NATIONAL SPASMODIC DYSPHONIA ASSOCIATION

New NSDA Board Member Profile:

Bev Matthews

We are excited to welcome Bev Matthews to the NSDA Board of Directors! Bev has been the Support Group Leader of the Circle City SD Group and has organized three conferences in the Indianapolis Area. In addition, Bev was the 2017 Recipient of the Midge Kovacs Award for all of her efforts to raise awareness. We asked her to share her diagnosis story and how she became involved with the NSDA.

Can you tell us about your SD journey? How did symptoms begin?
In my career, I frequently gave presentations to various sized groups. While innately an introvert, I became accustomed to these speaking opportunities, often taking the leadership role at conferences and workshops. Sometime in my mid-40s, I began having more and more trouble getting the words out and experiencing voice breaks. I found myself becoming more and more reluctant to speak, even in weekly staff meetings. I dreaded making phone calls and especially leaving a voice mail when I felt I couldn’t even say my full name properly.

At first, I believed I was just losing my confidence and I began seeing a therapist. This experience became frustrating as no improvement resulted. Becoming more and more stressed, anxious and depressed, my physician prescribed an antidepressant and kept trying different medications and dosages, with little results.

My husband had to withstand a lot of meltdowns when I came home from work and described my failures. He was my sole support system, not having explained the problem to my family or coworkers. I was too embarrassed to admit to anyone other than him, my therapist and my physician that I was having problems. I was also concerned about losing my job!

When and who diagnosed you?
Finally, in 2010 my physician realized my problem might be voice-related and recommended I see an ears, nose and throat (ENT) specialist. Upon examination, the ENT specialist suggested that I might have spasmodic dysphonia and recommended I see Dr. Stacey Halum, an otolaryngologist in Carmel, Indiana. Dr. Halum confirmed the preliminary diagnosis of adductor spasmodic dysphonia with tremor and suggested that I begin Botox® treatments. Now, I receive them typically every 3 to 4 months. I have also met with a speech therapist. Both treatments reduce my symptoms of SD.

How did SD impact your life?
After five years of searching for an answer to my speaking problem, it was a tremendous relief to be diagnosed with this unknown disorder. It had a name! My husband was just as relieved as I was. I was quick to tell my family, and over time, confessed to my co-workers that I had a disorder that made speaking in front of groups and on the telephone very difficult for me.
I was very lucky that my company’s CEO was very understanding and continued to treat me as a valued employee.

How did you get involved with the NSDA?
When diagnosed, I was anxious to know more about this disorder that was impacting my life. Research on the internet quickly led me to the NSDA website. I found a tremendous amount of resources which helped me to better understand SD. I also noted that there were SD support groups which really interested me since I felt a real need to find others who also had SD.

My husband and I attended a central regional NSDA symposium in Milwaukee in September 2011 where we heard presentations from several experts in SD and met so many people who also had SD. This was my first opportunity to meet NSDA President Charlie Reavis and Executive Director Kimberly Kuman. I was caught up in their enthusiasm.

How did you get involved with the Circle City SD Support Group?
There wasn't an Indiana Support Group listed on the NSDA website so I contacted the regional support person, John Comer. John suggested I consider organizing a support group in Indiana. Knowing how badly I wanted to meet others with SD, I felt compelled to help provide a forum for those with SD to be able to meet and share experiences.

The NSDA gave me a list of people with SD in Indiana and information on conducting support groups, so I set a date and location for the first meeting. There were 13 people at that first meeting and it began what is today the Circle City SD Support Group. I have since then continued to provide leadership, organizing the meeting dates and locations.

How has volunteering with the NSDA impacted you?
Support group meetings can be so memorable. When someone has SD, they often find it easier to express their true feelings when surrounded by others who also have SD and understand their frustrations. They, and even their spouses, often get very emotional when allowed to open up and just talk.

I'm one of the lucky ones who encountered SD at the more typical middle age. Too many are impacted by SD at young ages and spend a majority of their lives living with this frustrating, little known disorder. My heart goes out to them. This is why educating the public and finding a cure is so important.

What would you like to bring to the NSDA Board?
My experience with setting up the SD symposiums in Indiana leads me to want to focus on helping in the NSDA's continuing effort to raise public awareness.