

LIVING WITH CRPS

My 60th birthday was on April 16, 2010. This is not how I imagined living my “golden years.” I have been living with CRPS since March 6, 2004, but I am so lucky. I have two wonderful grandchildren, two sons, a wonderful husband (who by the way is an above the knee amputee so he keeps me motivated), and a job I love working as a Nurse Practitioner at The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins. I am able to work 20 hours a week on my Disability Work Incentive Program. And I have my swimming. My grandson text paged me on my birthday “You are the most active person I know, that is why I love you!” To celebrate my 60th birthday I completed a 1500 meter butterfly swim to raise money for The Johns Hopkins Patients and Family Fund. I started this Fund in 2005 when I swam 28.5 miles around Manhattan Island. The Fund assists needy cancer patients and their families with expenses not covered by medical insurance. My grandchildren were at the pool when I did the swim to help me and cheer me on. Over the years they have helped with many fund-raisers, most of which involved swimming. I am hoping by my example they are learning that nothing is impossible and helping others brings joy and happiness.

January 4, 2004 started like most other days since we purchased our 1896 home, built to be the Rayville, MD Coronet Band Rehearsal Hall. In April 2003, we moved into this building that needed to be renovated top to bottom. We decided to do the renovations ourselves. By January 4, 2004, we were seeing a light at the end of the tunnel. My job for that day was to move all of the cleaning supplies from the laundry room to the finished bathroom closet.

Before starting on the house we went shopping. I told my husband Charlie that I really needed slippers; the newly refinished hardwood floors and the painted kid’s step stool I was using to put things on the top shelves of the cabinets and closets were slippery. We looked for slippers, did not immediately see any, so we started home, anxious to get to work on that day’s projects.

At 3:30 PM I placed a newly purchased plush rug on the bathroom floor, got my painted kid’s wooden step stool, and put it in front of the closet. At 4:00 PM I was bringing the last load of cleaning supplies into the bathroom in my arms and had a piece of trash in my hand. When I went into the bathroom I turned towards the toilet and flicked the trash into the trash can. I was turning around as I climbed onto the step stool. When I stepped onto the top of the step stool in my socks my right foot slipped and flew into the air. I hit the edge of the step stool with the outside of my left foot and actually flipped it onto its side (impossible to do even if you tried), hit my right elbow on the door handle, and landed on my back, luckily on the plush rug, not the tile floor. I laid there wondering why I was crying, it was an out of body experience – I was in so much pain. My husband came in and asked if I broke anything. I told him no, but to just leave me alone for a few minutes to catch my breath. I finally agreed to get up and tried to take a step on my left foot with my husband’s help. It was the first weekend of NFL playoffs. I told my husband to pick a game to watch because no matter what I had to go to the ER.

X-rays of my foot showed a Jones fracture with displacement. I was given a prescription for oxycodone for the pain, a small boot, crutches, and was told to see an orthopedic surgeon on Monday. I went to a general orthopedic surgeon two days later. He took more films and as a Nurse Practitioner I knew I was in trouble when he brought other docs in with him to discuss the results. He said all fractures are bad – mine was nasty. He recommended seeing a foot specialist.

Three days after the fracture I went to see the head of Foot and Ankle Surgery at Johns Hopkins. He gave me the option of going right to surgery or trying a cast for 2 months. Since we had planned a trip to Disney World in February that year with our four year old grandson, which included a conference where I was a speaker, I opted for the cast. I continued using oxycodone 5-10 mg every 4-6 hours as needed to control the pain. I kept working full time in a wheel chair and the clinic gave me a special large room where I could see and examine my patients. By March it was obvious that the fracture was not healing. I went to surgery on March 9, 2004. A screw was placed in the bone. Ten days later I was back to work full time in a wheel chair.

By June I was pain free but continued with a big gap in the bone. The plan this time was to do a bone graft from my heel and put another screw in the bone. Apparently the screw did not bring the pieces of bone together so a plate was also placed along the entire surface of the bone. I woke up from that surgery in agonizing pain. The recovery room staff got really angry because they said I was disturbing the other patients but I could not stop screaming. They kept giving me boluses of dilaudid until I started to vomit. They wanted to admit me for pain management but I wanted to go home.

By September it looked like the bone was coming together but I remained in terrible pain. I went back to work 20 hours a week, with the plan to go back full time as soon as the pain subsided. I used a wheelchair and crutches and eventually a scooter to get around. My oxycodone was now up to 5-10 mg every four hours pretty much around the clock. In October when the cast was finally taken off and replaced with a fracture boot I immediately went to a local gym that has two therapy pools, a six lane 25 meter pool, and a masters swim team. The surface of the pool deck was rough, making it pretty safe to navigate with crutches.

I started swimming with a pull buoy (a Styrofoam device that keeps your legs floating without kicking) doing open turns and pushing off of the walls with my right leg. It hurt just having the water move over my foot, but I was determined to get back into the water after being out for 9 months.

Over the next 16 months the pain continued despite numerous medications and procedures. Although my friends and family members said swimming across the Chesapeake Bay, as I had done 11 times before, was an unrealistic goal my surgeon said “You are only a failure if you don’t try.” I placed second in my age group in 2005, with my grandson helping me into the water and me literally crawling over the finish line.

I begged my surgeon to take me back to surgery and take out the hardware. While he

said I had CRPS I was sure he was wrong, that the pain was from the hardware. Although he said the surgery would make me worse, not better, in February 2006, I again went to the operating room. This time they removed a neuroma, cut the sural nerve to the foot, did another bone graft, and removed the plate and screw. Before the surgery a popliteal nerve block (behind the knee) was put in to decrease the risk of progression of the CRPS. Unfortunately the resident who came to change the bag of medication failed to open the connection to the pump that evening. I begged all night for someone to be called to check the pump since it continuously beeped “occlusion” and I was in terrible pain. Instead they just kept giving me boluses of morphine. When the anesthesiologist came in the next morning he could not believe the bag of medication was still full. I was sent home with MS Contin and oxycodone, which did nothing for the pain. In fact, as predicted, after the surgery the pain continued not only in my foot but also up the outside of my calf. After a few weeks I told my surgeon I was stopping the MS Contin since I did not like the side effects it was causing. I continued to take short acting oxycodone, still a 5 mg tablet, but the frequency had increased to every three hours and I occasionally took two or three at a time. I again tried multiple medications and was even recommended for a spinal cord stimulator, which I declined, afraid it would keep me from swimming. We eventually even discussed amputation, but I was told the pain would be wherever they amputated and I would not be able to wear a prosthesis.

When the pain continued three months after the surgery it became obvious that I did in fact have CRPS. With the help of the pain clinic I found a cocktail of medications (including my usual oxycodone) that kept the pain at what I considered an acceptable level. In other words I could still drive and concentrate in the mornings at work, at least in the morning, by early afternoon I had to go home because of pain and fatigue. I decided to go back to work on a part time basis using my scooter and crutches. I even swam across the Chesapeake Bay again in 2006, finishing third in my age group. My surgeon used to say “It is a good thing you are not a runner!” I continued to swim, but had to make adjustments to decrease the pain. In 2008 I received a plaque for finishing the 4.4 mile Chesapeake Bay Swim 15 times. In 2009 I did not make it across; like many others I got caught in the current. They pulled me out against my protests. This has made me even more determined to make it across in 2010.

During the summer of 2009 I was having difficulty concentrating, very bad short term memory, and when it became obvious to me that it was not safe for me to practice as a Nurse Practitioner I took full disability. I saw my internist in September 2009, and she gave me the phone number of the Johns Hopkins Alzheimer’s Clinic and told me to be evaluated. I looked at their web page and it terrified me. I decided before getting saddled with that terrible diagnosis I had to try to get off of the oxycodone to see if it was contributing to the symptoms. At the time I was taking 5-10 mg every 2 hours. I know I should have allowed the pain clinic to help me taper off but I decided to do it myself. I would not recommend that to anyone – it is very dangerous to go cold turkey with narcotics, but I was lucky. On September 30, 2009, I took the first step to getting my life back and stopped the oxycodone. I threw all of my oxycodone away so I would not be tempted to take any. For the first 2-3 weeks I was very ill – I thought once I got it out of my system the withdrawal symptoms would go away, but that did not happen. I craved

oxycodone constantly. The only thing that kept me from going back to the pain clinic to get a new prescription was the thought of the Alzheimer's diagnosis and the hope of returning to work at least part time. Even with the withdrawal symptoms an amazing thing happened after the first few days off of the oxycodone. The fog lifted – everything appeared super crisp and bright – the world was a beautiful place and I wanted to stay in it. I went back to work in the beginning of November, once again 20 hours a week, but this time taking Wednesdays off and going in late on Tuesdays and Thursdays so I could do shallow water classes to music as rehabilitation.

Through all of this I developed severe bilateral carpal tunnel syndrome from crutch use. I am terrified of surgery and luckily have an understanding hand specialist who gives me injections of steroids every 8-9 months. I continued to wear the fracture boot as any shoe caused terrible pain. I decided I just had to suck it up and try to get into a sneaker. When I did this with crutches in January 2010, I tore the lateral meniscus in my bad leg when I turned and everything moved but my leg. I was told to get a different type of sneaker because the fracture boot would make the knee worse. Since I could walk short distances in the fracture boot, but could only put minimal weight on the ball of my left foot in the sneaker, I wore the sneaker to the pool, to the gym, and to work. I wore the fracture boot at home so I wouldn't need to use crutches.

As most of you know this disease just causes other problems to occur as we deal with the pain. When I tore the meniscus in my bad left knee I pretty much totally relied on the right leg. But that just caused more problems. I immediately started having right hip and knee pain that I attributed to overuse. It got much worse over time and when I saw my orthopedic surgeon on April 26, 2010, x-rays were done of both knees and my right hip. I was diagnosed with bursitis in the right knee and hip, but the biggest problem is severe arthritis in the right knee. I was put back into a fracture boot on my left foot with CRPS, this time one that blows up and is smaller and lighter, and I am using crutches, the scooter and a wheelchair to try and rest the “good” right leg. I am trying to look at this as a bump in the road and refuse to get upset or depressed.

So today is April 30, 2010. I am swimming six days a week, doing circuit weights five days a week, but am skipping the biceps and triceps because those weights are aggravating my carpal tunnel syndrome. I don't do any leg machines because of the CRPS pain. I take the shallow water classes twice a week. My grocery store has great scooters and “Helping Hands” so I grocery shop alone most of the time. But I love it when one of the grandchildren comes to help me. I have my grandkids over almost every weekend. Both of my grandkids say when they grow up they will always remember riding on the back of my scooter.

So overall life is good. I accept that there are going to be good days and bad days, but I wake up every morning, assess how I feel, and know I have two choices; go back to sleep and be miserable, or get up with a smile on my face and be happy. I choose to be happy.