

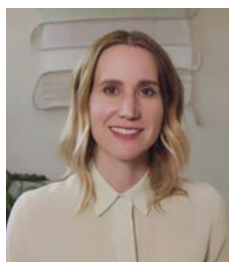
TURNING POINTS



TURNING POINTS | Moments of Change

Jaime Schmidt is the author of *SUPERMAKER: Crafting Business on Your Own Terms*, as well as founder and former CEO of Schmidt's Naturals, which was acquired by Unilever in 2017. Today, as an investor with her fund, Color, and through her media company Supermaker, Schmidt is elevating emerging and under-represented entrepreneurs. Jaime also has spasmodic dysphonia but this has not stopped her from pursuing her ambitious dreams. She was Keynote Speaker at the 2020 NSDA Virtual Symposium and shared her story about reaching a critical Turning point in her life. Here is a written summary from parts of Jaime's keynote address.

Jaime Schmidt opens up about the challenges of living with spasmodic dysphonia and her Turning point to taking control.



It was an unstable time in my twenties. An unhappy relationship plus a job that was not fulfilling me.

This was a time in my life when things were crashing down on me. I was scared and my life was difficult. This is when my symptoms started. My body was telling me something was wrong. I was in my boss's office and I sounded so nervous during a conference call. My husband at the time told me it was just a frog in my throat and to ignore it. At the time, I did not have the interest or patience to address this.

After my divorce, I moved to Portland and had my whole life ahead of me. I had this

vocal challenge but I just decided to work around it. I would clear my throat a lot or have a drink before a meeting or call, or speak around certain words. I did this for a long time. However, I was on this soul-searching journey, making hot dogs, sewing clothes and trying all kinds of new things. I applied for a position at a facility with developmentally challenged children. This is where I met my current husband. I enjoyed the job but knew it was just part of my journey.

I took a class on how to make body products in my kitchen. I was making a natural deodorant and filling a hole in the market. My business shot up. At the time, I was working from home and I got a call from Fox News for an interview.

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Our Voice is the official publication of the National Spasmodic Dysphonia Association. It is published to provide information to individuals with spasmodic dysphonia and related voice conditions, their families, healthcare professionals, and friends of the NSDA.

Founded in 1989, the National Spasmodic Dysphonia Association (NSDA) is a not-for-profit 501(c)3 organization. The NSDA is dedicated to improving the lives the people affected by spasmodic dysphonia and related voice conditions through research, education, awareness, and support. We are advancing medical research into the causes of and treatments for spasmodic dysphonia and related voice conditions, promoting physician and public awareness of the disorder through outreach, and sponsoring support activities for people with SD and their families through educational materials, annual symposiums, support groups, and internet resources.

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It is the editorial policy to report on developments regarding spasmodic dysphonia and related voice conditions but not to endorse any of the drugs or treatments discussed. We urge you to consult with your own physician about the procedures mentioned.

In Memoriam

We remember these special individuals who enriched the NSDA through their generosity, dedication, and commitment and who we miss dearly.



Anne Brett led the Erratic Voice Support Group in San Antonio, attended many NSDA Symposiums, and helped to establish the Dystonia On-Line Support Group and the SD inter-relay chat group which provided a new way for people to share their experiences with spasmodic dysphonia.



Mary Ann Culotta was an artist, art educator, and advocate for quality arts programs for school children in the greater Birmingham, AL area. While she had spasmodic dysphonia, it didn't deter her from her passion of bringing a sustainable arts program to children.



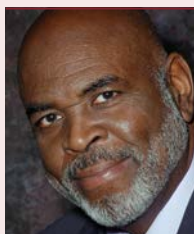
Phyllis Deal was her daughter's biggest advocate. Because of her mom's concern, Jackie Deal, was able to find a doctor and shorten her time to treatment for spasmodic dysphonia. Phyllis passed away peacefully with family at her side at age 100. She bequeathed her body to the University of Rochester Medical School.



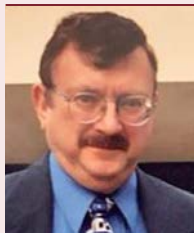
Dale Hardin was a humble, gentle, strong-willed soul. He was active in the New England Spasmodic Dysphonia Support Group for six years and attended the 2019 Symposium. Both added purpose and quality to his life having lived with SD since he was 26. Dale will be remembered by his bright smile.



Valerie F. Levitan, PhD, served as Executive Director of both the Dystonia Medical Research Foundation (1992 to 2001) and the NSDA (1997 to 2001). She was passionate, dedicated, and fearless. Always a teacher, Dr. Val dedicated her life to service and her legacy continues through the people she mentored and inspired.



Bernard Mixon, an actor and singer, was known as the *Voice of Distinction*. While he retired early because of challenges with spasmodic dysphonia, Bernard became an NSDA advocate. He used his voice to raise awareness of SD and inspired others especially at the NSDA events he attended.



Mark Porter was an R&D Vice-President for Nuclepore, and then became a teaching Pastor at Valley Bible Church. Even after being diagnosed with spasmodic dysphonia, Mark continued serving in the church for over a decade longer until he retired, not allowing his vocal challenge to stop him from sharing his message.

I decided I would just power through with my herbal remedies. There was no rehearsal and we were supposed to be done in one take. I was doing the Carol Alt Show, a TV show on healthy living. I captured my memory of this moment in my book:

“When the words came out I did not sound like the confident passionate person I was. Instead, my voice kept breaking. Even though I stood tall, smiled broadly, and was as well informed as anyone could be when it came to my ingredients, I could not control my shaky, strained voice. As soon as it was over I immediately asked for another take. I leaned over to Carol and said, “I am not as nervous as I sound, I just have this condition with my voice.” She smiled kindly and quickly reassured me. Then we started again from the top. Going through the same questions. At the end, I still wasn’t satisfied so asked if they could do another take. The crewmembers glanced at one another and looked at the clock. After 3 or 4 times an assistant walked up to me and said, “We have to move on” and ushered me back to the waiting room.

I sat down, flooded by a mix of emotions. I was relieved it was over, but terrified that I had done horribly. I had been told that the segment would air in a few weeks. I thought, what if they decided not to air it at all. When the assistant came back out, I took her aside and tried to explain my voice condition in full. “It’s ok, you were great”, she said. “You’ll get better with time.” I felt like no one understood what I was saying in more ways than one. I hung around the waiting room a little while longer, not ready to accept that I could not have one more take to

get it right. Finally, I left and decided to wait and see what happens. I stepped out into the busy streets of New York City and tried to forget about it.”

It was a pivotal moment when I saw the clip air a couple of months later. The first thing I did was panic as I saw myself standing on the screen and then, I just cried. I knew my voice was affected, but I hadn’t really heard myself or seen myself on TV and of course with nerves it’s even worse. That’s when I realized I had to take it seriously, I had to do something. If I was going to grow my business further, I needed to get control of it.

First, I had to know what was happening. Even if it meant an unstable voice forever that’s one thing, but just not knowing why this was happening was the scariest. That’s when I made my appointment with Dr. Schindler, who is still my doctor today. Immediately, he was like, yes, you have this disorder called spasmodic dysphonia.

I walked into my apartment, collapsed on the bed and thought, finally. Finally, I am relieved. Finally, I have an answer as to why I sound like this; I am not imagining this. Now that I knew what I had we could make a plan for treatment. That’s when I started Botox® injections. I am one of the people who is really fortunate that the injections work for. It came with challenges, like testing to find my dosage, and is hard to talk and present right after treatment, but it is a solution for me and I am grateful for it.

Telling people about my voice is a little scary, but by putting it out there that I have spasmodic dysphonia, it takes the pressure off. Once I opened up to my staff, it made things so much easier. Being honest about your voice is hard. SD is a stressful disorder. It’s heavy and hard, but if you love the work it’s all that matters.

That’s what we do when we have spasmodic dysphonia, we live with it and have to move on. Find a supportive community, make friends with others that have SD, inform family and friends, get a good doctor and be patient. SD has given me a new perspective; it’s given me the confidence to know that I can power through. Be relentless and find what will make you happy.

TURNING POINTS | STORIES OF COURAGE

MARY BIFARO



Turning points are defined as being a time when a decisive change in a situation occurs, especially one with beneficial results.

My favorite quote on turning points is by Jimmy Dean: “I can’t change the direction of the wind, but I can adjust my sails to always reach my destination.”

Turning Points on my personal spasmodic dysphonia journey include:

- Attending my first local SD support group meeting in 1989 – this was the first time that I heard the sound of another spasmodic dysphonia voice. I cried and stated that I felt validated by being in the company of others who had similar struggles to mine. I knew immediately that I wanted to be a part of the community as I could relate to them completely.
- Attending my first NSDA Board Meeting in 2004 – I felt a call to serve on the national level in some capacity. My heart led me to focus on the support end of our Mission.

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- Serving as NSDA Support Services Director since 2005 – I wanted to record and celebrate the important activities of our support network. I created *Voices of Support* in order to have a quarterly newsletter for them so that fellow leaders might be inspired by all of the tireless work that they do.

Simply put, I have found a place in service and it continues to be both a joy and a privilege to be involved.

SUSAN BECK



My turning point came after my diagnosis when I met someone else with spasmodic dysphonia. After months of agonizing about "What is wrong with my voice?", I finally went to my doctor who recommended that I see an Ear, Nose, Throat (ENT) specialist. The ENT diagnosed me within a few weeks and sent me to a speech pathologist who confirmed the diagnosis. The diagnosis process probably took only about six weeks for me. However, during these six weeks, I was in denial, frustrated and feeling totally overwhelmed and depressed. It was very hard for me to talk about my diagnosis with anyone during this time. I found out through my women's Bible study that there was a lady at my church that also has spasmodic dysphonia. I was able to meet with her one Sunday for about 15 minutes. Even though it was a very short meeting, our conversation changed my

whole perspective. I was able to hear her story and how she had lived with SD for over 20 years. I was also able to ask her about the Botox® injections which had been successful for her. This was my turning point because she gave me courage to pursue treatment and to meet others with SD. But most of all, because she gave me hope.

JESSICA RITTER

I felt broken and I had lost hope. I thought that if no one would hire me because of my voice, then I was going to go nowhere in life despite my intelligent mind and drive. I forced myself to go to the last interview I had scheduled. It was at a bagel shop that I had been going to for as long as I could remember. I stood in front of the doors just terrified, prepping myself for another rejection. I somehow knew that this was going to be the determining factor on whether or not I just gave up trying.

I walked in, sat down at the table across from the owner Ken, and said "Hi my name is Jessica and I have a speech disorder." There was a long pause as he just looked at me. Finally, he smiled and said "You are hired, Jessica." And that was a turning point in my life.

If a stranger could believe in me enough to hire me at a job that involved talking to customers all day long, I could believe in myself to be able to do it. I found the more that I talked to people, the easier it became. My voice hadn't changed. I still had to repeat myself to most customers over and over again. I had to

explain that I wasn't sick and didn't have a cold and that the quality of my voice was permanent. But something inside me had changed.

The way that I deal with my SD now is a very natural process. I attack it with kindness and connection. My voice is significantly worse when stressed. So I eliminate the stress. Reduce the difficulty is now my motto. I do this by practicing yoga, painting art that has a purpose and a mission to inspire people at my business, The Suave Sparrow, and forcing myself to talk to everyone I see. I realized that if I just went straight to talking to people, all people, I would have nothing to be anxious about. So I did, and I do. When I have bad voice days I still may have to force myself to talk to people, but for the most part I have decreased my spasms significantly by accepting and loving myself, surrounding myself with good people, and connecting and inspiring my community.

As I got older, I became thankful for my disorder. That bears the importance of reading twice. I became THANKFUL for my disorder. Through this disorder I learned to understand others who are struggling and to know that everyone is struggling with something. We all struggle, but beauty is born when we embrace those struggles and use them to create beauty. ■



PIVOTS, C-CHANGES, TURNING POINTS – OH MY!

(Yes, I had to work in the Wizard of Oz thing. I am from Kansas.) *By Dorothy Tannahill-Moran*



When I was diagnosed, I had already made a decision to become a career coach and was making my way through coaching school. I had already been through the first year of school and loved the people I was surrounded by, and the coaching I was learning. I had started

If you are an adult, you know by now that life isn't a straight line to any destination. Life is an ongoing journey of twists and turns augmented by the occasional U-turn. It might have been something your parents should have covered when they discussed important topics with you like the birds and bees. More than likely, you had to discover all of this fun stuff yourself.

And because you are the captain of your ship of life, making the decision of when to make changes and how much of a change to make is where the true art form of life occurs. Being an adult can be tough because a change of any sort is a truly challenging process.

And that's where most of us with spasmodic dysphonia (SD) and other voice problems can testify to the turning point(s) forced on us by our strange disorder. Notice it's not "just" one turning point. Sure, we all probably had to come to grips with a big turning point at the beginning of our voice journey but then several others followed it. It's probably still confronting us with some new Turning points to some degree, which makes it an important process for us to put under the microscope to learn about.

Before I discuss managing the Turning point, let me tell you my own quick story about my first Turning point with SD.

the second year when I got my first Botox shot and by the time I showed up to our next in-person class, you could barely hear me. Until then, quitting didn't seem like an option but now I was questioning the whole decision. I went ahead to my next class but before class started, I pulled our instructor to the side and explained the issue, and asked what she wanted me to do. I was prepared to leave if I needed to. I knew I couldn't actively contribute to the class. She said it wasn't an issue and asked if I was open to allowing her to speak about it to the class, and I agreed.

After starting class that day, she introduced my issue to the group and said I was unable to speak enough for them to hear. How did they choose to deal with it as a class? I was asked a few questions and eventually one of the students volunteered to be my mouthpiece for the day and they would each rotate during the week. They felt

it gave them an opportunity for greater listening. They also realized that not all of their clients would always have the use of all their abilities like speaking, hearing, etc. They needed to use this experience to figure out how to provide service and accommodate everyone. The united front and loving support I was given in that moment were enough to change the direction of what my Turning point was very close to becoming that day. I now had an unwavering belief in moving forward as a coach with my SD, even when people were being stupid or insensitive to me. I had one foot over the edge that was pulled back when those people pulled their chairs closer to me, simply so they could hear me better. I learned at that moment that being open and honest about what was taking place with me allowed them to truly see my humanity and allow them to be their best. We all won that day.

Turning points are really about the process of change, and change is a process that has discrete phases to it. And as you will see there is a huge emotional component to all of this like there was for me. While change is part of life, we don't do much to pass on the wisdom associated with it. Let's change that today.

This first chart (below) shows you 4 phases; there is a 5th but it doesn't apply to us.

STAGE	CHARACTERISTICS
Pre-contemplation	No recognition of issue or need to change
Contemplation	Recognize issue – define need
Preparation	Establishing environment to support change
Action	Making change happen

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With SD, it takes a while before there is enough consistency with our voice to recognize we might have an issue worth pursuing so this is the **Pre-contemplation phase**. We don't yet fully recognize an issue.

Eventually, with enough feedback from others and difficulty in a variety of places, we are now in the **Contemplation phase**. We recognize we have an issue and we need to do something but we don't know what to do yet. Realize a Turning point could be here. You could recognize you have an issue but choose NOT to do anything. You might call this "blissful denial".

But let's say you aren't in denial and you do think the voice issue is worthy of pursuing improvement you now go into **Preparation to change**. You establish an environment for change by doing research, getting resources like doctors and other people with voice disorders to provide support. But also understand at any one of the phases, some people make a decision – a Turning point that is as far as they will go for a variety of reasons.

Lastly, you **Take action** and this is where the real change is taking place. This is where the most recognizable Turning point is. You are now taking action to address the challenge with your voice.

Then your next Turning point might look like the chart at right.

Underlying all of this is the tremendous emotional transition that goes with change. One minute you're in denial and the next you're empowered, followed by defeat. You question all decisions and are fearful of what the future holds for you. It is the emotional turmoil that causes everyone to start and stop repeatedly until they have played through each phase and moved through each phase enough to where

they can finally take the action that ultimately leads to the Turning Point. You can't underestimate the emotional involvement that the change process takes. If you feel like an emotional mess when you've made a change or Turning point, then you're very normal!

emotional expenditure there becomes a sense of excitement and freedom. This side of a Turning point makes it all worthwhile.

And like my own story, I think we all want a reason to stay the course. We want to be talked off the edge of

“Turning points seem like one awesome moment of change. In reality, the lightning bolt of decision was preceded sometimes by agonizing hours, days, weeks, or even years of emotional consideration. Then, once the decision was made your work of transitioning into a new plan begins.”

Turning points seem like one awesome moment of change. In reality, the lightning bolt of decision was preceded sometimes by agonizing hours, days, weeks, or even years of emotional consideration. Then, once the decision was made, your work of transitioning into a new plan begins. Most people find that simply making it to the other side of a Turning point gives enough relief from the

indecision and you are told everything will be ok. I'm sure you'd like to hear that everything was ok. It was ok because I made it that way and that's another decision we can all make. We must learn to be resilient in the face of change. I learned to be a career coach with a voice disorder and I wouldn't trade that for anything. It wasn't part of the original plan but it was the plan I made. ■

MY JOB

STAGE	CHARACTERISTICS
Pre-contemplation	No recognition of issue or need to change: <i>I don't seem to have a problem on the job.</i>
Contemplation	Recognize issue – define need: <i>The boss and my peers continually ask me if I'm getting the customers supported. Do I have a problem?</i>
Preparation	Establishing environment to support change: <i>My job is getting hard to perform. My voice is getting in the way and I have a lot of anxiety. I'm working on my resume.</i>
Action	Making change happen: <i>I found a job I like better and that doesn't put as much demand on my voice. Whew!</i>

PRESIDENT'S MESSAGE | CHARLIE REAVIS



In 1989, Dr. Daniel Truong, a neurologist in Detroit, had the idea to establish a national organization to help people affected by spasmodic dysphonia (SD) cope with this debilitating voice condition. Dr. Truong enlisted SD patient Larry

Kolasa to work with him to turn this idea into a functioning organization. Larry became the first (Founding) President of the NSDA and continues to serve the organization as a member of the Board of Directors.

The purpose of the NSDA was to help people affected by spasmodic dysphonia live better lives through research, education, awareness and support. Throughout our history, many incredibly dedicated people serving as staff and volunteers, have given of themselves to keep the organization viable and growing in order to fulfill this Mission.

Over these 30-plus years, the NSDA has achieved much in encouraging research, educating the public and healthcare community about SD, increasing awareness and providing support for the thousands of people living with a voice condition. As we look forward and plan for the future, it is important to reflect on those founding principles and values. One of the areas reviewed was the scope of our Mission. Even though the initial focus of the organization was on spasmodic dysphonia, we have always welcomed and encouraged people with other voice conditions to participate in local groups and become members of our organization.

In 2019, the NSDA Board decided it was appropriate, and indeed time, to officially expand our Mission to include people with related voice conditions. In my view, there is no other organization that understands the challenges of living with a voice condition more, and is better equipped to help, than the NSDA. Our redesigned website, dysphonia.org, has information on vocal tremor, vocal fold paralysis/paresis and muscle tension dysphonia as well as spasmodic dysphonia. We will be expanding this information and developing more brochures/materials on all these voice conditions.

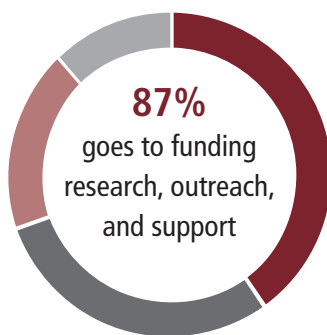
We have gained more understanding about voice conditions in the past 30 years; however, this understanding is limited and the treatment options are basically the same as they were 25-30 years ago. This serves to highlight the challenges and opportunities ahead of us. It is exciting that several research teams are interested in studying voice conditions and to see that the focus of this work is on basic research to gain more understanding about the cause(s) of various voice conditions. I am confident, with the continued support of everyone in our community, that we will be able to encourage and fund more research to allow us to learn more about the cause(s) which will lead to better and more effective treatment options and ultimately to a cure.

I am convinced that together our Vision for the NSDA: Ensure the ongoing viability of the organization that will continue to lead the effort to eradicate spasmodic dysphonia and related voice conditions – will become a reality. ■

NSDA FINANCIAL OVERVIEW

2019-20 REVENUE		Total
Total Revenues		\$348,856
2019-20 EXPENSES		Total
Total Expenses		\$319,712

From the audited statements for the year beginning April 1, 2019 and ending March 31, 2020



OUTREACH

41%

Educational programs, awareness materials, symposiums, medical conferences, advocacy, newsletter and website

RESEARCH

29%

Seed grants, research awards, support for the Global Dystonia Registry and Brain Bank

SUPPORT

17%

Network of over 50 Support Groups and 240 Area Contact Persons, virtual support, and Leadership Workshop

FUNDRAISING & ADMINISTRATION

13%

Support for all programs

RATINGS | The NSDA has been awarded the Gold Seal of Transparency by Guidestar, the largest source of information on nonprofit organizations. Charity Navigator nonprofit rating is based on the amount of money spent on management and general expenses. A top score is received if that spending is between 10% to 15%. The NSDA is currently at 13% for these expenses.

NSDA Board Leadership Changes

Special thanks to **Marcia Sterling** for her many years of service as Treasurer. Marcia continues to serve on the Board. Board member **Bev Matthews** has taken on the Treasurer role. **Susan Beck** has accepted a new position on the Board as Development Director.

New Member of the NSDA Honorary Board

John Edwardson

John is a veteran businessman with a successful track record at such industry giants as Northwest Airlines, Ameritech, and United Airlines. He is most regarded for his achievements as Chairman and CEO of CDW Corporation and is known for unorthodox motivational methods and an open-door management style. John has made significant contributions as a corporate citizen, both in Chicago and internationally. John shared his journey with spasmodic dysphonia as the Keynote Speaker at the 2019 NSDA Symposium in Boston, MA. *Read more about John on page 36.*



Special Thanks

After 16 years, **Stephie Mendel** has retired from the NSDA Board. We greatly appreciate her commitment to the Mission of the NSDA because she has been and continues to be a steadfast advocate for more research to discover a cure for spasmodic dysphonia. In 2015, Stephie received the Larry Kolasa Founding President Award for her generous contributions to the NSDA.



Stephie Mendel



Special thanks to **James Anderson** for his service on the NSDA Board. While James has resigned from the Board, he remains active as the Co-Leader of the Tampa Spasmodic Dysphonia Support Group.

James Anderson

New Member of the NSDA Scientific Advisory Board

Julie Barkmeier-Kraemer, PhD, CCC-SLP

Dr. Barkmeier-Kraemer is a speech-language pathologist and professor in the Division of Otolaryngology, Clinic Director for the Voice Disorders Center, and Adjunct Faculty to the Communication Sciences and Disorders program at the University of Utah. She has been active in voice research for many years and will join the other four members of this Board that is responsible for overseeing the NSDA research program. Dr. Barkmeier-Kraemer shared, "I am grateful for all of the advocacy and support the NSDA offers to those with SD. I am also enthusiastic to partner with the NSDA to support preliminary research and clinical work that will ultimately benefit those with SD. I look forward to working with the NSDA leadership toward supporting the training and mentorship of colleagues in speech-language pathology, otolaryngology, and neurology to assure that more healthcare providers have the necessary expertise to support those with SD."



► Read more at dysphonia.org



Jane Gordon

Jane is a native New Yorker who has spent almost half her life in Massachusetts; first as a college student, and later, raising her family. She is a graduate of Smith College (Northampton, MA) where she majored in cell and molecular biology. After college, she earned a Master of Public Health (MPH) from the University of Michigan, concentrating in epidemiology. In that field, she worked for the Environmental Protection Agency and Mobil Oil. She also earned a Master of Business Administration (MBA) from the NYU Stern School of Business, majoring in marketing. She was VP of marketing for the Solgar Vitamin Company, and held several consulting positions. She is currently a freelance writer for two regional newspapers. Her editor's college-age son also has spasmodic dysphonia (SD). She says, "Sometimes, it's a small world." Jane believes that she has had adductor SD since she was a young child, although decades passed before she was diagnosed. Since 1995, she has had more than 50 Botox® shots by Dr. Ramon Franco at Mass Eye and Ear. His compassion and perseverance has helped her get through daily life. Jane remembers the first time that she stumbled across the NSDA website. She says, "I held my breath when I heard recordings of people who sounded like me. Nobody knows what it's like to walk in someone else's shoes, but other NSDA members have a pretty good idea of it."



Dennis Kaszeta

Dennis is a Licensed Master Social Worker who graduated from Wayne State University with a Master's degree in clinical social work. He has a background in clinical practice providing assessment and treatment for addictions. While he is recently retired, he had both his own private practice and was also part of a nationally-recognized group practice that provided avenues of treatment for the sexual addict, spouse and family. Prior to the onset of the symptoms of his spasmodic dysphonia, he frequently spoke in public and presented to professional groups on mental health disorders and treatment. Dennis said, "After the onset I found myself increasingly nervous and self-conscious about my SD-influenced speaking patterns. This inhibited my speaking at conferences and/or assuming administrative positions offered to me. I let many opportunities pass me by. Now, I can say with Botox® injections tailored to me, I can time the injections around any public speaking I am scheduled to do. However, more importantly, I now have a support group which gives me emotional ease when speaking, knowing there are others like me!" Dennis helped to rejuvenate the Detroit Area Support Group and the group was recently awarded the NSDA's 2020 Midge Kovacs Awareness Award. Dennis said, "Through my leadership on a local level I came to appreciate that if I were on the Board, I could help other Board members brainstorm ideas, implement and execute programs/policies that are advantageous to all NSDA members at large. I hope I can use my previous grant-writing background to help our organization find sponsored support."



Dorothy Tannahill-Moran

Dorothy, from Kansas, is a career and life coach, author, and speaker. Dorothy guides people who want to remove barriers to professional and personal success. She has a unique perspective and deep knowledge on career development forged by twenty-one years of management at Intel Corporation and 12 years as a coach. When asked how having spasmodic dysphonia has affected her life, she says, "I have two answers to the question. 1. Not at all, and 2. Daily. By saying SD hasn't impacted my life it means I haven't let it hold me back from doing any of the things I wanted to do." Dorothy has also become a certified Vibrational Sound Therapist, and she donates the proceeds to NSDA. She shared, "I've had the attitude that if I could somehow help our cause, I needed to help however I could. I had already been the local support group leader when I was asked to write for the website and newsletter and I jumped on the opportunity. I have the same perspective about being on the Board. If the other Board members believe I can help our cause, I will serve." Along with leading the Kansas City SD Support Group and writing articles, Dorothy has also presented at NSDA Symposiums and webinars along with attending Advocacy Days.

Read more at
dysphonia.org

Over forty years ago I was diagnosed with a rare and strange vocal cord disorder called spasmodic dysphonia (SD). It was a relief to learn that I wasn't crazy because I couldn't control my voice. Symptoms range from mild hoarseness or breathiness to being totally unable to vocalize words. My condition was someplace in the middle. It was difficult for me to speak and the constant strain was exhausting. As a life insurance salesman, it definitely affected my career and my personal and social life. It stifles spontaneity and ruins your personality.

Not much was known about SD at the time except that it was believed to be a neurological problem which I describe as a short circuit between the brain and vocal cords. The only treatment option at that time was a surgical procedure that cut a section out of a nerve going to one of the cords. Even though it would paralyze one of my cords, I decided to try it. The short term results were good, but within nine months the spasms returned and I was back to square one.

After struggling emotionally and financially for about 10 years, a physician named Daniel Truong came to our local SD support group in Birmingham, MI to recruit people to participate in a double-blind study on the effects of Botox® injections to control the symptoms of SD.

My wife, Pam, asked me if I was interested, which I was, but I didn't want to be in the study group because there was a 50% chance of not getting the Botox®. She persistently called Dr. Truong's office every day until they agreed to inject me with Botox® prior to the study. I was their guinea pig!

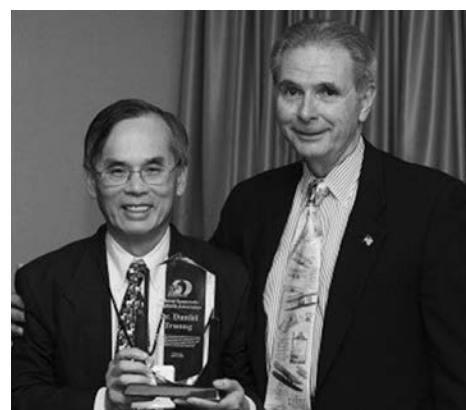
On March 11, 1989, my life changed when Drs. Daniel Truong and Michael Rontal (my otolaryngologist) gave me my first Botox® injection. They gave me way too much and even though I could only

whisper for several weeks, I instinctively knew it would work. And it has. It took time to figure out the proper dosage and since then I have received over 100 injections, about every 3 to 5 months. It works so well for me that if I don't tell Pam that I'm getting an injection, she would not know. In fact, at some SD meetings and symposiums, I have been accused of being an imposter! A title I totally relish.

In late April, 1989, Dr. Truong called to inform me that WE were going to form a national organization for people with spasmodic dysphonia and that I would be the first president. HUH? To say I was reluctant is an understatement. I thought if I ignored him, he would give up. But he was like a bulldog and did not let go until I realized that this was something WE had to do.

In the fall of 1989, we formed and incorporated the National Spasmodic Dysphonia Association (NSDA), a non-profit organization dedicated to improving the lives of people affected by SD through awareness, education, support and research.

In the early years we focused on awareness; not so much with the general public, but with the medical profession because so few knew about the condition. In the early 1990's Allergan (the pharmaceutical company that produces Botox®) did a study that reported that the average time it took to get a proper diagnosis was eight and a half years. During that time people were being misdiagnosed and mistreated with everything from Valium® to brain surgery. Within a few years our efforts reduced that time to several months. Before the internet and social media, I read hundreds of letters from people recently diagnosed with SD who told me of losing jobs, career changes, divorces and the loss of self-esteem. Some had even considered suicide. I often wonder if anyone did.



Dr. Daniel Truong and Larry Kolasa

The NSDA has done a great job providing education, support and awareness, but now we're on the verge of something spectacular. More research projects have been started in the past three years than in the entire 30 years since our inception. Investigators are studying everything from looking for the cause of our disorder to better treatment options, including non-invasive devices to improve the quality of our voices.

We provide seed money grants to researchers so that they can apply to major funding organizations like the National Institutes of Health (NIH).

Our biggest challenge has always been and continues to be raising money. Not only are we a very small group compared to other medical disorders, but we also can't create compelling images like the children of St. Jude's and Shriners' hospitals, or the abused animals of the ASPCA, or the very deserving wounded warriors of our country. We may sound bad, but we look great! However, that doesn't mean people with SD lead easy lives.

Throughout the last 31 years, we have had many "angels" that have helped to guide our organization.

We look forward to the future especially as we expand the Mission of the NSDA to include related voice conditions so we reach even more people. ■

NSDA LEGACY SOCIETY

Your bequest is an investment in the National Spasmodic Dysphonia Association. It is a simple way to ensure that important work can continue for years to come. Your generosity continues to:

- Fund research on spasmodic dysphonia (SD), with the hope that one day, it can be cured.
- Provide additional support services to those with SD and related vocal conditions.
- Increase awareness of the challenges for those living with vocal disorders.
- Support our expanding Mission to create resources for related vocal disorders.
- Increase awareness of medical professionals to ensure speedy diagnosis and treatment.
- Advocate for those who do not have a voice.

Ways to Leave a Bequest to the NSDA

There are three primary ways to leave a bequest to the NSDA:

1. Include a bequest to the National Spasmodic Dysphonia Association in your will or revocable trust.
2. Designate the National Spasmodic Dysphonia Association as a full, partial or contingent beneficiary of your retirement account (IRA, 401(k), 403(b) or pension).
3. Name the National Spasmodic Dysphonia Association as a beneficiary of your life insurance policy.

The next time you review your estate plan we would like to ask you to consider the NSDA!

► Learn more at dysphonia.org

The CARES Act 2020 can benefit both Donors and the NSDA

The CARES (Coronavirus Aid, Relief, and Economic Security) Act has some interesting provisions that apply to charitable giving to nonprofits like the NSDA. These changes were made by Congress to encourage increased giving to nonprofits feeling the strain of operating during this pandemic.

The new law **temporarily suspends the requirements for required minimum distributions (RMD)** for the 2020 tax year. This probably comes as a relief to many of you who would have had to withdraw a greater percentage of your retirement accounts. Many of our donors use their RMD to make a gift from their IRA. If you are 70½ or older, you can still make a gift from your IRA or name us as a beneficiary. In addition, there are some new ways you can receive financial benefits and help organizations like us.

It also **allows all taxpayers to take a charitable deduction of up to \$300, even if you do not itemize.**

You might think that this is a small amount and would not make a difference. But what if all of our donors gave “just” \$300? Such support would have a huge impact on our community!

For those who do itemize their deductions, the new law **allows for cash contributions to qualified charities such as ours to be deducted up to 100%** of your adjusted gross income for the 2020 calendar year.

We encourage you to consult with your financial advisor to determine how these opportunities may complement your personal, philanthropic and tax planning objectives. Thank you for your continued support!

WHY JOIN THE NSDA?

Discover a community that cares about you and your voice!

The best part of joining NSDA is the sense of belonging – being connected with people facing similar obstacles, people who truly “get it,” people we can learn from. Joining with other people living with a voice condition, we can make ourselves heard on issues like research, public awareness, and advocacy.

► You’re connecting with others living with voice issues.

Who better can understand what it’s like to live with spasmodic dysphonia than another person with the disorder? It’s a tremendous relief and very empowering to meet someone else with a voice condition with whom you can open up and speak freely about your situation and experiences. NSDA makes this possible!

► You’re speaking out for spasmodic dysphonia and related voice conditions and supporting others in the NSDA community

Would you like to start a support group? Host a fundraising event? Increase awareness in your community? Participate in research? Support new patients? Visit with members of Congress to discuss the importance of increased funding for research? Do you have other ideas about how to contribute? Contact us. NSDA is here to help you get your voice out there.

► You’re helping to tell the world about voice conditions

Years ago, it often took 5, 10 or even 20 years to get a diagnosis. Today, thanks to public and physician awareness, people are diagnosed in one or two office visits and treatments can begin right away. NSDA has grown to become an international presence with contacts all over the globe.

Membership is \$40 annually. Join online at dysphonia.org

Wearable Non-Invasive Neuromodulation Technology for the Symptomatic Treatment of Spasmodic Dysphonia



By **Jürgen Konczak, PhD**

Professor for Biomechanics and Movement Neuroscience at the University of Minnesota

The National Spasmodic Dysphonia Association funded a new pilot grant entitled, *Wearable Non-Invasive Neuromodulation Technology for the Symptomatic Treatment of Spasmodic Dysphonia*. Research has shown there is an improvement in symptoms for people with adductor spasmodic dysphonia. This grant will explore whether similar results can be achieved in abductor spasmodic dysphonia (AbSD). While AbSD is the rarer form of SD, it is also more difficult to treat with traditional methods like botulinum toxin and surgical interventions. This is the first grant the NSDA has funded specifically for abductor spasmodic dysphonia. We are hopefully that this study may lead to a potential new treatment option for those challenged by AbSD.

As presented as part of the 2020 Virtual NSDA Symposium

When a person speaks the laryngeal muscles that are involved in producing connected speech become active. When one compares a normal voice to someone who has laryngeal dystonia, the muscles responsible for speech are becoming overly active and muscle innervation may show unwanted “on” and “off” activity that causes the breaks in speech that many people with the disorder may experience.

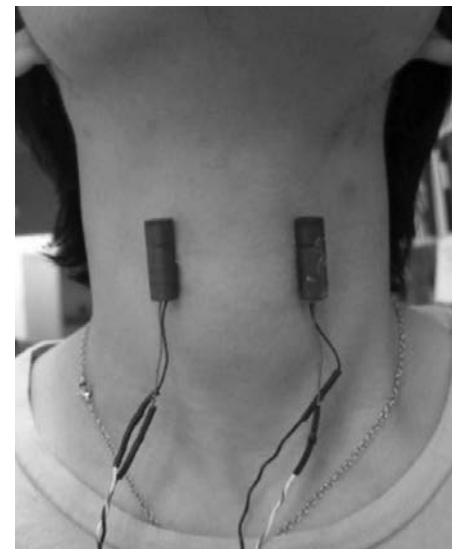
Activity in the motor cortex is ultimately responsible for the activation of the laryngeal musculature. While we see this excessive activity in the laryngeal muscles, the question is “where is it coming from?” Thus, we set out to record the cortical activity in persons with spasmodic dysphonia (SD) during vocalization. This article summarizes the results of this project that were recently published.

If one records cortical activity using EEG (electroencephalogram) technology, the neurons in the left side of the brain, over the left motor cortex begin to desynchronize, a phenomenon called movement-related desynchronization. In those with SD, the level of desynchronization is not as great when compared to a healthy person. What this means is that in people with SD, one can observe an excessive synchronization of somatosensory and motor cortical neurons during speech and even at rest.

We know that effective sensory tricks can help people with dystonia. For example, people with cervical dystonia may touch their neck to relieve dystonic symptoms temporarily. We know that there is a link between sensory input and motor output. So if we consider this for SD, we have the the speech motor system that produces an output, and for people with SD, this voice output is impaired. We also know that the somatosensory system, the part of the brain that deals with all body sensations, informs the motor system and, in turn, the motor system informs the somatosensory system.

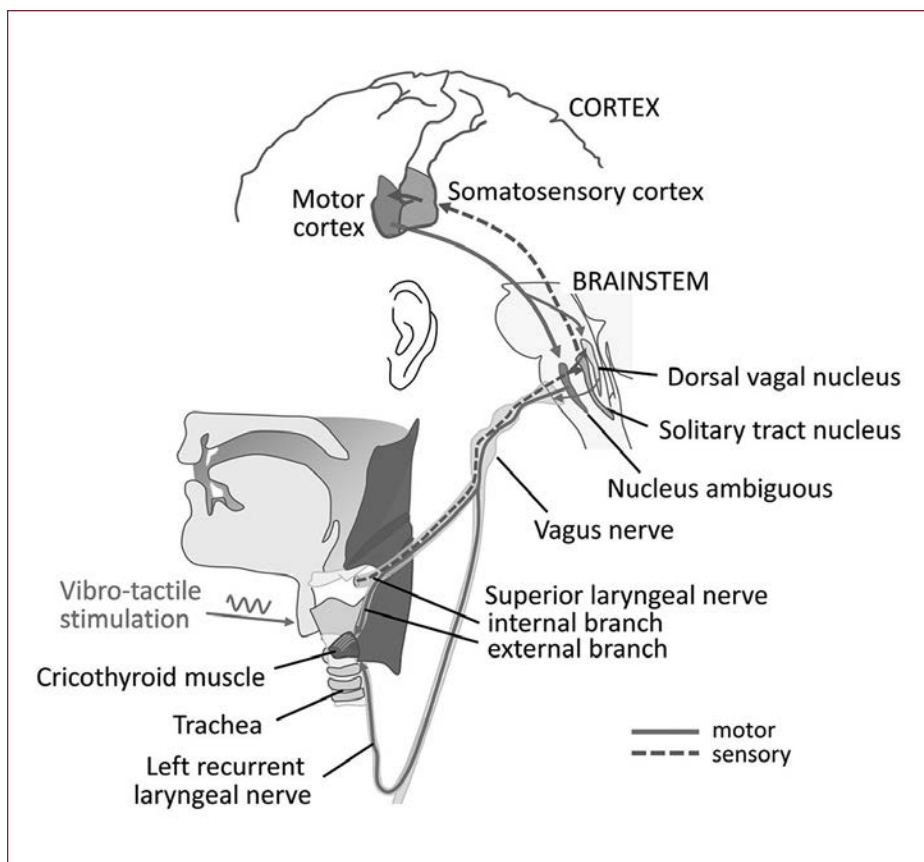
Our hypothesis is, if abnormal processing in the somatosensory system that is informing the motor system, is indirectly responsible for producing a disordered voice, would it not make sense to stimulate the somatosensory system directly? If we stimulated it in a certain way, would that help restore speech motor function? To do this we would have to stimulate mechanoreceptors in the skin and the laryngeal musculature that provide feedback to the somatosensory system about the state of the speech motor system.

We looked at vibro-tactile stimulation as a potential treatment for SD. Small electric vibrating motors were taped to the voice box. These vibrators are turned on by a power source and the patient feels a tingling sensation at their neck.



Why should this work? Vibration caused by the motors stimulates the mechanoreceptors in the skin above voice box and in the laryngeal muscles. These will send out a signal to the brainstem and from the brainstem to the somatosensory cortex. When it reaches the somatosensory system, that is, when the patient consciously feels the tingling. Since the somatosensory system is connected to the motor cortex, it modulates the activity there. Finally, the output goes from the motor cortex to the laryngeal muscles, closing the sensorimotor loop.

To determine how fast the observable effect of vibro-tactile stimulation was, we had people wear a EEG cap to record electrocortical activity with the vibrator taped to the throat. Then we asked them



to vocalize “AAAH”. After about four seconds, the vibrator turned on. This was done for about 100 times. Each participant received two 17-minute sessions of vibro-tactile stimulation (VTS). Thirteen participants, 12 with adductor SD and one with abductor SD participated. In this study, people with AdSD had not been treated with Botox® for 2-36 months while one person AbSD was never treated with it.

We found that when the vibrator is turned on, there was an immediate desynchronization of cortical activity in the motor cortex. Laryngeal vibration was suppressing the excessive neural activity typically associated with SD. We found that the event-related spectral power (ERSP) in the theta band was reduced in the group of SD participants when VTS was applied (VTS On). The drop in ERSP was seen in all three cortical areas of the brain involved in sensorimotor processing. That tells us that prolonged vibro-tactile stimulation reduces the amount of theta band synchronous activity to levels as seen in other dystonias where patients use sensory tricks for symptom relief.

The next step was to understand if VTS will have any meaningful impact on voice quality in those with SD. During testing, our SD participants spoke standardized sentences. We derived a measure called Smoothed Cepstral Peak Prominence (CPPS). CPPS is used to determine the degree of regularity in the voice data. This is an acoustic measure of speech quality defined as the logarithm of the Fourier Transform of the signal’s power spectrum with the unit being decibel (dB). A value above 2 dB would be a meaningful improvement in voice quality.

A sizeable group of people with SD responded to VTS while there were some participants who did not respond. In the group that responded, there was a marked decrease in the number of voice breaks. The study participants who did not show meaningful improvement had no change in voice breaks. They presented with milder cases of spasmodic dysphonia and, therefore, were likely less affected by the therapy. But 69% of the patients responded to the vibro-tactile stimulation after a single session.

Thus, our research shows that VTS improves objective markers of voice quality in spasmodic dysphonia.

Where do we go from here? We have received funding from the National Institutes of Health to test VTS during an 11-week, in-home, intervention. Unfortunately, due to the COVID-19 pandemic, the trial was put on hold, but reopened it at the end of June. We have to solve and address the following questions:

- What are the optimal stimulation parameters for VTS?
- What is the optimal dosage and how often?
- How long should the session last, 30 minutes per day?
- What is the best stimulation frequency? What frequency range is optimal?
- How can we deliver this treatment effectively?

In addition, we started to develop a wearable VTS device to apply vibration at home. The collar-like device contains a microphone and accelerometer that allows the user to apply the VTS only when the person speaks. This would provide flexibility in the usage and treatment options each person uses.

Special thanks to other members of the interdisciplinary research team which includes Dr. Peter Watson, a voice disorder specialist, and Dr. Yang Zhang, an expert in the analysis of cortical activity during speech. Dr. Goding from Otolaryngology represents the clinical partner in the team. He is an expert in SD and treats these patients regularly in the U of M Lion’s Voice Clinic. Dr. Divya Bhaskaran, Dr. Naveen Elangovan, Dr. Lucy Dunne, and Arash Mahnan complement the team.

We have received funding from the NIH for this work and a patent is in process for this wearable device. The NSDA has given great support for our research and we are excited for the future of this device as a treatment option for those with spasmodic dysphonia. ■



Validation of the Communicative Participation Item Bank as an Outcome Measure for Spasmodic Dysphonia

By **Yin Yiu, MD**, Assistant Professor of Otolaryngology, Houston Methodist

As Presented at the 2020 NSDA Virtual Symposium

I began this research study as a fellow at Columbia University, and I would like to thank all the collaborators and colleagues who supported this project including, Carolyn Baylor, Alyssa Bamer, Sandeep Shelly, Adam M. Klein, C. Gaelyn Garrett, and Michael Pitman.

This grant was supported by the National Spasmodic Dysphonia Association and the Cure Dystonia Now Foundation. Spasmodic dysphonia is a focal dystonia causing uncontrolled voice breaks during phonation, which has debilitating effects on a person's ability to communicate and participate in workplace and social situations. Current existing treatments are suboptimal as the current gold standard for treatment is the injection of botulinum toxin into the laryngeal musculature. Although this treatment has demonstrated clinical efficacy, it has significant limitations due to side effects, wide therapeutic window and a short-lived benefit.

Recognizing the need for a better treatment, many have sought to pioneer innovative techniques including:

- Selective laryngeal adductor denervation-reinnervation (SLAD-R) surgery
- Sodium oxybate
- Neuromodulation with implantable stimulator device or vibration collar
- Laser thyroarytenoid myoneurectomy

Outcome measurements for studying these therapies ranged widely. A recent systematic review was performed to identify the specific constructs in outcome instruments for SD. They determined that the 220 outcome measures were both "prolific in number and narrow in scope," preventing a unified approach to tracking outcomes for clinical and biomedical research.

The Movement Disorder Society Task Force critiqued rating scales for various dystonias. For laryngeal dystonia they recommended the voice handicap index (VHI) as an efficient disability scale; however they noted that it had no discriminant value and required further evaluation for dystonia despite inclusion of SD patients in their initial validation studies.

In 2004, the NIH started the PROMIS initiative to enhance and standardize the patient-reported outcomes for clinical research and practice. From this, the Communicative Participation Item Bank (CPIB) was developed by a group at the University of Washington, led by Dr. Carolyn Baylor. This tool measures the extent to which communication disorders interfere with the communicative participation which is defined as "taking part in life situations where knowledge, ideas and feelings are exchanged."

It uses Item Response Theory (IRT) to link observable behaviors to latent traits and though initial development started with an SD cohort, it has never been validated for SD. It has, however been validated for MS, Parkinson's disease, amyotrophic lateral sclerosis and head and neck cancer. The CPIB starts with "does your condition interfere with" ... followed by conversational situations. Scores are reported on a T-Scale with a mean of 50 with higher scores being more favorable.

Our main objective was to support the validity of the CPIB in its use with SD by doing the following:

1. Evaluating bias using differential item function (DIF)
2. Examining sensitivity to change in response to treatment

3. Investigating construct validity by correlating CPIB scores with VHI-10 scores.

We designed a prospective multi-institutional cohort study with participants recruited for the clinical practice side from three laryngologists from Columbia, Emory and Vanderbilt. The inclusion criteria for the study were people with SD of either subtype, with or without tremor, who are undergoing botulinum toxin injection. To feasibly achieve the recruitment goals, we included newly diagnosed participants as well as those with an established diagnosis.

Time point 1 was intended to capture a baseline assessment and was captured at the time of first injection or at least three months following the patient's last injection. Time point 2 was intended to measure response to treatment, so it was administered six weeks afterwards.

Time Point 1 (Date of botulinum toxin injection)

- Demographics
- VHI-10
- CPIB 46-question item bank

Time Point 2 (6 weeks later)

- VHI-10
- CPIB 46-question item bank

Study data was collected and managed using the RED Cap platform and data analysis was performed by the University of Washington Group that developed the CPIB. Here are the results.

190 participants completed the initial questionnaire and of those 139 also finished the follow-up survey.

Demographics: Our cohort had a mean age of 61 years and were predominately female.

Results of the DIF analysis for bias revealed statistically significant DIF on five of the forty-six items. Therefore, correlations of CPIB T-Scores before and after, adjusting for DIF were performed. Adjusting for these items had no significant impact on CPIB T-Scores confirming no clinically meaningful bias between the SD sample and the original calibration sample.

The results showed significant statistical differences between time points one and two. Our results strongly favor the CPIB being a valid and reliable outcome measure for the SD population without need for revisions. Our findings also suggest that both surveys are sensitive to capturing change with intervention.

	Columbia (n=24)	Emory (n=81)	Vanderbilt (n=85)	All (n=190)
Age (years)				
Mean	53.9	61.6	64	61.7
Range	26-75	21-84	21-93	21-93
Gender				
Male	10 (41.7%)	22 (27.2%)	21 (24.7%)	53 (27.9%)
Female	14 (58.3%)	59 (72.8%)	64 (75.3%)	137 (72.1%)
Ethnicity				
Hispanic	6 (25%)	1 (1.2%)	1 (1.2%)	8 (4.2%)
Non-Hispanic	18 (75%)	74 (91.3%)	80 (94.1%)	172 (90.5%)
Race				
White/Caucasian	18 (75%)	63 (77.8%)	80 (94.1%)	161 (84.7%)
Black/AA	3 (12.5%)	14 (17.3%)	2 (2.4%)	19 (10.0%)
Asian	0 (0%)	2 (2.5%)	0 (0%)	2 (1.1%)
More than one	1 (4.2%)	1 (1.2%)	1 (1.2%)	3 (1.6%)

Finally, correlations between the CPIB and VHI 10 were moderate, suggesting that these two methods have overlapping but not identical constructs.

The VHI and VHI-10 have long been regarded as the gold-standard in measuring the psychosocial consequences of voice disorder and continue to be highly relevant. However, the CPIB represents the next-generation of patient-reported outcome measurement as it was developed following the NIH's promise

guidelines that required systematic inclusion of patients, stakeholders, and rigorous qualitative item review and calibration using modern methods of IRT.

In addition, the CPIB can be used to measure the impact of communication disorders that cross systems beyond voice, such as cognitive linguistic issues. Based on these advances, we believe the CPIB should be adopted for clinical and research use in SD. You can find the CPIB online at <https://sites.google.com/uw.edu/cpib/home>. ■

PRESCRIBE THE NSDA

For Healthcare Professionals

The NSDA can be your patient's partner for this journey after the diagnosis of a voice disorder. With an expansive website, online and local support, awareness tools, and resources on how to live with a voice disorder, we are here for them! We have information on spasmodic dysphonia, muscle tension dysphonia, vocal tremor, and vocal cord paralysis/paresis. Please know, much of our material is applicable to the struggles of living with any voice condition.

We know your time is limited, so let us help your patients after the initial diagnosis, in-between treatments, and for the challenges ahead. By simply tearing a sheet off this handy pad and giving it to your patient, you are introducing them to a community that cares about their voice.

Email NSDA@dysphonia.org to order your pads today.

NATIONAL SPASMODIC DYSPHONIA ASSOCIATION

Being diagnosed with a voice disorder can bring many questions. The National Spasmodic Dysphonia Association (NSDA) is here to help. We are dedicated to improving the lives of people with spasmodic dysphonia and related voice conditions.



DISCOVER

Learn about treatment options.
Stay updated about the latest research.
Find helpful tools and resources
for your journey.

Meet people who understand the challenges of
living with a voice disorder. Find a local group.
Attend a symposium. Follow us on social media
and connect through online groups.



CONNECT



SHARE

Share your story and gain insight
from others. Find support. Get involved.
Become empowered. Discover a
community that cares about your voice.

GO TO [DYSPHONIA.ORG](https://dysphonia.org) | 800-795-6732

RESEARCH | EDUCATION | AWARENESS | SUPPORT
for spasmodic dysphonia and related voice conditions

HOW THE NSDA SUPPORTS *Research*

Funding Research Grants

The National Spasmodic Dysphonia Association funds seed grants to help nurture and support research for spasmodic dysphonia and related voice conditions. With these grants, we help investigators gather preliminary data so that they can apply to the National Institutes of Health for much larger funding. This type of investment allows us to support multiple projects to expand the understanding of these vocal disorders. We work with our Scientific Advisory Board, led by Dr. Gerald Berke, to review grant applications, foster relationships with researchers, and recruit investigators.

Providing Research Awards

The NSDA Research Award program provides awards and travel funds to annual meetings of the professional associations whose focus is voice, both for research and clinical advancement. By bringing investigators together to present their research on spasmodic dysphonia and related voice conditions, we are making connections that will help further their interest in voice conditions and ensure that it will continue to be an area of focus for future research. This type of collaboration positions the NSDA as not only an organization for people living with SD and related voice conditions, but one that is there to partner with researchers and healthcare professionals in the field and serve as an ongoing resource to them. We are currently partnering with the following organizations: American Academy of Otolaryngology, American Laryngological Association, Fall Voice Conference, Sin City Laryngology, Triological Society, and The Voice Foundation.

Dystonia Brain Bank

To help find the cause of a complex neurological disorder such as spasmodic dysphonia, we need to go to the source, the brain. Through the study of donated brain tissue, researchers are looking for important clues to find answers. The NSDA partners with other dystonia organizations to support the Dystonia Brain Collective. Working with the Harvard Brain Tissue Resource Center, they are responsible for collecting, preserving, and distributing human tissue to qualified scientific investigators who are conducting important spasmodic dysphonia research. When you enroll as a brain donor, you are giving a very precious gift which will benefit future generations.

“

My diagnosis of spasmodic dysphonia has been life changing. My hope is that by becoming a brain donor, I will have made an invaluable contribution. I envision the possibility that my donation could to be the final puzzle piece needed to pinpoint a cure.” – Mary F.

Global Dystonia Registry

The NSDA is proud to be part of the first-ever patient registry devoted to focal dystonias. This Registry is designed to collect data on persons affected by a focal dystonia(s), including spasmodic dysphonia, to assist in future research efforts and clinical trials. To date, close to 6,000 people have registered from over 60 countries. This is a collaboration between dystonia patient organizations, including the NSDA, and the research leaders of the Dystonia Coalition. Learn more at www.globaldystoniaregistry.org.

Clinical Trial Announcements and Dissemination of Information

One of the most challenging parts of research can be the recruitment of patients into clinical and research trials. We work closely with researchers to share information about how people can participate. The NSDA Community is wonderfully responsive and always eager to be part of these projects. We also present lay summaries so that our members understand the impact of this research.

Advocating on Capitol Hill

The NSDA is a proud partner of the Dystonia Advocacy Network. Working with other dystonia organizations we are making our voice heard annually on Capitol Hill regarding issues that affect our community. The number one priority is always to increase the funding to the National Institutes of Health, and in particular, those Institutes that focus on dystonia and spasmodic dysphonia. Over the years, we have seen an increase in funding of SD research through the National Institutes of Deafness and Communication Disorders (NINDS). We have also been successful in having dystonia listed as an eligible disorder for grants funded through the Department of Defense which has resulted in millions of dollars allocated to research for dystonia.

► Learn more at dysphonia.org

The NSDA Research Award Program provides awards and travel funds to annual meetings of the various professional associations whose focus is voice, both for research and clinical advancement. By bringing investigators together to present their research on spasmodic dysphonia and related voice conditions, we are making connections that will help further their interest in voice conditions and ensure that these fields will continue to be an area of focus for future research. We are currently offering Research Travel Awards to the following organizations: American Academy of Otolaryngology, American Laryngological Association, Fall Voice Conference, Sin City Laryngology, Triological Society, and the Voice Foundation. Below are brief summaries from four of our winners.

Dr. Anke Ziethe receives the inaugural NSDA Award at the 2019 Voice Foundation Symposium



Dr. Anke Ziethe received the inaugural NSDA Award at the 2019 Voice Foundation Symposium. Dr. Ziethe presented her research on "Analysis and Training of Feedback Mechanisms for Phonation and Speech in patients with Muscle Tension Dysphonia (MTD)." She shared, "By having the opportunity to attend the symposium I came in touch with a lot of interested people with whom I had wonderful and inspiring discussions and I also got input for my study regarding the technique. I was very surprised and happy to be given this award."

Alexis Worthley presented on the Symptomatology of Spasmodic Dysphonia at the 2019 American Laryngological Association Conference



Alexis Worthley in Dystonia and Speech Motor Control Laboratory at Massachusetts Eye and Ear Infirmary, presented on "The Separation of Innate and Learned Vocal Behaviors Defines the Symptomatology of Spasmodic Dysphonia" at the 2019 American Laryngological Association annual meeting with the support of an NSDA Research Award. Alexis shared this about attending the meeting; "I was given the opportunity to shed light on a critical component of the disorder, and share this information with physicians who work directly with this medical condition. I greatly appreciated the opportunity to do this."

Dr. Patrick McGarey presents at 2019 Fall Voice Conference on Practice Patterns and Barriers in Botulinum Toxin Injections for the Treatment of Voice Disorders



Dr. McGarey from the UVA Health System attended the 2019 Fall Voice Conference with the support of an NSDA Research Travel Award to present his research entitled, "Practice Patterns and Barriers in Botulinum Toxin Injection for the Treatment of Voice Disorders." He said that this travel award helped deliver the message that cost is an important part of medical care, and can sometimes prevent patients from being able to get access to care.

Dr. Rosemary A. Lester-Smith presents research on "The Effects of Masked and Delayed Auditory Feedback on Fundamental Frequency Modulation in Vocal Vibrato" at the 2019 Fall Voice Conference



Dr. Lester-Smith, from the University of Texas at Austin, received an NSDA Research Travel Award to the 2019 Fall Voice Conference and presented research that contributes to our understanding of expert vocal control and informs the development of strategies to improve vocal control in individuals with neurological voice disorders like essential vocal tremor. She shared, "This award supported the dissemination of research on neurological voice disorders to a diverse audience and facilitated the development of new research ideas."



Plasticity and Laryngeal Dystonia

By Mark Hallett, MD

Principal Investigator, Human Motor Control Section in the Medical Neurology Branch,
National Institute of Neurological Disorders and Stroke

Plasticity is the capacity to change. Neuroplasticity is the capacity of the brain to change. The brain is actually highly plastic; not only *can* it change, it is constantly changing. Whenever a person learns something new, a new fact or a new motor skill, the brain has changed. If a person develops laryngeal dystonia (LD), also referred to as spasmodic dysphonia (SD), the brain must have changed in some way so that abnormal vocal cord movement will happen.

The basic science of neuroplasticity is being actively investigated, and much is being learned about the underlying physiology. For example, the synapses between nerve cells can be modified to convey messages either more strongly or more weakly. Additionally, nerve processes can grow or shrink. The location in the brain where the alterations occur for different types of plastic changes is also being investigated. For learning a new fact, for example, there are changes in the part of the brain called the hippocampus. The site or sites of changes in relation to LD are not fully understood but are being investigated.

Plasticity processes in dystonia are not fully normal. In some experiments, learning new skills are slower than they should be. In other experiments, plasticity actually seems excessive and changes can go beyond expected limits. Dystonia might well be produced when plastic changes are more than a brain area can ordinarily tolerate.

So if LD results from an unwanted plastic change, might it be possible to reverse that plastic change? The brain still has its neuroplasticity, why not just go back the other way and return to normal? In other words, if there was the right training exercise, could LD be treated? This idea has been studied in several different

ways mainly with focal hand dystonia, particularly in patients with writer's cramp and musician's dystonia. These studies have had mixed success, and the idea is still being studied. Some therapists feel strongly that it works and have been promoting its use.

While there is certainly some reason that such approaches can work, at least with hand dystonia there are some alternate explanations for improvement with training. For example, since focal hand dystonia is often task specific, if the "task" is changed, then the dystonia is not apparent.

A pianist with musician's dystonia can get "better" just by altering technique – but in fact the original dystonia still remains with the original technique. Of course, this is a perfectly acceptable solution!

Alternative ways of speaking might well also help. For example, everyone with LD should be able to whisper without difficulty (since it does not involve the vocal cords). Some persons are able to sing even though they cannot speak normally. This uses an alternate method of vocal production. Rarely, it can also happen that there will be dysphonia for singing, but with normal talking. If there can be a plasticity changing therapy with hand dystonia, might there be something similar for LD? No such therapy has been developed yet (as far as I know).

Another way of making a plastic change is with brain stimulation, such as transcranial magnetic stimulation (TMS). TMS has been FDA-approved for the treatment of depression. There is some evidence that TMS might be beneficial in some types of dystonia, but the experimental results so far are limited. Dr. Teresa Kimberley at Massachusetts General Hospital Institute of Health Professions is currently studying TMS for laryngeal dystonia.

It was hoped when botulinum toxin therapy was introduced, that correcting the speech pattern with the injection might lead to a favorable plastic change that would outlast the weakness caused by the injection. Unfortunately, that doesn't seem to be the case, and points out that even if a favorable plastic change is induced, it is also critical to maintain that change.

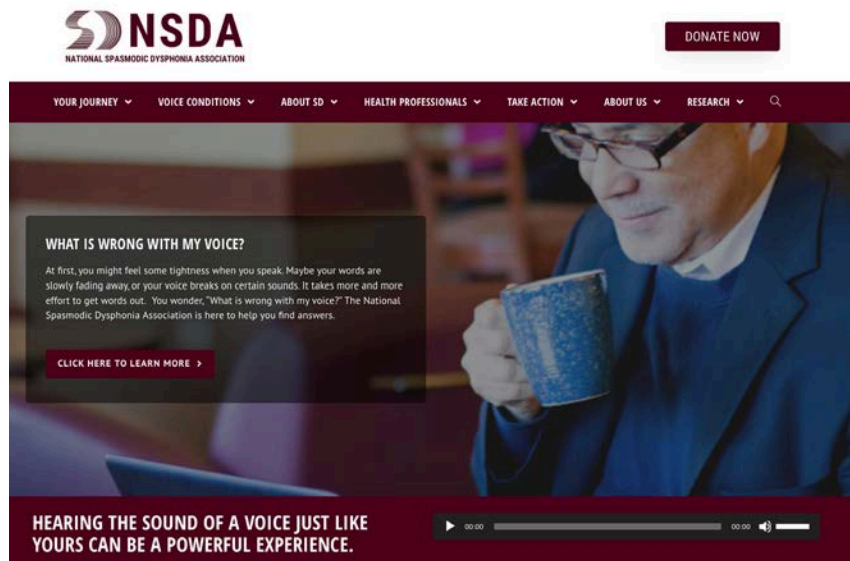
In summary, at the heart of LD, there is an unfavorable plastic change in the brain motor networks. It may well be possible to reverse that change, but a robust method is not yet available. Likely we will have to learn more about the pathophysiological changes before we can fully reverse them. ■

ABOUT MARK HALLETT, MD

Dr. Hallett obtained his A.B. and M.D. at Harvard University, had his internship in Medicine at the Peter Bent Brigham Hospital and his Neurology training at Massachusetts General Hospital. He had fellowships in neurophysiology at the NIH and in the Department of Neurology, Institute of Psychiatry in London, where he worked with C. David Marsden. Before coming to NIH in 1984, Dr. Hallett was the Chief of the Clinical Neurophysiology Laboratory at the Brigham and Women's Hospital in Boston and progressed to Associate Professor of Neurology at Harvard Medical School. He is currently Chief of the Medical Neurology Branch and Chief of its Human Motor Control Section. He is now Past-President of the International Federation of Clinical Neurophysiology. He has been President of the International Parkinson and Movement Disorder Society and Vice-President of the American Academy of Neurology. He served as Editor in Chief of *Clinical Neurophysiology*. His research activities focus on the physiology of human voluntary movement and its pathophysiology in disordered voluntary movement and involuntary movement.

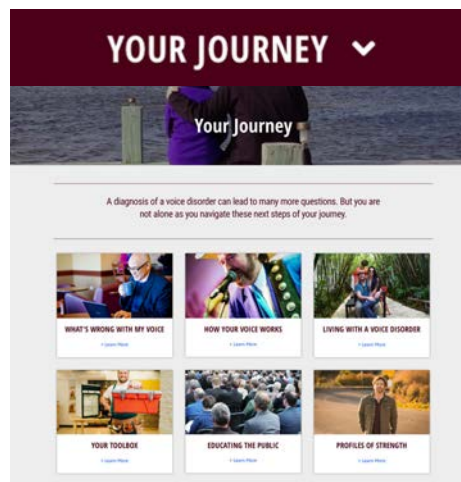
Exploring **Dysphonia.org**

WEBSITE OF NATIONAL SPASMODIC DYSPHONIA ASSOCIATION

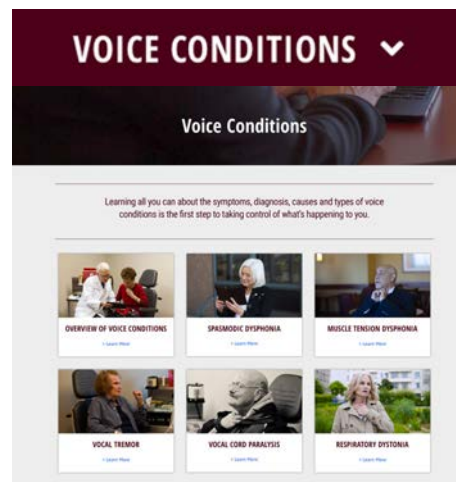


“What is wrong with my voice?”

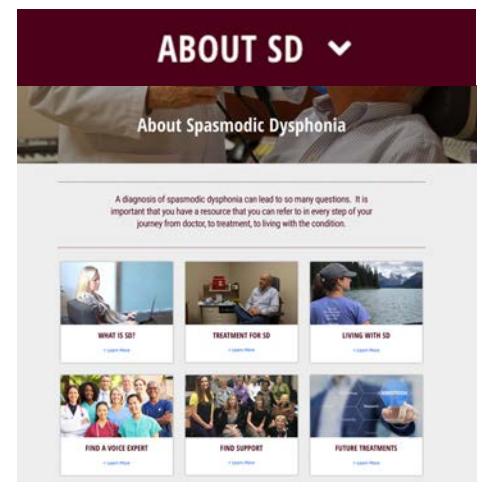
A question you may have asked yourself many times. The NSDA website can help you find answers. This extensive repository of information is a resource designed to give support, provide validation, and hopefully, encourage empowerment to people living with a voice condition like spasmodic dysphonia. The site is continually being updated and expanded, so we hope you will visit often.



Whether you are newly diagnosed or have lived with a voice condition for many years, this section can help you navigate living with a voice disorder. This road from “something is wrong with my voice” to acceptance is messy and emotional and we try to explore different aspects including relationships, employment, and socializing. The Toolkit provides guidance on topics like public speaking, managing stress, self-esteem and more. Downloads, quotes from our community, plus tips and tricks are all here. You may not need every section, but our hope is that you find what you need, when you’re feeling it.



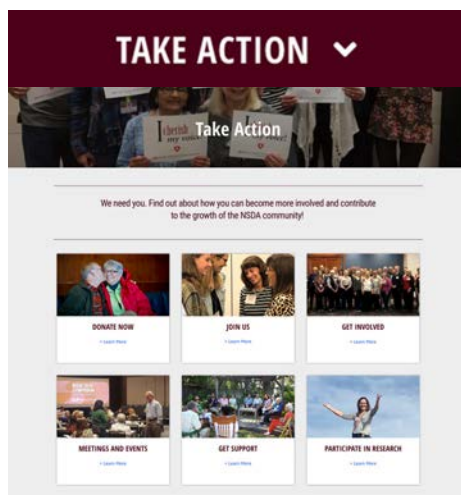
Learning all you can about the symptoms, diagnosis, causes and types of voice conditions is the first step to taking control of what’s happening to you. This section provides an extensive list of potential vocal conditions that can impact the voice as a starting point. It also delves into more detail about voice conditions related to spasmodic dysphonia so you can understand how these conditions can overlap. No matter the cause, a voice condition can have a big impact on a person’s life and having a diagnosis helps to determine the next steps.



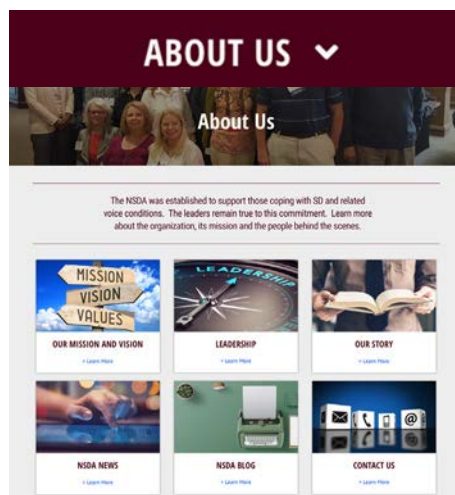
A diagnosis of spasmodic dysphonia can lead to many questions. Here is a resource that you can refer to; from finding a doctor, to treatment, to living with the condition. There is information about what to expect during an exam, the types of SD, and possible causes. There is no single treatment that works for everyone; it is usually a combination of measures that provide symptom relief. That’s why there is an expanded treatment section along with information on potential future treatments. In addition, there are helpful downloadable files.

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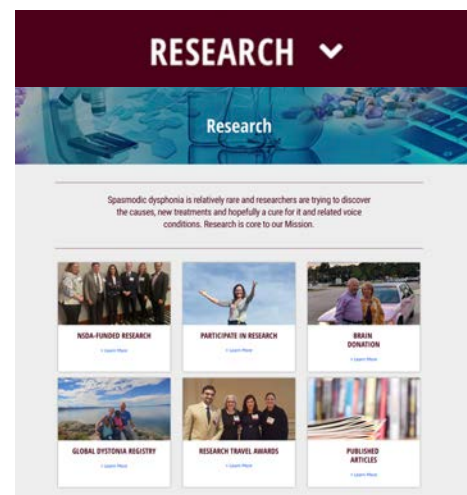
Exploring Dysphonia.org



There is no better person to represent someone with a voice disorder, than you. Explore this section to find all the ways that you can get involved with the NSDA. Advocate on Capitol Hill. Raise awareness on World Voice Day. Become an Area Contact. Find a local support group. Learn about upcoming meetings (both in-person and online). Shop for awareness items. Support the NSDA by donating or joining. Become part of this community that cares about you and your voice.



You can learn more about the NSDA, its leadership, and history. The NSDA News section will keep you up-to-date on research, treatment options and other important information. The NSDA Blog, which you can subscribe to, is more informal and provides a place to share the personal side of living with a voice disorder. A special place on the site is called 'In Memoriam', where we commemorate and honor the people who have been a part of the organization and provided inspiration.



This comprehensive section includes information on the grants currently funded by the NSDA, recipients of the NSDA Research Award Program, along with links to research articles. You can find out how to participate in current research studies, become a brain donor, and sign up with the Global Dysphonia Registry. Our hope is that one day we can say that there is a cure for spasmodic dysphonia and related voice conditions, but until then the NSDA will fund research to find answers.

HEALTHCARE REFERRAL LIST



You can look up a directory of healthcare professionals with experience in treating people with voice disorders. Different specialties are represented including laryngologists, otolaryngologists (ENTs), and speech-language pathologists. Healthcare professionals can also join or update their information in this section.

REAL PEOPLE



Losing one's voice can impact your sense of identity. The website is full of images of real people who are living with a voice disorder. *Profiles of Strength* tell the stories of people diagnosed at all different ages and in all kinds of careers. We want you to be able to see yourself in this site and know you have a partner in this journey.

QUICK LINKS

To help you find some of the most searched pages on the website, these quick links on the homepage will get you there fast.



FIND A DOCTOR



PARTICIPATE IN RESEARCH



CONNECT WITH OTHERS



ORDER FROM THE STORE



ATTEND A MEETING



SUPPORT THE NSDA

A Voice OF MANY COLORS



PAUL J. LONG ART SALE to Benefit The NSDA

The NSDA is excited to announce that on November 1, 2020, we are launching a virtual art sale titled, **A Voice of Many Colors**, on the NSDA website. NSDA Development Director Susan Beck has donated fine art prints from her father Paul J. Long's lifelong creative legacy. Susan tells us about her father's work below.

My father Paul J. Long was an accomplished artist and worked in many different mediums throughout his lifetime. His painting styles and subjects changed throughout his years and reflected many of the areas of Tennessee that he lived in. During his lifetime he was a resident of the following counties in East Tennessee: Monroe, Knox, Anderson, Loudon and Blount. The collection of his artwork donated to the National Spasmodic Dysphonia Association demonstrates many of these styles and locations.

My father died in 2015 at the beautiful age of 88. The works of art that will be available for purchase through the NSDA will include prints of oil and watercolor paintings from the 1970's through the 2000's. These are all limited edition fine art prints. Many are signed and numbered by the artist. There are also some that are signed by the artist but not numbered. These too are from a limited edition. As is typical for these types of limited editions – the printing plates were destroyed after the prints were produced.

As someone living with spasmodic dysphonia, I wanted to find a creative way to raise funds to support the NSDA. By donating these prints, everyone who purchases them will not only be able to enjoy my father's artwork but also know they are making a difference in the lives of people who are impacted by voice disorders.



About the Artist

Artist Paul J. Long was an East Tennessee native and was born May 27, 1927 in Tellico Plains. Paul became interested in painting and drawing at an early age. He considered himself to be basically self-taught and motivated to study and experiment with many different styles and media.

Paul was noted for his paintings of historic buildings, home portraits, and rural landscapes. One of his major paintings is the Battle of

Campbell Station, a Civil War scene located at what is now Farragut, Tennessee. The painting was purchased by a benefactor and donated to the Farragut Folklife Museum. Other historic paintings are the Blount County Courthouse, Loudon County Courthouse, the Rhea County Courthouse, and the boyhood home of Lamar Alexander in Maryville, TN. His art is in collections in the United States and several foreign countries. Many of Paul's original works of art can be found in the Museum Collection of the East Tennessee Historical Society in Knoxville, TN and the Charles Hall Museum in Tellico Plains, TN.

Paul retired from Martin Marietta in Oak Ridge where he worked as a Physicist and Registered Professional Engineer at the Y-12 Nuclear Weapons Facility for over 30 years. He was an alumnus of Tennessee Technological University, the University of Tennessee, and LaSalle University. Paul was also a World War II veteran.

Paul is the author of 4 books: Our Hill Country Heritage Volume 1, The Williams Family; Our Hill Country Heritage Volume 2, The Long Family; Thoughts in Many Colors; and Poems our Grandparents Read.

A Voice OF MANY COLORS



Blount County Courthouse | 14 5/8" x 20"



Tilson's Grocery | 14.25" x 20"



Loudon County Court House | 14 5/8" x 20"



Rhea County Courthouse | 14 5/8" x 20"



Fleeting Past of the Hills | 14.25" x 20"



Black-Eyed Susans | 18.75" x 14"



Daisies | 18.75" x 14"

► These limited edition prints will be available to purchase beginning on November 1, 2020 to support the NSDA. Listed next to the name of the print is the size of the image. All of the prints have a white border.

How can I qualify for disability benefits due to loss of speech?



By **Mark D. DeBofsky**

Attorney Mark D. DeBofsky is a member of the firm, DeBofsky Sherman Casciari Reynolds P.C., (www.debofsky.com) as well as an adjunct Professor of Law at University of Illinois-Chicago John Marshall Law School. He is a prolific author who has written many journal articles and has been a regular columnist for the Chicago Daily Law Bulletin since 2004. Mr. DeBofsky is also an annual contributor to the ERISA Survey of Federal Circuits published by the American Bar Association and served for many years as a senior editor of Employee Benefits Law published by Bloomberg. He has written articles for the NSDA on qualifying for disability benefits in the past and shared this update..

Almost all occupations require the ability to speak. Indeed, under the Social Security regulations, loss of speech from a condition such as spasmodic dysphonia can result in an award of disability benefits. Social Security has included in its index of impairments that are deemed disabling, the following Listing:

2.09 Loss of speech due to any cause, with inability to produce by any means speech that can be heard, understood, or sustained.

Proving disability, though, can be challenging. However, Social Security has issued a helpful roadmap explaining how to prove disability - SSR 82-57: TITLES II AND XVI: LOSS OF SPEECH. The Ruling, which is an explanatory policy statement issued by the Social Security Administration, emphasizes what is needed to establish proof of the three prongs of disability due to loss of the ability to speak – generating speech that can be *heard, understood, and sustained* in social and vocational settings. Social Security further explains:

Three attributes of speech pertinent to the evaluation of speech proficiency are: (1) *audibility* – the ability to speak at a level sufficient to be heard; (2) *intelligibility* – the ability to articulate and to link the phonetic units of speech with sufficient accuracy to be understood; and (3) *functional efficiency* – the ability to produce and sustain a serviceably fast rate of speech output over a useful period of time.

When at least one of these attributes is missing, overall speech function is not considered effective.

A diagnosis is not enough to establish a disability, though, and a detailed evaluation and assessment needs to be provided by an otolaryngologist with input from a speech therapist who personally listens to the patient and needs to report on the following:

1. The intensity of speech (audibility) – the conditions under which the individual can and cannot be heard (e.g., in quiet surroundings, noisy places, a moving automobile); the maximum distance at which individuals can be heard; whether their voices tend to become inaudible, and if so, after how long; and

2. The ability to articulate (intelligibility) – the frequency of any difficulties with pronunciation, the extent to which the individual is asked to repeat, how well he or she is understood by strangers unaccustomed to hearing esophageal speech; and

3. The rate of speech and the degree of ease with which the individual's speech flows (functional efficiency) – how long he or she is able to sustain consecutive speech; the number of words spoken without interruption or hesitancy; whether he or she appears fatigued, and if so, after how long.

A publication issued by the National Institutes of Health is also instructive: <https://www.nidcd.nih.gov/health/spasmodic-dysphonia>. The publication

lists diagnostic criteria, testing, and describes available treatment, although it acknowledges there is no cure for spasmodic dysphonia.

While these guidelines were established by the Social Security Administration, they are universally applicable to any type of disability claim. Claims brought under disability insurance policies should be framed utilizing the same standards. In our experience representing thousands of disability claimants, we have learned that all successful disability benefit claims share the same attributes:

- Diagnosis and ongoing treatment by specialist doctors and medical providers
- Objective testing confirming diagnosis and a longitudinal record of treatment
- Efforts at treatment, although neither the Social Security Administration nor private disability insurers can compel a claimant to undergo surgery or other risky treatment as a condition of receiving benefits
- Corroboration of impairing symptoms from multiple sources – doctors, employers and co-workers, family, and friends

The purpose of this article is to offer general suggestions. Disability claims are complex legal proceedings; and just as patients see medical specialists who are experts in treating their conditions, finding an attorney who is well-versed in the law and who has had appropriate experience is the key to navigating a successful disability claim. ■

Voice Amplification Systems



Prepared by Carol Doles, NSDA Eastern Regional Representative

I have always been a fixer. I like to believe that when I am faced with an obstacle, I will be able to find a way to conquer it or work with it to achieve my goal. Things were

no different when I developed adductor spasmodic dysphonia. It was one of the biggest obstacles I had ever faced and stood in the way of achieving a goal I had had since childhood, the goal of teaching.

It took six years of misdiagnoses to determine what was wrong with my voice. During that time, I tried hard to make my voice sound normal to my students. This made my voice worse by creating a hefty amount of muscle tension dysphonia in my throat. When I finally received my diagnoses, I was told that if I was able to continue teaching, it would be hard and exhausting. I knew I wanted to try. I chose to pursue voice therapy and botulinum toxin injections.

I found that if I could stop pushing my voice to project across the room, then my broken voice sounded a little better.

Then, I had my first injection and experienced breathiness and a quiet voice that could not be heard unless someone was very near to me. I quickly found a personal voice amplifier with a wired headset that I could wear on a belt around my waist. This device increased the volume of my whisper to a level that could be heard across the room. I could continue teaching! I was thrilled! As the effects of the medicine began to wear off and the spasms and tightness returned, I used the voice amplifier to talk softer, and it helped tremendously. Over the years, I have found the amplifier useful in many situations. I have also wished that I had it with me when I had left it somewhere else.

I recently discovered that there are apps for smartphones that can turn them into microphones. I always have my phone with me. Now, all I need is a speaker, Bluetooth or wired, and I have an amplification system at my fingertips. While solving the problem of how to make my voice louder, I still needed a solution for situations when I wanted to be able to talk with my husband in noisy environments where a voice amplifier isn't appropriate.

Although we very much enjoyed date nights at restaurants for example, my soft voice meant that we could not carry on a conversation in most of them. This was discouraging, and we either chose to skip the experience, or went but did not enjoy ourselves fully. On a vacation, I walked past a tour guide talking with his group. I noticed that there was lots of noise from traffic, people, and other tour groups happening all around and yet the participants appeared to hear the guide well. I researched and finally found some companies that would allow us to try their transmitter/receiver combination to see if it would work for our purpose. Imagine our delight when we dined out and could talk with each other. This was a game changer for us. After almost twenty years of struggling with my voice, we can use this to enjoy activities together again. The problem of making my voice louder and the problem of being heard in noisy situations have been helped. Now if I could just talk with a mask on.

► Find links along with a checklist on considerations for choosing a personal voice amplifier at dysphonia.org

PORTABLE VOICE AMPLIFIER

- Increases the volume of your voice
- A small speaker is worn on a belt, armband, lanyard, or on an article of clothing
- The microphone can be a headset, lapel mic, or hand-held
- The microphone can be wired or wireless

Pros: Portability, inexpensive options, adjustable volume, options available to match activity

Cons: Feedback if microphone is too close to speaker, may be too loud for listeners close to the speaker



SMARTPHONE APP USED WITH A SPEAKER

- Smartphone provides the microphone used to amplify voice
- An external microphone can be plugged into phone and used as the microphone
- Phone can be held, worn on the belt, in an armband or placed in a pocket
- Phone can be connected to a speaker by a wire or through Bluetooth
- Multiple paid and free apps are available

Pros: Low cost, flexibility to connect to different speaker systems, could be used as an intercom

Cons: Feedback when the phone/microphone is too close to the speaker



NSDA Awareness Facemasks Available

Having a voice disorder can be challenging, but having to wear a mask can make it even harder with the additional effort required to project your voice. With these awareness masks, you can let people know that you have a voice disorder without having to say a word. Our NSDA volunteer leaders provided valuable input on the design and wording. Special thanks to Carol Doles for the original inspiration and to Nancy Peltier who helped to source a vendor! They are \$10 each including shipping (within the US) and can be ordered at dysphonia.org

There are three different styles and they all include the NSDA website to raise awareness.

- "Please bear with me, I have a voice disorder" and a little bear dots your nose!
- "Not Sick, I have a voice disorder"
- "Speak Out for Spasmodic Dysphonia and Related Voice Conditions" Family and friends can wear this mask too to help support a loved one with a voice condition.

The 3-ply mask is burgundy on the outside, white on the inside with black piping and ear straps. It cinches around the nose for a snugger fit. Lightweight and 100% polyester, these masks are machine-washable for extended use. Please note this is a non-medical grade mask.

Measures 6.75" L x 4.5" W



TOUR GUIDE SYSTEM

- These systems typically involve a transmitter/microphone device (used by tour guide) along with multiple receiver/headset devices (used by tour participants)
- The person with a voice disorder wears a small transmitter on a lanyard around the neck and uses a headset, lapel, or hand-held microphone
- Listeners wear a small receiver on a lanyard around the neck and use a headset or ear buds



Pros: Background noises are greatly reduced, allows for communication with intended listeners, two-way systems are also available

Cons: A device must be worn, need extra receivers if there are several listeners, headsets would be cumbersome if dining, but lapel mics would likely pick up more background noise

I found two companies that will sell the number of transmitters and receivers that you need rather than the packaged set sold in larger quantities:

Retekess | www.retekess.com

System that was evaluated (approximately \$70 for one transmitter/microphone and one receiver/ear buds, lanyards and charging cables) was the Reteless TT109 Tour Guide System 2.4GHz One Way Transmitter and Receiver. I originally ordered the headset with the transmitter and later ordered a lapel microphone. I am waiting on the lapel microphone from Reteless, but am using a different lapel mic until it arrives.



Tourguide Solutions | www.tourguidesolutions.com

This company offered a free demo for its products. I tried the standard option and the cost was approximately \$660. They also offered different options for microphones and listening devices with cost adjusted accordingly. You could choose to use your own microphone/ear buds/etc. which would reduce the cost. They are great to work with and the product worked well. ■

Please Note: The NSDA does not endorse or recommend specific products but rather provides this information as possible tools to help support people with spasmodic dysphonia and related voice conditions. Special thanks to Carol Doles for testing and assembling this information. Carol has adductor spasmodic dysphonia and serves as the Eastern Regional Representative for the NSDA.

REVIEW OF 'Text-to-Speech' Applications for People with a Voice Disorder

The National Spasmodic Dysphonia Association invited the community to participate in an online evaluation of text-to-speech applications and provide feedback based on the guidelines provided. We thank all who shared their experiences.

This article reviews the use of apps that support text-to-speech for those with voice disorders. It is not an exhaustive list and only covers the apps evaluated in the survey. The information included is accurate at time of printing.

The overwhelming number of responses believed that text-to-speech apps are good for casual, quick short sentences, but that once they were used in a one-to-one conversation, the app was less helpful because typing for the speech engine was slower than a regular conversation. Most believed that the solutions could be used in any type of situation, but individual tools rated better or worse depending on the situation.

In general, most of the apps are free to download, but require an in-app purchase in order to add functionality or remove ads. The use of ads was prevalent in all apps except for Speech Assistant AAC. Their funding was achieved by reducing the in-app feature set. Included is an overview of the apps that were tested.

Read
a written
summary regarding
each app at
dysphonia.org

App Name	Voice Output	Different Voices	Vocabulary	Create and Save Phrases	Cost	Platform Supported
TouchChat	X	X	X	X (with upgrade)	\$149.99 \$300 to quickly create and save sentences	iOS
TexttoSpeech	X	X		X Limited to 5000 characters	FREE	Android (Samsung Galaxy, Google Pixel, Amazon Kindle) and iOS
Speak4Me	X	X		X Limited Capacity unless you pay	FREE to download, 0.99 cents to remove ads and get storage for saved phrases	Android (Samsung Galaxy, Google Pixel, Amazon Kindle) and iOS
Speak	X	X		X	FREE to download, \$1.99 purchase required to remove ads	iOS
Speech Assistant AAC	X	X (Different voices must be downloaded)	X	X	FREE to download but \$7.00 to get full functionality. (\$14.99 for iOS)	Android (Samsung Galaxy, Google Pixel, Amazon Kindle) and iOS
Natural Reader	X	X			FREE to download plus a monthly fee of up to \$18.99	Android (Samsung Galaxy, Google Pixel, Amazon Kindle) and iOS
Aloud! Text-to-Speech	X				FREE	iOS
Talk for Me	X	X (different voices must be downloaded)	X	X	FREE	iOS
Translate All	X				FREE to download with lots of ads, \$1.99 per item to upgrade.	Android (Samsung Galaxy, Google Pixel, Amazon Kindle)

Supporting Someone with a Voice Disorder

As a family member or friend of someone with a voice disorder, your kindness and understanding can go a long way towards helping them feel confident. But we often don't realize our body language is also delivering a very powerful message to them as well.

Consider these behaviors:

- Checking a watch or looking away. This signals, "I'm not really listening."
- Nodding when they talk, but not making eye contact during a conversation. This means "I've superficially judged you and what you're saying is less relevant because it doesn't sound normal."
- Finishing sentences for you, or maybe constantly interrupting. This means "I don't have time to wait for all your words to finally come out."

Your non-verbal signals can actually convey a tremendous amount of information. Facial expressions are universal. Even when someone doesn't express their thoughts verbally, most people exhibit clues that show what they're thinking and feeling. Our body language – as well as their reading of others' – happen without conscious awareness.

Here are some non-verbal ways that you can show support to someone you care about:

- **Eye contact** – the number-one way to show responsiveness and caring is to look at the person who is talking. Put down your cell-phone or move away from whatever you were originally doing.¹
- **Body orientation toward the individual** – shifting your body so you are facing the other person and sometimes even moving closer to them as you realize the conversation is becoming more serious.
- **Active listening behaviors** – these include nodding, verbal acknowledgments of following the conversation such as "ahuh", "yep", "I see", etc., and asking questions that are in line with the topic of the conversation.
- **Physical touch** – when appropriate, can reinforce that you care and want to help.

This type of validation is the simplest way to convey the most important messages of emotional support – I see you, I understand, I care about you, and I'm here for you.

¹ (Source: <https://www.psychologytoday.com/us/blog/stressing-communication/201906/formula-providing-emotional-support>)

PLANNING FOR AN EMERGENCY WITH A VOICE DISORDER

BY CREATING A PLAN, YOU WILL HAVE SOMETHING TO CALL ON IF THERE IS EVER AN EMERGENCY. THIS EXERCISE CAN EMPOWER YOU TO RISE TO WHATEVER CRISIS COMES YOUR WAY.

CALL 911

Keep in mind that 911 operators are trained listeners because they receive phone calls from people completely unable to speak. Don't hesitate to call them. You will both do your best to communicate and they will respond to your emergency. Take a deep breath and say "help". It's the start they need to respond.



PRE-PLAN YOUR EASIEST EMERGENCY STATEMENT



Each voice disorder has difficult sounds. If you are like others with abductor SD, adductor SD or vocal tremor, you think of better ways to say things that optimize your voice all the time. Create your ideal sentence in advance. Do it right now. How can you say "I need help" with the least resistance from your voice disorder? Make one for "there's a fire" or "we need an ambulance".

WHEN IT'S YOU AND ONLY YOU

There may be situations where 911 is either not available or isn't the best first step for you to take. It could be a situation like discovering a house fire and needing to quickly alert the residents to get them aware and evacuating. Use whatever voice you have and be prepared to be as loud as you can get. Use anything available to make noise to get others attention. Look around you right now and think about things you could use to get someone's attention. It could be a house bell, car horn or even a noise app on your phone. You might be surprised at just how creative you can get, especially when someone's life depends on it.



PRACTICE, PRACTICE, PRACTICE



It's not surprising that first-responders suggest families practice leaving the house and plan a meeting location in the event of a fire. Practice is the key to preparation. If you spend time on the lake with poor cell service, you might plan something like waving your arms to other boaters as your primary source of communication. If you're in your apartment, maybe you bang on the neighbor's wall. Think about potential situations and make a plan. Doing this will make you more confident and more prepared.

The NSDA has created handy cards that help explain that you have a voice disorder. A sheet is included on page 39 and you can order more at dysphonia.org

Voice Disorders — NOT ALL ONE AND THE SAME

Not all voice disorders are the same. Each has its own unique characteristics so proper diagnosis is important to ensure right treatment can be utilized. The following is a discussion of two common voice disorders that can be both confused with spasmodic dysphonia and co-exist with it, muscle tension dysphonia and vocal tremor. *Special thanks to Christie DeLuca, MS, CCC-SLP, for preparing these fact sheets.*

MUSCLE TENSION DYSPHONIA

What is it?

Muscle tension dysphonia, or MTD, is a hyperfunctional voice disorder that is caused by excessive tightening or squeezing of the muscles in and around the larynx during speech. The excessive muscle use and strain during speaking prevents efficient phonation and causes a strained vocal quality.

It is believed that there are two types of MTD: Primary MTD and Secondary MTD. Primary MTD develops in the absence of any structural or physiological abnormality in the larynx. Secondary MTD, on the other hand, develops as a compensatory method for speaking with a voice pathology/voice disorder or any other disease that may affect normal phonation patterns.

For example, secondary MTD can develop secondary to spasmodic dysphonia, tremor, vocal fold atrophy or paralysis, vocal fold lesions, laryngopharyngeal reflux and more. In both cases, the muscles in and around the larynx are uncoordinated and develop a pattern of excessive force to get voice out.

Symptoms

Individuals with MTD may experience symptoms of both change in quality of the voice but also experience symptoms of how speaking feels. He/she may

notice increased hoarseness or a strained quality to the voice. Some may experience breathiness and some with more severe MTD may note periods of strain but where the voice will fail to come out at all (called aphonia). MTD can present with voice breaks or cuts off in sounds if the tension in and around the voice box is severe.

There may other "throat" symptoms related to these increased sensations including the feeling of mucus or something present in the throat, frequent need to throat clear, frequent discomfort in the throat, or sometimes even difficulty swallowing solid foods and/or discomfort with swallowing.

Some with severe MTD may also experience tightness in muscle groups surrounding the larynx like the neck, shoulders, upper body and jaw as he/she works harder to produce voice. Individuals may feel more tenderness, discomfort or pain upon palpation of the neck muscles and spaces between laryngeal cartilages. Symptoms for most with MTD will typically worsen with more voice use or continuous speaking.

Characteristics

MTD is more prevalent among women than men. Some research suggests that individuals with high levels of stress, certain personality types, or those who have high vocal demands may be more likely to develop MTD. The symptoms of MTD tend to be consistent across speech contexts and are not sound-specific (this is unlike spasmodic dysphonia).

Causes

There are many potential causes for the development of MTD. Secondary MTD often develops as a method of compensating for another voice disorder or disorder that makes it harder to voice in a normal manner.

The muscles of the larynx begin to engage too much, in attempts to either make

the voice sound normal again, or to get a more consistent or more functional voice to meet one's speaking demands that are now more challenging given the underlying voice disorder.

Primary MTD can develop after an illness like an upper respiratory infection, or acute laryngitis, as your body gets used to pushing to make a voice during an acute illness.

This pattern of excessive muscle strain may not go away on its own, even after the illness or virus goes away, resulting in MTD that remains despite the lack of an underlying disorder any longer. Primary MTD can also be caused by significant ongoing stress.

Diagnostic Tools

Muscle tension dysphonia can best be detected in connected speech. A full diagnostic assessment is usually completed by both a speech language pathologist and otolaryngologist. You may be asked to read sentences that will collect acoustic measures, qualitative voice evaluations, and aerodynamic measures.

You may also be asked to complete tasks to help to differentially diagnose muscle tension dysphonia versus other similarly presenting disorders, like spasmodic dysphonia. The treating otolaryngologist or speech language pathologist will likely palpate the muscles in your neck to feel for any tension in the muscles surrounding the larynx or in the upper body region. He/she may determine if a trial of laryngeal massage results in decreased strain or increased vocal quality.

Flexible or rigid laryngoscopy with videostroboscopy should be performed to look at the anatomy of the larynx and vibration of the vocal folds during speech. In individuals with MTD the muscles around the vocal folds often can be seen compressing or "squeezing" during phonation during laryngoscopy.

Differentiating Voice Disorders



Muscle Tension Dysphonia

Symptoms apparent in all speech contexts

No change with certain sounds/tasks

Excess laryngeal tension as primary symptom

Functional voice disorder (caused by inefficient voice patterns), not neurological

Onset at any age

Remediated with voice therapy

Spasmodic Dysphonia

Symptoms elicited with certain speech contexts (i.e. vowel onsets, or after voiced/voiceless phonemes)

Sound-specific phonation breaks

Response to “sensory tricks”

Typically no symptoms with high pitch, singing, laughing, emotional speech

May show improvement with alcohol

Laryngeal tension is secondary/compensatory

Typically progressive for up to two years, then stable

Onset typically 4th-5th decade of life

Often responsive to Botox® injections

Vocal Tremor

Symptoms elicited best in sustained vowels or vowel-laden sentences

Regular fluctuations in pitch or loudness

Some may have improvement in symptoms with alcohol

Neurological in origin

Botox® treatment is not as effective as for spasmodic dysphonia

It may be difficult to get an accurate diagnosis for MTD because MTD can co-occur as a secondary or compensatory response to an underlying voice disorder. The MTD symptoms or excessive muscle tension may sometimes mask symptoms of the underlying or primary disorder. Sometimes, once the overlying muscle tension is reduced, symptoms of the underlying voice disorder may emerge or may become more apparent.

Voice therapy “stimulability” will be conducted by a speech language pathologist to determine if the person would benefit from voice therapy, based on the individual’s response to voice therapy probes.

A “trial” of voice therapy may be conducted to help differentially diagnose between MTD and spasmodic dysphonia. If the person has resolution of symptoms

within the first several sessions the diagnosis is clarified as MTD.

If the person does not make quick, easy or steady progress with therapy than most likely the individual has another disorder that presents similarly to MTD (i.e. spasmodic dysphonia) or secondary MTD masking another primary voice disorder.

Treatment Options

Voice therapy is the standard treatment for muscle tension dysphonia. Individuals are taught ways to speak with less effort and with decreased muscle tension. Muscles are taught to relax during speech, rather than strain. Individuals may be given techniques to increase more efficient coordination of the speech subsystems and the muscles involved in voice production. Some examples are getting a patient to more efficiently use airflow, using laryngeal massage to

manually release tension in the larynx and neck, and using resonant voice techniques to increase accurate voice placement and efficient phonation patterns.

Generally, only a few voice therapy sessions will be needed to retrain muscles to reduce MTD. If an individual has MTD secondary to another voice disorder the primary voice disorder will be targeted through a comprehensive treatment plan with a speech language pathologist along with an otolaryngologist.

Sometimes treatment of the underlying voice problem is enough to eliminate secondary MTD. However, sometimes the MTD will remain despite resolution of the primary voice problem. If this is the case, voice therapy will target the remaining MTD symptoms.

continued on page 30

ESSENTIAL TREMOR OF THE VOICE

What is it?

Essential tremor of the voice is a form of essential tremor. Essential tremor is a neurological disorder (disorder of the central nervous system) that causes parts of the body to rhythmically shake, due to an abnormal control of muscle contraction.

When essential tremor affects the larynx and other structures involved in speech production (i.e. tongue, soft palate, pharynx, muscles of respiration), it results in essential tremor of the voice.

Essential tremor of the voice results in involuntary periodic (regular), rhythmic changes in pitch and loudness of the voice and may be perceived as a “shaky” vocal quality. Many patients with essential tremor of the voice experience tremor in other parts of the body (i.e. limbs); however some individuals can present with only tremor of the voice.

Characteristics

Essential tremor is the most common movement disorder. Essential tremor of the voice typically develops in middle age (50’s-60’s) and its onset is typically gradual. Severity of essential tremor typically progresses with age but the rate of progression is often very slow. About one-third to one-half of cases of essential tremor of the voice are familial in type (meaning the individual with tremor has a relative with tremor).

The severity of the tremor (i.e. variation in the amplitude/strength of the tremor and the frequency (oscillations per second) may vary from person to person.

Symptoms

Symptoms may worsen in certain conditions like emotional stress,

speaking on the phone, or fatigue. Tremor may be perceived by others as an individual sounding “nervous” due to the shaky quality of the voice. The vocal tremor may result in increased effort during speech production as one attempts to compensate for or manage the tremulous vocal quality and may present with decreased ability to be understood by others.

Essential tremor of the voice is not correlated with development of Parkinson’s Disease or the voice tremor that co-occurs with Parkinson’s Disease.

Cause

There is no known cause for essential tremor. Neurophysiological and genetic factors are not yet fully understood.

Essential tremor of the voice is suspected to originate from dysfunction in the cerebellum in the brain. It is hypothesized that both genetic and environmental factors play a role in the development of the disorder.

Diagnostic Tools

Tremor can best be detected in sustained vowel notes like an “ah” held out for a period of time. You may notice vocal tremor more in sentences with more vowels.

A full diagnostic assessment is usually completed by both a speech language pathologist and otolaryngologist. You may be asked to read sentences that will collect acoustic measures, aerodynamic measures, and may be provided with tasks to help to differentially diagnose tremor from other similarly presenting disorders.

Location, extent, and severity of essential tremor of the laryngeal and pharyngeal structures may be seen on a flexible or rigid laryngoscopy exam, through the rhythmic movements of the laryngeal structures. Videostroboscopy during this exam will allow for visualization of tremor during phonation.

Treatment Options

There is no standard treatment option for tremor at this time, as tremor cannot be cured. However, several treatment options exist for patients. Botulinum toxin injections are sometimes used to minimize the severity of tremor. Botulinum toxin functions to temporarily block the muscle contractions and temporarily “weaken” the tremor that typically occurs with muscle contraction.

Botulinum toxin injections are not as effective for tremor as they are for spasmodic dysphonia, however. This is partly due to the fact that many tremor patients have tremor in several structures that are involved with the dysfunctional speech.

Although voice therapy will not cure or take away the vocal tremor, voice therapy may be helpful to have patients learn how to more effectively compensate for the tremor. Using a slowed speaking rate, more efficient airflow and resonance, and effective ways to project can help a person to work with the tremor rather than against it.

Medication to control essential tremor may also be recommended in some cases. Medication that is typically prescribed to control essential tremor in other parts of the body may not be as effective in managing essential tremor in the voice. Medication management in regards to essential tremor will be handled by a neurologist. Sodium Oxybate is currently being trialed as a potential medication to treat symptoms of vocal tremor.

Deep Brain Stimulation (DBS) (typically targeting the thalamus of the brain) has been proposed as a method to reduce symptoms of tremor. Long term research on this treatment method is ongoing. ■

NSDA Awareness & Support

The NSDA is thankful for our volunteer leaders, generous supporters, and the vibrant community that we have built together over the past 31 years. Together, we have raised awareness, educated many, spread the word on social media, and supported one another. All of our efforts have helped bring visibility to spasmodic dysphonia and related voice conditions and have worked to generate research.

NSDA Leadership Workshops



2019 NSDA Leadership Workshop Attendees



2020 NSDA Virtual Leadership Workshop Attendees (not everyone who attended is pictured)

2019 | Thirty leaders gathered in Boston for the 2019 Leadership Workshop including Board Members, Support Group Leaders, Special Projects Leaders, Area Contact Persons, and Staff. The half-day program was viewed as being informative, interactive, and inspirational. Discussions were held on support, fundraising, and awareness. They also had the opportunity to be guests at the 2019 NSDA Research Workshop that followed immediately after.

2020 | The 2020 Leadership Workshop was held virtually for the first-time. Support Group Leaders, Regional Representatives, Special Projects Leaders, Area Contact Persons, Speech-Language Pathologists and Staff Members attended. The participation was our largest-to-date with 61 leaders from 27 states in the US and three international countries represented. It was well-received as being fast-paced and engaging.

Larry Kolasa Founding President Award



Charlie Reavis and Dot Sowerby

This award, honoring the leadership of Founding President Larry Kolasa, is bestowed upon individuals who have helped to shape the future of the NSDA. At the 2019 NSDA Symposium, NSDA President Charlie Reavis presented Dot Sowerby with the Larry Kolasa's Founding President Award in appreciation for all her work. Dot's many contributions to the NSDA include being a founding member of the NSDA Board of Directors with continual service; being elected as the NSDA President from 2002-2005; authoring her biography, *Speechless, Living with Spasmodic Dysphonia*, organizing support groups and regional symposiums, representing the NSDA at numerous medical and voice conventions, and continual outreach to new people with voice issues. Dot is a hero and a legend in our community and we are so admiring and grateful for all of her efforts. Dot shared, "I was so honored to receive the Larry Kolasa Founding President Award for my 30 years of service; what a surprise and pleasure. The NSDA has been my focus and mission for these years and seeing it grow and bloom is very fulfilling."

NSDA Awareness & Support



Mary Bifaro (left) and
Adrienne Simons

Dot Sowerby Pioneer Award

Since 2015, the NSDA takes great pride in bestowing the Dot Sowerby Pioneer Award honoring founding Board Member Dot Sowerby to recognize her many accomplishments in raising awareness about spasmodic dysphonia. The recipients follow in her footsteps through their impact in the NSDA community.

2019 | The winner of the 2019 award was NSDA Support Services Director, Mary Bifaro and it was presented by the award's namesake, Dot Sowerby. Mary is the leader of The Charlotte Spasmodic Dysphonia Support Group, joined the NSDA Board of Directors in 2003, and since 2005, serves as the Support Services Director. In this role, Mary oversees support activities including writing 57 issues of *Voices of Support* highlighting the work of the support network quarterly; chaired 16 NSDA Leadership Workshops in conjunction with our annual symposiums; helps moderate NSDA Support Leadership Facebook Group; and leads the NSDA Support Group Leader Committee which created the Support Group Meeting Topics Workbook. Mary has also served on the committees for both the Share Your Story and Celebrating Our Voice Contests. Thank you for your dedication, passion, leadership and being the heart of the NSDA's Support Network.



Carol Doles

2020 | The 2020 Dot Sowerby Pioneer Award was presented to Eastern Region & Canada Representative, Carol Doles, virtually by the award's namesake, Dot Sowerby. Carol founded the Greater Columbus and the Central Virginia support groups. She serves on the Support Leadership Committee and is an Administrator of the NSDA Support Leadership Facebook Group. In addition, she has served on several Planning Committees for our Leadership Workshops. According to Carol, "I felt humbled and honored to receive the award. Dot was one of the first to welcome me and let me know that I was not alone in my journey with SD. Dot provided valuable mentorship and included me in her network of leaders. These leaders have all supported, taught, and encouraged me every step of the way. My goal has been to follow these great examples and let every SDer know that a community awaits them. Living well with SD is within their reach."



Dennis Kaszeta

Midge Kovacs Annual Awareness Award

Since 1999, the NSDA takes great pleasure in bestowing the Midge Kovacs Annual Awareness Award. Midge started one of the first NSDA support groups and she wrote a newsletter in order to share information and raise awareness. In presenting the Midge Kovacs Annual Awareness Award, we honor the outstanding work of an NSDA support group.

2019 | The winner of the 2019 award was New York City Support Group Leader, Adrienne Simons with Mary Bifaro presenting it to her. Adrienne served the NSDA as Northeast Regional Coordinator. She and Midge Kovacs organized the Eastern Regional Conference in 1996. The New York City SD Support Group was founded by Midge Kovacs in 1987 and remains one of the longest standing groups in the NSDA support network. Adrienne Simons has been a dedicated support group leader for more than 25 years. The article which Adrienne wrote for *Prevention* magazine in 1990 was a significant advancement in awareness and education about spasmodic dysphonia.

2020 | The 2020 Midge Kovacs Annual Awareness Award was presented to Greater Detroit Support Group Leader, Dennis Kaszeta virtually by Founding President, Larry Kolasa. Dennis re-established the Michigan group. He conducted site visits in anticipation of the 2020 NSDA Symposium. He participated in spasmodic dysphonia research which is looking at vibro-tactile stimulation. Dennis was recently elected to the NSDA Board of Directors. Dennis also serves on the Walk for Talk Planning Committee and his support group will be participating in this first-ever virtual event.



NATIONAL SPASMODIC DYSPHONIA ASSOCIATION

Walk for Talk

Use your feet to help us defeat
Spasmodic Dysphonia & Related Voice Conditions

OCTOBER 22-25, 2020

The first-ever NSDA Virtual Walk for Talk is a four-day event from October 22-25, 2020. It includes both a 5K and a Fun Walk to benefit the National Spasmodic Dysphonia Association. You can participate no matter where you live. You pick the route – whether it is in the park, through your neighborhood or on a treadmill. Invite your family and friends (and even your dog) to join your team! There is no cost to participate but all donations will be doubled by a special match up to \$50,000. The goal is to bring together the NSDA community to both increase awareness of vocal disorders and to raise money to help us fund vital research to defeat spasmodic dysphonia and related voice conditions. Learn more at dysphonia.org.

Dystonia Advocacy Day

The NSDA is a proud member of the Dystonia Advocacy Network (DAN), a grassroots advocacy network that brings together dystonia-related patient groups to speak out with a single, powerful voice on legislative and public policy issues and funding that impact people with dystonia.

2019 | NSDA was represented at the 2019 Advocacy Day by DAN Chair Emma Mattes, Scott Flanagan, Alice Larson, Deb and Scott Lindsay, Lisa and Lee Stennert, Dorothy Tannahill-Moran, and Executive Director, Kim Kuman, and our leaders. They gathered with dystonia advocates from across the US. While there, Kim and Scott also attended the meeting of the DC Metro Support Group which is led by Lois Jackson.

2020 | The annual Dystonia Advocacy Day in Washington, DC was canceled in 2020 due to the COVID-19 pandemic. A Virtual Advocacy Day was planned and advocates contacted Senators and Members of their House of Representatives in order to share their experience with dystonia via email and phone. Instructions were given on contacting the local district offices of their representatives in a webinar.



Scott Flanagan had the unique opportunity to address the full Nebraska delegation at a breakfast for constituents during the 2019 Advocacy Day. Here is Scott (right) talking with Senator Benjamin Sasse.



◀ “Cookie”, the short film about spasmodic dysphonia by film maker Shane Hartline had a private screening in Atlanta in December of 2019. NSDA President, Charlie Reavis, and NSDA Executive Director, Kim Kuman, attended and were on a panel discussion after the film was shown. The NSDA presented Shane with a plaque to thank him for his help in raising awareness about spasmodic dysphonia. This short film is premiering virtually as part of the Charlotte Film Festival in September of 2020.

Ruth Stuart, the wife of the late Richard Stuart, accepted this award in his memory to honor the impact he made on the NSDA community through his efforts of advocacy, education and support. ►



ESSAY WINNER | JASON SHERLOCK



The Journey of a High School Principal with Spasmodic Dysphonia

High school principals make many public appearances and presentations. As they say, first impressions are everything; principals and public officials are judged by their appearance and how they speak. A strong voice is arguably a principal's greatest asset. I became a high school principal six years ago; it was shortly after I was hired that I realized something was wrong. My voice slowly worsened – I sounded like a stammering, old, nervous man. Speaking on the phone and in loud rooms were extremely difficult for me. For two years, I dealt with not knowing why this was happening. After seeing a doctor, I was diagnosed with a neurological voice disorder.

During my first two years as principal, my voice deteriorated. People had a hard time hearing me – especially over the phone and times in which I did not have a microphone. Parents would constantly ask me if I was sick or if I had a sore throat. My outgoing personality, which made me a good educator completely changed. I avoided noisy areas and felt very uneasy about making announcements over the PA system. Public speaking engagements and especially events such as graduation were very difficult for me because of the volume of speaking that was required. At times, I wanted to quit the principal position because I felt I was always being judged. Had it not been for supporting my

beautiful wife and four children, I may have looked for a new career path. The last straw for me to seek help was when a student on a website called Rate Your Teacher commented, "Every time the guy speaks, he sounds like he is going to cry." I knew I either needed to quit being a public figure or seek help from a doctor.

I decided to make an appointment with a specialist. When I sat down with this doctor, I immediately became very emotional and told her everything I was feeling inside. Over the last few years, I saw my personality change completely; I became introverted, didn't like to speak on the phone, avoided parties and social situations, and didn't volunteer to coach my kids. After listening to my story, the doctor said she knew what was wrong and told me that she believed it could be treated. She believed that I had something called spasmodic dysphonia, but needed to do more tests to confirm the diagnosis.

After months of tests and ruling out serious illnesses, the doctor told me that I was a candidate for Botox®. This gave me great optimism. Shortly after the diagnosis, I decided to tell my staff about my medical condition. I told them about spasmodic dysphonia; it is not painful, it is not life threatening, and it is treatable in most cases. My staff and administration gave me tremendous support and more importantly I felt much better because people knew there was a reason why my voice sounded awful most of the time. It was not because I was nervous, introverted, or that I was afraid to speak in front of a large crowd.

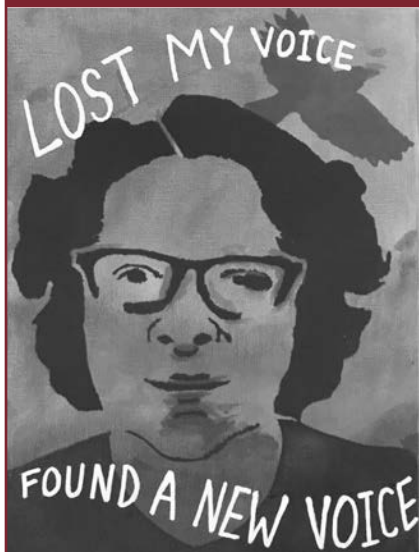
After the first year of Botox® injections, I experienced minimal success. My optimism soon turned back into despair because I was not getting the results of a better voice. I started to fall into a funk again, but I was not going to give up. I decided to see

another doctor. He injected the Botox® in a different location in my throat. After the first new injection, I lost my voice for 8 weeks right before school started – it was clearer but I could only muster a whisper. Unlike the other injections, I began to hear and feel a change in my voice, although completely losing it was not my desired result. I started school with a microphone when I spoke to the faculty and could only speak for five minutes.

As a principal, the spring is filled with speaking engagements: awards assemblies, banquets, and graduation. For the first time in five years, my voice sounded great! It was an amazing feeling to not be nervous – that nervous anticipation of how bad my voice would be that day. Would it be a 2 or a 4 today? This past summer I also coached my son's little league all-star team. I had the courage to speak again.

Spasmodic dysphonia is physically debilitating, but it is far more mentally debilitating. It paralyzes your vocal chords, but I let it paralyze my personality for a short time. Fortunately, my family gave me the strength to help me through this difficult journey and loved me no matter how bad my voice sounded. I learned how to be a better listener and to persevere through difficult times. Patience, hope, good doctors, and the willingness to speak about SD have helped me recoup my personality. I will have spasmodic dysphonia for the rest of my life, but it does not define me. I am resigned that my voice will never again be perfect. However, this journey made me a better principal and has taught me that I have the strength, perseverance, and courage to accomplish anything.

ARTWORK WINNER | LAURA RAHUBA



Found a New Voice

Laura submitted her original artwork titled: Found a New Voice (see image on left). Laura describes her journey: "Voice is a part of one's identity. When I lost my natural speaking voice, I lost a part of myself. After the grief passed, I learned to love and accept my new voice, both literally and figuratively."

POETRY WINNER | JODY NARAYAN



SD Reflections

Not heard, not seen, unhooked
Strangled voices, uncertain looks
They mask the true me

The friendly stranger across the room
The words come bubbling to my lips,
so soon depressed.

My words live unexpressed
burrowing holes in my chest.

Like worms they crawl all over me,
flatten personality,
burrow underneath my veins,
hold secrets in their setae.

What's happened to the gregarious me?
It's changed my personality
I'm not the person I used to be
The words are locked inside of me

Every night when I pray
Dear God, give me a clear voice I say
Let me speak easily every day
Let me not struggle to convey

There's music in my veins,
Silent songs on my lips
The restrained melody struggles to be free
The rhythm stays imprisoned inside of me

"You sound like you're dying" the recruiter said
Her words compressing my chest
I cried myself to sleep that night
But perhaps there was someone watching over me
For the very next day she congratulated me
On a job well got

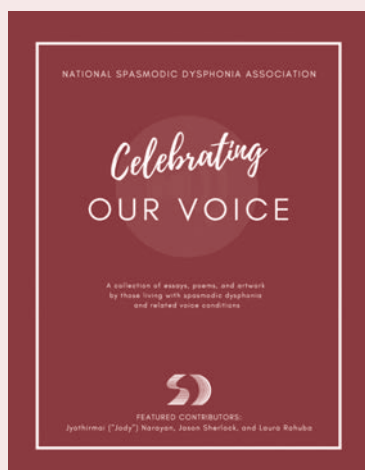
"Introduce yourselves" they say
It's a meeting for which I'd rather not stay
I wish I could just sneak away
For I have nothing to say

Computers are an integral part of me
So it's not surprising in the least
That I think of this in computer speak
My CPU is fine but my I/O is weak

Every few months I take the day off
And take the long train ride
To New York, New York
For my tryst with the fickle Botox

I push myself to speak
To the friendly stranger across the room
She's not sure what she heard from me
"Get better soon" says she
"Is 35 years soon enough?"
Says the inner voice in me

But I will not let this diminish me
I will be the best that I can be
For blessed am I in so many ways
Bitterness in my mind will not stay
And perhaps, some day or life, it is meant to be
That a glorious voice will inhabit me.



Stories of determination, resilience, and courage can be found in the book, "Celebrating Our Voice" published by the NSDA. This collection of essays, poems and artwork commemorates the 30-year anniversary of the organization. Designed as a contest, the winning entries are included here, but the book contains the whole collection. Be inspired by amazing people in our NSDA community and order it online at dysphonia.org.

PERSONAL PROFILE | JOHN EDWARDSON



Mr. Edwardson is a veteran businessman with a successful track record at such industry giants as Northwest Airlines, Ameritech, United Airlines, and CDW Corporation. He is known for unorthodox motivational methods and an open-door management style. John was recently appointed to the NSDA Honorary Board and was the Keynote Speaker at the 2019 NSDA Symposium in Boston, MA. He shared, "it feels very special to be with a group of people who sound just like me. I don't know a lot of people with spasmodic dysphonia, but I know we are usually the best at diagnosing what we have when we hear someone else's voice." This article is a written summary from parts of John's keynote address at the symposium.

◀ John with his wife, Fran, at the 2019 NSDA Symposium

The first time I heard a recording of my voice was in Freshman Spanish class in high school. I listened to myself speaking Spanish, and I wondered, who is that old man? I couldn't believe what I sounded like. At that time, there were no spasms, there were no cracks, no words were getting cut off, I just had a very deep, gravelly voice for a fourteen-year-old kid.

Fast forward to my college years at Purdue University, I took to public speaking, and became comfortable speaking in front of groups. At the age of 34, I was named the Chief Financial Officer of Northwest Airlines, the youngest CFO of a Fortune 500 company at that time. I was reasonably ambitious and had my sights on being the Chief Executive of a large company and was confident that I was on my way to making that happen.

Then in my late thirties, something began to happen to my voice. Not only was it gravelly, but it would catch. I would try to say things, and it would just stop. I occasionally found it hard to tell people what my name was, and then it became difficult to talk on the telephone. I couldn't figure out what was going on. I could talk to my dog and never have spasms, but the minute I held a phone to my mouth, the words wouldn't come out.

It also became difficult to project my voice in a room without a microphone. I was often in an airplane hangar, two or three days a week, and I would find myself standing on a chair talking to a group of mechanics or other workers. I also had appearances on CNBC and other television stations. I would ask myself why my voice failed at certain times and not at other times. Interestingly enough, no one would complain or comment about my voice.

Then I found it increasingly exhausting to get up in front of people. Like many others with spasmodic dysphonia, I would begin to say a certain word, realize I would not be able to say it, then I would quickly try to think of another word that I could substitute. It kept compounding until I finally realized that I needed to go talk to someone about this. Since I did not think this could be a physical issue, I made an appointment and went to a psychologist in Evanston, IL.

I had two meetings with this doctor and at the end of the second meeting he said, "I would like you to see an Ear, Nose, Throat (ENT) doctor who is right down the hallway from me. I think I may know what is wrong with your voice, but I am not a medical doctor, so I am not allowed to give you a diagnosis." I had that meeting with the ENT. He referred me to Dr. Robert Bastian.

Dr. Bastian told me that I had spasmodic dysphonia, what it was, and that one of the only treatments was to use botulinum toxin. He suggested that in conjunction with the Botox® injections, I work with a voice coach. What I learned that day was that I had a physical condition, not a psychological one. Even though I knew it was now physical, it did not help me get over the fear I had developed about making a speech and having my voice sound not the way I would like it to. Unlike most people with SD, from the time I went to my first doctor to my diagnosis and first Botox® treatment was only six weeks. I feel very fortunate for that.

After my first treatment, I got in my car, turned on an oldies station and sang at the top of my lungs. I knew what was wrong with my voice, and I had a treatment that I thought was going to work. Unfortunately, I had not listened very well to the doctor about what the side-effects would be.

That Monday after the treatment, I woke up and went to work and realized I sounded like Minnie Mouse. This was going to be a challenge because every Monday we would have an Executive Committee Meeting at Ameritech. I was sitting next to the CEO and after he heard my voice he said to me "Whatever you have, I don't want it," and he got up and moved to the other end of the table and left me there by myself. After the meeting was over, I called Dr. Bastian's office.

Dr. Bastian was kind, as he always was, and said "John, I told you this could happen, that you could have a breathy voice." My response was, "but this isn't breathy, I sound like Minnie Mouse." He said that it's going to be like this through several treatments as we figure out the proper dosage.

Learning how to live with it once I knew what I had

As public speaking was part of my job description, scheduling the best time for treatments proved very difficult. Every quarter I had to meet with financial analysts and had other important events for which I needed a good voice.

After I moved back into the airline industry, one of the things that I had to do was go through training and practice sessions on how to speak to the press if an accident happened. We had local TV stations and newspapers come in and set up TV cameras, and for a day after I would literally be pelted with questions. I would have to simulate explaining what happened, why did the plane crash, how many people were injured or killed, etc. After the training was over, I would leave the room for a half-hour and then I would come back in so they could critique my performance. My voice cracked more than usual. I began to worry about what if this was a real situation and a plane did go down. What if it was right after I had a Botox® injection and I couldn't talk.

I started doing research online and found out about the selective adductor denervation reinnervation (SLAD-R) surgery that Dr. Gerald Berke was performing. I flew to California and met with him at UCLA. At that time, was still fairly new, and I realized I just wasn't ready. With a three-month recovery time after the surgery,

I questioned how I could have 100,000 people reporting to me with no voice.

I found that people did get used to my voice. While working, I never told anyone I had spasmodic dysphonia except close family and friends. I was always trying to substitute a word to make the point that I wanted to make. I got feedback like that from time to time, but for the most part people were supportive and kind and patient with me when I was having trouble making the point I wanted to make.

There were some rough patches though. During a 360-degree performance evaluation, I remember a Board member saying, "Why don't you just spit out what you want to say, John? You take twice as long to say anything and make your point as the rest of us do."

Another time, the leader of the pilot's union was retiring and I went up to him to congratulate him. I asked if there would be anything he was going to miss. He said, "I will miss the airplanes, but I will not miss hearing your voice in these quarterly meetings." These hard things to hear and it does make you think "should I or shouldn't I" say something about my voice condition? There are times when I will be in a meeting and I have a point to make, but my voice may not be that good. I have to decide whether I should speak or not. I think it is normal for all of us who have SD to think that way.

Another time I was giving a speech to the Commercial Club of Chicago. There were hundreds of people in the room including CEOs along with the Governor of Illinois in the front row. We were talking about securing new landing rights at O'Hare Airport, and I could not make my voice work. A colleague came up and finished my speech.

That was the most embarrassing moment for me publicly. I had gone over a year without a Botox® injection because of the lengthy breathy period but thought I have got to get this treatment figured out.

I went back to Dr. Bastian so we could work on the dosing for a better outcome. After a few years, I get a lower dose more frequently, giving me a pretty consistent voice. Slowly, I have been able to increase the time between injections, and now am at about five and a half months. Even with the low dose, I still get the breathy period and choke a little at the beginning. I try to plan the injections right before I go on vacation, so I have time to recover. I am now on a fairly level path and usually know what to expect.

Moving Forward

Even though I may have asked myself why I have this voice disorder, I do not feel helpless about it. When I do talk about my voice disorder, I seldom use the term 'spasmodic' in reference to the disorder. I use laryngeal, because I feel it is a better description and people seem to be less skeptical about it. I also find it helps to say "I am having trouble with my voice" if you know you are going to have difficulty speaking. When I do that, my voice seems to relax and it performs better.

While I don't think SD should prevent anyone from pursuing the betterment of their career or following their dreams, this disorder is always in the back of my mind. There is still a lot of work that needs to be done to raise awareness about SD and the NSDA, not just in the US, but around the world. But when I attended the 2019 NSDA Research Workshop and listened to the researchers, I felt so hopeful that in the future others diagnosed with this disorder will have more options than what many of us have had. ■

NSDA SYMPOSIUM HIGHLIGHTS

NSDA Symposiums are always filled with fellowship, education, and fun. They bring together the leading experts in the field of spasmodic dysphonia and related voice conditions while providing the opportunity to meet others who share a similar experience.

2019 | 30th Anniversary Symposium

Over 150 people gathered to celebrate the 30th anniversary of the NSDA at the 2019 Symposium on April 27, in Boston, MA. The Welcome Party on Friday was a powerful evening of sharing. Research dominated the program at the Symposium along with a message of empowerment from Keynote Speaker John Edwardson. Dr. Andrew Blitzer was honored for pioneering work in the field of SD. On Sunday, friendships were formed with a tour of Boston and followed by a baseball game at historic Fenway Park.



Above Row 1: Drs. James and Dawn Lowery | Dr. Andrew Blitzer | Drs. John Ingle and Thomas Carol
Row 2: Drs. Laurie Ozelius, Gerald Berke, Kristina Simonyan, Christopher Honey, Teresa Kimberley, and Michael Pitman | Toni Gold
Left: SLP Glenn Bunting, Jane Gordon and Dr. Ramon Franco | Ruth Stuart and Dr. Gregory Grillone



Row 1: Gerald Berke | Juliana Codino | Christie DeLuca | Glendon Gardner | Michael Hammer | John Ingle | Jürgen Konczak
Row 2: Ross Mayerhoff | Michael Pitman | Dorothy Tannahill-Moran | Charlie Reavis | Adam Rubin | Yin Yiu
Row 3: Kimberly Kuman, Yiu Yin, Jürgen Konczak, Arash Manhan, Michael Hammer, Charlie Reavis, Carolyn Baylor | Jaime Schmidt | Warren Bandel, Christie DeLuca, Mary Bifaro, and Scott Flanagan

2020 | Virtual Symposium

In mid-March, the difficult decision was made to cancel the in-person 2020 Symposium due to COVID-19. We quickly shifted gears and migrated all the meetings to a virtual format. The NSDA Symposium was re-envisioned to be a combination of pre-recorded presentations and live panel sessions. The four live sessions took place on May 2, 2020 via Zoom and Facebook Live. There were three panel discussions including a Q&A with Healthcare Professionals, Q&A with Researchers, and Living with a Voice Disorder. Participants could send in questions. Keynote Speaker Jaime Schmidt shared her personal journey that inspired all. Over 600 people attend the live sessions – our biggest symposium!

SAVE THE DATE | NSDA SYMPOSIUM | MAY 21, 2021 | DETROIT AREA

I HAVE A VOICE DISORDER

Please be patient with me and try to listen closely
as it may be challenging for me to speak.



It helps to eliminate background noise
as my voice may not have a lot of volume.

I'm not nervous,
sick or upset.



I may need to write down what I am
trying to say or type it on my cell phone.

I can repeat.
Just ask.

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I HAVE A VOICE DISORDER

PLEASE BEAR
WITH ME

*Try to listen closely as it may
be challenging for me to speak.*



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YOUR PATIENCE IS APPRECIATED

I HAVE A VOICE DISORDER

Speaking can be
challenging for me.

NATIONAL SPASMODIC DYSPHONIA ASSOCIATION | DYSPHONIA.ORG

I am not sick

IT IS A VOICE
DISORDER

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CUT AND KEEP THE CARDS ABOVE IN YOUR WALLET

CUT AND KEEP THE CARD BELOW TUCKED IN YOUR CAR VISOR

I HAVE A VOICE DISORDER

Please be patient with me and try to listen closely
as it may be challenging for me to speak.



MY VOICE MAY BREAK, SOUND STRAINED OR SHAKY. I MAY ONLY
BE ABLE TO SPEAK IN A WHISPER OR IT MAY SOUND BREATHY.



It helps to eliminate background noise
as my voice may not have a lot of volume.

I'm not nervous,
sick or upset.



I may need to write down what I am
trying to say or type it on my cell phone.

I am happy to repeat.
Just ask.

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AN ORGANIZATION'S RESPONSE TO A PANDEMIC

Embracing Change and Connecting the NSDA Community

By Kimberly Kuman
NSDA Executive Director



When 2020 began, plans were underway for walks, support meetings, and the 2020 NSDA Symposium. Then COVID-19 hit and everything shifted.

PIVOTS | Within two weeks in March, all events were canceled. A heaviness and a sense of disappointment surrounded these decisions. Our first priority is always the safety of our community, and as we moved into April, there was no doubt the right decisions were made.

CHANGES | Challenges push us to be creative, and so we did by embracing technology to keep our community connected in new ways.

Webinar Series | A webinar series was launched with two expert volunteers who both have spasmodic dysphonia. Career and Life Coach Dorothy Tannahill Moran addressed the impact of being quarantined on emotional health. And Speech Language Pathologist Christie DeLuca walked people through voice techniques to manage symptoms including helpful "tricks" and tools.

COVID-19 Resources | A dedicated page was created on the NSDA website as a resource for questions on COVID-19. In response to the availability of telemedicine, an option was added to our online Healthcare Referral Directory and those professionals listed were emailed to update their profile.

Virtual Symposium | The NSDA Symposium was re-envisioned to be a combination of pre-recorded presentations and live panel sessions that generated over 14 hours of new content which is available now on the NSDA YouTube channel. Over 600 people attended the live virtual sessions – our biggest symposium yet!

On-line Support Sessions | With all in-person support meetings canceled, Support Services Director Mary Bifaro and I launched virtual support sessions in May, and since then, over 30 meetings have been held with many more planned.

New Awareness Tools | New masks are now available with messaging that helps to explain voice issues and raise awareness, along with an expansion of awareness tools like buttons and information cards.

Virtual Events | Our first-ever Virtual Walk for Talk to benefit the NSDA will take place in October. This four-day event is accessible to everyone with the goal of raising awareness and funding research, education, and support while bringing our community together.

TURNING POINTS | No one could have predicted the COVID-19 pandemic or its impact on all of us. My own personal reluctance to be on camera needed to be put aside. By embracing this technology, the gift we have received is meeting people from all around the world, and, in turn, they are getting to know the NSDA and our volunteers. I have never felt so connected to our community, and for that, I am grateful. In-person meetings will return in time, but this is a Turning point for our organization. We have opportunities to expand and connect, which is limited only by our imagination.