

Area Contact Leader Spotlight | BONNIE SIMPSON

Bonnie Simpson from North Carolina was our spotlight speaker at the Quarterly Meeting for Area Contact Leaders on August 10, 2024. She shared her voice journey, her ever-evolving role with Dysphonia International to help raise awareness, and her dedication to helping others with voice disorders both locally and internationally.

Prior to being diagnosed with spastic dysphonia in July 1999, I worked as an administrative assistant. I was active in church as a choir member. I enjoyed teaching Sunday School or Bible Study. There were times I was called upon to sing or speak on special occasions.

Music was a refuge. I invested in voice training when opportunities to sing or to speak increased. I rearranged hymns to build my repertoire of songs. I dabbled in songwriting. I had no idea how my life was about to change.



For two weeks or so, I waited for what I thought was a chronic case of laryngitis to clear up. I made an appointment with an Ear, Nose and Throat (ENT) specialist. At my job, I shared in answering the phones. A frequent caller who was a good friend of my co-worker, asked, "When are you going to see someone about that voice?" I said, "I have an appointment tomorrow," then I transferred the call.

Living with laryngeal dystonia (adductor spasmodic dysphonia) is a challenge because it is a hidden disability. It took me years to get to the point where I found the words to say when people said, "Well, at least it's not cancer." I said, "It's not life-threatening, but it is life changing." I felt insignificant for years because I only have a voice disorder, not cancer. I had to get comfortable with the fact that some people may get offended by my response.

Anyway, I was advised to rest my voice until my appointment with a speech language pathologist (SLP). The next available appointment was six months away. I had so many thoughts about what the rest of my life would be like with a voice disorder.

At the time of diagnosis, my vocal cords were slightly irritated from trying to force air to speak. There was pain in my eyes and ears. That pain had me looking forward to the relief of resting my voice. The next six months were isolated. I never felt lonely, but I was not as engaging, and it was

noticed. There were questions, “Is it because you sing a lot?” At the time, I could not say yes or no. So, I started doing research to learn what was going on with my voice.

I resigned from my office job to look for work where I did not have to answer the phone. I went to the unemployment office to search for such work. I explained that I was following the doctor’s advice to rest my voice; and that is why I was looking for a job that does not require phone work. I was shocked that I was told I had to prove that I could work. I could not get documentation to that effect because so little was known about spasmodic dysphonia at that time.

I believe in lifelong learning. It was during my search that I found out about the National Spasmodic Dysphonia Association (now Dysphonia International). For the next few years, I visited the message board hosted by Allergen. I read the stories. I shared my story. I gained so much insight into how others were coping with their voice disorders.

During those years on the forum, I started college as a non-traditional student. My COMP1 professor was a certified SLP! She gave me information on where to get a personal voice amplifying system. I participated in a job training program at the college, got a new job, and graduated with my degree in psychology. The vocal therapy and personal amplifying equipment afforded me some improvement with my voice. I returned to office work.

Fast forward to World Voice Day 2018, I checked my email and saw the information for the “Cherish My Voice” campaign. It took me that long (19 years) to go all in raising awareness about spasmodic dysphonia.

Since that time, I attended Zoom meetings hosted by Mary Bifaro and Rebecca Cole-Taylor of the Charlotte North Carolina Support Group. When Rebeca Cole-Taylor announced she would be away on assignment for a while, I was presented with the opportunity to be co-moderator. I accepted the opportunity to get back into the flow of being with people, this time, with people who shared a common goal, to be a source of hope for others on this journey.

As of this writing, I would have to look at the timeline of events between taking part in Walk for Talk 2020 and growing into the position of a volunteer Area Contact Leader for Upper North Carolina in conjunction with the Charlotte Group.

When I realized that the attendees of the Charlotte Group were not all from North Carolina, I was inspired to support others here and across the pond.

I appreciate the leadership of Dysphonia International.