



## PERSONAL PROFILE

# Brad Schmitt

Brad and Shanna Schmitt lead the Minnesota Dystonia Support Group and organize the Twin Cities Dystonia Zoo Walk. They are dedicated awareness advocates and have participated in Dystonia Advocacy Day in Washington, DC.

### How did your symptoms start and how were you diagnosed?

My symptoms started in 2007 as back pain near my shoulder blade. Gradually it increased to the point where I would go to bed in the evening and within two or three hours I would wake up because the muscles in my back and chest and shoulders had seized up so much that it was difficult and painful to breathe. I saw a neurologist in 2008 who took one look at me and said you have dystonia. I flippantly made a comment about isn't that a Baltic republic that used to be part of the Soviet Union? I've since learned that is not remotely an original joke, but that was exactly what I was thinking.

### What was the impact on your daily life? Your career?

I was a technical field service representative and drove all over the metro area working on television and computer systems in hotels. There were days I would call my boss and tell him I've just slept so poorly I don't feel safe driving. I would nap a little bit and go into work later. I was also schlepping around bags with 25 pounds of equipment or a 50 pound computer, and as the muscle pain and tightness got worse, it became much more difficult for me to do the physical aspects of my job. I was probably the last person to accept that I was not going to be able to work. I discovered the Minnesota Vocational Rehab Services about the same time that my employer decided I had to go on short term disability. Vocational Rehab Services work with people who have become physically unable to do the job they've been trained to do and assess what their skills and aptitudes might be, and make recommendations to move them into another profession. They put me through tests to assess my mental aptitudes, my interests, my ability to learn new skills, but they observed how unpredictable my symptoms were. I might be fine one minute and need to sit down with an ice pack to calm the spasms the next. Ultimately they told me my symptoms are too unpredictable for anyone to give me a job. They

recommended applying for Social Security disability benefits. That was not something I wanted to hear at 38 years of age. I always joked that I wanted to retire by the time I was 40, but that wasn't what I had in mind. It took a long time to mentally come to terms with that.

### What treatment works best for you?

Botulinum toxin injections are the primary treatment. The other stuff is my way of coping in between the injections. My regimen involves medication for the spasms, massage therapy and physical therapy, and I have a TENS unit. I have a variety of heating pads and ice packs. I still have good days and bad days. One of the tricks I use is when I'm doing something around the house, like laundry, I'll set a timer for 30 minutes and after the time is up I stop whatever I'm doing. If I wait until my body tells me I've done enough, then it's too late and it may knock me down for a week or even two weeks if I have pushed too far. So I may work for 30 minutes and then need a two or three hour break because my muscles are twitching so badly and my tremors are going.

### What has kept you going? Any advice for others?

Having a support network is vital and in my case that starts with my wife. There's no way I could do this without Shanna. If you don't have that spouse or partner who can provide that support then you need to find it somewhere—a relative or support group, even Facebook. I also try to keep a sense of humor. I'm home all day by myself and having a cat that's my constant companion is definitely something that's improved my situation, having a pet in my life. The temptation, when you have pain or you have anything chronic going on, is to want to crawl into a shell. But you need to go out and live your life as best you can. If you need a support group or a psychologist for help, you need to make that happen so you can be out in the world.