

Thanksgiving, November 2000.

Veronica, being 4 at the time, walked into Aunt Liz's living room and asked for everyone's attention. Sitting Indian style in the middle of the floor, and without much hesitation, she proceeded with the following announcement:

"You know what? I was talking to my teacher at school and I decided something... I decided that we all need to learn sign language so Laurie doesn't feel so left out. Here -- this is what I learned so far [Veronica makes a sign]; it means 'I love you.'"

How I managed to get through the rest of that day without breaking into tears is something I'm still trying to figure out.

Dear Family/Friends/Colleagues:

In July of 2000, I was diagnosed with Spasmodic Dysphonia (SD). With my voice strained, trembling and cutting off on every vowel, Spasmodic Dysphonia is a life changing, or at least life-interrupting, disorder. It's difficult to imagine what losing the ability to freely communicate can do to a person, so difficult that I wouldn't encourage anyone to try!

Spasmodic Dysphonia is a focal form of Dystonia, a rare neurological disorder causing frequent involuntary spasms of the muscles that control the vocal folds. Following Parkinson's Disease and Essential Tremor, Dystonia is the third most common movement disorder. Yet, most people never heard of it or met a patient with it. This makes getting a diagnosis particularly vexing. While it seemed like an eternity being diagnosed 3 months after the onset of my symptoms, many patients have gone years if not decades without a diagnosis.

That's where the National Spasmodic Dysphonia Association (NSDA) comes in. It's almost impossible to describe what this organization has done for me and my emotional well-being over the years. After being diagnosed (having spent 15 hours a day on the computer, in tears, looking for a doctor and wondering what in the world could be wrong with me for weeks on end!), I found the NSDA bulletin board. Desperate for information, support or anything really, I logged in and made a post. Within hours, I was flooded with supportive messages from other patients around the world. **There was hope.**

Six years later, coping with SD is much easier. My path may have changed, but life does go on. It has to. While it's never out of my mind completely, I feel I have my life back. Periodic Botox® injections help the physical symptoms tremendously. Being involved in the NSDA, attending national conferences and local events, and connecting with other patients provides priceless support.

The NSDA is the only organization dedicated to helping SD patients. The mission of the NSDA is to advance medical research into the causes of and treatments for spasmodic dysphonia, promote physician and public awareness of the disorder, and sponsor support groups for patients and their families. And they fulfill their mission quite well. But, as with many non-profits, funds are limited. This is where you can help.

I am writing to ask that you donate to the NSDA and help advance our mission. Your support will help us continue to reach out to new and old patients, implement new programs, spread awareness and fund crucial research aimed at identifying the underlying cause, better treatment, and, ultimately, a cure for this disorder. *No donation is too small.*

Donations can be mailed to NSDA, 300 Park Boulevard, Suite 415, Itasca, IL 60143 (by using the enclosed envelope). You may also donate on-line with a credit card at www.dysphonia.org by clicking "Join or Donate" in the upper right corner. Cash or checks (made out to NSDA) can also be mailed to my attention and I will forward them to NSDA. If you have any questions, please let me know (LaurieC13@gmail.com).

All contributions are tax-deductible. The NSDA is a non-profit 501(c)3 organization and its U.S. Tax ID Number is 38-2918042.

Thanks for your support!

~Laurie