My Journey of Hope
by Melanie S. Levine, Ph.D.

It was the Wednesday before Memorial Day weekend, 2009. I was walking down the stairs at work, when I felt a straining in a tendon in my right foot, right under the ankle. I didn't think much of it, as I had had pain in that foot before due to taking dance classes my whole life and working out at the gym. That evening I even went to the gym! The next day, however, things got worse. The pain intensified, and while I was sitting down, my right leg would shoot out without warning. My foot was also beginning to swell and turn this funny color purple I had never seen before. Now this was strange. The next day I could no longer walk. If I tried to put any pressure at all on my foot, I was rewarded with a striking, electric like shooting pain like I had never felt before, all the way from my ankle up through the top of my leg. My foot was also now swollen to almost three times its size and was an awful color. I could not fathom what was happening to me. I decided it was finally time to go see a doctor about this situation, however, it was the Friday of Memorial Day weekend in New York City. Who was in? Almost nobody. I finally found a sports podiatrist willing to see me, so I hopped, literally hopped, shoeless because none of my shoes would fit on my foot, into a cab to this doctor's office. Upon examination of my foot, the doctor wanted to take an xray. So I had to hop down to the xray room. Then he wanted me to put my foot down flat on the xray machine. "I can't", I said. Doctor asked, "Why not?" Is he serious? I am about to cry or punch him in the face. He tells me to do the best I can. Lo and behold nothing is broken. Duh, I could have told him that. So he gives me a shot of cortisone (for the swelling), wraps my ankle in this very tight blue ace bandage and sends me home! Hopping!

Later, my foot begins to swell around the ace bandage! This isn't good. So I cut it off. Now I realize I am not going to get any relief at least until Tuesday because of the holiday. Ok. I can deal with this. I have been through worse, and I actually had a wedding to go to that weekend out east on Long Island. So I called my best friend, explained what happened, and she immediately went to the drug store, bought me some pain relievers, and came to get me. She also lent me crutches she happened to have at home. She took me to the wedding and also outlet shopping that weekend (in a wheelchair). She is a trooper :) That weekend I decided if I can get through a wedding and shopping in that much pain, I can do anything.

Over the next several weeks, I visited 6 more doctors, and their diagnoses ranged from mild tendonitis to "stop being a baby and walk". Um, excuse me? I can barely let you touch me, I can't get my sneaker on, I can't bathe myself, my foot is purple, I cry from electrical currents going up and down my leg, and you are telling me I am a baby? Hmmm...I don't think I have found the right doctor or the correct diagnosis yet. By trade I am a scientist (I am a psychologist), and I know when something is not right. These doctors are not right. Something is not adding up.

My uncle is a podiatrist, but had been away on vacation, nice timing? Finally he is back! I went to his office and he examines me. He says he has an idea what is wrong but would like me to see the podiatrists across the street for confirmation. I say sure. So we get an appointment for that day. As soon as the doctor there sees me he knows immediately what’s wrong with me. He says, "you have RSD". What? What is that? He says, it's a neurological disorder." What???? Of all the things I had imagined, something wrong with my brain I did not. He advises me when I go home to not look it up on the Internet. He would like me to go see a Pain Management doctor. Ok.

So what's the first thing I did? Whipped out my iPhone and looked up RSD. Oh My God. No. No. No. This is not happening to me. But it is then that start I feel thankful that I just have it in a small part of my body, when all of these people I am reading about have it in multiple parts. One of my favorite mantras from my mentor at work is "Do, Don't Stew". So that's what I did. Instead of dwelling on the diagnosis, I began researching pain management doctors, medicines, treatments, etc. My mission became, how am I going to get better? How am I going to beat this thing? I am not going to let RSD win. I am going to win.

It was so helpful to have a strong attitude, but still I was on crutches, and couldn’t even make it to the refrigerator to get water for myself. I couldn't shower, couldn't go to the bathroom without screaming in pain from having to sit down, I couldn't walk up stairs at my parents' house to sleep in a bed so I slept on the couch. When I moved back to my own apartment I couldn't do anything for myself. I would start crying out of nowhere because the striking pain would come out of nowhere. How was I going to manage this? Action.

Luckily I wound up at Weill Cornell Medical Center, seeing Dr. Devin Peck for pain management. He was so kind, gentle and attentive. What a change! He agreed with the RSD diagnosis and put me on Topamax, Cymbalta, and Celebrex. He also suggested physical therapy twice a week. I was so excited to get started. I was on my way to getting better. The Celebrex brought the swelling down a great deal, and within a few weeks the Topamax and Cymbalta helped ease the pain a bit. Whew.

I called Physio Sports Center in NYC and made an appointment with physical therapist Kirsten Cesped. I was very nervous about the PT, however. I had not walked on my foot in many weeks, and I was frankly tired of people touching my foot. When I met Kirsten I liked her immediately. She was friendly and warm and knew a lot about RSD. She asked me about all of my symptoms and made me feel very comfortable. She did touch my foot that day but it was ok. She was very gentle and explained everything she was going to do. Amazingly she even got me to walk a few steps! She knew just the right amount to push me. I began attending physical therapy twice a week, as well as doing exercises at home. In addition, the physical therapy center had a gym, so I was able to start working out again, just my upper body at first. It felt very nice to be somewhat active again. That said, getting to the center was difficult. It was quite a distance from my apartment. I tried first to take the bus, actually two buses, but the proved to be too much for me. So I sucked up the cost and took a taxi both ways. Even getting into the car was sometimes hard, especially in the inclement weather, but sometimes a random stranger would help, sometimes not. On that note, many New Yorkers were very helpful to me when I was on my crutches, holding doors, helping me get on and off the sidewalk in the snow and ice, assisting me in carrying things, but some were downright rude. I learned to appreciate the kind people, but I admit the mean ones did make me cry at times. I am only human.

I was very fortunate that I could take a taxi to work as well as sit most of the day for my job, since I am a Clinical Psychologist. I never missed a day of work since all of this began. My work was part of my own therapy, as well as the medication and physical therapy. I wanted to show myself and my patients that the RSD was not going to win, that one could get hit with something very difficult and cope and survive. I needed to be a role model for them. I also knew I had two choices: let the RSD get the better of me, give up on my life and never enjoy anything ever again, or I could fight it, learn what I could to beat it, and never stop trying to do everything I could to get better, and keep active in my life. I believe that when we are dealt cards like this is life, it is the world's way of telling us to take a breath, take a moment, stop, and take stock. Is there something in your life that is making you unhappy? Stressed? Angry? Something you are not dealing with? I was actually in a place of employment that was causing me an enormous amount of dissatisfaction. I love being a psychologist, but I was extremely stressed and unhappy in the place where I was employed. A funny thing happened after I quit and opened up my own practice. Two months later I got rid of my cane and started to walk without any devices at all! There is a very strong connection between emotion and pain. I felt better emotionally, and my body followed suit. Three years later am so much happier now, and my RSD is at a very manageable level.

The lessons I have learned from my RSD experience: find the best fit in terms of a pain management doctor, go for physical therapy as soon as possible, as often as possible, with the correct therapist, go for mental health counseling, take stock of your life and examine if there are areas in which you are experiencing too much stress, anger, frustration, dissatisfaction, and do not stop being active in your life! Warm wishes and good health…Dr. Melanie Levine