



Embracing Resilience on the Journey with Voice Disorders

In the journey of navigating a voice disorder, resilience becomes an invaluable companion. Whether you're personally facing challenges or supporting a loved one, developing resilience is key to maintaining a positive outlook and effectively managing the impact of voice disorders on daily life.



Understanding Resilience

Resilience is not about avoiding difficulties but rather about

bouncing back from them. In fact, when looking at the definition of resilience, words like toughness, flexibility, strength, and adaptability are all mentioned. It's the ability to withstand and recover quickly, even in the face of adversity. Resilience can involve becoming more accepting of the condition, finding

ways to deal with it, and embracing a positive mindset. Those living with a voice disorder know all about that, and we asked them to share their experiences.

Jaime stated, "For me, in regard to my voice, resiliency is never letting the sound of my voice be a reason to quit." Katie shared a similar sentiment, "It is the determination to keep pushing forward in spite of misunderstood difficulties." Don defined resilience as "the ability to get 'knocked down' a few times and my willingness to get right back up and face whatever challenge it is, head on, and with my best attitude."



Empower Yourself with Knowledge

One of the pillars of resilience is



Though communication is difficult, it doesn't stop me from doing what I want, going where I want, being who I am etc. But most importantly, it doesn't stop me from saying what I have to say, even if it is more physical effort to do so than those without voice disorders." **SARAH**

knowledge. Understanding the nature of voice disorders, available treatments, and coping strategies empowers individuals to actively participate in their well-being. Iris feels that "education is key in building resilience when

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Our Voice is the official publication of Dysphonia International, a nonprofit 501(c)3 organization. Founded in 1989, our Mission is to improve the lives of people affected by spasmodic dysphonia and related voice conditions by finding answers through research, building understanding through education and awareness, and raising hope through support for those living with these challenging vocal disorders. We are a community that cares about you and your voice.

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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.

someone is diagnosed with a voice condition. Learning as much as possible about my condition has given me a sense of control and how to traverse the challenges that come with it.” Attending support group meetings and symposiums, engaging with healthcare professionals, and seeking out reliable resources, like those on dysphonia.org, are just a few ways to help make the journey less isolating. Jean thinks taking advantage of education and support from Dysphonia International strengthens her resilience. Robin also mentioned that finding the right doctor who can give appropriate and effective treatment and is able to answer your questions is important. Elizabeth mentioned that people should consider asking for accommodation at work for their vocal challenges.



Build a Supportive Network

Resilience is often nurtured through connections with others. Share your journey with friends and family. “Being more open about my experience helped friends understand what I was going through,” said Elizabeth. Robin is grateful for her family and friends who understand and want to do what they can to help if/when she asks for help. For example, her husband has become helpful and supportive when he previously complained when she asked him to make a call or speak with someone for her.

Establishing a network that understands and empathizes with your experiences can provide emotional support and practical advice. “Find people with similar issues. This organization, in addition to Facebook groups, has been critical to getting through so I don’t feel alone.” Eileen said that when she attended her first Dysphonia International Symposium, she knew from the outset that what the group had in common was having been forged in adversity. “I met people who not only survived their disorder but thrived despite it.” Mary reminds us not to give up,

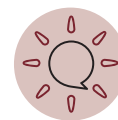
“Read all of the Dysphonia International website at dysphonia.org. Find a virtual event that you can participate in. Know that there is help and hope.”



Other strategies suggested included:

Rose remembers her parents’ message about “choosing to be happy even when things are hard.” She also feels that speaking with others with a voice condition to “learn their tricks for coping” is also helpful.

Jill makes “a conscious decision to hold people listening to me fifty percent responsible for understanding our communication when communicating with someone for the first time. I decided it was not up to me completely to make myself understood. When I experienced uncooperative listeners, I would overtly ask them how to make myself heard and understood. Usually, that was enough to jolt them into listening better.”



Process the Grief

Grief and resiliency are intertwined facets of the human experience, each influencing the other profoundly. While grief encompasses the complex emotions and reactions triggered by loss, resiliency represents the innate capacity to adapt and recover from adversity. In the midst of grief, individuals may feel overwhelmed by sorrow, anger, and despair, yet resilience can emerge through the process of grieving. Michele reflected, “I am usually a fighter...but this has shut me down in a way I have never been. Joining a support group has helped me feel like I belong. The support from people with this disorder has been great, and I don’t feel alone.” James shared that his voice condition made him more of a fighter in life. Toni acknowledges that when her voice worsens, her resilience declines, but she has redirected her energy into organizing a support group

and fundraising events to help move her forward and be part of a larger community.

The gradual acceptance of loss coupled with the emergence of hope characterizes the resilient journey through grief. Cheryl explained, “Feel all the emotions it brings. It’s like a death, and you will grieve the loss. Focus on the positive and how you can embrace your voice disorder. If you do, others will also.” Over time, Sarah has learned to “embrace both the negative and positive emotions that your voice brings. Accept that life may be different, but there is so much freedom knowing life can still be lived to the fullest despite a different voice.” Sue feels that moving through the grief process has helped her deal with her voice along with helping others manage their journey.

Personal counseling was the key for Vicki, who has “accepted my limitations. I do what I can when I can. I don’t try to be social when I’m breathy after a Botox® injection. I take the downtime. I keep my social engagements with my friends but limit the time. I am not a victim, and don’t step into that role.”



Practice Letting Go

Resiliency is the cornerstone of personal growth and emotional



I never let my voice be my identity.
I have so many other things to offer.
I focus on the positive, not the
negative things that life brings
with SD.” CHERYL

well-being. Learning to let go is a vital aspect of cultivating resilience. It involves acknowledging that some things are beyond our control and accepting them without allowing them to hinder our progress. Letting go doesn’t imply giving up; rather, it signifies releasing the grip of attachment to outcomes or situations that no longer serve us. It’s about embracing change and trusting in our ability to adapt and thrive despite adversity. Cheryl has “quit feeling ashamed of my voice and chose to accept it instead of trying to hide it. I ‘own’ it and am open with how it interacts in my life and all those who cross my path. Once I was able to embrace my SD, others took it into stride also.”

By relinquishing the weight of past disappointments or unmet expectations, we create space for new opportunities and experiences to unfold. Through the practice

of letting go, we discover inner strength and resilience that empower us to navigate life’s challenges with grace and optimism. Iris shared what has strengthened her, “I first had to learn to be very compassionate towards myself, and it took me years to do this. However, once I did this, it naturally took its course and spread everywhere else. I truly believe that compassion is the key to happiness, feeling strong and resilient, capable, and confident to meet whatever challenges we face.”

Jennifer realized that people who were shocked when she began to speak meant no harm. She used that as an opportunity to educate people who are curious and ask questions about her voice, thus empowering herself. Fiona shared that learning to be accepting of your voice disorder means it doesn’t have to control your life, as you can be in control of how you respond and manage it. Jill decided to make her way through the world with her unique voice and stop trying to control how she is perceived. “I gave up control. I let the chips fall where they will. I decided to gravitate to people who show an interest in listening to WHAT I am saying rather than how it sounds.” Dot says not to shy away from things but rather tell people up front that you have a voice problem.

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Gratitude

By Charlie Reavis

Now more than ever is a time when showing gratitude and kindness to others goes a long way. Expressing our appreciation is a wonderful way to improve our health, and being grateful can lead to a positive lifestyle as a result.

Gratitude is the act of feeling thankful and appreciative for everything that surrounds us. When we are grateful, we take more time to stop and recognize what we have, instead of what we don’t. It allows us to be more compassionate, positive and respectful toward others. While it might not be easy to stay positive all the time, gratitude is a trait that can be built and strengthened so that we’re able to change our outlook about our experiences and become happier with our life.

Expressing gratitude indicates that we are able to navigate through our feelings and those of others. When we take the time to acknowledge the good around us, we invite more happiness in our lives. Letting our loved ones and friends know how thankful we are for everything they do is a great way to strengthen the bond we have with them and reinforces the trust we have for one another.

Volunteering is the easiest way to meet new people and bond over what means the most to us. When we help each other, gratitude and positivity comes back to us infinitely. It takes patience and practice. But, when we remember to be grateful in our circumstances, we are happier whatever life brings.



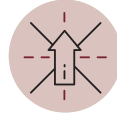
Engage in Self-Care

Recognizing the connection between mental and physical well-being is crucial. Engaging in self-care practices, such as mindfulness, exercise, adequate rest, and healthy nutrition, replenishes our physical, emotional, and mental reserves, enhancing our capacity to cope with life's demands. Through self-care, we prioritize our needs and cultivate a supportive environment that fosters resilience. We fortify ourselves against burnout and exhaustion, enabling us to face challenges with renewed energy and clarity. Fiona takes time to "reflect on identifying stressors and try to reduce them. For those I can't control or do anything about, I look at how I can control how I react to them and take measures not to allow them to affect me, like using mindfulness techniques and relaxation." Stephie meditates, "which helps me to focus on the present moment and to be more at ease with myself" which has helped her to "speak up more than I used to." Sue looks for the blessings in her day, "I know sometimes it is hard for me to talk, but I slow down and try to work on my breath work and this helps."

While Sarah has learned that she "can't help when anxiety or low moods come. But when they happen, I've grown to understand my emotions and their root causes and act accordingly so that I'm not too consumed by my feelings." Ginny uses meditation and running as stress relief. Joseph offered this advice, "Try to focus on activities and encounters that feed your soul." A healthy mind-body balance positively influences the management of voice disorders. Gratitude is another powerful tool. Laura practices gratitude and feels it "strengthens my resilience because it helps me see the good things in a bad situation. Having a voice condition and meeting so many others with the same or similar condition helps me put things into perspective because it reminds me that a) I'm not alone

and b) there's always someone worse off than you or better off than you."

Eileen has come to care less and less about others' opinions. "I won't hide the sound of my voice. I definitely used to be more concerned about others' beliefs about me."



Celebrate Small Victories

In the pursuit of resilience, celebrate every triumph, no matter how small. Whether successfully completing a speech or engaging in a conversation, overcoming challenges with your voice, deserves acknowledgment. These victories are stepping stones to greater resilience. Katie regularly needs to communicate vocally at work and has "learned a few tricks to warm up my voice before stepping forward just as I am and to also tell others comfortably, I have a voice disorder so that they feel more comfortable in my presence as well." She continues, "it's hard to sound different. It's hard to have to repeat ourselves or make lifestyle changes because of our voices, but that doesn't mean we don't have something worthwhile to say." Dennis encouraged people to listen to those who have lived with their diagnosis and found life may have obstacles but not insurmountable.

Pat shared that she developed a better sense of humor and changed the way she approached things, "I have become a better listener and ask questions, so I don't have to talk too much. Remember to continually pat yourself on your back. You have to be your own best friend."



Accept the new voice, accept it as something that is out of the norm and decide you're not going to let it keep you from anything. This is a choice we must make to thrive. I would give anything to sound normal, but there are so many ways to shine regardless of the sound of your voice. In fact, the abnormality often puts others at ease because it is implicit that we are not all perfect." **JAMIE**

Helen said, "Although the voice disorder affects many aspects of my daily life, I am still able to function and do things and enjoy life, for which I am extremely grateful. So, a positive outlook and doing things to help yourself is important. Therefore, I try to plan things to look forward to or do things I enjoy to recharge my batteries and offset the difficulties of living with a voice disorder."

Iris expressed that "a voice condition can definitely change things, but it can also broaden one's perspective and open doors that one never bothered to go through before. Though challenging and trying, it might also bring new and unexpected life adventures, friends, and other gifts."



Pursue On-Going Education and Skill Development

Continued learning and skill development contribute to resilience. Explore voice therapy techniques, communication strategies, and technologies that may enhance your ability to express yourself despite the challenges posed by your voice condition. Adrienne took a bold position, "I have sought out public speaking opportunities, from Toastmasters to stand-up comedy, and learned to deal with the anxiety that goes with it." Remember, the journey to resilience is ongoing. Jean talked about how important introspection is. She suggested that conducting a personal inventory of all the relationships and favorite activities is important. "Look for the things you can still do. Give those focus and more attention. Build in time for research and to try things that

improve your voice condition.” Jamie worked for many years as a trainer, where she “added a step to my agenda in order to teach the audience about my voice.” Stephie said raising her hand in a noisy room would let folks know she wanted to say something. Over the years, Liz has adapted to using technology, “trying new ways to communicate helped to keep me connected and manage calls when my voice failed. It gave me hope.”

Bonnie shared that one significant strategy that helped her develop resilience was enrolling in college as a non-traditional student a couple of years after being diagnosed. “My voice condition was the incentive. It provoked me to do all I can to get my voice back to a level where I can resume my interests in music and public speaking.”

Sarah offered this insight, “Acceptance of my voice, which naturally (eventually) led to a change in my mindset, is where it began. I’ve realized I might need to make requests/adaptations to make life easier for myself due to this. But it’s also very relieving once I realized they can make life somewhat easier, so why not? If I can live with a voice disorder, then I can pretty much conquer anything!”



Encourage Resilience in Others

To support those with voice disorders, fostering resilience involves creating an understanding environment. Open communication, actively listening, and providing encouragement are just a few things that can help those struggling with their voice condition. Jennifer is more aware now when she encounters someone else and thinks about their struggles and challenges. Laura encourages people to be role models by normalizing living with a vocal disorder. Colleen expressed, “Believing in yourself, you can build resilience. Do not give up!” Denny’s advice is to “be true to yourself. Don’t worry about what others think. Seek out others



Never give up hope. You will have very discouraging moments, but you have ALWAYS overcome them.” **DON**

with a voice condition and see what works for them.” Rose reminds us to keep talking with confidence no matter what you sound like. Rod encourages people to recognize what might be best accomplished and what limitations might be appropriate.

Jill provided this inspiring message, “It comes down to a decision: Are you willing to be honest? Are you willing to allow compassionate, kind people to see you and support you no matter how you sound? Are you willing to believe people will pleasantly surprise you? Can you practice not taking unkindness personally? Will you decide to see yourself as unique and interesting rather than defective or disabled? I would tell them to think of their voice condition as their memorable calling card, and that upbeat, positive, personal energy and a sincere interest in others’ lives is a great diversion from an unusual voice.” An amazing message for every one of us.

Dysphonia International provides community that understands. We can support and learn from one another. We can empower each other to face voice disorders with strength and determination; that’s resiliency in action.

One anonymous member shared these powerful words, “Give yourself time and grace because this is a journey. You will be met with challenges but rewarded with new friendships and new opportunities that will surprise you in the best of ways. Our voice fails us, but it doesn’t mean we fail. In fact, it means the opposite. We try harder, again and again, until we succeed in being understood. That is resilience.”



President's Message | Charlie Reavis



As we gather to celebrate the remarkable milestone of our 35th anniversary, I am filled with gratitude for the incredible journey

we have undertaken together. From our humble beginnings as the National Spasmodic Dysphonia Association, thanks to our Founder, Dr. Daniel Truong, and Founding President, Larry Kolasa, we have grown into a global force dedicated to finding answers for spasmodic dysphonia and related voice conditions. *See page 15 for highlights.*

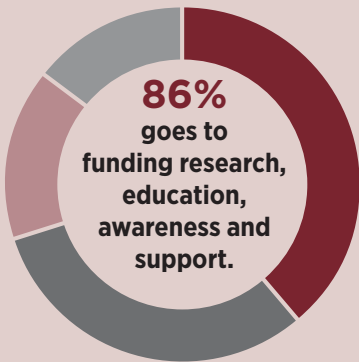
Over the years, our organization has evolved in response to the changing landscape of voice disorders and the diverse needs of our community. The decision to transition from the National Spasmodic Dysphonia Association to Dysphonia International was a significant change that symbolized our dedication to embracing a broader range of conditions. This transformation allowed us to reach a wider audience, providing support and resources to individuals facing various voice challenges.

The change in name also better reflects the expansion of our Mission. We have tirelessly worked to advance research, educate and raise awareness, and provide invaluable support to those affected by spasmodic dysphonia and

related voice disorders. Looking forward, we remain committed to our Mission of creating a world where individuals with voice disorders can lead fulling and empowered lives without the challenges of a 'broken voice'.

As we reflect on the past 35 years, let us take pride in the progress we have achieved together. Each milestone reached, every life touched, and all the challenges overcome have contributed to the legacy of Dysphonia International. Looking forward, we remain committed to our Mission of creating a world where individuals with voice disorders can lead full and empowered lives. Together, let us continue to make a difference and strive for a future where the power of voice knows no boundaries.

FINANCIAL OVERVIEW



39%

RESEARCH

Seed grants, augmentive grant funding, research travel and conference awards, support for the Global Dystonia Registry and Brain Bank

31%

EDUCATION & AWARENESS

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

16%

SUPPORT

Network of over 30 Support Groups and 75 Area Contact Leaders, virtual support, and Leadership Workshops

14%

DEVELOPMENT & ADMINISTRATION

Support for all programs

RATINGS

Our organization has been awarded the Gold Seal of Transparency by Candid, formerly known as 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%. We are currently at 14% for these expenses.

BOARD UPDATES / CHANGES IN LEADERSHIP



Jane Gordon

Board member Jane Gordon stepped down from Dysphonia International's Board of Directors in April 2023. She has remained committed to the Mission by continuing to volunteer her time as an Area Contact Leader for Massachusetts and as a member of the Education & Awareness Committee. We thank her for her years of service on the Board.



Susan Beck

Board member Susan Beck assumed the role of Vice President in April 2023. We are grateful for Susan's continued dedication to the organization and excited for her leadership in this new capacity. Susan will also continue to serve as the Chair of the Development Committee and a Support Group Leader for the Knoxville area.

CREATING YOUR LEGACY: Become a *Beacon of Hope*

The Legacy Society Program of Dysphonia International is a meaningful way for you to make a lasting impact on an organization that you care about. A bequest designated today is a simple yet impactful way to ensure that your passions live on.

► Empower Your Giving

By including Dysphonia International in your estate plan, you have the opportunity to make a significant contribution that may not have been possible during your lifetime. This will enable you to support programs that matter most to you.

► Customize Your Legacy

You have the opportunity to request how your bequest will be used, whether to fund research or contribute to a specific initiative that is consistent with the Mission of Dysphonia International, ensuring your legacy reflects your shared priorities.

► Ensure Long-Term Sustainability

Your gift will help fund critical resources that enable us to continue to serve our community and expand our reach to help even more people. Your support will allow us to navigate challenges and seize opportunities for positive change.

► Leave a Lasting Impact

By making a bequest, you join a community of individuals who are dedicated to making a difference, not just today but for generations to come. Your legacy will inspire others to follow in your footsteps and continue the tradition of giving back.

As a Dysphonia International Legacy Society member, you will have the comfort of knowing your gift will ensure the ongoing viability of our organization, which is dedicated to leading the effort to eradicate spasmodic dysphonia and related voice conditions.

We understand that estate planning is a deeply personal and thoughtful process, and we appreciate you considering Dysphonia International as a possible beneficiary. Your support is a beacon of hope, and your legacy will continue to shine brightly in the lives of those we serve.

To learn more about how you can become a member of the Legacy Society, please email voice@dysphonia.org.

WAYS OF GIFTING

Gifting Through Your Retirement Accounts

Donating retirement assets to charity as part of your estate plan can offer significant tax advantages. When you name a charity as a beneficiary to receive all or a portion of your IRA, 401(k), or 403(b) assets upon death, the benefits will multiply. Neither your heirs nor your estate will pay income taxes on the charitable distribution. Moreover, since Dysphonia International is tax-exempt, the entirety of your gift will directly support the programs of Dysphonia International.

Gifting Through Your Donor-Advised Fund

A donor-advised fund (DAF) is a valuable tool to ensure your philanthropy wishes, enabling you to contribute during and after your lifetime. You can ensure that Dysphonia International will continue to be supported by naming it the beneficiary of the entire account or designating it to receive a percentage of the fund through annual grants until your DAF assets are depleted. The DAF can be funded in many ways, including securities and real estate, which can provide tax advantages. Please get in touch with your financial advisor, who manages your DAF, to discuss options.

Gifting Life Insurance

Life insurance is an excellent way to make a charitable gift. You can leave a portion of the policy to Dysphonia International and still benefit your family. However, you can also transfer the policy to the charity. When you do, you are entitled to immediate charitable deductions for income tax purposes and the policy is removed from the estate. To make a gift of life insurance, please contact your insurance provider, request a beneficiary form and add Dysphonia International as a beneficiary on your policy.

Gifting Through Your Will or Trust

When creating your will or revocable trust, you can designate a percentage or fixed amount of your assets to be gifted to Dysphonia International. To enable a gift through your will or trust, please consult with your lawyer.

The Tax ID for Dysphonia International is 86-3907079.



RESEARCH Update



Providing funding for seed grants nurtures and advances research into spasmodic dysphonia and related voice conditions. Through these grants, investigators are able to collect preliminary data, enabling them to seek more substantial funding from the National Institutes of Health. This strategic investment enables us to back multiple projects, fostering an expanded understanding of these vocal disorders. These grants are up to \$75,000 annually. Many of our grants focus on potential new treatments, improved diagnostic tools, and identifying areas of the brain impacted by voice disorders.

Expansion and Progress Over the Years

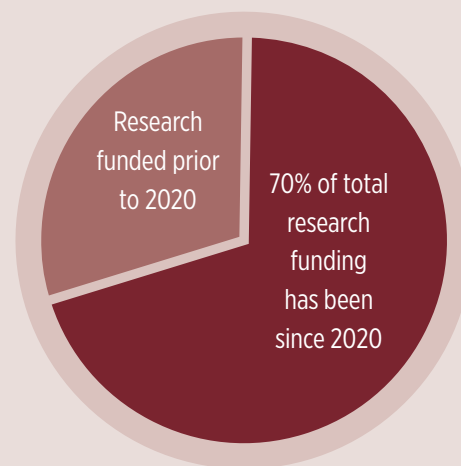
In 2007, when our Scientific Advisory Board was established, grant funding was limited to a range of \$10,000 to \$20,000. While this amount was significant for our organization at that time, attracting applications posed a challenge. Thanks to the steadfast support of our community over the years, we have increased the research grant funding up to \$75,000 annually, making it significantly more appealing for potential investigators. Furthermore, we have eliminated the application deadline, firmly believing that valuable research should not have to wait.

We have also seen an increase in new investigators who are focusing on voice research, particularly in spasmodic dysphonia and related voice conditions. Increased funding has certainly played a role, and we have actively pursued the recruitment of new researchers through direct outreach, participation in international research conferences on dystonia, and networking via our Scientific Advisory Board. Our research program has undergone expansion to include Travel Research Awards, enabling us to establish collaborative partnerships with professional voice organizations and provide valuable support to emerging investigators.

Our unwavering goal remains constant—to accelerate our understanding and propel the science forward in the quest for improved treatments and cures for spasmodic dysphonia and related voice conditions.

Increased Research Funding

Out of the \$800,000 funded in research grants for spasmodic dysphonia and related voice conditions, over half a million dollars has been distributed in the past four years.



Dysphonia in the Digital Age

Yaël Bensoussan, MD, and Stephanie Watts, PhD | University of South Florida, Tampa, FL



Yaël Bensoussan, MD



Stephanie Watts, PhD

This study addresses a Quality of Life (QOL) challenge with Automatic Speech Recognition (ASR) systems. Researchers are trying to understand specific acoustic (sound) and aerodynamic (breath) features of voice that impact the ability of individuals with dysphonia to interact successfully with automatic speech recognition systems (ASR). To do this, researchers plan to recruit patients with vocal fold paralysis, spasmodic dysphonia, and tremor to participate in data collection. Participants will complete an assessment at two time points (1) at an initial visit and (2) following the appropriate treatment for their voice disorder (Botox® versus injection augmentation). Typically, this will be 1-2 weeks following intervention when voice is maximally benefited. The evaluations, using AI, will include an acoustic and aerodynamic voice assessment, completion of quality-of-life scales and interaction with ASR systems. Researchers will determine error rates for the ASR pre- and post-treatment. They will then calculate which acoustic measures may be impacting the error rates. The researchers are hopeful that, unlike approaches in the past, this information will be useful for informing algorithms/neural networks for better signal detection.

Objective Measures of Laryngeal Dystonia Severity and Treatment Efficacy

Zhaoyan Zhang, PhD | University of California, Los Angeles, CA



Zhaoyan Zhang, PhD

Spasmodic dysphonia is often evaluated in various subjective assessments, including auditory-perceptual evaluation, clinical visual evaluation of vocal fold vibration, and patient self-reported scales. These assessments are subjective in nature and rely heavily on clinician experience, and thus suffer from high inter- and intra-rater variability. These limitations often introduce outcome measure errors that confound treatment effects in clinical trials, making it difficult to evaluate and compare the efficacy of different treatment options convincingly. An important goal of SD research is thus to identify objective measures of severity. In a previous study through the Dystonia Coalition, a computer algorithm was developed that automatically extracts metrics of vocal fold vibration in SD patients. The preliminary results showed that changes in these metrics were correlated with the perceptual ratings of SD. This study aims to further evaluate these metrics' effectiveness in quantifying treatment efficacy in alleviating SD symptoms and improving voice quality in SD patients.

Neurosurgical Treatment of Spasmodic Dysphonia: Thinking Outside the Voice Box

Christopher Honey, MD | University of British Columbia, Vancouver, BC, Canada, *in collaboration with*
Stacey Halum, MD | Indiana University, Indianapolis, IN



Christopher Honey, MD



Stacey Halum, MD

Our Dysphonia-International-sponsored trial of deep brain stimulation for six patients with adductor spasmodic dysphonia showed that this technique was safe and could improve both the quality of voice and the quality of life for these patients. That successfully completed Phase 1 trial has been accepted for publication in the prestigious peer-reviewed journal *Neurosurgery*. This funding is to support a Phase 2 surgical trial to confirm that deep brain stimulation can improve the quality of life in patients with severe spasmodic dysphonia. This trial will involve ten patients with adductor SD and six patients with abductor SD. This double-blind study will eliminate any possible placebo effect. Patients will have DBS surgery, and then their stimulation will be turned “on” for 3 months or “off” for 3 months without the patients knowing. Their voice and quality of life will be measured during each of these settings and then compared to see which was better. The safety of this treatment will also be assessed by recording any complications or adverse events. Confirmation of diagnosis will be done in conjunction with Dr. Stacey Halum at Indiana University. We hope to provide new treatment options for patients. While we are studying the benefits of this therapy, we plan to investigate the brain pathways causing spasmodic dysphonia. This will provide novel insights into the cause of this condition and may allow new non-surgical treatments in the future.

AUGMENTIVE FUNDING FOR GRANTS

Dysphonia International plays another role in research by providing smaller grants to our investigators. A modest infusion of funding can be critical in assisting our researchers in advancing a project. This typically ranges between \$10,000 to \$25,000. This could involve recruiting additional participants to enhance the robustness of a study, co-sponsoring a grant with another institution, or expanding the number of medical devices available for testing in a study. The following investigators/institutions received funding for their ongoing research in 2023.

Novel Application of rTMS in Abductor Laryngeal Dystonia | Teresa Jacobson Kimberley, PhD

Wearable Non-Invasive Neuromodulation Technology for the Symptomatic Treatment of Spasmodic Dysphonia | Jürgen Konczak, PhD

DAXXIFY Clinical Trial | UCSF Voice & Swallowing Center

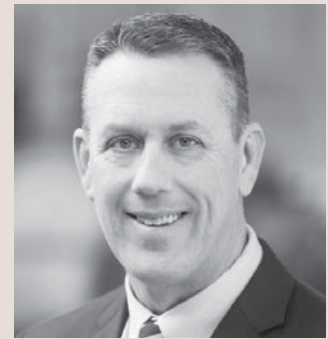
Brainstem Activation after Injection Laryngoplasty for Unilateral Vocal Fold Paralysis | G. Desuter MD, PhD

Patient Center-Outcomes Project of the Dystonia Coalition

Direct Quantification of Adductor Spasmodic Dysphonia with High-Resolution Manometry | Jesse D. Hoffmeister (co-funded with the Dystonia Coalition)

Clinical Trial for New Neurotoxin Launched

Dysphonia International recently partnered with the UCSF Voice & Swallowing Center to augment funding for a new clinical trial to evaluate the effectiveness of DAXXIFY as a treatment for people with adductor spasmodic dysphonia. Dr. Clark Rosen (pictured) is leading the study on this new neurotoxin.



VIRTUAL WORKSHOP HOSTED FOR INVESTIGATORS



Gerald Berke, MD

In 2019, Dysphonia International convened its researchers for an in-person half-day conference in conjunction with the annual symposium. On November 3, 2023, we once again hosted a meeting, but this time virtually, which included a number of Dysphonia International-funded investigators, all of whom are studying spasmodic dysphonia, a form of focal dystonia. The overall concept for the meeting was for these researchers to identify areas of commonality and discrepancies in their conceptual framework regarding the cause or causes of spasmodic dysphonia. We wanted to explore these various approaches and increase the collaboration amongst our investigators, as much of the currently funded research could complement another grant.

Dr. Gerald Berke, the Chair of our Scientific Advisory Board, moderated the meeting and prepared the summary that provides an overview of the participants' research. It is apparent from the discussion at this seminar that there continues to be a functional connectivity issue in patients with spasmodic dysphonia affecting the basal ganglia, cerebellum, thalamus and cerebral cortex (*See page 19 for more information*). Patients with spasmodic dysphonia also seem to demonstrate a somatosensory defect in their ability to control the excitatory function of the cortical speech center and in other areas of the brain. Specifically, why this is occurring, whether it is a chemical imbalance or a structural defect, is a subject of ongoing research.

We were pleased to see the interaction and interest among the attending researchers. All in attendance were supportive and appreciative of the suggestion to continue discussions with additional workshops in the future. We appreciate the commitment of our researchers in seeking answers to enhance our understanding of spasmodic dysphonia and related voice conditions, ultimately striving to discover a cure.

2023 TRAVEL SCHOLARSHIPS AND AWARDS INFORMATION

Dysphonia International provides awards and travel funding for annual meetings hosted by professional associations with a focus on voice research and clinical advancement. By facilitating the attendance of investigators at these gatherings to present their research on spasmodic dysphonia and related voice conditions, we foster connections that enhance their engagement with voice-related issues. The administration of these award programs is handled by the respective organization, and they decide on the type of program that aligns most effectively with their conference. The

awards typically range between \$250 to \$1000. In 2023, we funded fourteen travel scholarships and two conference awards. We also partnered with two new laryngology associations in Europe. This collaborative approach aims to sustain interest in voice conditions and ensure their continual focus in future research endeavors. This strategic collaboration positions Dysphonia International as an organization supporting individuals with SD and related voice conditions and as a dedicated partner for healthcare professionals and researchers in the voice field, serving as a valuable ongoing

resource for them. The response has been wonderful, and we continue to expand this program to work with even more professional associations.

2023-24 Award Organizations

- American Laryngological Association
- The European Laryngological Society
- The Fall Voice Conference
- The Voice Foundation
- Triological Society
- Winter Days of Laryngology



Dr. Cesare Piazza and Dr. Gregory Postma present Prof. Rūta Pribušienė (center) the first award from Dysphonia International at the 2023 European Laryngological Society Conference



Dr. Peiyun Zhuang receiving the award for Dr. Xinlin Xu with Dr. Robert Sataloff at the 2023 Voice Foundation Symposium

THE VOICE OF OUR COMMUNITY ADVANCES RESEARCH

CONVERSATIONS TURN INTO RESEARCH

Dysphonia International collaborated with Dr. Michael Johns and his colleagues on a study exploring the use of cannabinoids as a treatment for spasmodic dysphonia. The inspiration for this study arose during a virtual meeting of the Los Angeles Support Group, where a presentation on cannabis highlighted the lack of available data regarding its use in individuals with spasmodic dysphonia. Subsequently, we worked with Dr. Johns on an electronic survey, which was disseminated to our community, and the study results were published in the *Journal of Voice* in June 2023.

MODEST FUNDING EXPANDS STUDIES

After the webinar featuring Dr. Jürgen Konczak, there was notable excitement from the attendees about the potential symptom reduction in spasmodic dysphonia through the use of vibrotactile stimulators. Subsequent discussions with Dr. Konczak revealed that modest support could fund the production of additional devices that could be distributed, and the study could be expanded. Recognizing the direct benefit to our community, the Board of Directors wholeheartedly approved this initiative!

OUR COMMUNITY STEPS UP

Recruiting participants for research and clinical trials, particularly for a rare disorder, often poses a significant obstacle to advancing a study. Over the years, we've collaborated closely with our researchers to facilitate the identification of participants. Through email communications, virtual meeting presentations, and peer-to-peer discussions, we've consistently moved studies forward and even broadened their scope to encompass abductor spasmodic dysphonia. We have confidence that our members will always respond to the call from our researchers.

The primary responsibilities of our Scientific Advisory Board (SAB) are to review grant applications, chart future research directions, and foster collaboration with researchers. We are excited to announce the recent appointment of three new members of the Scientific Board: David Lott, MD (Laryngology), Scott Norris, MD (Movement Disorders), and Susan Thibeault, PhD, CCC-SLP (Speech Pathology).

Led by Chairperson, Gerald Berke, MD (Laryngology), they will be joining our current members Craig Evinger, PhD (Neuroscience), Laurie Ozelius, PhD (Genetics), and Julie Barkmeier-Kraemer, PhD, CCC-SLP (Speech Pathology). Each one brings their own unique perspective to voice research, and we are honored that they have volunteered to serve on behalf of our community.



DAVID LOTT, MD

Professor of Otolaryngology at Mayo Clinic College of Medicine and Science, Chair of the Department of Otolaryngology–Head and Neck Surgery/Audiology at Mayo Clinic Arizona, Director of the Head and Neck Regenerative Medicine and Transplantation Program at Mayo Clinic and the Associate Director of the Mayo Clinic Center for Regenerative Biotherapeutics

Fellowship: Laryngeal Surgery and Professional Voice, Harvard Medical School/Massachusetts General Hospital

Residency: Otolaryngology–Head and Neck Surgery, Cleveland Clinic Head and Neck Institute

Degree: MD, University of Iowa Carver College of Medicine

Dr. Lott shared, “Every day in my practice, I see the huge impact voice disorders have on quality of life. Our current treatment options are good but not good enough. It is incredibly important to better understand the cause of voice disorders and determine better treatment options. More research is being done on voice disorders than ever before. What is even more exciting is the interest and partnership with patients with voice disorders. This collaborative approach will foster even more interest, excitement, and validation of the importance of this research. I am honored to be a part of this Scientific Advisory Board. I have witnessed the passion of the members and researchers associated with this team for many years. It is truly inspiring, and it is a privilege to now be a part of it.”

DR. DAVID LOTT

Mayo Clinic College of Medicine and Science, Phoenix, AZ



SCOTT NORRIS, MD

Associate Professor of Neurology and Radiology and the Section Chief in the Movement Disorders Section at Washington University School of Medicine, St. Louis, MO

Fellowship: Movement Disorders, Washington University School of Medicine, St. Louis, MO

Residency: Movement Disorders, Washington University School of Medicine, St. Louis, MO

Degree: MD, University of Missouri-Columbia School of Medicine, Columbia, MO

Dr. Norris shared, “In the first week of movement disorders fellowship training, I was asked to evaluate a patient presenting with an isolated voice disorder. Despite years of medical education to date, I was quickly humbled by recognizing insufficient knowledge to adequately diagnose and manage this patient’s condition. I quickly grew curious about observations that subtle brain dysfunction may contribute to particular voice disorders. I set out to further explore the relationship between brain dysfunction and voice disorders by applying non-invasive advanced neuroimaging tools. I’m grateful for the opportunity to share expertise with the Scientific Advisory Board from the perspective of a movement disorders-trained neurologist. The ability to partner with speech-language pathologists, otolaryngologists, neurologists and others with both clinical and research experience offers a unique opportunity to meaningfully advance scientific discovery. I’m most excited that Dysphonia International provides direct connections with affected patients to better understand their current needs and help advance scientific discovery in a meaningful way.”

DR. SCOTT NORRIS

Washington School of Medicine, St. Louis, MO



DR. SUSAN THIBEAULT
University of Wisconsin,
Madison, WI

SUSAN THIBEAULT, MS, PhD

Medical Director of the Speech & Hearing Services at UW Health and the Diane M. Bless Endowed Professor in the Department of Surgery, Division of Otolaryngology-Head & Neck Surgery, at the University of Wisconsin-Madison

Fellowship: Shock Trauma Center, Maryland Institute for Emergency Medical Service System, Baltimore, MD and Executive Leadership in Academic Medicine Fellowship Drexel University College of Medicine, Philadelphia, PA

Residency: Otolaryngology-Head and Neck Surgery, Cleveland Clinic Head and Neck Institute

Degrees: MS, Communication Sciences and Disorders, State University of New York in Buffalo, NY, and PhD, Communication Sciences and Disorders, University of Wisconsin, Madison, WI

Dr. Thibeault shared, “When I was working as a master’s level SLP clinician, I became very interested in voice and voice disorders. As I was interested in doing a PhD, it just seemed like a natural fit for me. While doing my PhD, I was directed by my mentor, Dr. Diane Bless, to study the biology of voice, as not many people were studying this area. Because I had a bachelor’s degree in biology, I was able to take this on. This is an exciting time to be working in voice research. The field is evolving quickly. With various advancements in technology, we are able to understand the biology of the vocal folds at a deeper level than ever before. This research will provide foundational information that is vitally needed in the field and will have an impact on many types of voice disorders, SD included. I am honored to be asked to be on the Scientific Advisory Board of Dystonia International. The upward trajectory of this nonprofit organization is very impressive, and I hope to contribute in a meaningful way.”

CHANGES AT THE NATIONAL INSTITUTES OF HEALTH | NIDCD

The primary source of funding for research on spasmodic dysphonia is the National Institutes of Health (NIH), specifically the National Institute on Deafness and Other Communication Disorders (NIDCD). For numerous years, Dr. Lana Shekim served as the Program Officer for the Voice and Speech Program at NIDCD. Her contribution has been critical in ensuring that spasmodic dysphonia and related voice conditions were incorporated into the comprehensive strategic plan for NIDCD. Dr. Shekim collaborated closely with investigators and actively engaged with Dysphonia International. She frequently attended our local support group meetings and symposiums in Washington DC, particularly when they were held in the DC area.

Dr. Shekim recently retired from her position, and in September 2023, Dr. Lisa Kopf, PhD, assumed that role. Dr. Kopf received a bachelor’s degree in speech pathology and audiology from the University of Virginia, a master’s degree in speech-language pathology from the University of Iowa, and a Ph.D. in communicative sciences and disorders from Michigan State University. She completed a postdoctoral fellowship at the University of Iowa, working with faculty in communication sciences and disorders and neurosurgery. Dr. Kopf’s primary research interest is in clinical voice disorders. During her doctoral training, she worked with NIDCD-funded investigators in the area of voice disorders. We thank Dr. Shekim for her years of dedicated service and extend a warm welcome to Dr. Kopf and look forward to working with her.

In addition, Executive Director Kimberly Kuman was able to meet Dr. Lisa Kopf in September 2023 when they were both participating in the National Deafness and Other Communication Disorders Advisory Council meeting. Kimberly was recently invited to serve as an ad hoc attendee. She is honored to serve in this role and be able to represent the voices in our community.



Dr. Lana Shekim



Dr. Lisa Kopf

PERSONAL PROFILE | PETER HASKELL

Award-winning reporter Peter Haskell reflects on the past year since he publicly revealed his spasmodic dysphonia diagnosis on World Voice Day in 2023.



My instrument wasn't anything fancy or unusual and it wasn't particularly loud or powerful. But it did the job, hitting the high notes during moments of elation and exhilaration and striking the low notes during somber, reverent times.

My instrument is my voice, and it served me well during my career as a radio reporter. For nearly 30 years, I worked for WCBS Newsradio 880, an all-news station in New York City. I could play any kind of tune; cover any kind of story. I had a front-row seat for eight national political conventions, four New Hampshire Presidential primaries, seven World Series, two Super Bowls, NBA Finals, Stanley Cup Finals, 20+ NYC Marathons, a horse-racing triple crown and quite a few ticker tape parades. I covered 9/11 at Ground Zero for months and the stories that followed since then; the Sandy Hook shooting, Superstorm Sandy and more than a few hurricanes; an earthquake in Haiti, JFK, Jr's plane crash on Martha's Vineyard, the Miracle on the Hudson, the arrest of the Boston Marathon bombing suspect and shared the stories of doctors, researchers, and patients during the Covid-19 pandemic.

My instrument had been reliable, durable and predictable. Until it wasn't. Several years ago, I noticed subtle changes in my voice. I couldn't reach the high notes, my range was compressed, and I was running out of air. When I read a script in my head, I heard the soaring strings of a symphony; melodic and sweet. But it sounded much different when I opened my mouth to speak.

After seeing many different doctors, I was finally diagnosed with spasmodic dysphonia. I was candid with my bosses from the beginning, and they were always supportive, gracious, and kind. But as time went on, it became clear that what I was doing was unsustainable. I knew it was time to leave.

I shared my announcement with the public on April 16, 2023, World Voice Day, which is dedicated to reflecting on one's vocal instrument. Through printed editorials, radio and TV interviews, I expressed gratitude to my listeners for their years of support while hopefully raising awareness about voice disorders.

At that time, I wrote, "I'm not sure what comes next, but it's not retirement. We can't always choose the path we want to take, but we have to acknowledge reality and keep moving forward. I'm figuring out my second act and am open to suggestions and opportunities. I'm leaving with a swirl of emotions, most notably gratitude.

What's happened in the past year would have been hard for me to imagine. I've been fortunate enough to find two new career passions.

In the fall, I started full-time with the Tunnel to Towers Foundation. The nonprofit was born from the ashes and debris of the World Trade Center after 9/11. It helps first responders, military members, and their families. My job in the Marketing and Communications department is to help them tell stories. It's something I've done my entire career, but those skills are being used slightly differently. Now, I'm using my voice to tell stories without speaking.

In January, I became an Adjunct Professor, teaching journalism at Fordham University in the Bronx. It's been a way to share my experiences as a reporter with a new generation of students, who will tell stories on different platforms and in ways that didn't

exist when I started in the business. While I do have to speak, the focus is on the content of my lessons, rather than the quality of my voice.

I have also been volunteering with Dysphonia International, including teaching two virtual workshops for the organization's support leaders.

Did I reinvent myself? Not really. I've repurposed and repackaged my skills (whatever they might be) to shape new narratives and young minds. It's been invigorating and fun.

I felt so much gratitude when I left my reporting career, and that's been compounded by the good fortune I've found in my new careers. There are opportunities out there if you're persistent, look for them and stay positive. I understand my experience might not be representative of others, who might have different or worse vocal experiences. As we've heard on some TV commercials, results may vary.

A year ago I wrote, "My instrument isn't what it once was, but it won't be silenced. And neither will I. I might have trouble speaking, but I haven't lost my voice." Today, I still may have trouble speaking, but I can say I'm finding my voice. Metaphorically, of course.

DYSPHONIA INTERNATIONAL | 2023-24 PROGRAM HIGHLIGHTS

While 2023 marked the inaugural year under our new name, Dysphonia International, our mission has remained the same: to improve the lives of people affected by spasmodic dysphonia and related voice conditions through research, education and awareness, and support. We are excited to share highlights of what has been accomplished working together in this past fiscal year. Your support has been the driving force in helping us to make these significant strides, and we look forward to achieving even greater milestones as we commemorate our organization's 35th Anniversary.



RESEARCH

Finding answers to develop better treatments and discover a cure

This past year, we have:

- Funded three new research grants.
- Provided augmentive funding to support five research projects, including a treatment clinical trial on a new neurotoxin.
- Awarded twelve Travel Awards and two Conference Awards to individuals presenting at the annual meetings of professional voice associations.
- Established partnerships with two new professional laryngology societies in Europe.
- Organized a virtual Research Workshop for investigators funded by Dysphonia International.
- Appointed three new members to our Scientific Advisory Board.
- Participated in two scientific symposia, including one international.



EDUCATION & AWARENESS

Building understanding to share knowledge and increase sensitivity

This past year, we have:

- Hosted our first in-person Symposium since 2019.
- Exhibited at three professional voice conferences.
- Presented to Laryngology Fellows at the Fall Voice Conference.
- Sponsored eight webinars with a total of 3,100 people registered from an average of 30 countries.
- Launched a World Voice Day awareness campaign highlighting the theme Your Voice Matters.
- Coordinated ten presentations for the Guest Speaker Program to graduate-level Speech-Language Pathology students.
- Organized the 4th Annual Walk for Talk, which included both worldwide individual participation and 22 in-person events. Ten of these were first-time walks, and many of those were hosted by healthcare professionals. Our community raised an unprecedented \$124,566, and with the dollar-for-dollar match, a grand total of \$249,132 was generated to fund research and programs.



SUPPORT

Raising hope to ensure no one feels alone

This past year, we have:

- Organized and promoted 55 virtual, 29 in-person, and five hybrid support group meetings.
- Hosted an in-person Leadership Workshop for the first time since 2019.
- Launched a monthly series of virtual meetings for our Support Network Leadership, rotating between Area Contact Leaders, Support Group Leaders, and joint leadership.
- Introduced a Spotlight on a Leader Program, highlighting the great work of our volunteer leaders.
- Created a Leadership Library - a robust online resource site for our leaders.
- Sponsored two Media Workshops with reporter Peter Haskell for our Support Leadership Network.
- Presented the Midge Kovacs Award, the Dot Sowerby Awareness Award, and the Larry Kolasa Founding President's Award.
- Published the quarterly online newsletter, *Voices of Support*, highlighting the work of the volunteer Support Network.

**2023 WALK FOR TALK
IN-PERSON EVENTS**

- Birmingham, AL*
- Decatur, AL
- Scottsdale, AZ
- Chico, CA*
- Oakland, CA*
- Playa Vista, CA
- San Mateo, CA*
- St. Petersburg, FL
- Cumming, GA
- Pleasant Hill, IA
- Shreveport, LA
- Troy, MI
- Roseville, MN*
- Rochester, MN*
- Matthews, NC
- Tinton Falls, NJ*
- Cincinnati, OH*
- Huntsville, TX*
- Irving, TX*
- Murray, UT*
- Gravenhurst, ON, Canada

**New Location for 2023*

**2023 WALK FOR TALK
PLANNING COMMITTEE**

- Mary Bifaro, *Chair*,
- Dennis Kaszeta, Cathleen McCulloch, Ron Langdon, Sue Payne, and Esther Zack

2023 Walk for Talk Highlights

Our gratitude goes out to all who took part in and contributed to the 2023 Walk for Talk! Thanks to your generous support, we achieved our highest fundraising total ever, reaching \$124,566, which was then matched, resulting in a grand total of \$249,132 to advance research efforts!



Special Thanks to Our 2023 Sponsors!





Walk for Talk

SAVE THE DATES | OCTOBER 17-20, 2024

In 2020, we launched Walk for Talk to unite people virtually, expand awareness and raise funds for research for spasmodic dysphonia and related voice conditions. We saw participation worldwide, all to support our voice community. Over time, Walk for Talk has expanded, including more in-person events, increased involvement of healthcare professionals and researchers, new sponsors, and expansion into more countries. We would love to see this grow even more for the fifth year, so start planning our 2024 Walk for Talk from October 17-20. This will be our “focus” weekend, but events will occur all month.

We also want to emphasize that Walk for Talk is an inclusive event accessible to EVERYONE, regardless of your location. There is no charge to participate, and you can raise awareness about the challenges faced by individuals with voice conditions and truly MAKE A DIFFERENCE! And you don't just have to walk – you can run, bike, peddle, paddle, golf, surf – well, you get the idea! So, the choice is yours on how you would like to use your feet to help us beat spasmodic dysphonia and related voice disorders.

There are countless ways to get involved, and here are just a few ideas:

- Take a walk (or choose to run or bike) in your neighborhood while sporting Walk for Talk swag. Share a photo of your activity on social media using the hashtag #WalkforTalk.
- Create a video to post on social media, sharing your personal experiences and how your voice disorder has impacted your life.
- Launch an individual fundraiser and help us reach our goal of raising \$100,000 for 2024, which will support further research to find solutions for spasmodic dysphonia and related voice conditions.

Walk for Talk has embodied our collective commitment to making a lasting impact. Every step we take during this walk symbolizes a step towards a brighter future for those we serve. We hope you will join us!

Learn more at walk4talk.org

Every Step Gets Us Closer to a Cure!





EMPOWERING VOICES, TRANSFORMING LIVES

As we commemorate our 35th anniversary, we share some of the milestones that have shaped our organization's journey. Our Mission has been clear and unwavering from the start – to improve the lives of people affected by spasmodic dysphonia and related voice conditions through research, education and awareness, and support.

From humble beginnings, our organization continues to expand, committed to advancing knowledge and support for those facing voice-related challenges and striving to fund research to find answers. The evolution of our identity reflects our continuous adaptation to better serve the global community and ensure everyone's voice is heard.

Together, we stride into the future, united in our mission to make a meaningful difference and improve the lives of those affected by spasmodic dysphonia and related voice conditions. Thank you for your continued support!

HIGHLIGHTS | 1989-2024

- 1989**
Incorporated the National Spasmodic Dysphonia Association in Michigan
- 1990**
Published first NSDA Quarterly Report
- 1991**
Article on SD published in *Prevention Magazine*
- 1993**
Hosted the first Symposium in Irvine, CA
- 1993**
Opened in first office Birmingham, MI
- 1994**
Exhibited at first professional medical conference
- 1995**
Appointed first Medical Advisors
- 1996**
Dystonia Online Support Group established
- 1997**
Created the AOL SD Chat Group
- 1997**
Partnered with the DMRF for management
- 1998**
Released the award-winning video, *What is SD?*
- 1998**
Established the Midge Kovacs Award
- 1999**
Established the SD Bulletin Board
- 1999**
Published *Speechless No More*
- 2001**
Launched the first NSDA website at dysphonia.org
- 2005**
Established new management in Itasca, IL
- 2006**
Hosted the inaugural Leadership Day and Symposium on World Voice Day
- 2006**
Published the first issue of *Voices of Support*
- 2006**
Coordinated first NIH SD-Focused Research Planning Workshop
- 2007**
Established the Research Grant Program
- 2008**
Appointed the first Scientific Advisory Board
- 2008**
Established the Medical Advisory Board
- 2008**
Published *Easier Done than Said: Living with a Voice Disorder*
- 2009**
Awarded first international SD research grant
- 2009**
Dystonia Coalition funded by NIH
- 2011**
Global Dystonia Registry established
- 2011**
Dystonia Brain Collectives established
- 2012**
Relaunched website
- 2012**
Published first issue of *e-Voice*
- 2013**
Published *Share Your Story*
- 2014**
Funded first professional medical association Research Travel Awards
- 2015**
Established the Dot Sowerby Pioneer Award and Larry Kolasa Founding President's Award
- 2016**
Hosted Research Workshop
- 2018**
Launched a redesigned and expanded website
- 2019**
Expanded mission to include related voice conditions
- 2019**
Hosted a Research Workshop
- 2019**
Published *Celebrating Our Voice*
- 2020**
Hosted first virtual Symposium
- 2020**
Launched first virtual support meetings
- 2020**
Created Walk for Talk
- 2021**
Published *Speechless No More: A Life Transformed by a Voice Disorder*
- 2021**
Incorporated Dysphonia International in Illinois
- 2023**
Officially launched Dysphonia International
- 2023**
Surpassed \$800,000 in research funding
- 2023**
Provided augmentive funding for smaller grants
- 2023**
Hosted virtual Research Workshop
- 2023**
Expanded Scientific Advisory Board
- 2024**
Celebrating the 35th Anniversary
- 2024**
Hosting the 5th Annual Walk for Talk

UNRAVELING SPASMODIC DYSPHONIA:

The Role of Altered Brain Pathways



Could a breakdown in communication internally be the cause of a breakdown in communication externally?

The complexity of the human brain lies not only in the sheer number of neurons (an estimated 86 million) but also in the vast network of connections, or synapses, between them. The brain communicates with other parts of the body through the transmission of signals along specialized pathways, allowing the brain to coordinate and control various functions throughout the body, including voluntary and involuntary movements, sensory perception, and the regulation of physiological processes.

This intricate interplay of neurons that are carrying messages enables the brain to perform its diverse functions. However, communication can break down if there is a disruption anywhere along the pathway. Dystonia is considered a network or circuit disorder involving abnormal interactions in regions of the brain that coordinate and control movement. In spasmodic dysphonia, a form of focal dystonia, signals are misfired to the muscles of the larynx, causing those muscles to adduct (close) or abduct (open) unexpectedly, affecting the sound of a person's voice.

The basal ganglia-cortical network, which includes interconnected brain regions

responsible for planning and executing voluntary movements, is thought to be affected in dystonia. There is a breakdown in sensory input and motor output integration causing uncontrollable movements. Here we explore some of the areas that are part of this network and the role they play in normal movement.

Basal Ganglia

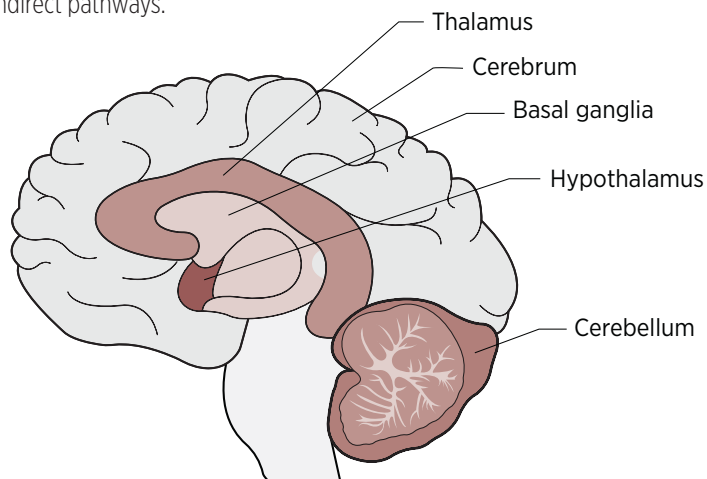
WHAT | The basal ganglia is a collection of neurons that form specific brain regions that play a crucial role in motor control and is involved in various functions, including the regulation of voluntary movements, motor planning, and coordination. These structures are interconnected in a complex circuitry that involves both direct and indirect pathways.

The basal ganglia work in collaboration with other brain regions, such as the thalamus, cerebellum and cerebral cortex, to regulate motor functions and contribute to motor learning.

WHERE | The basal ganglia are a group of neurons located deep within the brain, near the base of the forebrain. They are situated on both sides of the brain, with each side containing its own set of basal ganglia structures, the major components being the striatum, globus pallidus, subthalamic nucleus, and substantia nigra.

Cerebellum

WHAT | The cerebellum is a large, separate brain structure that contributes to the smooth execution of movements, maintenance of balance, and the learning of motor skills. Its intricate connections with other parts of the nervous system make it a central player in motor control and coordination.



WHERE | The cerebellum is located in the back of the brain and directly connects to the spinal cord, brain stem, and thalamus. Via these connections the cerebellum plays a fundamental role in coordinating voluntary movements and maintaining balance and posture.

Thalamus

WHAT | The thalamus is an integral part of the motor control circuitry in the brain. While it doesn't directly generate movements, its role in relaying sensory information and integrating motor signals from different brain regions is crucial for the smooth execution and coordination of voluntary movements.

WHERE | The thalamus is found above the brainstem and cerebellum, and below the cerebral cortex and basal ganglia. It is composed of two symmetrical halves, or hemispheres, each containing several nuclei that relay motor and sensory signals to different regions of the body or cerebral cortex, respectively.

Cerebral Cortex

WHAT | The cerebral cortex is intricately involved in the control of high-level voluntary movement, with different regions contributing to various aspects of motor planning and execution. The cerebral cortex integrates sensory information with intended motor plans to execute intended movement.

WHERE | The cerebral cortex is the outermost layer of the brain, often referred to as the

“gray matter” of the brain due to its gray appearance. It makes up the majority of the brain's mass and is divided into four main lobes.

Somatosensory System

WHAT | The somatosensory system monitors the environment via sensory receptors, nerves, and brain regions. This system is responsible for detecting, processing, and interpreting sensations related to touch, pressure, temperature, pain, and body position (proprioception). It provides essential feedback for spatial awareness and motor control and optimizes interactions with the environment. Integration of somatosensory information occurs at various levels of the nervous system, including the basal ganglia, cerebellum, thalamus, and cerebral cortex, allowing for a comprehensive understanding of the body's external and internal states.

WHERE | The primary components of the somatosensory system are distributed throughout the body, including sensory receptors, peripheral nerves, spinal cord, brainstem, thalamus, and cerebral cortex.

DYSTONIA RELATES TO MANY ABNORMALITIES IN THE NERVOUS SYSTEM

Neurotransmitter Imbalance

Disruptions in the balance of chemical messengers in the brain (neurotransmitters) occur in dystonia. The basal ganglia-cortical network relies on precise neurotransmitter signaling for smooth motor control and imbalances can result in increased activity of motor circuits, contributing to dystonic movements. Specific to dystonia, the most commonly affected neurotransmitter systems include dopamine, GABA, and acetylcholine. Disruptions in neurotransmitter balance may contribute to abnormal brain signals that affect precise control of laryngeal muscles. The exact mechanisms and their relationships are complex and not fully understood.

Genetics

While many cases of dystonia are considered sporadic and occur without a clear family history, there are genetic factors that contribute to certain forms. Some individuals may have a genetic predisposition to dystonia, meaning that their genetic makeup increases their likelihood of developing dystonia. Currently, there are no identified genes that directly cause spasmodic dysphonia.

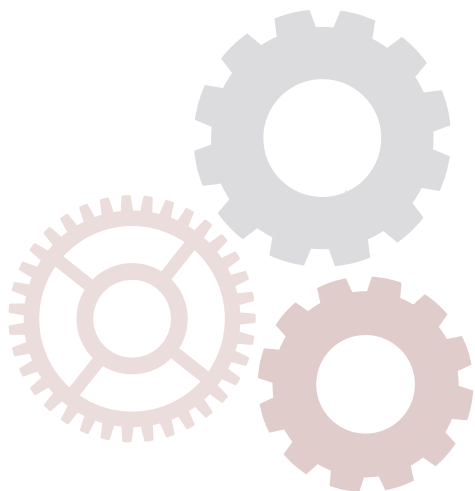
Environmental Factors

Environmental factors, such as trauma, stress, infections, or illness, may have a role in the onset of spasmodic dysphonia. It is unclear whether these things directly trigger spasmodic dysphonia or if they exacerbate pre-existing conditions. In addition, when combined with genetic susceptibility, environmental factors may contribute to the development of spasmodic dysphonia.

Abnormal Sensory-Motor Integration

Dystonia is associated with abnormal sensorimotor processing, affecting the integration of sensory information with motor commands. Continuous feedback loops between the somatosensory system and motor areas contribute to adjusting movements in real-time based on sensory input. In dystonia, the brain struggles to interpret feedback from the body correctly, leading to abnormal muscle contractions.

The somatosensory system for voice involves sensory receptors in the vocal tract, larynx, and other related structures that provide feedback to the brain about the position, movement, and tension of the vocal apparatus. When this system is disrupted, it can impact speech production and the perception of one's own voice. It can lead to abnormalities or impairments in the sensory feedback system related to the production and perception of speech and vocalization.

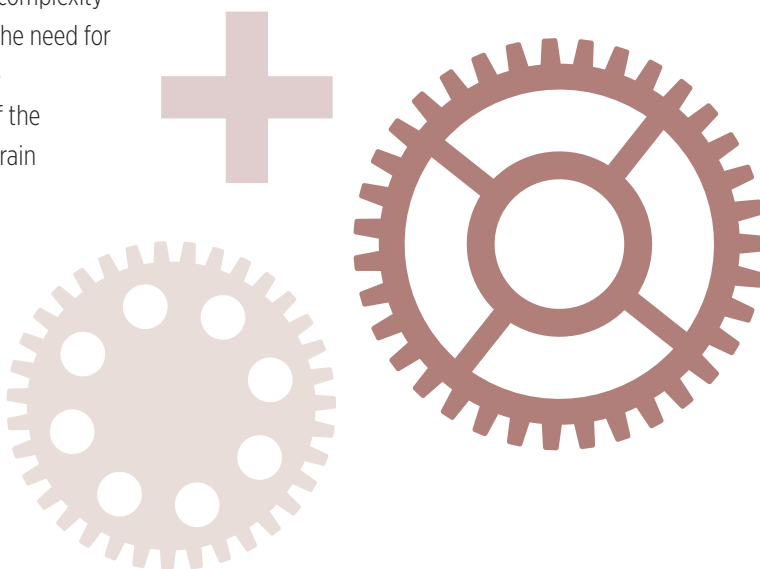


Abnormal Neuroplasticity

Neuroplasticity refers to the brain's capacity to change and reorganize itself by altering existing or new connections throughout life. Mechanisms of neuroplasticity are being actively investigated, and much is being learned about changes in the brain that cause this. For example, connections between nerve cells can be modified to convey more strong or weak messages. Additionally, nerve processes can grow or shrink. The location in the brain where these alterations occur remains unclear and is being investigated. In dystonia, the role of neuroplasticity is not fully understood, but there is evidence to suggest that unfavorable neuroplasticity changes affect the brain's motor networks. It may be possible to reverse these changes, but a robust method is not yet available. More understanding of the cause is needed before these changes can be reversed.

Network Dysfunction in the Brain

It has long been believed that connections between the basal ganglia and cerebral cortex form a connection (network) disrupted in patients with dystonia. There is growing evidence that disruption of additional brain connections may contribute to dystonia, including those that involve the cerebellum, thalamus, and cerebral cortex. These complex interactions lead to the consideration that dystonia results from the disruption of signals in a brain network that controls movement. This perspective underscores the complexity of dystonia and the need for a comprehensive understanding of the interconnected brain regions involved



in motor control. Better understanding of common dysfunctional parts of this network contributes to the development of targeted treatments and interventions for individuals with dystonia.

CONCLUSION

As each person's brain is unique, disruptions in how brain regions communicate in one individual's brain may not align precisely with that of another. Nonetheless, strides have been made in comprehending this variability among individuals and refining methods to map the specific brain networks in each person. Understanding these networks and contributing factors is critical for developing targeted treatments and interventions that address the specific mechanisms underlying spasmodic dysphonia. We are hopeful that with ongoing funding of research, answers will be found that will lead to a cure for spasmodic dysphonia.

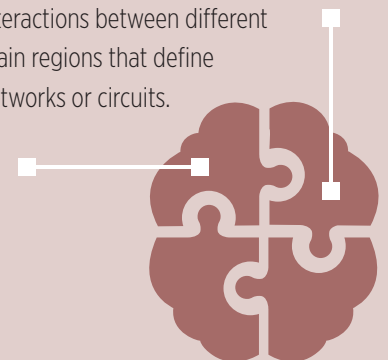
NETWORK VS. CIRCUIT DISORDER

The terms “network disorder” and “circuit disorder” are often used interchangeably in the context of neuroscience and neurology. Both refer to conditions that involve abnormalities or dysfunction of neural networks or circuits within the brain. However, there can be subtle distinctions in how these terms are used, depending on context.

“Network disorder” typically implies a broader perspective, referring to abnormalities or dysregulation in the communication and interactions among various brain regions. It emphasizes the interconnectedness of different brain structures and their roles in supporting specific functions or behaviors. Examples of network disorders include conditions resulting from disrupted communication between brain regions, resulting in problems with cognitive, sensory, or motor function.

“Circuit disorder” highlights specific brain circuits or connections that are dysfunctional. It often implies a more focused consideration of particular brain circuits involved in a specific function or behavior. Examples of circuit disorders include conditions where specific pathways, such as those in the basal ganglia-cortical circuit, are implicated in the cause of a disorder.

In essence, both terms emphasize the idea that neurological disorders may arise from disturbances in any part of intricate connections and interactions between different brain regions that define networks or circuits.





How Mindfulness Can Help People with Voice Disorders

By Catherine Kay Brown



I am a singing and mindfulness teacher with vocal fold paresis. When I first received my diagnosis, I was also given a secondary diagnosis of muscle tension dysphonia (MTD). I enrolled in a mindfulness course and found that the combination of voice therapy and mindfulness helped me release physical tension and adjust to my new reality. I regained much of my lost vocal range, and my vocal stamina improved dramatically.

I began to wonder if mindfulness might help others with voice disorders, so I enrolled in a graduate program and conducted a study. The resulting article, “Effects of an 8-Week Mindfulness Course in People with Voice Disorders,” is now available in press in *Journal of Voice*.¹

I would like to offer some thoughts on how specific mindfulness exercises can help people with voice disorders. (Please see the links below for mindfulness courses and recordings.)

WHAT IS MINDFULNESS?

Mindfulness is “awareness that arises through paying attention, on purpose, in the present moment, non-judgmentally.”² Mindfulness-based interventions are structured, multi-week group classes led by a trained instructor. They include meditation, movement, and group discussion. Daily home practice is encouraged.

The Sitting Meditation

This classic meditation exercise involves simply sitting and observing the breath as it enters and exits the body. As thoughts or anxieties arise, we acknowledge them without judgment and let them go.

People with voice disorders face a variety of challenging stressors. Additionally, stress may worsen voice symptoms and hinder treatment.³ **Mindfulness may not help us reduce the stressors in our lives, but it can give us new ways to manage stressful situations.**

The Body Scan

This meditation encourages you to gently bring awareness to each area of the body. In my recording, we spend extra time on the neck, tongue, and jaw. Participants are encouraged to approach these areas with compassion and acceptance.

People with voice disorders frequently experience physical tension and discomfort — or even pain — in their throats.⁴ **Mindfulness can help patients release tension and reduce chronic pain, making it particularly helpful for patients with MTD.**

Mindful Yoga

I recommend practicing yoga with a voice-knowledgeable yoga therapist. Examples include Sarah Whitten (www.sarahwhitten.com) and YogaVoice® founder Mark Moliterno (www.theyogavoice.com). They both work in person and online and provide private sessions, group classes, and online video content.

Mindfulness (particularly mindful movement and the Body Scan) has been shown to increase somatic (or interoceptive) awareness.⁵ This component of mindfulness may make vocal learning more efficient for anyone who has low somatic awareness, is new to voice work, or has not responded well to voice therapy in the past.

Mountain Meditation

This beautiful and descriptive meditation invites you to imagine yourself as a mountain: calm and still, despite constant change, including loss.

In a group of people with voice disorders, grief and loss quickly comes to the surface as people discuss their vocal limitations. A mindfulness teacher can help them begin to acknowledge and move through grief. **Mindfulness encourages reappraisal, a process by which we reframe the meaning of difficult events.**⁶

The Loving Kindness Meditation

In this exercise, you are invited to practice extending loving kindness to someone you know and love, to someone you feel neutral about, to someone you dislike, to yourself, and to the world at large. In my mindfulness classes, I invite participants to extend loving kindness to their voice, thanking it for the ways it serves them. This can be both challenging and deeply rewarding for those who feel their voice has let them down.

For anyone who struggles with self-criticism, including of their voice, mindfulness can provide a pathway towards acceptance. For patients whose voice disorder has drastically altered their lives, acceptance may feel threatening. They may need to view acceptance as a long-term goal. (You can accept your voice as it is while still trying to achieve specific vocal goals.) In my mindfulness courses, patients with spasmodic dysphonia have found working towards acceptance particularly meaningful.

Expanding Awareness Meditation

Here, we focus on the breath, then add awareness of the body, sound, thoughts, and emotions. Then we go into “choiceless awareness” in which we simply notice whatever arises internally or externally. This exercise often helps us notice patterns of thinking or feeling that may have otherwise gone unnoticed.

Mindfulness can restore a sense of agency or control to voice disorder patients. Agency erodes when we have little control over or understanding of what is happening to us. **Mindfulness can increase our sense of agency by highlighting what we can and cannot control.** A spasmodic dysphonia patient may not be able to control their vocal spasms, but they can change how they respond to the frustration of being misunderstood. Accepting difficult things allows us to save our energy for situations where it can make a difference.

Course: Mindfulness for People with Voice Disorders

A skilled mindfulness teacher can guide the learning process and help you overcome any difficulties or misconceptions that inevitably arise.

Practicing mindfulness in a group has been shown to produce better outcomes than practicing alone.⁷ The popular press frequently touts the health benefits of mindfulness but rarely states that those benefits are almost always gained in group settings. **Many voice disorder patients do not know anyone else with similar struggles. The group format of a mindfulness class helps participants feel less alone.**

Resources

- For upcoming mindfulness courses, visit <http://www.catherinekbrown.com/mindfulness>
- For other voice-related mindfulness resources, including recordings or meditation scripts used in the study, visit <http://www.mindfulvoicecollaborative.com>. This website is a collaboration with Julia Gerhard, CCC-SLP, DMA.
- Dysphonia International webinar: “Mindfulness for People with Voice Disorders: Research and Resources,” <https://www.youtube.com/watch?v=92KB-anOh9I>

Catherine Kay Brown is an adjunct voice instructor at Immaculata University and a private voice teacher in Downingtown, PA. She has presented on mindfulness and the voice for the Voice Foundation, the Pan-American Vocology Association (PAVA), and Dysphonia International. Her singing students have performed with professional theaters and have been accepted to top performing arts colleges and university programs. She holds a B.A. in music and German from St. Olaf College and a graduate certificate in applied mindfulness from West Chester University.

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2023 Dysphonia International SYMPOSIUM SUMMARY

Congrats to Dysphonia International, formerly the National Spasmodic Dysphonia Association on reaching its 34th anniversary! Our 2023 Dysphonia International Symposium was our first in-person symposium since 2019 and the first symposium since our transition to Dysphonia International. The 2023 Symposium theme was “Strength in Community”. The speakers at our 2023 Dysphonia International Symposium presented in a manner that was understandable, empathetic, and helpful. Close to 75 people were in attendance, including people from the US (17 states), Canada, and Pakistan. The weekend proceedings were informative, educational, and fun. The spirit of family, friendship, and camaraderie was palpable and wonderful to be immersed in.

For first-time attendees, the Ambassador Program connected people prior to the Symposium with a “buddy” who has been at prior meetings, so they feel more connected at the meeting. One person shared, “It was nice to know there was someone I could reach out to with questions beforehand and support during the day.”

On Friday evening, many of the attendees joined us for the Welcome Party. This is an opportunity to meet new friends and reunite with others. Participants also had the opportunity to introduce themselves and share some of their voice journey during the “pass the mic” session. For some, this is the first time they are meeting others who sound like them, so it can be both empowering and emotional. Family and friends in attendance were also encouraged to share. One powerful statement from a husband whose wife has a voice disorder was, “We have SD,” reinforcing the strength and importance of the support of loved ones.

SATURDAY MORNING PRESENTATIONS

These presentations were recorded and will be made available on both the Dysphonia International website and YouTube channel later.

Welcome and Overview of Dysphonia International

Charlie Reavis, President

Charlie has served as President since 2010. He commented on the impressive issue of “Our Voice”, the newsletter of Dysphonia International, Volume 30, which was recently published. It is 36 pages and can be downloaded from our website at dysphonia.org. Approximately 88% of our budget goes to funding research, education and awareness, and support. This is a record that we can all be proud of. He expressed his appreciation for the support and commitment of our Dysphonia International community and our professional healthcare providers and researchers, as evidenced by their participation in our programs and activities. He pointed out that our leaders, staff, and volunteers are actively engaged in many efforts to fulfill our Mission. He added that we welcome people with all voice conditions to our unique family and community.

Everything You Wanted to Know About Voice but Were Afraid to Ask

Adam Rubin, MD, and Juliana Codino, PhD, CCC-SLP

This team from Lakeshore Professional Voice Center in MI have supported our Detroit group with Walk for Talk and have been involved with annual World Voice Day concerts. Dr. Rubin stated that the voice is complex and voice problems can be caused by a number of factors, including cancer, neurological disease, pulmonary disease, and cardiovascular disease. They stressed the importance of paying

attention to changes in vocal quality. There is a physical, social, emotional, and economic impact to our voice. Dr. Rubin brought a sense of humor to his comments. Dr. Codino brought passion and musical references to her remarks. She mentioned the complex processes of delivering sound to the listener and the need to maximize our power sources (oscillator, resonator, etc.)

Creating a Treatment Plan with Your Healthcare Team

Ross Mayerhoff, MD, Henry Ford Health, MI

Dr. Mayerhoff discussed the shared decision making and collaboration involved in a patient’s health. Coming together are patients, healthcare professionals, and caregivers. It is not a matter of a doctor telling the patient what to do. It is also not a matter of the patient telling the doctor what to do. Medical treatments regarding the voice are patient-driven. The patient is at the center of the shared decision-making. Sometimes, a case manager and lawyer are involved. There may be input from an online support community. The voice care team typically includes a laryngologist who has advanced training. There may be a voice airway or swallowing specialist involved. Part of the team is the Speech Language Pathologist who has done a clinical fellowship. Some questions that are determined include: 1. Has a diagnosis been made? 2. Is more testing needed? 3. Has the patient filled out a Voice Related Quality of Life Survey or Voice Handicap Index? Since there are multiple treatment options, it is important to have a clear understanding and seek a second opinion when necessary. Communicate your goals, concerns, and personal family issues. Manage the information overload. Summarize the key points. Use the “teach back” method where you repeat to the healthcare team what you understand. Keep a journal and be a good steward of your health and part of the care team.

Surgical Approaches to Vocal Issues

N. Scott Howard, MD, University Hospitals Cleveland Medical Center

Dr. Howard opened his remarks by commenting on the positive spirit of the community at the Welcome Reception. He stressed the importance of considering your quality of life in deciding on a treatment for a voice condition. He mentioned the social, emotional, and spiritual components of living with a voice disorder. It is important to understand the options and learn what the healthcare provider can offer. Maintaining good hydration is part of vocal health. When considering surgical options, weigh the risks and benefits. When practicing when working for the military, Dr Howard treated phono-traumatic injuries. There are medialization surgeries for thickening and micro laryngology surgeries for reinnervation. Botox® helps treat many patients but repeated injections have the up and down effect in results.

Managing Stress and Your Voice

Anjli Lodhavia, MS, CCC-SLP, Henry Ford Health

Anjli spoke about her participation in the Voices of Michigan team in our Walk for Talk events. She stated that stress exacerbates voice symptoms and stress is messy. No one wants to hear that your voice problems are all in your head. Voice therapy helps many patients to learn breathing techniques, lip trills, straw phonation, warmup, and other vocal exercises. Remember to stay hydrated. The benefit of circumlaryngeal massage was briefly discussed. Some people try acupuncture and hypnotherapy. Seek an Employee Assistance Program if your company has one. They may offer counseling services. Anjli concluded with a Progressive Relaxation Exercise.



2023 Symposium Medical Speakers: (from left to right) Adam Rubin, MD, Juliana Codino, PhD, CCC-SLP, Ross Mayerhoff, MD, Scott Howard, MD, Anjli Lodhavia, MS, CCC-SLP



Nick Prefontaine delivering his presentation.

continued on page 26

Next Steps: Motivational Speech

Nick Prefontaine, Founder and CEO of Common Goal

Nick was an extraordinary speaker who delivered an inspiring, motivating, and entertaining speech. He told his personal story about surviving a snowboarding accident and how he had to learn how to talk and walk all over again. His methodology is one step at a time. His story is moving, heartwarming and a testimony to the power of belief, family, and the human spirit. In overcoming a traumatic situation, you need to identify and utilize your STEP: S (Support), T (Trust), E (Energy), and P (Persistence). After recovering from the accident, Nick developed a voice issue. He credits Dr. Phillip Song from Boston and Botox injections for helping him restore his voice. His message is to keep stepping forward to reach your potential. Every step taken gets you closer to your goal. To learn more, visit his website at: <https://nickprefontaine.com/step/>

SATURDAY AFTERNOON SESSIONS

There was much engagement and conversation at lunch. Afterward, there were two rounds of small group discussions. *Please note that these were not recorded.* The first one focused

on medical procedures and voice therapy. Dr. Howard answered a range of questions about symptoms, treatment, and more. SLP Anjali Lodhavia provided a hands-on session for voice therapy, including laryngeal massage.

Next were the roundtable discussions with the options of attending one on living with a voice condition or the impact of a voice condition on family and friends. Questions were provided, and small group discussions happened at round tables with Support Group and Area Contact Leaders leading the conversation.

We all came back together for a final session where Planning Committee Chair Mary Bifaro announced that the 4th Annual Walk for Talk will take place October 17–20, 2024. She encouraged each person to participate in their own way. It was enthusiastically announced that our 2024 Dysphonia International Symposium will take place on May 4, 2024, in Tampa, Florida. Ron Langdon, who co-leads the local support group in Tampa, invited all to attend!

At the optional dinner on Saturday evening, we honored the legacy of our Founding President, Larry Kolasa, who passed away last November, with many of his family members present. President Charlie Reavis

was presented with the Larry Kolasa Founding President's Award to honor him for all his work with NSDA and Dysphonia International over these 20-plus years.

Our symposium offered a great opportunity to meet old friends and make new ones. So many people commented on all the great connections made at the meeting. They also appreciated the warmth and accessibility of the healthcare professionals. Our talented and hardworking staff, headed by Executive Director Kimberly Kuman, did an outstanding job coordinating our meetings to ensure their success.

This weekend also provided the opportunity to think about the important mission work of our organization, as it included our annual Board of Directors meeting, a Strategic Planning Session, and our 19th Annual Leadership Workshop. The three pillars of our organization are Research, Education and Awareness, and Support. Our virtual meetings continue to attract more participation with renewed energy and enthusiasm. Our support network leaders provide energy and enthusiasm in their active communication. There are many ways to engage, and we welcome your participation as we are a community that cares about you and your voice!



Attendees of the 2023 Leadership Workshop



2023 Symposium Speaker Nick Prefontaine and Dysphonia International President Charlie Reavis



Symposium attendees discussing topics during breakout sessions.



Christine, a first-time attendee, purchased a Walk for Talk t-shirt to help raise awareness.



Panel of expert medical professionals answering questions from the audience.



SLP Anjali Lodhavia demonstrating laryngeal massage.



Michelle Donovan and Meredith Sexton led a session on living with vocal cord paralysis.



Edda Cantos and her husband found community by attending the 2023 Symposium.

YOUR VOICE MATTERS

April 16th
WORLD VOICE DAY

DYSPHONIA.ORG

Awareness is a critical factor influencing early diagnosis, best treatment practices, funding for research and, hopefully, cures for spasmodic dysphonia and related voice disorders. Every year on April 16, World Voice Day helps support these goals. It is an annual awareness event dedicated to recognizing the importance of the human voice and raising awareness about various voice-related issues. It is an opportunity to acknowledge the significance of vocal health, expression, and communication.

For World Voice Day 2023, the theme was Your Voice Matters. We saw many community members choose to raise awareness and participate in various ways, including recording videos, posting on social media, and creating art and music. Healthcare professionals also recognize the importance of raising awareness and participate in many ways, including hosting vocal health fairs and screenings, webinars on vocal health, and even a concert featuring performances by people treated for voice conditions.

We hope the 2024 World Voice Day theme of **Resonate, Educate, Celebrate** has you excited to participate this year! Some easy ways include utilizing social media platforms like Facebook, Instagram, and LinkedIn to spread information about World Voice Day. Share your story about your own experience of living with a voice condition. You can record a video or share graphics. Be sure to use #WVD so we can find your post. By engaging in these initiatives, you can help raise awareness about the importance of the voice and empower individuals to take proactive steps to maintain vocal health and express themselves effectively.

Guest Speaker Program for SLP Students

Dysphonia International's Guest Speaker Program opens a gateway to connect personal experiences of living with a voice disorder to the educational landscape of college and university classrooms. The program's overarching objectives include deepening the comprehension of future healthcare professionals regarding the profound impact of voice conditions on an individual's quality of life, equipping aspiring professionals with the knowledge to provide empathetic support to patients grappling with voice conditions, and contributing to a broader awareness of vocal disorders, with the aim of reducing diagnosis time and facilitating timely intervention. This year, thanks to the dedicated efforts of volunteers from all corners of the country, a total of nine presentations were successfully organized.



Eileen Meehan with Cleveland State University in Cleveland, OH

Scenes from the Support Network



Birmingham, AL Support Group Leader, Judith Rodwell, Dr. Edie Hapner, and the team from UAB Voice Center exhibited at the 2023 UAB Otolaryngology Conference.



Ray Schumacher attended the 5th Annual Benefit Concert hosted by Warren Bandel.



Great turnout at the Valley of the Sun Dysphonia Support Group Meeting.

Professional Medical Conferences

Dysphonia International continued its commitment to raising awareness and fostering collaboration by actively participating in several professional medical conferences throughout 2023. These meetings served as crucial platforms for sharing knowledge, engaging with healthcare professionals, and contributing to the ongoing dialogue surrounding voice disorders. For 2023, we participated in the Fall Voice Conference in Washington DC, the Voice AI Symposium also in Washington DC, the American Speech-Language-Hearing Association Convention in Boston, MA, the New York Laryngological Society in New York, NY, and The Samuel Belzberg 6th International Dystonia Symposium in Dublin, Ireland. Many of these meetings also included the sponsorship of Travel and Conference Awards. Through participation in such conferences, Dysphonia International reinforces its position as a valuable contributor to the medical community, working towards a future with increased awareness, understanding, and support for individuals with voice disorders.



Dot Sowerby and Susan Beck at the American of Speech-Language-Hearing Association (ASHA) Convention in Boston, MA



Nicole Leitner and Susan Beck at the Fall Voice Conference in Washington DC

Webinars

In 2022, Dysphonia International launched an exciting series of virtual educational webinars.

Designed to raise awareness, offer resources for patients, and showcase innovative medical research, these webinars provide a platform for researchers to share findings and the community to ask questions. All sessions are recorded for later viewing on our YouTube channel, allowing widespread access. We're thrilled to have seen registrations from nearly 70 countries, expanding our reach and ensuring more individuals have access to valuable resources globally. Looking forward to continuing this impact in the coming year!

Webinar Titles

A Tour of Voice Disorders with a Focus on Spasmodic Dysphonia

Advances in Spasmodic Dysphonia Research

Ask the Expert: Q&A Session on Spasmodic Dysphonia and Related Voice Conditions

Diagnosis and Management of Vocal Fold Paresis

Botulinum Treatment Options for Spasmodic Dysphonia

Vocal Cord Dysfunction: A Poorly Named Common Laryngeal Disorder

Understanding The Role of the Laryngologist

Laryngeal Vibration Can Reduce Voice Symptoms of Laryngeal Dystonia: New Findings

Quantitative Measures for Adductor Laryngeal Dystonia & Overview of rTMS as a Possible Intervention

Laryngeal Dystonia: Exploring Brain Circuits in Pursuit of a Personalized Approach

Ask the Experts: A Q&A Session

Focus on Voice Research: A Conversation with Gerald Berke

Mindfulness for People with Voice Disorders: Research and Resources

The ADA and Workplace Accommodation for Employees with Voice Disorders

AWARDS

MIDGE KOVACS ANNUAL AWARENESS AWARD

In commemorating the 25th annual presentation of the Midge Kovacs Annual Awareness Award, we take immense pride in honoring the exceptional efforts of the Greater Los Angeles Dysphonia Support Group, led by Toni Gold. This award, named after the late advocate Midge Kovacs, honors the outstanding work of a Dysphonia Support Group.

Over the years, Toni has forged meaningful connections with healthcare professionals and SD patients, organizing events like the Educational Seminar on SD with Dr. Michael Johns and the annual Walk for Talk event. Toni's commitment extends to the virtual realm, where she hosts engaging meetings, sharing her own dysphonia journey. Having lived with spasmodic dysphonia for 50 years, Toni refuses to let it define her. Instead, she uses her story to comfort others facing similar challenges, contributing significantly to Dysphonia International's Mission. Toni Gold's leadership and impact resonates in her own words: "I will always strive to uphold the values that this award represents and do my utmost to promote the Mission of Dysphonia International."

As we applaud Toni Gold and the Greater Los Angeles Dysphonia Support Group, we recognize their unwavering dedication to making a difference in the dysphonia community. Their collective efforts exemplify the spirit of the Midge Kovacs Annual Awareness Award, and we look forward to witnessing their continued impact in the years to come.



Toni Gold

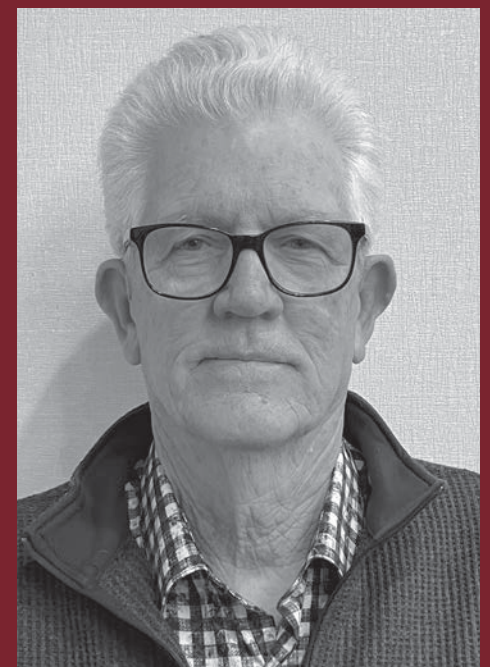
DOT SOWERBY PIONEER AWARD

In 2015, Dysphonia International established the Dot Sowerby Pioneer Award to commend individuals making significant positive impacts on the voice community. This year marks the ninth presentation of the award, and we are delighted to recognize John Comer for his outstanding commitment and leadership.

John has played a vital role in forming new support groups and expanding existing ones, contributing to the growth and outreach of the organization. A valuable member of the Support Network Committee, John, residing in both Minnesota and California, serves as a Regional Coordinator. In this role, he fosters a sense of community and support for those affected by dysphonia. In his own words, John emphasizes the collective strength of the dysphonia community, stating, "All of you who are involved with spasmodic dysphonia ARE our organization." His commitment to supporting the community and advancing the goal of finding a cure is evident in his tireless efforts.

Upon receiving the Dot Sowerby Pioneer Award, John expressed his appreciation, acknowledging the honor and recognizing Dot Sowerby as a true inspiration. John reflected, "Being able to connect with a person who shares our voice issues, frustration, and lack of proper diagnosis has been very rewarding. Thank you for the award and especially for being honored with an award named for our warrior, Dot Sowerby."

Dysphonia International extends its gratitude to John Comer for his exceptional service. His contributions have played a vital role in the organization's growth, outreach, and support for individuals facing voice-related challenges. Congratulations, John, on this well-deserved recognition!



John Comer

LARRY KOLASA FOUNDING PRESIDENT'S AWARD

At the closing dinner of our 2023 Symposium, Past President Charlie Womble presented the Larry Kolasa Founding President's Award to Charlie Reavis. It is given to a dedicated individual whose leadership and service have profoundly shaped the direction and future of the organization. This marks the third presentation of the Larry Kolasa Founding President's Award in the organization's history. Previous recipients include Stephe Mendel in 2015 and Dot Sowerby in 2019, highlighting this recognition's rare and distinguished nature. For over 20 years, Charlie has served the organization with strong dedication, commitment, and hard work.

Charlie joined the Dysphonia International Board of Directors in 2002 with a mission to increase awareness of spasmodic dysphonia and find answers through research. He has been instrumental in driving the organization's transformation and growth, including the change in administration in 2005 and the relocation of the office to Itasca, IL. Serving as President since 2010, Charlie also led the change of the name of the organization to Dysphonia International and led the effort to include "related voice conditions" in our mission statement, thereby allowing us to include and support people regardless of their voice condition. Beyond his role as

President, Charlie has represented Dysphonia International at various conferences, received mayoral proclamations for World Voice Day, and actively contributed to medical discussions on dysphonia.

Larry Kolasa, the award's namesake, passed away in November of 2022, but Larry's family was in attendance to help us continue honoring his legacy through this award. His son Lawrence, Jr., shared on behalf of the family, "We are deeply grateful for having been invited to this event, which honored my father. It meant a lot to all of us to share in the life of my dad from the perspective of Dysphonia International. We know he gave so much of himself to your organization, but it was another thing entirely to hear from your members directly. As we grieve his passing, it is comforting and healing to know how much he was loved by others."

Charlie Reavis shared, "I was completely surprised and very humbled by the award. It is a great honor for me to receive this special award named in recognition and memory of my dear friend and 'Brother' – Larry Kolasa! The award has even more significance since it was presented to me in the presence of Larry's wife, Pam, and their sons, Lawrence and Stephen and their wives. My commitment

to our organization is to help us grow and be viable in order to improve the lives of more people with voice disorders. I am blessed with the opportunity to work with some of the most incredible people I have ever known. Thank you!" Charlie's extraordinary contributions continue to shape and uplift the dysphonia community, embodying the spirit of this prestigious accolade.



Charlie Womble Pam Kolasa and Charlie Reavis

From left, Lawrence Kolasa, Sylvia Fantin, Mary Kolasa, Stephen Kolasa, Pam Kolasa, Charlie Reavis, Bruce Menk, Charlie Womble, and Cherie Lovett



SCHEDULE

MAY 3, 2024

Welcome Reception
7:30 PM

MAY 4, 2024

Symposium
9:00 AM - 4:45 PM

OPTIONAL

35th Anniversary
Dinner
6:30 PM

MAY 5, 2024

OPTIONAL

Tour of Tampa
9:00 AM - 12:00 PM

HOTEL

INFORMATION

Embassy Suites Hilton
Tampa Airport
Westshore Hotel
555 N. Westshore Blvd
Tampa, FL

*A special rate of \$169 plus
tax for a single or double
room is available.*

**SCAN TO LEARN
MORE AND REGISTER**



Celebrate 35 years of collaboration, innovation and community with Dysphonia International at our Anniversary Symposium. The meeting will take place in Tampa, FL, on Saturday, May 4, 2024. Be a part of a milestone event that brings together people living with vocal disorders with medical experts in the field of spasmodic dysphonia and related voice conditions.

Speakers include: Yassmeen Abdel-Aty, MD | Yael Bensoussan, MD | Candace Hrelec, MD
Darla Freeman-LeVay, CCC-SLP | Yolanda León, PsyD | Elijah Moothedan | Scott Norris, MD
Megan Urbano, CCC-SLP with more to be added!

What can you expect if you attend the 2024 Symposium?

- Meet new friends at the Welcome Party on Friday evening before the Symposium.
- Sign up for the Ambassador Program and have a "buddy" at the meeting.
- Hear from experts in the fields of laryngology and speech and language pathology.
- Have your questions answered during panel discussions with the medical presenters.
- Attend breakout sessions for more intimate exchanges with other attendees.
- Sign up for the 5th Walk for Talk and pick up the latest swag.
- Find fellowship, education, and fun!