DYSPHONIA INTERNATIONAL

Support Group Leader Spotlight | LAURA RAHUBA

Laura Rahuba from Georgia was our spotlight speaker at the Quarterly Meeting for Support Group Leaders on June 13, 2024. She shared her voice journey, the ways she gets involved in the Dysphonia International community and how she found a new reason to express her creativity.

My name is Laura Rahuba, and I currently serve as Support Group Leader in Atlanta, GA. I've had Spasmodic Dysphonia since 2005, the AD adductor type. I receive Botox injections, which generally work well for me.

Laura Rahuba

ONSET & DIAGNOSIS

In early 2005 I caught a flu virus accompanied by a high fever – several days at 102 degrees. I believe that the viral infection and/or the fever is what triggered the onset of my Spasmodic Dysphonia. As I recovered from the flu, my voice didn't return to normal. At first, I brushed it off as extended recovery time. As months passed, I started to notice that my voice behaved oddly when I said specific words, most notably those with the Long A sound, as in the number "eight". At that time, I was a phone rep working in a call center; many times per day I had to tell customers our company's fax number. Repeatedly reciting the 10-digit number, which happened to include 3 or 4 "eights", I noticed my voice cutting out oddly on those syllables. Not trusting my self-perception (to make sure I wasn't imagining it), I asked my co-workers to listen: "Hey, does my voice sound funny to you?" They could hear it too.

During a routine visit with my primary care doctor, I mentioned "something weird is going on with my voice," but he brushed it off. When I mentioned it again six months later, he still didn't seem concerned, but he placated me with a referral to an ENT. The ENT misdiagnosed the issue as Muscle Tension Dysphonia and referred me to a Speech Therapist. The speech therapist, thankfully, was very familiar with Spasmodic Dysphonia. After directing me to repeat a series of vowel-filled sentences ("We eat apples and eggs every day" etc.), she diagnosed me with AD SD and suggested I seek treatment at Vanderbilt Voice Center. The SLPs & doctor at Vanderbilt confirmed that diagnosis. My path to correct diagnosis took one year and 4 medical professionals. I believe that increased awareness about SD & related voice conditions – with both the general public and the medical community – will lead to quicker more accurate diagnoses…which is why I mention SD to practically every doctor, nurse, or therapist I encounter!

TREATMENT

I've received approximately 60 Botox injections over the years, most of which have resulted in a "normal-ish" speaking voice. So far, I've been treated at 3 different facilities, by 4 different doctors, with 2 different techniques. We've experimented with dosage and bilateral versus unilateral. I think it's important to mention that all changes to my treatment have been initiated by myself, rather than offered or suggested by the doctor. It frustrates me a bit that I learn more about treatment options from fellow SD patients than from my medical providers. But this confirms two things that most of you already know: First, that we must take an active role in our care & self-advocate. Second, that community is so important to us – support group meetings, social media groups & chat rooms, webinars, etc.

PAST CHALLENGES

In the early part of my SD journey, I experienced grief due to a sense of loss of my identity. My voice was part of what made me "me", and that new broken strangled-sounding voice that I wasn't accustomed to didn't seem like me at all. The two things that helped me through that were 1) time, and 2) Karen Adler Feeley's book "Easier Done Than Said".

During the first few years, I experienced so much muscle tension in my neck and shoulders, resulting in exhaustion at the end of each workday. Sometimes headaches and pain too. But eventually, I learned not to "fight against" the spasms, not to force the sounds. And I became more aware of where I was holding tension in my body – relaxing the muscles, doing stretches, adjusting my posture, etc.

The "red tape" of health insurance policies when I relocated to a different state. In 2017, I moved from Nashville, TN to Atlanta, GA. My health insurance at that time, would pre-approve the Botox injections for a period of one year. The approval document - I was frustrated to learn - could not be altered, modified, or canceled prior to its expiration date. Because the approval document was very specific – X number of treatments from such-and-such provider, during a specified timeframe – this basically this meant I couldn't switch providers yet. I literally had to take a 250 mile road trip to get my Botox shot from my old doctor Nashville, despite already having a new doctor lined up in Atlanta.

When the success of Botox injections shifted from being predictably reliable to a "hit or miss" situation with way too many misses. It's hard to say exactly why my results declined, because there are so many variables – different doctors, the equipment, the Botox solution itself, my body's anatomy and physiology. I do know one factor is that I developed a Vocal Tremor, which added a level of complexity to my voice challenge. I experimented with several things – I switched doctors, I tried several oral medications to help with the tremor (they didn't help), and finally I switched injection methods. After many years of getting my shots through the front of the neck, I now get them from the inside, via laryngoscope. This is working; more about that later.

CURRENT CHALLENGES

At this point in my voice journey, I'm in a good place, physically and mentally. I've learned to deal with the social-emotional challenges of having a voice condition. I've found a doctor and procedure from whom I'm getting good results & get to have a normal voice for a couple of months at a time. But there are still a few things that bother me sometimes.

The cost. Even with insurance coverage, my portion of the cost of Botox injections is significant. Sometimes I feel resentful that I have to spend so much money just to perform a basic body function that other people can do freely and effortlessly. Sometimes I feel wistful about the other things I could be spending that money on.

Discomfort of trans nasal injection procedure. A tube containing both a camera and a needle is inserted up my nose, down my throat. The good news is the doctor can see exactly where he's injecting, and I've had excellent results. The bad news is it's an uncomfortable and mildly traumatic experience. The worst part is when the doctor drips the liquid numbing agent onto my vocal folds, because my body reacts instinctively to the feel of "drowning" – I cough and gag. I hate it, but I'm willing to endure 10 minutes of discomfort for 2 ½ months of good voice.

The frustration of my tone not matching my emotions and my intentions. I hate it when I feel confident, but sound nervous. I hate it when I feel perfectly fine, but sound angry or sad. I hate that when I try to crack a joke or make light-hearted small talk with a stranger, my voice doesn't reflect the desired friendliness and humor.

BENEFITS/REWARDS OF HAVING SD

1. *Friendship and community*. I've met so many interesting, inspiring, and supportive people through SD. Several of the friends I made in support group or at symposium have become long term friendships

that extend beyond our shared condition. Most noteworthy are: My oldest SD friend, Jill, who I've known 15+ years. She keeps me on my toes intellectually and culturally. When we lived in the same city, we attended film & theater events together. Now despite our distance, we exchange handmade cards and swap art supplies through the mail. My Canadian friend Becky, who I met at a symposium. Her love and enthusiasm for her tiny quaint town two hours north of Toronto inspired me to travel to Ontario, Canada to visit her. I can call myself an "international traveler" because of the NSDA bringing us together.

2. *Becoming a better listener & being more intentional about speaking*. I used to be the type of person who voiced every thought that popped into my head. Now that speaking is more effortful (and potentially embarrassing), I take time to consider if what I have to say adds value to the conversation… because I'm weighing whether or not it's worth the effort.

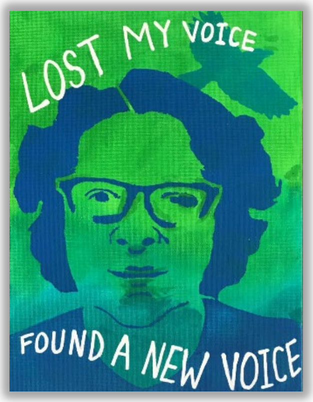
3. *Empathy & awareness of other disabilities and accessibility issues*. Having a voice condition brought into sharp focus the things that others take for granted that are difficult for me – for example, ordering food from a drive-thru. This realization opened my mind to other people's struggles. What things am I taking for granted that are difficult for others?

NSDA/DI PARTICIPATION

- Member of Nashville Support Group & Atlanta Support Group
- Leader of Atlanta Support Group
- Miscellaneous: Participated on discussion panels, traveled to Washington DC for Dystonia Advocacy Day, served as "social media ambassador", created SD-inspired art & poetry.

Within the Dysphonia International community, one thing I'm known for is my creativity. While I've always been a creative person, the scope of my creativity has shifted to encompass my voice disorder, and to be an alternate form of self-expression, supplementing my literal voice. In my youth, my arts & crafts were solely decorative. Through online art classes and communities, I've learned to use art to process my thoughts & emotions, and a way to connect with others. The SD-related pieces I've made include:

- A painting with self-portrait stencil for *Celebrating Our Voice* contest in 2018
- A word collage* for World Voice Day 2023
- A "found poetry" poem for World Voice Day 2024



Laura's self-portrait for Celebrating Our Voice

Laura's collage for World Voice Day 2023

A story about that collage: I first had the idea to make a collage about my SD experience in 2017. I began collecting words from magazines & flyers, which I stored in an envelope labeled "voice collage". In fall of 2017, when my husband & I relocated from Tennessee to Georgia, that envelope was packed away in a moving box. Generally, I'm not the type of person who loses things…but after the move I couldn't find that envelope for YEARS; I guess it was tucked among a stack of papers. Finally, 5 years later, that envelope surfaced…just in time for upcoming World Voice Day. As I started assembling the collage, I realized that my attitude and perspective had changed. Some of the words I'd cut out 5 years prior were a bit pessimistic and didn't reflect my current viewpoint. I abandoned previously collected words like "lonely" or "struggle" and instead perused magazines in search of more positive words like "hope" and "community".