Hat.” Boring.

Summer ended and Dr. Dyke continued to schedule me for tests to confirm or rule out possibilities for my arrhythmias. I can no longer remember all the tests I did but sometimes, in medicine, figuring out what the problem is takes a lot of figuring out what it's not. So, I had been giving my same story to everyone who walked in the door. And, that was a lot of people. They all wanted to test their theories.

Was it an infection? No. Was it a heart attack? No. Was it related to my other elusive cellular condition? No.

Finally something started pointing Dr. Dyke in the direction of a condition called sarcoidosis. I now know sarcoidosis as the disease that contributed to the death of comedian Bernie Mac and professional footballer Reggie White, but at that time I had never heard of it. Sarcoidosis is a disease in which abnormal collections of chronic inflammatory cells, aka granulomas, form as nodules in multiple organs, particularly the lungs and lymph nodes. Lung scarring or infection may lead to respiratory failure and death. The majority of sarcoidosis sufferers have the lung version.

However, I am not normal. I have cardiac sarcoidosis. Of course I would have to have one of the more rare versions. Symptoms can range from conduction abnormalities to fatal ventricular arrhythmias. I've read that, although cardiac involvement is present in about 20-30% of sarcoid patients, only about 5% are symptomatic, like me. Similar to Reggie White, I could suffer a fatal arrhythmia which could lead to my death.

Having a name to what's wrong with me didn't necessarily make it easier to accept. Especially since not much is known about why people, especially African American females, get sarcoidosis. But I began reading up on the disease, getting a crash course on the inner workings of the heart. Terms like V-tach and V-fib became part of my everyday vocabulary. Even so, it took a simple story of a train on a railroad track to put into perspective what was happening to my heart. This is the story, as close as I can remember:

“Your hearts primary function is to pump the blood through your body, giving you life. Electrical impulses tell your heart to contract, or as you might say, beat. Now imagine the electrical impulses as a train and the train tracks are what the electrical impulses follow in order to get to its destination, which is where your heart beats, or Beatsville! In a normal heart, the train follows the shortest, most direct route to Beatsville. Remember those old silent movies where the villain lays his hostage across the train tracks to stop the train and rob it? That hostage on the train tracks is the sarcoid granulomas on your heart's electrical tracks, which can impede the train from reaching Beatsville (in a timely manner or even, ever). This causes the train—the electrical impulses—to have to jump the track. In the worst case scenario, the train stops. But in your case, your train jumps to another track, running out of control and now you have a runaway train, or an arrhythmia. You need an ICD to stop the train from jumping the track and running out of control.” A simple story but it made sense.

Dr. Dyke continued scheduling me for tests to try and figure out where exactly the sarcoid was located on my heart. The thought was that if they could remove the sarcoid granulomas, or that hostage lying across my electrical tracks, they could stop the arrhythmias. They biopsied a part of my heart, but the part they biopsied didn't have the sarcoid and they couldn't locate it. So he ordered a procedure called an ablation. In its simplest form, an ablation is the removal of material from the surface of an object by vaporization, chipping or other erosive processes (source, Wikipedia). Say what?!? I remember once some kids had spray painted the side of my high school and a company came out and essentially did an ablation by sandblasting the graffiti away. So, that was what they were going to do to my heart!

Seriously though, non-surgical ablation, used for many types of arrhythmias, is performed in a special lab called the electrophysiology (EP) laboratory. During this non-surgical procedure a catheter is inserted into a specific area of the heart. A special machine directs energy through the catheter to small areas of the heart muscle that causes the abnormal heart rhythm. This energy "disconnects" the source of the abnormal rhythm from the rest of the heart (source, WebMD). It would have been sweet, if it had worked. But it didn't. And a few months later, my train jumped the track.

It was a normal work day and I was trying to finish up a project before the end of the day. I stood up at my desk to go to the bathroom and immediately got dizzy. I stood there for a moment or two and held on to the desk to stop the room from spinning. One of my co-workers happened past my office at that exact moment. She was shocked to see my face was white as a sheet and ashen. She helped me sit down and brought me a glass of water.

Trying to stop her fussing, I said I was okay but she kept telling me I didn't look okay. Luckily my PCP's office was right across the street in the student health center, so I went over to get a walk-in appointment. Upon running an electrocardiogram, my PCP ordered me to go directly to the University hospital. Do not pass go, she said. She had called ahead and they were expecting me in the ER. She wouldn't even allow me to drive myself, even though the hospital was just a few blocks away. I would later find out that I had third degree heart block. Oh boy!

So it was here, at the University of Michigan hospital, that I stayed for about two weeks as they tried to figure out what to do next. A parade of doctors, nurses and specialists descended on my room. However, I was an exemplary patient, never grouching about the tests I was scheduled for, only requiring that anyone who wanted to enter my room to introduce their self and the reason for their visit—had to do it in layman terms. I told them if they couldn't make me understand it, they weren't good doctors! It was the only way I could keep from feeling like a human lab specimen.

I became quite the celebrity, since I was always up and had my "face" on at 6am, cracking jokes with the residents as they made their morning rounds. Many doctors and residents would stop by just to say hi and to follow my case, even if they weren't assigned to me. It was a fun room because I never had my TV droning on, like the other patients. Since I worked every day, I had no interest in watching Maury Povich (You are not the father!) or the People's Court. My radio was always tuned to the local R&B station, a party just waiting for some party-goers. The staff teased that I was the only patient on the floor who always had at least one visitor a day.

Although it was kinda fun being in the hospital, it really wasn't until that fateful Saturday night, watching Saturday Night Live and having my heart rate skyrocket, did the full weight of my condition come crashing down on me. After the ruckus died down that night and the staff left my

room, John, my favorite resident, returned to check on me. We sat in my dark room—me lying in bed, John perched at the window—and reviewed what had happened. Since I hadn't really felt anything, I kept telling myself it wasn't so bad; John thought otherwise. He reached out to my hand, concern lacing his words.

He explained how sudden my heart rate could elevate and subside. Because of that, he wanted to move me to the Cardiac Intensive Care unit in the hospital. Here I would be closely monitored and have a staff member right outside my door, just in case. He also wanted to consult with a cardiologist who specialized in ICDs. He felt strongly that I needed one now.

The next morning, I was moved to the ICU and was to stay there until my scheduled ICD implantation, which was three days away. Even after talking further with the specialists about ICDs, I still wasn't too keen on getting this device but kept remembering John's concerned voice from the previous night. As I think back, it really was his concern that made the difference. Of course, as a doctor, he would present all the options for me to make an informed decision to protect myself. But he spoke to me that night as a friend and it really touched me. In addition, the other residents all came by after they heard I had been moved and they too shared their concern for me.

March 6, 2006. I was not mentally prepared when they told me I was scheduled a day early to get my ICD. What?! But no one was around. It was a Monday, all my friends were working and, wouldn't you know it, not a soul came to visit me that day (My parents were deferring their visit until the next day to be around for the surgery). I couldn't get anyone on the phone and was trying hard not to flip out and leave weird "my-life-is-passing-in-front-of-my-eyes" messages on my sister's and parent's answering machines. I had begun to panic, thinking I couldn't go into surgery without seeing or at least talking to my parents, when my mom finally called. She tried to calm me down by phone but it just wasn't the same. We prayed together, then hung up.

While I laid there staring up at the ceiling, waiting for them to wheel me away, the oddest person walked into my room. It was a Catholic priest, looking for the previous occupant of my room (who I knew had unfortunately passed away). I tentatively asked if the priest would pray with me, even though I was Lutheran. He chuckled and said we were all sisters and brothers in Christ. He began praying. Hearing the similar words of his prayer, I felt a sudden calmness and knew everything would work out all right. Now I understand the saying, "He might not come when you want him, but God is always right on time." Amen!

Waking up, it was still hard to believe I had something implanted near my heart. Well, that was until I tried to lift my left arm. Oh, the pain. The next few days were a blur and I couldn't keep anything down because of the anesthesia. But I still managed to wake up for the morning rounds to talk and joke with the residents. That was the best part of my day.

The rest of the day I began to grow more and more concerned about my heart rate, sometimes staring at the monitor for minutes on end watching my heart rate increase (oh no!) or subside (phew!). The doctors had conservatively set the upper limit of my ICD at 150, which is pretty low, to protect me from the arrhythmias they couldn't predict. Afraid I might increase my heart rate to the point of shocking myself, I rarely got up from my bed or walked around my room. I even stopped laughing. The doctors began to worry about me. John and the other residents tried to cheer me up, one even made me a cd of songs that he knew I liked. Each day they'd talk to me about how the ICD was there to protect me and that I shouldn't be afraid to live.

Leaving the hospital a few days later, with my left arm in a sling, should have been a celebration. Instead, it was the scariest things I'd ever done in my life. I had been in the hospital for over three weeks, protected by scores of people around who knew me and were trained to help me, if anything were to go wrong. Walking from the car to my apartment, I was very aware of everything going on in my body and attuned to every little thing. I secretly kept checking my pulse at my wrist or neck. If my heart started beating faster, I was concerned. If it skipped a beat, I was concerned. If it beat correctly, I was concerned.

That night, I tried to get a comfortable position in bed. I couldn't lie on my back, because it hurt my shoulder lying flat. I couldn't lie on my preferred left side because of the sling. In addition, on my left side, I could hear my heart beating against the mattress. Imagine listening to your heart beat—beat—beat—skipped beat—beat! That just didn't work. I stayed awake all night, getting only a few minutes of sleep.

My sister had driven in from Pittsburgh to stay with me for the week. When it came time for her to go, I cried. I didn't want to be alone. What if something happened? What would I do if I got a shock? For my peace of mind, I ordered the Lifeline systems for use in my apartment. Yes, at 36, I wore a button similar to that silly commercial, "Help I've fallen and I can't get up." I didn't care how stupid it sounded or looked. Actually, the "pendant" is quite fashionable—NOT! But I felt safe. In my apartment, that is. Out in the world was another story.

I was convinced I could control whether or not I got a shock. My theory? Don't do anything to raise my heart rate! I began wearing my exercise heart rate monitor all the time. To keep my heart rate down, I would walk very slow everywhere I went. I avoided stairs and inclines. It got so bad that before agreeing to go somewhere, I had to research the environment. What floor was it on? Was there an elevator? How far was the elevator from the entrance/exit? A lot of things needed to fall into place for me to feel okay about venturing out.

Afraid of getting a shock while driving, I convinced the hospital social worker to "prescribe" me a discount ADA (**Americans with Disabilities Act**) pass for the city bus & cab system. With this pass, I got reduced cab rides to and from any medical appointments or rides to take care of things like grocery shopping or errands. Sometimes we'd have to stop and pick up other riders, making a short trip to the doctor's office take several hours instead of 60 minutes. But I didn't care, as long as someone else was around to help me, should I need it. I didn't like being alone.

There was no one around the first time I got shocked. Tired of watching my waistline expand (due to medications & inactivity), I tried to get back into my workout routine. Staff at the Cardiac Rehab Center had suggested I start with 15 minutes of walking on the treadmill on the days I didn't attend Phase I rehab classes. Treadmill, really?!? I was used to complicated step aerobics routines and kickboxing not a boring treadmill, but I was willing to give it a go. Pre-ICD I had been a daily fixture in my apartment's exercise room, regularly bringing my aerobic step and video tapes to play in the VCR or my sparring gloves for kickboxing. So one day after dinner, I decided to walk myself over to the clubhouse, which was about 350 feet away from the building I lived in, and do my 15 minutes on the treadmill. All my life I had counted things to occupy my mind, so yes, I knew it took about 350 steps to get to the clubhouse. Weird, I know!

Before leaving I called my mom to let her know where I was going. She knew how distraught I was with my weight gain and I groused with her about just how effective could 15 minutes really be in peeling off the pounds. Normally I would exercise for at least an hour each day after work, and

there would be 2 or 3 other residents in the clubhouse. But at 7:00 pm, there was no one else around and, even though there was a security camera in the room, no one was monitoring it since the leasing office was closed.

It all happened so quickly. I stepped on the belt and started the treadmill going, slowly beginning to walk. I guess my heart rate had been a little elevated from the walk over, because when I casually looked down at the monitor on my wrist a few minutes later, it read 148. 148!?! If accurate, that was only 2 points away from the dreaded 150. And I knew my monitor was accurate, as I had calibrated it with the high tech monitors they used at Cardiac Rehab. I quickly sat down on the nearest thing I could find, a recumbent exercise bike, and tried to control my heart rate through breathing. No dice. Since I was just short of flipping out, deep breathing was not going to stop it. It now read 158. I braced for the shock I knew was coming.

Boom! The first time is really not that bad. Since you have nothing to compare it with, it's just something that happens and you experience it with a little bit of awe tinged with fear. Everyone always wants to know what it feels like. There is really no way to accurately describe it. I guess if I had to, I'd say it feels like a very large firecracker went off in your chest. You can feel it deep in your chest as your heart knocks against, what I imagine, is your rib cage. I'm not sure if it makes a sound that others can hear, but I could hear it. It sounded like a deep, booming clap of thunder that comes out of the blue and startles you, no matter what you're doing. The scariest part is not knowing when it's going to happen.

But I had my heart rate monitor on, so I knew that it was going to happen. And, I could see that my heart rate was not subsiding, so I knew it was going to happen again. Boom! Slowly my heart rate started to decrease. I sat there frantically searching my mind trying to figure out what to do. Then it came to me. Even though I had my bulky cell phone (remember this is 2006!), I didn't know the address to the clubhouse and I didn't think I could go through explaining what was happening to some random person at 911. In my mind, I needed to get to the safest place I knew—my apartment. I needed my Lifeline. So I began the walk home.

I made it out of the clubhouse and down the pathway before getting shocked again. That was #3. In my mind, I just keep repeating, "I need Lifeline"...20 steps...Boom!..."I need Lifeline"...20 more steps...Boom! Thinking back, I'm not sure how I managed to stay on my feet. I guess it was my single-minded determination that kept me going. I needed my Lifeline.

Finally, by counting my steps, I reached the door to my apartment building. Boom! Another shock. Once inside I quickly pressed the Lifeline button around my neck, knowing that Lifeline would send an ambulance even if I couldn't verbally respond. Thankfully, I lived on the first floor, because I'm not sure I physically could have handled climbing a flight of stairs. With uncannily steady hands, I used my key to open the door to my apartment. Boom! I walked directly to the Lifeline transmitter I kept in the dining room next to the wall phone. I clumsily sat down at my glass topped dining room table, just as my Lifeline call connected. "Phyllis, this is Lifeline. Do you need help?" I turned to the transmitter as if it were an actual person and said, "Yes, I'm getting shocked. I need help now." The representative sprang into action, first calling for an ambulance and then starting to call my emergency phone tree.

When you first subscribe to Lifeline, you set up a list of people who should be called for you in case of an emergency—your first responders. These should be people who can get to you relatively quickly and have access to your residence. Luckily a few weeks earlier I had stepped out on faith and

asked my upstairs neighbors (a couple who I had only talked to in passing) to be my first responders and had given them a key to my apartment (talk about faith indeed!). After receiving the call, my neighbor rushed right down, with her eight month old baby in her arms. Even though she had a key, she courteously knocked at my door before realizing I had accidentally left it ajar. She sat down at the table and after confirming an ambulance was on the way, just held my hand. Just having her there made a world of difference. However, my heart rate continued to be elevated, and each time I got a shock I would let out a short scream, like a hiccup. The baby thought it was a game and she joined in, eerily synchronizing her shouts with mine.

Where I live, the local fire department is the first response team. So a few minutes later, in walk two guys in full fireman gear! (This story just keeps getting better and better!) After making sure I was not on fire, they took my vitals and wanted to get me up on the stretcher for the arrival of the ambulance. But every time I tried to get on the stretcher I got a shock, so I stubbornly refused to move. The ambulance arrived and I still refused. All this time, my connection to Lifeline was still active and the rep could hear everything that was happening. With me connected to Lifeline, my mom had been trying to get through on the phone but couldn't. She called Lifeline directly. The rep briefed my mother and then patched her through the Lifeline transmitter.

Out of the blue I hear, "Phyllis Arlene, this is your mother. Get up on that stretcher so these good people can help you!" Well, that did it. Her voice brooked no refusal. I dare you to tell me what adult, when hearing their full name called out by their mother, would not comply. She meant business. I got on the stretcher, receiving a shock for my efforts. They wheeled me to the ambulance and then drove to the hospital, where I stayed for several days. When it was all said and done, I had received a total of 11 shocks. Wisely, the doctors raised the limit on my ICD to 178, instead of 150. Hallelujah!

I wish I could tell you that I never was shocked again. Unfortunately I developed a real panic driven aversion to shocking. I believe I had at least 2, maybe 3, more incidents of shocking that year that led me to the hospital. I do know that one time, the shock was due to an actual arrhythmia, but the other times were all anxiety-based. I began avoiding locations I had been shocked in, which included my shower. I became so afraid to shower, that I convinced the hospital social worker I needed help bathing (as you can see, I'm a pretty persuasive woman!). She "prescribed" a bathing assistant to come to my house every other day. She would stand in the bathroom, while I showered with the curtain half open—oh boy, did water spill everywhere! Everyone was sympathetic, but I could tell they were starting to get fed up with me. And so was I.

My PCP recommended a therapist to help me cope. So twice a week, I'd take an ADA cab(!) over to see this guy and we'd talk about all sorts of things, including my fears of being shocked. There were lots of tears and lots of grieving for my former self. I truly believe it helped, and after a while I told myself to snap out of this funk that I was in. And really, I think that's what did it. I had just had enough. Enough of feeling sorry for myself. Enough of being scared. Enough of being always on alert. Everyone, I reasoned, had something wrong with them. Mine just happened to be a really weird thing that I couldn't control. Deal with it! And, so I played the hand I was dealt.

I went back to work and started driving again. I rearranged my work schedule to allow me to exercise at the Cardiac Rehab Center. I would attend Phase III, which is like a health club for patients who are no longer participating in the mandatory rehab classes. There are treadmills, elliptical machines, bikes, weight machines, free weights, swiss balls, and a cardio room complete with a dance floor, music and a wall-to-wall mirror—basically anything you'd find in a health club.

But with the added benefit of exercise physiologists and nurses to respond if anything were to happen. After you arrive, they take your blood pressure and chart your weight, then off you go. You are free to do your own thing, or if you ask, any staff member will work out with you. They'll even check your heart rate intermittently, if you don't have your own monitor.

Since I knew all the staff and interns, it was a comfortable place to work out. My favorite machine to use was the elliptical. But one day all three were taken, so I decided to tackle my old nemesis—the treadmill. Just thinking of getting on that thing caused panic. So I asked one of the exercise physiologists, who knew my history with treadmills well, if he would just walk on the treadmill next to me and talk while we both walked. The first time, I was still so scared that I didn't really participate in the conversation because that, of course, would raise my heart rate. So he just talked to me about what was happening in his life. The next few times got better and after about 4 times, I was able to get on the treadmill sans a chaperone.

Unfortunately, the Cardiac Rehab Center doesn't have health club hours and it closes at 6 pm. Normally, I'd leave my office at 4:30 on the dot, and drive the few miles to Domino Farms where Phase III is located, getting there by 4:45. I'd have at least 1 hour to get in a good workout. However recently, because of afterhours work events and new responsibilities helping my mom, I had been unable to get in during those limited times. Frustrated that I was missing my workouts, I decided to buy an elliptical machine for my home use. I have recently bought a house and turned the room designated as an office, into an exercise room instead. And, of course, I have Lifeline in my new house.

If this were a made-for-TV movie, this would be the part where the actress playing me would show how I've overcome adversity by running a 15K marathon or climbing a snow-capped mountain, standing at the top shouting, "Drago" like Sylvester Stallone in that *Rocky* movie. But it's not and, no story can be neatly wrapped up with a pretty little bow. Yes, I still have my freak out moments, here and there. Yes, I still take a boat load of pills to control my arrhythmias. But there are good things too. Like last fall, I started ballroom dancing lessons. I'll admit that the first few times I wore my heart rate monitor (just to get a feel for things, thank you), but now I'm practically old salt at it, and I know when to put on the steam and when to pull it back some. And, since I wear black & white swing shoes with the ribbon laces tied in neat bows, I guess things *can* be wrapped up nicely!

With the exception of one appropriate shock in January of 2008, I have been shock free for five years. I have had the battery replaced once in my ICD and continue to see Dr. Dyke on a quarterly basis. In addition, I have the pleasure of seeing the always amusing, Dr. Sisson on a bi-annual basis. He's my pulmonologist and teases me unrelentingly about my love life! Between my three doctors, I'm lucky to have this pretty amazing medical team looking out for me.

When Helen at the Device Clinic first called to ask me to write this chapter, I didn't call her back. It has been six years since I received my ICD and, even though I had spoken on a panel a few years ago at the annual ICD conference for young adults, I really didn't want to go through remembering all the things that had happened to me and trying to get them down on paper. But a week later, I was attending a conference about diversity, when one of the speakers said something that made me pause. He said, "Everyone has a story to tell and everyone's story should be told." So here's my story. I've told it. I don't necessarily feel any better or any worse. But I wanted to write this chapter to help others know that there is someone else out here that has experienced what they're going through and is still standing. I'm still standing and laughing and loving and crying and

dancing and exercising and living, with my ICD. So when Helen called the second time, I answered the phone.

This chapter is lovingly dedicated to my father, Raymond (1932-2011) and mother, Gladys (1937-2012).