

"After a hand injury in 1997, I began to really struggle with playing solo guitar.

It wasn't just the swollen knuckles. Something had crept in....into my hand, my wrist, my arm....an unwanted guest that wouldn't leave. I had no name for this visitor who caused my fingers to suddenly curl, caused the music to veer out of control as audiences cringed, caused my solo career to slowly (against all my stubborn nature) grind to a halt. The doctors call it focal dystonia (FD) and musicians dread the diagnosis. More often than not, FD spells the end of what typically begins as a love affair between the player, the melody, and the audience. Like Parkinson's, the body no longer can relax naturally when it should. Practiced movements become unpredictable and so very frustrating.

Initially, the diagnosis was a relief. I truly thought I had been going crazy. In fact years ago, musicians with focal dystonia were labeled "hysterics." Finding out it wasn't "in my head" (even though every neurological disorder is of course in your head) was a relief. I had never heard of focal dystonia or that such a condition existed. I had attended a major university school of music for a performance degree and never heard a word about this career ending malady. I never saw it mentioned in a guitar magazine or music education publication. No wonder I thought I was losing my mind! The relief only lasted until I began learning more about what I was up against...what I am still up against.

Dystonia comes in many forms. Some types affect the whole body. Those are called general dystonias. There is an amazing documentary called Twisted that shows how the entire body is affected by that kind of dystonia. The filmmaker, Laurel Chiten, did an incredible job of showing how difficult it is to be trapped in a dystonic body and how some treatments are showing tremendous promise.

The dystonia I have is called focal because it is limited to one area of my body – my left forearm, hand, and fingers. One treatment uses botox to weaken the muscles that are overreacting involuntarily when I play. I am told that I am at a higher risk of developing additional dystonia but that it might not spread at all. At this time there is no cure but research continues. The Dystonia Medical Research Foundation is based in Chicago and publishes a newsletter for the broader dystonia community called Dystonia Dialogue.

I have met many excellent doctors along the way including Dr. Jennine Speier (Sister Kenny Institute – Musician's Clinic/Abbott Northwestern Hospital, Minneapolis) Dr. Demetrius Maraganore (Mayo Clinic/Rochester), and Dr. Barbara Karp and Dr. Zoltan Mari (National Institute of Health). Someday soon I hope to meet Dr. Steven Frucht and Dr. Seth Pullman from Columbia University who also specialize in dystonia. I know the hard work of these and many other dedicated individuals can lead to a cure if enough support for research can be generated.

My dystonia affects me everyday. I am playing music again because I found a way around it for now. I would like to someday say that I am cured and until I can, I will work to raise awareness of dystonia and support for research towards a cure. No one should miss out on playing music, or painting, or walking upright and straight, or living a normal life because I didn't do enough while I had a chance to help. To learn more, please use the links provided above or conduct your own websearch. I hope to have an interactive part of this site working soon for people to share stories and information so please check back soon with your ideas and findings.