

RSD (Reflex Sympathetic Dystrophy) and Acupuncture

John came to China in March of 2007 with cautious optimism. He had exceeded all hope in the U.S. of finding an answer to his continuing battle with RSD pain. Read his story below:

My name is John L. My RSD developed after a Lisfranc fracture of the left foot. Foot surgery was required and I had no problems post surgery. Three weeks following surgery I developed severe, unrelenting pain and was sent to the Arnold Pain Management Center at Beth Israel Hospital in Boston. Doctors there diagnosed me with RSD and were hopeful, since the disease was in the early stages, that the pain management team could relieve my pain. Over the next six months I had sympathetic blocks, epidural steroid injections, epidural infusions, a spinal cord stimulation trial, narcotic trials. None of the procedures gave me permanent pain relief. Relief from some of these procedures lasted hours, others, days.

Before I developed RSD I lived independently in an apartment in the Boston area. The apartment was just a three block walk from the train. Now that I had RSD, I could see the train from my apartment window, hear it, but was no longer able to use it. I went from being an independent adult to being wheel chair bound. Shopping for groceries, getting a haircut, even doing laundry, required assistance.

Following one last procedure, my doctors advised me to return to live near my family where I could receive assistance and seek help from Duke Medical Center in Raleigh, North Carolina.

I returned to Asheville to live with my mother and stepfather and began seeing doctors at Duke along with several pain centers in Asheville. By now I was using narcotics to manage my pain. Nothing else gave me relief. I took pain pills all day long and kept increasing the amount of medication just to get the same effect. Along with pain meds, sleep meds were prescribed so that I could sleep three hours at a stretch each night. My foot became so sensitive I couldn't tolerate the weight of a sheet on it. I took pain meds in order to tolerate the discomfort of putting on my shoes.

All these medications had side effects. They made me unsteady on my feet the days I wasn't in a wheelchair or using a cane. I fell repeatedly. The falls led to further anxiety about re-injuring my foot. I was deconditioned from being in a wheelchair and tired easily. Doctors appointments filled my life. I saw a neurologist, internist, psychotherapist, psychiatrist, physical therapist and pain management doctor. Riding in a car, albeit one with excellent suspension, felt as if road vibrations drove stabbing pain through my foot. My mother and stepfather put 8,000 miles on their cars from November until March driving me to and from medical appointments. Occasionally, I could work in alternative medicine in between other medical appointments. I tried acupuncture, Reiki and meditation. I went to a local acupuncturist and the treatments he gave helped at first, then failed to touch my pain.

The following spring I made a desperate attempt to live on my own again. I hated being dependent and wanted have my own life. I moved into an apartment one half hour away from my family and attempted to use the city disability van services to transport me to my appointments. I signed on line for college courses hoping to get back to school. Several months later, I was back at my mother's house. I couldn't manage on my own. I met with the pain management team at Duke and a pain management neurosurgeon. Duke doctors told me that they could not help me as my other neurological conditions could interfere with any further treatments. No one seemed to know what to do for RSD.

It was all I could do now to dress myself or focus long enough to listen to a book on tape. I no longer had the ability to concentrate well enough to read. My foot became frozen in place. I had limited mobility, despite physical therapy from skilled therapists with knowledge of RSD. My doctors told me I'd gotten back all the function I was going to get. My weight skyrocketed from multiple medications and lack of mobility. I felt isolated with RSD. I spent more and more time in my bedroom when I wasn't seeing doctors or going to physical therapy feeling hopeless and stuck. My depression increased.

The acupuncturist who had treated me called me and told me about an article he'd read in Stroke Survivor Magazine. It was about a program called China Connection and he urged me to try it. I was afraid to leave what was familiar: my doctors who, even though they weren't finding solutions for me, were compassionate. I'd never been so far away from everything familiar. I was fearful of what of what the cabin pressure in an airplane would do to increase my foot pain. Traveling by air from Boston to Asheville, a two and a half hour trip, had been horribly painful. How would I manage a thirteen hour plane trip?

My family encouraged me to consider trying Traditional Chinese Medicine that was offered in at Tianjin Regional Medical Center in China. Even though I'd been to the best pain management centers in the country it was clear I wasn't improving. My doctors didn't say no to my going, but they were concerned about whether I could receive a guarantee of recovery. I could not. When I was accepted in the program the doctors told me would do all they could to help me. Faced with the last option in the US, placement of a morphine pump in my body, I decided to go to China. I was willing to try anything to get rid of the agonizing pain. If the doctors had told me to jump five feet in the air I think I would have tried.

I traveled to China in March, 2007. At first the staff at Tianjin Medical Center were perplexed. They'd never seen RSD before, but had great success with movement disorders from stroke and other neurological disorders. I began an intensive program of acupuncture, herbal soaks, vigorous massage called tuina, exercise therapy, and herbs six hours a day six days a week. It was slow medicine. When I spoke to my family in the US, I joked with them that the two words I heard most from the Chinese doctors were "rest" and "later". I lived in a hospital setting with American and international patients, all of whom were experiencing this same challenging program. Three weeks after I arrived I emailed my family to tell them of the first miracle. I had regained full mobility of my frozen foot. I gave up my cane. Over the next months I saw other changes: I began to sleep through the night, I lost weight, I had days when my pain was manageable. I went on several outings and began to socialize again. Soon, I was going to the gym six days a week walking on a treadmill, riding an exercise bike. I rediscovered laughter. Before I left the hospital in June I took a six hour bus trip to the Great Wall and climbed the hundred steps with the other stroke survivors on that trip.

By the time I left the hospital I was able to sleep through the night. I'd stopped all pain medications. I'd lost forty pounds. My depression diminished. I began working in the community room at the hospital, opening and closing the room for the American staff and providing programs for international patients there several nights a week. It was exhilarating to be of use to others, to be productive again.

Today I am pain free most days, although weather changes can cause foot to ache. I'm continuing to loose weight and I'm working in the hospital where I was a patient where I was a patient. I enjoy a good night's sleep, regular exercise, and regained my prized independence. I'm grateful I took the risk to find an answer to this cruel and perplexing disease, RSD..