DYSPHONIA INTERNATIONAL
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OUR VOICE

Newsletter of Dysphonia International

The Power of Connection and Collaboration

For individuals living with a voice disorder, communication is more than a way to speak—it's a connection to identity, relationships, and everyday life. When that communication becomes difficult, it can lead to isolation and frustration. That's why connection and collaboration are so vital: they help bridge the gap between the challenges of a voice disorder and the possibility of living a full, engaged life.

Why Connection Matters

Many in the Dysphonia International community shared how voice disorders have affected their ability to interact socially and professionally. "People have no idea what a voice disorder is and the impact it has on your activities of daily living and ability to communicate with others," said Lyndsey. Lisa added, "I used to love talking on the phone, but after my diagnosis, it became exhausting. I avoided calls and started feeling disconnected from friends and family."

Even in professional settings, connection can be a struggle. "In meetings, I felt like I was fading into the background because I couldn't jump into conversations as easily. I worried that people saw me as less competent," said David.

Yet, connection is also where healing begins. Karen shared, "The worst thing I did was pull away from people. When I finally started explaining my condition instead of hiding it, I found that most people wanted to help—they just didn't know how." Laurie added, "Connection is meaningful because it helps reduce loneliness, brings joy to be with my friends and my wife."

Support groups are often a turning point. "The support group sessions I have attended have been an eye-opener for me," said Jane. "Hearing how others cope... has been an amazing experience."

The Impact on Relationships and Daily Life

A voice disorder can reshape how we relate to others. Some withdraw from social settings entirely. "It's difficult to make new relationships when you can't speak. I rely more on my friends and family to speak for me," said Dianne.

continued on page 2

IN THIS ISSUE

6 Research Updates
8 Neuromodulation for Voice Disorders
12 Walk for Talk Highlights
15 Navigating Life with a Voice Disorder
16 Vocal Hygiene: Tips for Protecting Your Voice
18 2024 Symposium Summary

Scan to read more online

OUR VOICE

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.

The Power of Connection and Collaboration

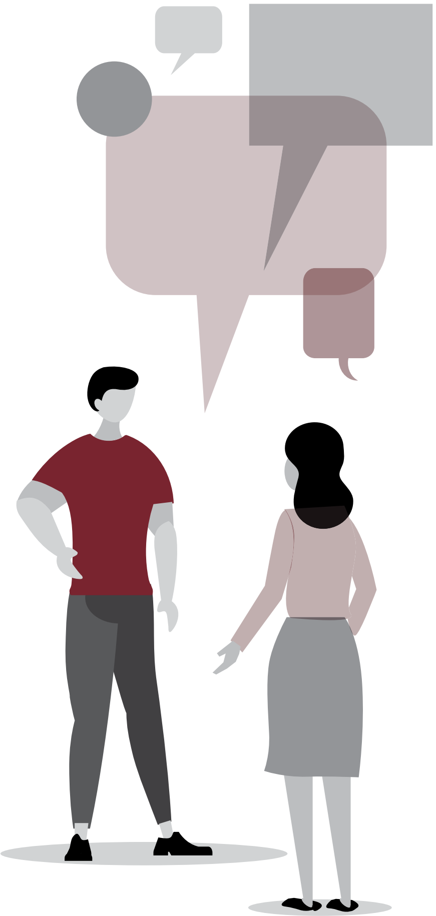
from page 1

Another person added, "I feel like people don't listen to me when I try to speak… I'd rather not go and isolate myself."

In the workplace, voice disorders can limit roles and change career paths. Michaela shared, "I've had to avoid speaking on the phone with my clients. I can't do interpreting or language teaching anymore." Beverly, who works in a high-stress job, said, "I can't overtalk those who speak louder… so I just don't bother."

Still, some have found workarounds. "I was a special education teacher… I could work one-on-one with children who were very accepting," said Pat.

Emotionally, the impact can be deep. "I can't act in shows anymore," said Marianne. "I spend so much more time being quiet and weighing when I can make a comment or if it is worth the effort." Kate reflected, "I do feel that my chances of ever finding a partner have lessened… because the voice is such an essential part of self-expression and identity."



Strategies for Staying Connected

Despite the challenges, many have found tools and strategies to maintain their social and emotional connections.

Technology helps. Laura said, "I use text messaging instead of making phone calls. Young people and many businesses actually prefer texting." Luis added, "I carry a tablet that allows me to write my ideas or messages and clear it easily with a button."

Amplification tools also make a difference. Rene shared, "I wear a microphone and a speaker at work. I take breaths before words." Mary noted, "I wear a headset with a microphone during Zoom meetings. It's less difficult for me to articulate my words."

Support groups are another vital tool. "Join a support group to find people who truly understand," said Stevie. Jean agreed, "The Zoom meetings are a lifeline."

Being open about the condition can reduce stigma. "I've gone from not explaining my spasmodic dysphonia to telling everyone," said Cheryl. "It's better they understand my treatment and the quality of my voice changing."

Others have embraced non-verbal communication. Laura shared, "Hosting art meet-ups has been therapeutic because we don't have to talk—we can speak through art." Writing, social media, and small gestures—like Abby raising her hand at work—also help individuals stay engaged.

The Role of Collaboration

Connection and collaboration go hand in hand. When people feel emotionally supported, they're more likely to advocate for their needs and find practical solutions.

Some, like Amanda, have had excellent experiences with care providers: "My healthcare professionals have been so wonderful... my primary care doctor listened to me when I said I was having trouble speaking, and I credit her with getting a diagnosis quickly." Eileen echoed that, saying her ENT and SLP take a collaborative approach, reviewing progress and planning treatment together.

Unfortunately, others face a harder path. Some drive hours to receive Botox® because there are no local providers. Laurie shared, "My speech therapist has been wonderful, but my insurance has stopped approving visits, and out-of-pocket expenses are too high."

Family and friends can be just as essential. "My husband was my voice when I didn't have one," said Sonja. Philip added, "My family and close friends are very supportive and listen to me when my voice is soft or having problems."

As many have learned, **collaboration provides the practical tools to move forward, while connection offers the emotional support needed to keep going**.

Advice for the Newly Diagnosed

From those who've been on the journey, here are a few words of wisdom:

"Find a support group, find medical professionals that can work with you and make you comfortable. Don't be afraid to drive to seek out treatment if needed."
– Cheryl

"It's surprising how kindly most people respond when you just explain you have a voice disorder."
– Kate

"Use a small mic and speaker so you can relax and not strain your voice."
– Marianne

"Know your limitations, your abilities, your work-arounds. Don't be a hermit—no matter how much effort and courage it requires."
– Kim

Your Voice Is Powerful—However It Sounds

A voice disorder may present significant challenges, but with connection and collaboration, you don't have to face them alone. Whether through support groups, compassionate professionals, adaptive strategies, or a strong circle of loved ones, there are many ways to stay engaged, advocate for yourself, and live fully.

As Mary put it, "People care less about the sound of your voice than you do. Explain your situation and ask them to listen carefully. Stand up for yourself, share the knowledge you have... and raise awareness about voice conditions."

Visit **dysphonia.org** to connect with others, share your story, and find support.

Quick Tips: Staying Connected & Collaborating with a Voice Disorder

✓ **Advocate for Yourself** – Explain your voice condition to colleagues, friends, and family to create understanding.

✓ **Use Technology to Stay Engaged** – Try text-to-speech apps, voice amplifiers, and video captions for easier communication.

✓ **Join a Support Group** – Connecting with others who understand your experience can provide emotional and practical support.

✓ **Educate Your Workplace** – Request accommodations like email communication options, quiet meeting spaces, or voice rest breaks.

✓ **Communicate Expectations to Loved Ones** – Let friends and family know how they can best support you, whether it's speaking more slowly, listening patiently, or adjusting conversations.

✓ **Find Alternative Ways to Express Yourself** – Writing, texting, and even non-verbal communication can help reduce vocal strain.

✓ **Work with Your Healthcare Team** – A speech-language pathologist (SLP) or ENT can help develop strategies to protect and strengthen your voice.

✓ **Give Yourself Grace** – Some days will be easier than others, but your voice—however it sounds—still has value!

✓ **Visit dysphonia.org to learn more** – Join a support group, attend virtual events, or help raise awareness! Visit Dysphonia International's website to learn more.

President's Message | Charlie Reavis

At Dysphonia International, we know that living with a voice disorder is not just about the physical challenges—it's about navigating a world that often doesn't understand the impact of losing one's voice. That's why connection and collaboration are at the heart of everything we do.

Our community is made up of people living with voice disorders, their family and friends, dedicated healthcare professionals, researchers striving for breakthroughs, and members of the general public who want to learn and support. Each person plays a crucial role in raising awareness, advancing research, and ensuring that no one faces these challenges alone.

When people with voice disorders share their stories, they educate and inspire. When family and friends offer encouragement, they reinforce resilience. When physicians and speech-language pathologists provide care, they change lives. When researchers push the boundaries of science, they bring us closer to new treatments. And when the broader public listens and learns, they become allies in our mission.

Collaboration fuels progress. By working together—across disciplines, experiences, and backgrounds—we amplify our impact. Whether it's through support groups, awareness efforts, research initiatives, or everyday conversations, our collective voice is stronger than any individual one.

At the forefront of this effort are researchers who are determined to uncover the causes of voice disorders and develop better treatments. Their work spans from understanding the neurological foundations of conditions like spasmodic dysphonia to testing innovative therapies, including neuromodulation and regenerative medicine. Every study and every discovery brings us closer to solutions that could restore voices and change lives.

The search for answers is ongoing, but with each breakthrough, hope grows stronger. Scientists' commitment, combined with the voices of those affected, drives forward the momentum needed to find a cure. By supporting research through participation, funding, and advocacy, we are investing in a future where voice disorders no longer hold people back.

Thank you for being part of this incredible network. Your involvement, in whatever way you contribute, matters. Let's continue to build connections, foster collaboration, and create a future where every voice is heard and valued.

With gratitude,
Charlie Reavis
President

BOARD/LEADERSHIP UPDATES

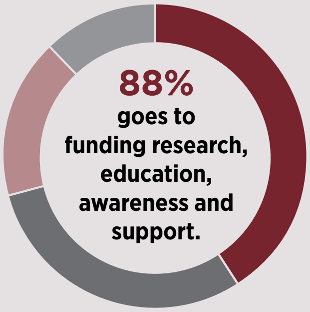
Sue Payne

We are excited to welcome Sue Payne to the Dysphonia International Board of Directors! Since being diagnosed with spasmodic dysphonia in 2017, Sue has been a dedicated advocate, playing a key role in Walk for Talk and serving as an Area Contact Leader in both Georgia and Florida. She is also an active member of the Development Committee, helping to increase the organization's financial support. Sue's passion for community, fundraising, and advocacy makes her a valuable addition to the Board.

Scott Flanagan

Scott Flanagan brings a unique voice to the Dysphonia International Board of Directors, combining his passion for quilting with his dedication to raising awareness for voice disorders. Since his spasmodic dysphonia diagnosis in 2017, he has turned his platform as a nationally recognized quilt designer into a powerful advocacy tool through his "Quilting Is My Voice" initiative and annual World Voice Day fundraisers. As an Area Contact Leader, Scott has contributed to support groups, guest speaker programs, and symposium discussions. His commitment to education and outreach will be a great asset to the organization.

FINANCIAL OVERVIEW



41% **RESEARCH** Seed grants, augmentative grant funding, research travel and conference awards, support for the Global Dystonia Registry and Brain Bank

30% **EDUCATION & AWARENESS** Educational and awareness programs, symposiums, medical conferences, advocacy, newsletter and website

17% **SUPPORT** Network of over 25 Support Groups and 75 Area Contact Leaders, virtual and in-person support meetings, and Leadership Workshops

12% **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 12% for these expenses.

Securing the Future: The Dysphonia International Legacy Society and the Power of Planned Giving

At Dysphonia International, our mission is to support individuals with voice disorders, advance research, and raise awareness to improve lives. But ensuring that this work continues for future generations requires long-term vision and commitment. That's where planned giving through our Legacy Society plays a crucial role.

Why Planned Giving Matters

Planned giving allows individuals to make a lasting impact beyond their lifetime, ensuring that the programs, research, and advocacy efforts of Dysphonia International continue to grow. Through bequests, beneficiary designations, and other estate planning tools, donors can support the organization in a way that aligns with their personal and financial goals while securing resources for future breakthroughs in voice disorder treatment and support.

By including Dysphonia International in your estate plans, you help sustain:

- **Groundbreaking Research** – Funding studies that explore new treatments and potential cures for voice disorders.
- **Support Networks** – Expanding resources for individuals living with voice conditions and their families.
- **Awareness Efforts** – Strengthening the voice of the dysphonia community to educate and raise awareness about the challenges of living with a vocal condition.

Introducing FreeWill: A Simple Tool for Estate Planning

We understand that estate planning can feel overwhelming, which is why we are excited to offer FreeWill, an easy-to-use online tool that simplifies the process. FreeWill allows you to:

- ✓ Create your own legally valid will for free in just 20 minutes.
- ✓ Designate Dysphonia International as a beneficiary if you choose.
- ✓ Notify us of your planned gift, allowing us to recognize your generosity and include you in the Legacy Society.

Even if you already have an estate plan, you can use FreeWill to document your intention to support Dysphonia International, ensuring that your legacy aligns with your commitment to improving the lives of those with voice disorders.

Join the Dysphonia International Legacy Society

When you make a planned gift, you become a member of the Dysphonia International Legacy Society, a group of dedicated supporters committed to making a lasting difference. Legacy Society members receive special recognition and updates on how their generosity will continue shaping the future of voice disorder research and support.

How to Get Started

If you're considering including Dysphonia International in your estate planning, we encourage you to explore FreeWill and take the first step toward securing your legacy. Whether you leave a bequest, designate a retirement account, or set up another planned gift, your generosity will ensure that the voices of those affected by dysphonia continue to be heard.

To learn more and begin your estate planning with FreeWill, visit our website at dysphonia.org. If you have already included Dysphonia International in your plans, we'd love to hear from you so we can express our gratitude and officially welcome you to the Legacy Society.

Together, we can create a future where every voice matters. Thank you for considering this meaningful way to make a lasting impact.

Honoring the Legacy of Kate Meyer

Dysphonia International is honored to recognize the life and legacy of Kate Meyer, a dedicated advocate for people with voice disorders who passed away in 2024, leaving a lasting gift to the organization as part of our Legacy Society.

Kate's commitment to the voice community began in the 1990s, when she was diagnosed with spasmodic dysphonia. At a time when resources and understanding were limited, Kate took it upon herself to start organizing support groups—not only as a way to navigate her own journey, but more importantly, to help others feel less alone. Her passion for connection and education quickly became a lifeline for many who were struggling with similar challenges.

Over the years, Kate remained deeply involved with Dysphonia International, always expressing immense gratitude for the diagnosis, treatment, and support she received. The organization was a central part of her life, and she never stopped advocating for awareness and community-building.

As part of her legacy, Kate generously designated funds from her estate to support the ongoing mission of Dysphonia International. These gifts, arriving through various means, will help ensure that others living with voice disorders can access the same support, resources, and hope that meant so much to her.

Kate's generosity and advocacy will continue to make a difference for years to come. We are deeply thankful for her contributions and honored to carry forward her vision of a stronger, more connected voice community.

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.

NEW GRANT FUNDED ON BRAIN NETWORK MAPPING

Daniel Corp, PhD
Deakin University,
Australia

Juho Joutsa, MD, PhD
University of Turku,
Finland

Dysphonia International has recently awarded a new grant for a project titled Lesion Network Mapping of Brain Circuits in Spasmodic Dysphonia. Led by primary investigators Dr. Daniel Corp and Dr. Juho Joutsa, this project will employ innovative neuroimaging techniques used to identify abnormal brain networks involved in movement disorders. Drs. Corp and Joutsa have previously used these methods in other types of dystonia and will now extend their research to focus on spasmodic dysphonia. They will also be collaborating with Dr. Scott Norris, who is using fMRI technology to study how different regions of the brain communicate in people with SD.

This research may also complement other ongoing projects funded by Dysphonia International, such as Dr. Teresa Kimberley's work on repetitive transcranial magnetic stimulation (rTMS) and Dr. Vincent Gracco's studies on transcranial direct current stimulation (tDCS) neuromodulation. Thanks to the support of our community, we can continue advancing research to find effective treatments for spasmodic dysphonia and related voice conditions.

ABOUT THE GRANT

Spasmodic dysphonia (SD) is believed to result from subtle alterations in the brain regions responsible for normal speech production. This research project will examine brain lesions—such as localized damage to brain structures from events like strokes—that cause neurological symptoms either immediately or shortly after the incident. By studying the location of these lesions and how they are connected throughout the brain, this team may be able to identify the specific brain regions involved in triggering particular neurological symptoms.

Dr. Corp and his team have already applied this technique, known as "lesion network mapping" (LNM), in other types of dystonia (Corp et al., 2019, 2022), and their findings have led to a clinical trial using brain stimulation to treat dystonia symptoms. This new project aims to apply LNM to SD by analyzing the location and connectivity of brain lesions thought to contribute to SD symptoms. If successful in identifying the relevant brain network in SD, this could lead to the development of testable targets for future brain stimulation trials, offering potential symptom relief for those affected by SD.

Update on DAXXIFY® Clinical Trial

Clark Rosen, MD

VyVy Young, MD

For many years, the primary treatment for spasmodic dysphonia has been regular injections of botulinum toxin type A (BoNT-A), which temporarily weakens the overactive muscles to improve voice symptoms. However, these treatments typically require re-administration every two-three months, prompting the exploration of longer-lasting alternatives.

DAXXIFY® (DaxibotulinumtoxinA-lanm), developed by Revance Therapeutics, is a novel botulinum toxin formulation recently approved by the FDA for the treatment of cervical dystonia and glabella lines in adults. Its unique peptide-based stabilization technology has demonstrated an extended duration of effect compared to traditional BoNT-A products.

A clinical trial led by Drs. Clark Rosen and VyVy Young at the UCSF Voice & Swallowing Center investigated the efficacy and safety of DAXXIFY® for individuals with adductor spasmodic dysphonia. This open-label study aimed to assess whether DAXXIFY® can provide longer-lasting symptom relief, potentially reducing the frequency of injections required for SD patients.

The trial began in October 2023 and has enrolled twenty-two participants. It is complete and the results will be presented at the annual meetings of the American Laryngological Association and the American Broncho-Esophagological Association in May 2025. Preliminary outcomes suggest that DAXXIFY® may offer an extended duration of symptom relief compared to traditional BoNT-A treatments, with some patients experiencing up to 50% longer intervals between necessary injections. No significant side effects were observed, and voice outcome following injection was similar to BoNT-A.

The potential of DAXXIFY® to prolong the therapeutic effects of botulinum toxin injections represents a significant advancement in the management of spasmodic dysphonia. By potentially reducing the frequency of treatments, patients may experience improved quality of life and decreased healthcare visits. As the study progresses, more comprehensive data will elucidate the long-term benefits and safety profile of DAXXIFY® for SD patients.

This study was funded in part by Dysphonia International, Revance and the Lewis F. Morrison, MD Endowed Chair at the UCSF Department of Otolaryngology-Head & Neck Surgery.

2024 Travel Scholarships and Awards Information

Dysphonia International supports voice research by funding travel and conference awards for professionals presenting on spasmodic dysphonia and related conditions. Administered by each hosting organization, these awards typically range from $250 to $1,000. In 2024, we funded 13 travel scholarships and two conference awards and partnered with two new European laryngology associations. This growing program strengthens ties with researchers and healthcare professionals, helping to keep voice disorders a priority in ongoing research.

2024 Award Organizations

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

Advancing Research Through Brain Donation

Phyllis Lachowyn

The brain holds the key to unlocking the mysteries behind disorders like spasmodic dysphonia. While advancements in imaging have significantly improved our ability to study the brain, the donation of brain tissue plays a crucial role in confirming and deepening our understanding of these conditions. This was especially important to Phyllis Lachowyn, who lived with spasmodic dysphonia. An active member of Dysphonia International in the Cleveland area, Phyl led a support group, helped plan an Eastern Regional Symposium, and participated in research studies.

As her health declined and she entered hospice, her family reached out to our organization, wanting to honor their mom's wish to donate her brain for research. We worked closely with her family and the Harvard Brain and Tissue Resource Center to ensure this happened. Phyl's family found comfort in knowing they could honor her desire to contribute to research. We are deeply grateful for her leadership and her selfless gift, which will help advance the understanding of spasmodic dysphonia. If you would like to learn more about being a brain donor, please contact Dysphonia International at **voice@dysphonia.org**

NEUROMODULATION FOR VOICE DISORDERS

Advancing Neuromodulation Research for Voice Disorders

Ongoing research is focused on mapping the brain and nerve pathways involved in voice control to develop more precise and effective treatments. Neuromodulation techniques, such as transcranial electric/magnetic stimulation (tCS, TMS), deep brain stimulation (DBS), and vibro-tactile stimulation (VTS), have the potential to personalize treatment based on an individual's unique neural patterns. These approaches are being currently investigated for their efficacy and safety in spasmodic dysphonia and other voice disorders, offering alternative therapies beyond Botox®. Dysphonia International is a key supporter of this research, funding critical studies to develop long-term solutions for those with SD, vocal tremor, and related voice conditions.

High-Density Transcranial Direct Current Stimulation (HD-tDCS)

High-Density Transcranial Direct Current Stimulation (HD-tDCS) is a non-invasive technique that delivers weak electrical currents to specific brain areas through a higher number of smaller electrodes arranged in a precise pattern. This method enhances the focality and intensity of brain stimulation compared to conventional tDCS.

How HD-tDCS Works

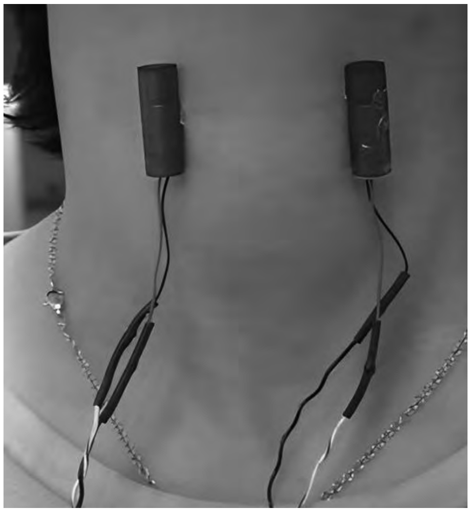
- Electrode Configuration: Unlike standard tDCS, which typically uses two large electrodes (anode and cathode), HD-tDCS uses multiple smaller electrodes arranged in a ring-like or grid pattern. This setup allows for:
  - More targeted stimulation of brain regions.
  - Greater control over current flow.
  - Less spread to unintended areas of the brain.
- Mechanism of Action:
  - A low-intensity direct current (1-2 mA) is applied to the scalp.
  - This modulates neuronal excitability by shifting the resting membrane potential:
    - Anodal Stimulation (Positive Electrode): Increases neuronal excitability (potentially enhancing function).
    - Cathodal Stimulation (Negative Electrode): Decreases neuronal excitability (potentially reducing excessive activity)

Potential for Voice Disorders

HD-tDCS is being investigated as a potential treatment for spasmodic dysphonia (SD), vocal tremor, and other dystonic voice disorders by modulating neural circuits involved in motor control and voice production. By targeting a network of regions responsible for speech production, HD-tDCS may help reduce involuntary spasms and enhance voice stability. Research on standard tDCS for speech rehabilitation has already demonstrated encouraging results, and the greater precision and focal stimulation of HD-tDCS suggests it could be an even more effective tool for improving vocal function in individuals with neurological voice disorders.

"As one of the patients enrolled in the initial study on HD-tDCS at Yale, I achieved a very positive result. Almost five weeks of normal speaking, with two treatments. I will be participating further in their research to accomplish even more of a positive outcome in April." – Craig

Vibro-Tactile Stimulation (VTS)



Vibro-Tactile Stimulation (VTS) is a non-invasive sensory stimulation technique that uses vibrations to activate mechanoreceptors in the skin, influencing neuromuscular function. This method is being explored as a potential therapy for spasmodic dysphonia (SD), vocal tremor, and other neurological voice disorders.

How VTS Works

- Small vibratory devices are placed on specific areas of the neck, throat, or other body parts.
- These devices deliver controlled vibrations at precise frequencies and amplitudes that stimulate receptors embedded in the skin and muscles.
- The stimulation affects sensory-motor pathways, potentially:
  - Modulating abnormal muscle activity in conditions like dystonia.
  - Reducing tremors or spasms by influencing neural circuits.
  - Enhancing voice stability and fluency.

Potential for Voice Disorders

Vibro-Tactile Stimulation (VTS) shows promise as a non-invasive neuromodulation technique for improving voice disorders by influencing sensory-motor pathways. In spasmodic dysphonia (SD), research has shown that VTS may help reduce voice breaks and improve vocal control by modulating the nerve signals from the vibrated skin and muscles, unlike Botox®, which temporarily blocks the transmission of nerve signals to the affected muscles. For individuals with vocal tremor, VTS has the potential to dampen involuntary voice oscillations by enhancing sensory feedback loops, helping to stabilize vocal output. Additionally, in Parkinson's disease-related speech disorders, VTS might contribute to enhancing speech clarity by improving muscle coordination, offering a potential therapeutic approach for managing speech difficulties associated with neurodegenerative conditions.

"While using VTS, I was less breathy and able to talk louder. When talking to a classroom, I was able to project without having to repeat myself. I was able to speak better for a few days." - Carol

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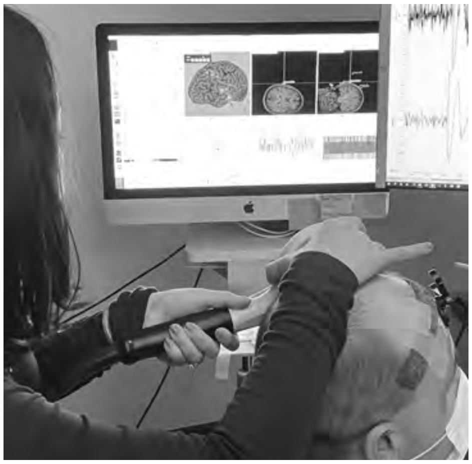
Transcranial Magnetic Stimulation (TMS)



Transcranial Magnetic Stimulation (TMS) is a non-invasive neuromodulation technique that uses electromagnetic fields to stimulate specific areas of the brain. It is widely used for neurological and psychiatric conditions and is now being explored as a potential treatment for voice and speech disorders like spasmodic dysphonia (SD), vocal tremor, and speech-related dystonias.

How TMS Works

- A coil placed on the scalp generates magnetic pulses.
- These pulses induce small electrical currents in targeted brain regions.
- The stimulation modifies neural activity, either:
  - **Increasing excitability** (for underactive areas).
  - **Decreasing excitability** (for overactive or dysfunctional pathways).

There are different types of TMS:

1. **Single-pulse TMS** – Used to measure a person's brain excitability.
2. **Repetitive TMS (rTMS)** – Multiple pulses to induce longer-lasting brain changes.
3. **Deep TMS (dTMS)** – Reaches deeper brain structures.

Potential for Voice Disorders

Transcranial Magnetic Stimulation (TMS) is being explored as a potential therapy for voice and speech disorders by targeting abnormal neural activity in the brain. It may also be useful in helping to differentiate between people with spasmodic dysphonia (SD) and those who have muscle tension dysphonia. In SD), where disrupted motor control affects vocal function, repetitive TMS (rTMS) may help modulate brain circuits, improving voice control. Research has investigated the effects of repetitive TMS on the primary motor cortex with some studies showing temporary voice improvements. For individuals with vocal tremor, rTMS is being studied for its ability to reduce involuntary muscle contractions that disrupt voice stability. In particular, rTMS over the cerebellum has been explored as a potential method for tremor suppression, offering a non-invasive approach to improving voice steadiness.

"I was excited about the opportunity to participate in the TMS study. The two sessions for this study (the scanning and the TMS) were fascinating. It's gratifying to see the efforts of talented neuroscientists to understand the complexity of this condition."
- Jane

continued on page 10

Deep Brain Stimulation (DBS)

Deep Brain Stimulation (DBS) is a neuromodulation therapy that involves implanting electrodes in specific areas of the brain to deliver controlled electrical impulses. These impulses regulate abnormal neural activity, making DBS an effective treatment for movement disorders and potentially for spasmodic dysphonia (SD) and other neurological voice conditions.

How DBS Works

- **Implantation of Electrodes** – Thin electrodes are surgically placed in targeted brain regions.
- **Pulse Generator (IPG)** – A battery-powered stimulator (similar to a pacemaker) is implanted under the chest or abdomen.
- **Continuous Electrical Stimulation** – The device delivers controlled electrical pulses, modifying abnormal brain signals.
- **Adjustable Settings** – Stimulation levels can be adjusted via an external programmer.

Potential for Voice Disorders

Deep Brain Stimulation (DBS) is being explored as a potential treatment for voice disorders by targeting abnormal motor control pathways in the brain. In spasmodic dysphonia (SD), where laryngeal function is disrupted due to dystonia-like neural dysfunction, DBS may help regulate motor signals. Research has focused on the globus pallidus internus (GPi) and subthalamic nucleus (STN), which are commonly targeted in dystonia treatments, with some patients reporting improvements in voice control following DBS. For individuals with vocal tremor, where essential tremor (ET) affects the larynx, DBS has shown promise in reducing symptoms. Specifically, stimulation of the thalamus (ventral intermediate nucleus, VIM) has been effective in reducing both hand and voice tremors, suggesting DBS as a potential therapeutic option for stabilizing vocal function.

> ***"I have tried the Botox® with no results. I have suffered from abductor spasmodic dysphonia and have been waiting for treatment for 30 years. I had the procedure done, and it has been amazing. I consider it a miracle and life changing."*** – Mark

Neuromodulation and Neuroplasticity in Voice Disorders

Neuromodulation and neuroplasticity are closely linked concepts in neuroscience. While neuromodulation refers to techniques that alter nerve activity using electrical, chemical, or mechanical stimuli, neuroplasticity is the brain's ability to reorganize and adapt by forming new neural connections. The goal of many neuromodulation therapies is to enhance neuroplasticity, helping the brain retrain dysfunctional pathways in conditions like spasmodic dysphonia (SD), vocal tremor, and other voice disorders.

What is Neuroplasticity?

Neuroplasticity, or brain plasticity, is the nervous system's ability to reorganize itself by forming new neural connections. It occurs throughout life, allowing the brain to:

- Recover from injury (e.g., stroke rehabilitation).
- Learn new skills (e.g., vocal therapy for dysphonia).
- Compensate for lost function (e.g., re-routing speech pathways in neurological disorders).

Neuroplasticity is experience-dependent, meaning it is influenced by stimulation, training, and therapy. This is why neuromodulation techniques aim to induce neuroplastic changes in conditions where neural circuits are dysfunctional.

How Neuromodulation Enhances Neuroplasticity

Neuromodulation can induce, accelerate, or guide neuroplasticity by:

1. **Stimulating Neural Pathways:** Electrical or magnetic stimulation strengthens underactive circuits.
2. **Suppressing Maladaptive Signals:** Reduces overactive brain regions responsible for tremors or dystonia.
3. **Enhancing Learning & Adaptation:** Works best when combined with voice therapy or speech training.

Examples of this include the use of Repetitive TMS (rTMS), which can strengthen voice-related brain pathways, while Vibro-Tactile Stimulation (VTS) may normalize sensory-motor feedback in the larynx.

Current Research Funded by Dysphonia International on Neuromodulation

High-density transcranial direct current stimulation (HD-tDCS)

Nabin Koirala, PhD *(left)*
and **Vincent Gracco, PhD**
Haskins Lab at Yale University, New Haven, CT

Vibro-Tactile Stimulation (VTS)

Jürgen Konczak, PhD
University of Minnesota, Minneapolis, MN

Transcranial Magnetic Stimulation (TMS)

Teresa Jacobson Kimberley, PhD, PT
MGH Institute of Health Professions, Boston, MA

Deep Brain Stimulation (DBS)

Christopher Honey, MD
University of British Columbia, Vancouver, BC

PERSONAL PROFILE | EILEEN MEEHAN

Eileen Meehan, an Ohio area Contact Leader, shared her voice journey, how she found a home at Dysphonia International, and how she continues to support our community.

My voice journey began three years ago, though it seems like yesterday, and at the same time a million years ago. At the time, I was a long-time early childhood special educator, constantly using my voice to sing, read aloud, and engage young learners. One of my primary hobbies was choral singing at my church, and I served as a cantor and occasional soloist. I come from a culture and heritage of storytelling. Growing up, telling a good story, holding the attention of the room, or even getting laughs meant you had arrived!

The first serious issue with my voice came during a stressful time when my husband was undergoing surgery as part of his cancer treatment. We were all masked, and I realized all the medical professionals were judging the breaks in my voice to be weeping. I hated that they misinterpreted my emotional state and tended to treat me like a child. It was demeaning but also got in the way of good communication.

For nearly a year, I blamed my voice issues on allergies, colds, or even COVID. I pushed forward, balancing work, family, and caregiving. Eventually, during a trip to the Shaw Theater Festival in Niagara-on-the-Lake, my voice noticeably worsened, frustrating conversations and making social interaction difficult. When I returned home, I finally made an appointment with an ENT, who diagnosed me with GERD. Two weeks of treatment helped my reflux—but my voice remained unchanged.

That's when I went to the Cleveland Clinic Voice Center. After a stroboscopy, the ENT asked what I thought was going on. I said, "spasmodic dysphonia," recalling a colleague with similar symptoms. He was surprised but agreed, and added "essential tremor" to the diagnosis. That same day, he recommended Dysphonia International as a resource.

In November 2022, I began receiving botulinum toxin injections every three months. We're still adjusting the dosage and placement, but targeting my false vocal cords seems most effective. We may have landed on the right dose.

After my diagnosis, I started using voice amplification at work. My young students adapted quickly, and my colleagues were understanding. But staff meetings, essential in special education, became nearly impossible to manage. I had to lean on my speech-language pathology colleagues to present findings. I also lost the ability to express emotion through my voice—particularly humor and sarcasm, which had helped ease classroom tensions.

The moment I knew it was time to retire came when a student imitated my voice—with its tremor and breaks—while working on vowel sounds. I couldn't risk their progress being compromised. Combined with my husband's medical needs and my own fatigue, I retired a year early.

From the moment I was diagnosed, Dysphonia International became an essential resource. It helped me understand my condition, and it gave my husband a way to support me. When we saw that the 2023 symposium was taking place in Detroit, we signed up immediately. It felt meant to be.

After the symposium, I volunteered to become an Area Contact Leader (ACL). I hoped to give back, but instead, I found myself supported and uplifted by fellow ACLs and Support Group Leaders. Our Ohio Dysphonia International group is small but mighty. I now share openly on social media about my diagnosis and the vital role Dysphonia International plays in my life. I've created resource cards for my otolaryngologist and SLP to share with others, and I know they're being used—after all, my doctor was the one who introduced me to the organization.

I'm proud to now serve on the Education Committee and have presented to graduate SLP classes at two universities. I even worked with a grad student on her thesis about the psychosocial effects of voice disorders and continue to help spread awareness through podcasting.

Radical acceptance of my new normal as an individual with a voice disorder involved, and continues to involve, helping others, however I can, in this community, this club, that no one wanted to be a member of. I hope to move forward with an attitude of continuous improvement, finding new and better ways of reaching affected individuals and supporting Dysphonia International's education, support and research programs.

Eileen being interviewed by Dr. Paul Bryson for the Head and Neck Innovations, a Cleveland Clinic Podcast.

Expanding Awareness Through Podcasts

Dysphonia International has launched a new podcast initiative to give a voice to individuals affected by voice disorders. Spearheaded by Area Contact Leader Eileen Meehan, this outreach effort connects members of the dysphonia community with various podcast platforms to share their experiences and raise awareness.

Eileen recently joined Dr. Paul Bryson on Cleveland Clinic's Head and Neck Innovations podcast, where she discussed her journey with spasmodic dysphonia and Dysphonia International's mission. Other collaborations include Speech Path Pod, hosted by Aiden Osborne, where Eileen and fellow guests shared personal stories and insights into living with a voice disorder.

Through these conversations, Dysphonia International continues to foster greater understanding, provide education, and amplify the voices of those navigating life with a voice condition.

2024 Highlights

2024 Total
$251,820
Including matching funds

In-Person Events
25 Events
Five new locations

Top Fundraiser
Risa Clay
Team New Jersey

Global Reach
Eight countries represented

Step Challenge
Six Participants
1,014,101 steps

Total since 2020
$1,226,980
Including matching funds

THANK YOU FOR YOUR AMAZING SUPPORT OVER THE PAST FIVE YEARS!

2024 Walk for Talk Snapshots

Special thanks to our 2024 Walk for Talk Sponsors

USC Caruso Department of Otolaryngology Head and Neck Surgery
USC Voice Center
WHISPP
STAVOLA
ONE OAK MEDICAL
CME ASSOCIATES
MAYO CLINIC
HOLMDEL ACUPUNCTURE & HERBAL MEDICINE CENTER
mazda / SCHWARTZ Family Owned And Operated Since 1919.
JASON'S DREAMS FOR KIDS
IOWA ENT CENTER PLLC
STARKEY, KELLY, KENNEALLY, CUNNINGHAM, TURNBACH & YANNONE COUNSELLORS AT LAW
voice solutions llc
Stage
PRODUCTION ACCESSORIES Co
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NJPI AGENCY
GREGORY ALESSI RE/MAX Synergy
LAKESHORE
JOHNSTONE SUPPLY
Frank Dittschar
NJ LEAF DISPENSING WELLNESS
ELEVATE PERSONAL TRAINING
TOAD BUSTERS WE AIN'T AFRAID OF NO TOADS
PITA WAY
EMORY VOICE CENTER
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Lighthouse Counseling & Sand Play Training Center, LLC
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NJ SPORTS SPINE WELLNESS
USF Health USF Tampa General Physicians
USF Health Voice Center
GRACE hair studio
VG VIN GOPAL CIVIC ASSOCIATION
Edward Jones SCOTT KEEN | CUMMING, GA
CaptionCall by Sorenson
K&M PRINTING

Walk for Talk

OCTOBER 16-19, 2025

Make Plans for the 6th Annual Walk for Talk

Since 2020, Walk for Talk has brought people together around the world to raise awareness and fund research for spasmodic dysphonia and related voice conditions. Now in its sixth year, the momentum continues to grow, with more in-person gatherings, global participation, and support from healthcare professionals, researchers, and amazing supporters like you.

Walk for Talk is for EVERYONE—everywhere.

It's free to participate, and you can take part however you like: walk, run, bike, paddle, golf, surf—anything goes! The goal is to raise awareness and show support for the voice community. The focus weekend will be October 16-19, but events take place throughout the whole month of October.

Here's how you can get involved:

- Go for a walk (or ride, or run) wearing Walk for Talk gear and post a pic with #WalkforTalk
- Participate in the Step Challenge or the Larry Kolasa Memorial 5K
- Organize a local event *(we can help!)*
- Share your story in a video and tell the world how a voice disorder has impacted your life
- Start a fundraiser and help us hit our $100,000 goal for 2025

Let's walk, talk, and make a difference together!

Every Step Gets Us Closer to a Cure

SPASMODIC DYSPHONIA AND RELATED VOICE DISORDERS

Lace up your shoes and let's get walking!
Scan the QR code find out what it's all about and how you can get involved!

2024 EVENT LOCATIONS

Birmingham, AL
Scottsdale, AZ
Chico, CA
Playa Vista, CA
Redwood City, CA*
Fort Myers, FL*
St. Petersburg, FL
Decatur, GA
Pleasant Hill, IA
Kansas City, KS*
Shreveport, LA
Troy, MI
St. Paul, MN
Matthews, NC
Tinton Falls, NJ
Allison Park, PA
Greenville, SC
Louisville, TN
Chota Hills, TN
Austin, TX
Huntsville, TX
Salt Lake City, UT
Seattle, WA*
Bala, ON, Canada
London, England, UK*

**New location for 2024*

2024 WALK FOR TALK PLANNING COMMITTEE

Mary Bifaro, *Chair*
Risa Clay
Dennis Kaszeta
Cathleen McCulloch
Ron Langdon
Sue Payne
Esther Zack

Support And Hope Halfway Around The World

From left, Winifred Wanjiru Ndung'u, Esther Wairimu Ndung'u, Judy Rodwell, Robert Rodwell, and Solomon Njunji Mbuthia

When Esther stumbled upon the Alabama Dysphonia Support Group's virtual meeting link, she wasn't sure what to expect. Since her diagnosis of spasmodic dysphonia fifteen years ago, she had been searching for a sense of connection. Even though the group was halfway across the world, Esther decided to join. Little did she know that a surprising coincidence was about to unfold. On the call, Esther shared that she was from Nairobi, Kenya, and Judy, the Support Group Leader, blurted out, "Why Esther, I'll be in Nairobi in a week. Can we meet?" Everyone on the call was stunned.

When the day finally arrived, they met for lunch. Esther's sister and brother-in-law also joined the gathering, along with Judy's husband. During the visit, Judy shared materials from Dysphonia International. Esther presented Judy and her husband with custom-made blankets, each embroidered with their names and the word "Welcome" in Swahili. Their connection, formed over a screen, blossomed into shared understanding and mutual support. Judy said, "Esther has reminded me of how lucky we are to have such wonderful doctors in the United States and to have Dysphonia International helping us on our journey. Bound by hope, we shore each other up."

Their meeting became more than just a coincidence; it was a symbol of what support groups stand for—building bridges across distances and fostering a sense of community. Esther and Judy left their meeting inspired, knowing they were part of something far greater than themselves.

Running for Research

On April 15, 2024, Bill Slaney completed the Boston Marathon, running not only for the challenge but to raise awareness and funds for Dysphonia International. For Bill, this run was deeply personal. He shared, "For those who have spoken to me over the past 30 years, you know, at times, I struggle to speak in my normal voice. As many of you also know, I don't do anything halfway. So, I'll run the Boston Marathon for the first and probably last time. Hopefully, someday, this will lead to a cure, and I can find my old voice."

Not only did Bill finish the race strong, he raised over $2,000, sharing, "I was able to finish my fourth marathon—not a record, but a good time for a warm day. I actually felt good the whole way and posted some of my best mile times on the last stretch into the city. Thank you to all my supporters who were able to donate and post words of encouragement!" I was able to finish the marathon and raise some money and awareness for Dysphonia International.

Bill, your dedication to raising awareness for spasmodic dysphonia and supporting ongoing research is truly inspiring. Thank you for your passion, your perseverance, and your years of commitment to our community.

Bill Slaney

Classic Brass: A Decade of Music and Giving for Dysphonia International

From left, Janet Olsen, Steve Williams, and Tony Boldt, Ellington Starks and Warren Bandel

For the past decade, Warren Bandel has turned his passion for the trumpet into a way of raising both research funds and awareness for spasmodic dysphonia. He and the Classic Brass Quintet have hosted 17 benefit concerts in Rochester, MN (8); Sun Prairie, WI (6); and Mankato (3), raising over $33,000 to benefit Dysphonia International.

Classic Brass, founded by Warren in 1992, includes longtime friends and musicians: Ellington Starks (Horn), Janet Olsen (Trumpet), Steve Williams (Trombone), and Tony Boldt (Tuba). Warren and Steve have been friends since junior high school, and the two, along with Ellington, have been performing together since 2000. Tony joined in 2011, and Janet is the newest member, having joined nine years later.

Their next benefit concert will be held this September in Sun Prairie, WI, hosted by Warren's sister, Diane Padrutt. This annual event continues to uplift and inspire. We are grateful to Warren and Classic Brass for their continued support. Through music, they are giving a voice to those who struggle to be heard.

NAVIGATING LIFE
with a Voice Disorder

For many people, communication is effortless—an exchange of words, ideas, and emotions. But for those living with a voice disorder, even simple conversations can be physically exhausting, frustrating, or anxiety-inducing. Whether at work, in social settings, or even with family, challenges like being misunderstood, struggling to project your voice, or facing stigma can create barriers to connection. However, with the right strategies and support, you can maintain meaningful relationships and thrive in both personal and professional settings.

1. Workplace Communication: Advocating for Yourself

A voice disorder can present unique challenges in the workplace, but there are ways to ensure your voice is heard—both literally and figuratively.

- **Be upfront about your needs**: If your job requires frequent speaking, consider having a conversation with your employer about accommodations, such as voice amplification tools, flexible meeting formats, or the ability to respond via email instead of phone calls.
- **Use assistive technology**: Text-to-speech apps, email communication, or even AI-generated voice assistance can help reduce strain.
- **Conserve your voice wisely**: Take breaks when needed, hydrate frequently, and practice vocal relaxation techniques to prevent fatigue.

2. Social Settings: Breaking Down Barriers

Maintaining an active social life with a voice disorder may require adjustments, but it's possible to stay engaged without straining your voice.

- **Set expectations with friends and family**: Let them know about your condition so they can be patient and supportive. Educating loved ones can reduce misunderstandings.
- **Choose voice-friendly environments**: Loud restaurants or crowded events can be challenging. Opt for quieter settings where you can communicate more comfortably.
- **Leverage alternative communication methods**: Texting, writing notes, or using speech-to-text tools can help in situations where speaking is difficult.

3. Dealing with Family and Friends

Navigating relationships with loved ones can be one of the most complex aspects of living with a voice disorder. Family and close friends may not always understand the daily challenges you face, but clear communication and patience can help strengthen these relationships.

- **Educate them about your condition**: Many people have never heard of spasmodic dysphonia or other voice disorders. Share resources, explain the nature of your condition, and let them know what support looks like for you.
- **Encourage active listening**: Sometimes, others may unintentionally speak over you or finish your sentences. Gently remind them that while it may take you longer to speak, you still want to be heard.
- **Set boundaries for voice conservation**: If you need to rest your voice, let your loved ones know that you're not ignoring them but simply taking care of yourself. Suggest alternative ways to communicate, like texting or using a voice amplifier.
- **Ask for patience, not pity**: Your voice disorder does not define you, and it's okay to let others know that you appreciate support but don't want to be treated differently.

4. Building Confidence and Managing Reactions

A voice disorder can sometimes lead to self-consciousness or anxiety in social interactions, but you can empower yourself by:

- **Owning your voice**: Confidence can make a big difference in how others perceive and respond to you. If you need to repeat yourself, do so without hesitation.
- **Handling reactions with grace**: Some people may not be familiar with voice disorders and may react with confusion. A simple explanation—"I have a neurological voice condition that affects my speech, but I can communicate just fine"—can ease discomfort.
- **Finding support**: Connecting with others who understand your experience, whether through support groups or online communities, can provide encouragement and useful strategies.

5. Embracing Different Forms of Expression

Communication isn't just about spoken words—gestures, writing, and even creative outlets like music or art can be powerful ways to express yourself. Finding new ways to connect can be empowering and fulfilling.

You Are More Than Your Voice

Having a voice disorder does not define you or your ability to connect with others. With the right tools, strategies, and support, you can continue to foster meaningful relationships, excel professionally, and live a full and connected life.

For more resources and support, visit Dysphonia International's website at **dysphonia.org** and connect with our community.

Your Personal Communication Checklist

Use this checklist as a starting point to create a support system that works for you—whether you're newly diagnosed or further along your journey. Customize it to suit your needs, and revisit it as those needs change.

Work Accommodations

- ☐ Voice amplifier or microphone
- ☐ Email or text-based communication preference
- ☐ Adjusted speaking schedule (meetings, calls)
- ☐ Use captions or transcription tools for meetings

Social Strategies

- ☐ Choose quiet environments
- ☐ Inform close friends about your condition
- ☐ Use assistive communication apps when needed

Family & Friends

- ☐ Share resources about your voice disorder
- ☐ Set expectations for voice conservation
- ☐ Ask for patience, not pity

Boosting Confidence

- ☐ Prepare a short explanation of your condition for new interactions
- ☐ Join a support group or online community
- ☐ Practice self-care and vocal rest

Technology & Tools

- ☐ Explore text-to-speech apps
- ☐ Try voice amplification devices
- ☐ Use written notes or digital messaging as backup

VOCAL HYGIENE:
Essential Tips for Protecting Your Voice

Just as we take care of our physical health through exercise and nutrition, we must also protect our voice to prevent strain, reduce irritation, and support overall vocal function. Whether you have laryngeal dystonia (aka spasmodic dysphonia), vocal tremor, muscle tension dysphonia, vocal fold paralysis, or another voice condition, small daily habits can make a big difference in preserving your vocal quality and comfort. Vocal hygiene refers to practices that help maintain a healthy voice and prevent additional strain or damage to the vocal folds. While it won't cure a voice disorder, vocal hygiene can help manage symptoms and improve vocal efficiency. Here's an overview of essential vocal hygiene practices that everyone should incorporate into their routine to protect their voice.

❶ Stay Hydrated

One of the most important aspects of vocal hygiene is hydration. The vocal folds rely on moisture to vibrate efficiently, and when the body is dehydrated, the mucus lining of the vocal cords can dry out, making them more vulnerable to irritation and increasing voice effort. Aim to drink at least 8 glasses of water (or non-caffeinated drinks) a day, including water-rich foods.

TIP: When you drink water, it does not touch the vocal folds directly (otherwise you would choke!), so using a form of topical hydration, such as a room humidifier, a portable steam inhaler, or a portable handheld nebulizer with 0.9% isotonic saline solution, can help maintain optimal hydration, particularly in dry environments or if you're speaking or singing for extended periods.

❷ Warm Up and Cool Down Your Voice

Just like any other muscle in the body, your voice benefits from warm-up exercises before heavy use. Whether you're singing, giving a speech, or engaging in any activity that requires significant vocal effort, warming up your voice helps prepare it for activity and reduces the risk of strain.

TIP: Simple humming or gentle sirens (sliding from low to high notes and vice versa) are great ways to warm up the vocal cords. After heavy use, a gentle cool-down session is equally important to help your vocal folds relax and recover.

❸ Practice Proper Breathing Techniques

Proper breathing is the foundation of a healthy voice. Breathing with good lower rib cage expansion, rather than shallow chest breathing, helps provide more support for the voice, preventing unnecessary strain on the vocal folds.

TIP: Practice relaxed, abdominally focused breathing, where your abdomen expands as you inhale and contracts as you exhale, to build strength and support for your voice. You can optimize your breathing pattern by working with a speech-language pathologist.

4 Avoid Excessive Throat Clearing

Throat clearing can be a natural reaction to the sensation of mucus or discomfort, but it can be damaging to the vocal folds over time. The act of the vocal folds harshly rubbing together during throat clearing can lead to irritation of the vocal fold tissue.

TIP: If you feel the urge to clear your throat, try sipping water or swallowing instead. If you're still having issues, consider consulting a speech-language pathologist (SLP) for strategies to minimize throat clearing.

5 Reduce Vocal Strain

When you have a voice disorder, reducing vocal strain is essential to maintain vocal function and minimize discomfort. Strategies such as speaking in a relaxed manner, using shorter phrases, and incorporating pauses can help reduce effort and tension.

TIP: To relieve muscle tension, try relaxation exercises, such as neck, tongue, and jaw stretches and massage.

6 Practice Moderation in Consumption

Smoking or vaping can irritate the vocal folds and cause chronic inflammation. While some individuals with voice disorders may find that alcohol temporarily eases vocal spasms, excessive consumption can lead to dehydration, including the vocal folds. Both habits can have long-term consequences for 'both vocal health and general health.

TIP: Prioritize vocal-friendly habits by choosing alternatives that support your voice health. If you're looking for ways to relax or manage vocal spasms, consider hydration, vocal rest, or gentle breathing exercises instead of relying on substances that may cause long-term harm.

7 Mind your Posture

Maintaining good posture helps optimize breath support and vocal function. Slouching or hunching can restrict airflow and limit diaphragm movement, increasing strain on the voice. Standing or sitting upright allows for better breath control and reduces vocal fatigue.

TIP: When speaking or singing, keep your body aligned, with your shoulders back and head held in a comfortable neutral position. This allows for proper airflow and reduces tension in the throat.

8 Use a Microphone when needed

If you need to speak in a large space or a noisy environment, use a microphone or personal voice amplifier to reduce strain on your voice. Forcing your voice to project over background noise can lead to vocal fatigue.

TIP: Invest in a quality microphone so you don't have to strain to be heard.

9 Consult a Professional

An otolaryngologist (ENT - ear, nose, and throat doctor) or a speech-language pathologist (SLP) specializing in voice can help assess your vocal health and provide personalized advice.

TIP: An SLP can share voice therapy techniques that help you use your voice efficiently while minimizing strain, including (but not limited to) resonant voice therapy, vocal function exercises, and manual therapy for muscle tension.

10 Be Mindful

A voice disorder can be emotionally challenging, leading to stress, anxiety, or frustration. Managing mental health can improve overall well-being and reduce overall throat tension. Engaging in stress management techniques like meditation or deep breathing may also help.

TIP: Join a virtual or in-person Dysphonia International support group and meet others who understand the challenges of living with a voice disorder for encouragement and shared experiences.

Conclusion

A voice disorder doesn't have to limit you, but it does require thoughtful care. By practicing good vocal hygiene, you can reduce strain, improve vocal efficiency, and maintain better voice function over time. Small daily changes can lead to greater comfort, confidence, and control over your communication.

For more tips and resources, visit Dysphonia International's website at **dysphonia.org** and connect with our support network community.

Plan to Attend the 2025 Symposium ▶

Join us for the 2025 Dysphonia International Symposium on Saturday, May 3, in Phoenix, AZ. This special event offers a unique opportunity for individuals living with vocal disorders, their families, and voice professionals to connect, learn, and share insights. Through expert-led presentations, interactive discussions, and community support, attendees will gain valuable knowledge about spasmodic dysphonia and related voice conditions.

Speakers include Larry Bergstrom, MD | Gerald S. Berke, MD | Sara Charney, CCC-SLP | Sara Davis, CCC-SLP
Stacy Holyfield, CCC-SLP | Adam Kravietz, MD | Meredith Levy, CCC-SLP | David G. Lott, MD
Manikandan Sugumaran, MD | Melissa Zheng, MD

Whether you are seeking the latest research, treatment options, or a supportive network, this symposium is designed to empower and inform. Connect with others who share similar experiences, and feel understood in a welcoming environment where no one questions your voice. We hope you will join us!

May 3, 2025

Embassy Suites by Hilton
Phoenix Biltmore
2630 E Camelback Road
Phoenix, AZ 85016

Scan to learn more!

2024 Dysphonia International SYMPOSIUM OVERVIEW

The 35th-anniversary celebration kicked off at our annual meetings in Tampa, FL, from May 3-4, 2024. The agenda was packed with significant events, including the annual Board of Directors meeting, the 20th Leadership Workshop of our Support Network, and the Symposium.

The weekend drew close to 75 participants and was filled with educational, informative, and enjoyable activities. Tampa Support Group Co-Leaders Ron Langdon and James Anderson hosted the event, extending a warm welcome to all attendees. The Ambassador Program was particularly beneficial for first-time attendees, pairing them with experienced "buddies" from previous meetings to foster a sense of connection. Friday evening featured a Welcome Party, where attendees had the chance to forge new friendships and reconnect with old ones. During the "pass the mic" session, participants introduced themselves and shared their voice experiences. For many, it was a powerful and emotional first encounter with others who share similar voice conditions.

Saturday was packed with activities from morning to evening. The speakers at our Symposium delivered their talks in a clear, understanding, and supportive manner. All presentations were recorded and are available for viewing. Additionally, breakout sessions offered attendees the chance to connect in smaller groups. We also hosted exhibitors from Whispp and Sorenson Communications, who offered various tools and solutions to enhance communication. Eastern Regional Coordinator Carol Doles gathered a range of technologies for participants to test and evaluate, along with resource materials.

That evening, we hosted an optional dinner, followed by a bus tour of Tampa on Sunday. The atmosphere was filled with a sense of family, friendship, and camaraderie—it was truly delightful. We extend our thanks to everyone who presented and all who attended. Mark your calendars for our next meeting in Phoenix on May 2-3, 2025. We look forward to seeing you there!

PLEASE NOTE: The videos from the Symposium are available to view on YouTube at https://www.youtube.com/@dysphonia-international

Welcome and Overview of Dysphonia International

Charlie Reavis

Charlie has served as President since 2010. He stated that over $500,000 in research funding has been distributed in the past four years. Approximately 86% of our budget goes to funding research, education & 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, as well as 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.

Understanding Voice and Speech

Darla Freeman, SLPD, CCC-SLP

Megan Urbano, CCC-SLP was not able to attend because of illness. Dr. Freeman presented her slides in her absence. She discussed the three subsystems of voice production: respiratory, phonation, resonance. Their interaction is not linear but is complex and dynamic. SD and related voice conditions can coexist with other diagnoses. The role of the speech-language pathologist is to develop treatment approaches. They often collaborate with laryngologists and neurologists on voice care. ASHA (American Speech-Language-Hearing Association) is the national professional and credentialing association for its members, which include speech-language pathologists.

Evaluating and Treating Voice Disorders: Role of the Speech-Language Pathologist

Darla Freeman, SLPD, CCC-SLP

Dr. Freeman mentioned that social communication is something we do from birth to death. Speech Language Pathologists look at receptive and expressive language. They examine breathing and swallowing. One of the goals in treating voice disorders is to help the patient make individual choices with their voice. Voice and speech are intertwined. Education is key to voice therapy. Speech-Language Pathologists look, listen, and review objective data. Patients give a history and take a Voice Handicap Index evaluation. There are many techniques used, including bubble exercises, lip and tongue trills, warm-up, and cool-down exercises in a holistic approach.

Botulinum Toxin Injections for the Treatment of Voice Disorders

Yassmeen Abdel-Aty, MD

Dr. Abdel-Aty has an academic philosophy centered on the integration of education, patient care, and research. She stated that botulinum neurotoxin is used to treat SD (laryngeal dystonia), tremor, and MTD (muscle tension dysphonia). They are neurological, intention-induced, and disorders of the central motor processing. About 80% of SD patients have adductor SD with strangled breaks from closing vocal cords. 20% of SD patients have abductor SD with open breathy voice breaks. Often, Botox® injections are given with EMG (electromyography) guidance which measures muscle response or electrical activity in response to a nerve's stimulation of the muscle.

A Discussion on Challenges and Successes in Laryngology

Yaël Bensoussan, MD, MSc, FRCSC

Dr. Bensoussan completed a fellowship in laryngology. Her background includes a degree in Speech Pathology and a prior career in music. This led to her passion for voice and laryngeal disorders. She believes in multidisciplinary care. Dr. Bensoussan is a co-principal investigator of the Bridge2AI grant, a multi-institution project to integrate the use of voice as a biomarker of health in clinical care. It is funded by the National Institutes of Health (NIH). Since she is passionate about optimizing the efficiency of health systems and care algorithms, she is building bridges to integrate technology to optimize the quality of care provided to her patients. Some of the comments made by Dr. Bensoussan include: 'It is important to get a second opinion. With MTD, clinicians try to teach muscles how to function behaviorally. Laryngeal Dystonia (SD) is a rare disorder. The voice is the most difficult instrument to play. Tweaking Botox® dosages can take years; Botox® forces the muscles to relax. There is often a lack of humility on the part of the clinician. We need to use our voice to advocate and make change.'

Dysphonia in the Digital Age

Elijah Moothedan, MS

Elijah is a research assistant to Dr. Bensoussan, contributing to various projects at the USF Health Voice Center. This includes the Dysphonia International funded initiative of the same name. He stated that nearly 1/3 of the population is impacted by an issue with dysphonia. Voice disorders can lead to a reduced quality of life, social isolation, depression, and other psychosocial issues. Technology is evolving to help with communication barriers and raise awareness about voice disorders: talk to text, ASR (automatic speech recognition) products, voice assessment tools, and computerized speech labs.

Empowering Voices: Deciphering Relevant Brain Network in Spasmodic Dysphonia Research

Scott Norris, MD

Dr. Norris is a dedicated clinician, researcher, and educator. He uses advanced neuroimaging techniques to explore the connections between brain dysfunction and movement disorders, including SD. Dr. Norris serves on the Scientific Advisory Board for Dysphonia International. He referred to the excellent article on the role of altered brain pathways in the most recent issue of "Our Voice". He praised the exponential growth of voice research and the seed funding that Dysphonia International continues to provide, and applauds patient advocacy efforts. Dr. Norris commented that SD reflects brain dysfunction and stated that voice disorders are spectrum disorders involving the cerebellum and basal ganglia areas of the brain. He applauded the opportunity to set up a brain donation after death which allows researchers to have a better understanding of what happens in the brain.

Neuropsychological Considerations in Dysphonia: Identity, Adaptive Coping, and Family Systems Dynamics

Yolanda C. Leon, PsyD, ABPdN and
K. Brianalysse Nicolena Cedeño, BA

Dr. Leon is a clinical and forensic neuropsychologist. Ms. Cedeno is a psychometrist in clinical and forensic

continued on page 20

Linda Fetters, Sue Payne and Carrie Darlington

Tanja Turner Bell and Antoine Bell

James Anderson, Darla Freeman, and Ron Langdon neuropsychology. These colleagues discussed the impact of neurological disorders on family systems dynamics and other neuropsychological manifestations. The ability to adapt is critical. There is a three-step communication skill with the acronym, BEN. B is your behavior regarding the voice disorder; E is your emotional response to it; N is what do you need or want from others to cope. Cognitive behavior therapy sessions may help. We need to develop a strong support network of family and friends.

Spotlight on Communication Devices

Sorenson is a leading language service provider specializing in communication for deaf and hard-of-hearing individuals. They are now investigating the challenges faced by people with voice or speech disorders. They want to find out how their services could support during phone conversations. They want to connect with individuals who might benefit from using a communication assistant while making calls. https://sorenson.com/

Whispp is an app that uses real-time assistive voice technology for people with a voice disability. Its language-independent AI technology and calling app convert whispered speech and vocal cord-impaired speech into a clear and natural voice of your choice without any delay. Users can recreate their own personal voice by submitting recordings of their healthy voice. They can choose one of the preset voices. https://whispp.com/

Eastern Regional Representative, Carol Doles, has researched and resourced communication tools that might be helpful to people living with a voice disorder. She has curated a lot of information on various options with a list of key considerations. In Tampa for our 2024 Symposium, she gathered a range of technologies for participants to test and evaluate.

Roundtable Discussions

Two separate breakout sessions, with preset questions and discussions led by our support network volunteer leaders, provided symposium attendees with an opportunity to share their thoughts about their dysphonia journeys. The Living with a Voice Condition session was facilitated by James Anderson, Mary Bifaro, Jan Lant, Jean McMahon, Denny Richey and Marcia Sterling. The Family and Friends session was facilitated by Warren Bandel and Patrick Bifaro.

Walk for Talk: Honoring the First Step

with Kimberly Kuman and Mary Bifaro

Executive Director, Kimberly Kuman, shared her vision in creating the annual Walk for Talk to raise funds for research, expand awareness, and unite people across the globe. Planning Committee Chair, Mary Bifaro, talked about the excitement and empowerment that individuals and groups felt in making a difference and participating. Every step gets us closer to a cure! This October event has embodied our collective commitment to making a lasting impact. In the past four years, Walk for Talk has raised close to half a million dollars. With the match, we reached one million dollars! We are already making plans for the Fifth Annual Walk for Talk to take place from October 17-20, 2025.

In recognition of their work on the Planning Committee of previous Walk for Talk events, the following members were given the "First Step Award" for their outstanding leadership in developing Walk for Talk, which has empowered our community to step forward together to raise awareness and find a cure for spasmodic dysphonia and related voice conditions: Mary Bifaro, James Anderson, Dennis Kaszeta, Sue Payne, Ron Langdon, Vicki Orazem, Laura Rahuba, Denny Richey, and Esther Zack. Kim was also honored for her leadership in Walk for Talk and was presented the Trailblazer Award.

Final Thoughts

The three pillars of Dysphonia International are: Research, Education & 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. Our educational webinar series has been well received. Our annual Walk for Talk events in October have generated tremendous excitement and have become our primary fundraising and awareness-raising campaign.

Overall, our symposium offered a great opportunity to meet old friends and make new ones. With great enthusiasm, it was announced that our 2025 Dysphonia International Symposium will take place on May 2-3, in Phoenix, Arizona.

President Charlie Reavis

Symposium participants

Carol and Roger Doles

Leadership Workshop Participants

Lara Bruce and Tyler Kropf

Roundtable Discussion

Akash Raj Komarlu and Joris Castermans

Honey Shara and Toni Gold

Yolanda Leon and K. Brianalysse Nicolena Cedeño

Darla Freeman, Yassmeen Abdel-Aty, Yaël Bensoussan, Elijah Moothedan, Scott Norris, and Joris Castermans

World Voice Day, observed annually on April 16, is a global event dedicated to recognizing the significance of vocal health and raising awareness about voice-related issues. In 2024, the theme "RESONATE. EDUCATE. CELEBRATE!" encapsulated the day's mission to promote vocal health, expression, and communication.

Dysphonia International spearheaded a variety of initiatives to engage the community and amplify the significance of voice. One standout activity was the "Write a Haiku" campaign, inviting individuals to craft haikus inspired by the theme. This initiative not only encouraged creativity but also provided a meaningful platform for participants to share their experiences with voice disorders.

Beyond this, Dysphonia International leveraged social media to spread awareness, using the hashtag #WVD to share personal stories, educational content, and event updates—fostering a global, supportive community. Additional efforts included organizing marathon runs to raise awareness, securing municipal proclamations recognizing World Voice Day, sharing powerful personal journeys through podcasts, and speaking engagements with various groups to advocate for vocal health.

The participation in 2024 World Voice Day exemplified a collective effort to resonate, educate, and celebrate the human voice, reinforcing the significance of vocal health and the need for continued advocacy and awareness.

Looking ahead to World Voice Day 2025, we invite you to join us in continuing this important mission. The theme, "Empower Your Voice!", encourages individuals to embrace their voices, advocate for vocal health, and share their unique experiences.

A Year of Impact: Highlights from Our Guest Speaker Presentations

This past year has been nothing short of incredible for our Guest Speaker Program! Through this program we have connected the personal experience of living with a voice disorder to educational settings, reaching students, professionals, and community members alike. The program aims to enhance understanding of the challenges faced by individuals with voice conditions, equip future healthcare professionals with the tools to offer compassionate support, and raise awareness of vocal disorders to improve diagnosis times and facilitate early intervention. Last year, we reached over 750 speech-language pathology (SLP) students across 22 presentations, spreading awareness and education about voice disorders. Our speakers engaged with students, professionals, and community members across the country and even internationally, in London, Ontario, Canada. From classrooms to student groups, each presentation sparked conversations, deepened understanding, and empowered individuals with knowledge about voice disorders. Thank you to our incredible speakers and attendees for making this year such a success! We can't wait to see what next year brings!

Rod Carter with California State University, Chico SLP students

Support Group Highlights

At Dysphonia International, our support groups are the heart of our mission, fostering connection, education, and empowerment for those affected by voice disorders. This year, we introduced a new and exciting connection opportunity—virtual support meetings led by Area Contact Leaders. These gatherings offered a welcoming space for open discussion, where participants could share their experiences, challenges, and triumphs. In total, we hosted three Area Contact Leader-led support meetings, including our inaugural meeting in the UK, creating an invaluable space for global connection and support. Many groups welcomed guest speakers who offered expert insights on voice disorders and research.

Virtual meetings expanded accessibility, while themed discussions and social meetups strengthened community bonds. A special thank you to our dedicated volunteer leaders who continue to lead and grow these groups, ensuring no one feels alone. As we look ahead, we remain committed to expanding our support opportunities by building a strong and supportive community for all those affected by voice disorders. We hope you'll be able to join us to connect, share, and find strength in a supportive community.

COLLABORATION AT MEDICAL CONFERENCES:
Advancing Voice Disorder Awareness

In 2024, Dysphonia International continued to champion awareness and collaboration by engaging in several medical conferences. These gatherings proved essential in advancing conversations about voice disorders, providing opportunities for knowledge exchange, and facilitating connections with healthcare professionals who are crucial in shaping the future of voice care.

This year, we were proud to participate in the Fall Voice Conference in Phoenix, AZ, the American Speech-Language-Hearing Association Convention in Seattle, WA, and the Voice Foundation Symposium in Philadelphia, PA.

Our ongoing presence at these conferences reaffirms Dysphonia International's role as a key player in the medical community, advocating for timely diagnosis, improved treatment options, and better support for those living with voice disorders. We are excited to continue fostering collaboration and drive positive change in the year ahead.

Susan Beck and Nicole Leitner at the Fall Voice Conference

Susan Beck, Philomena O'Neill, and Dot Sowerby at the American Speech–Language–Hearing Association Convention

Mickey Tuck, Cathie Leister, and Fred Hosier at the Voice Foundation Symposium

Support Network Awards

Midge Kovacs Awareness Award

Risa Clay and granddaughter Ava

The Midge Kovacs Annual Awareness Award, established in 1999 to honor those who significantly impact the spasmodic dysphonia community, is presented this year to Risa Clay and the New Jersey Dysphonia Support Group. Risa has dedicated herself to support group leadership, fundraising, and raising awareness for Dysphonia International. As a retired high school principal and top fundraiser for Walk for Talk 2023, she has helped raise over $12,000 and continues to inspire others. Risa's empathy, leadership, and commitment to the community make her a deserving recipient of this award. Upon receiving the award, Risa commented: "I definitely, wholeheartedly believe that everything I have encountered working alongside everyone at Dysphonia International, my fellow Support Group Leaders, Area Contact Leaders, and the people in our support group – it's life-changing. Knowing that you are not alone and being able to help others know they are not alone – it's everything really."

Dot Sowerby Pioneer Award

Bruce Menk

The Dot Sowerby Pioneer Award, created in 2015 by Dysphonia International, honors individuals who have made a significant positive impact on the community. This year, Bruce Menk receives the award for his many contributions, including serving as Past President, Board Member, and pro bono Legal Counsel. Living with adductor spasmodic dysphonia since 1989, Bruce has inspired others with his leadership and unwavering support for those affected by voice disorders. Dysphonia International is deeply grateful for his exceptional dedication and long-term impact on the organization and its community.

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DYSPHONIA INTERNATIONAL | 2024-2025 PROGRAM HIGHLIGHTS

RESEARCH

Finding answers to develop better treatments and discover a cure

This past year, we have:

- Funded two new research grants and the second year of an existing grant
- Streamlined the research application process to include a letter of inquiry before full application submission
- Awarded thirteen Travel Awards and two Conference Awards
- Presented and sponsored a workshop at the annual Bridge to AI Conference
- Hosted meetings with the Scientific Advisory Board along with researchers to encourage voice research projects
- Provided ongoing support for the Brain Bank and Global Dystonia Registry

EDUCATION & AWARENESS

Building understanding to share knowledge and increase sensitivity

This past year, we have:

- Hosted a successful Symposium in Tampa, FL
- Exhibited at three professional voice conferences
- Presented to a group of 50 Laryngology Fellows at the Fall Voice Conference
- Launched a World Voice Day awareness campaign highlighting the theme *Resonate, Educate, Celebrate!*
- Coordinated 22 presentations for the Guest Speaker Program to graduate-level Speech-Language Pathology students
- Participated in interviews on six podcast episodes
- Organized the 5th Annual Walk for Talk, raising an unprecedented $125,910, and with the dollar-for-dollar match, a grand total of $251,820 was generated to fund research and programs

SUPPORT

Raising hope to ensure that no one feels alone

This past year, we have:

- Organized 64 virtual, 31 in-person, and four hybrid support group meetings
- Hosted two skill-building Leadership Workshops (in-person and virtual)
- Continued the rotation of virtual leadership meetings, which includes Area Contact Leaders, Support Group Leaders, and joint leadership
- Enhanced the Leadership Library with new resources for leaders
- Presented the Midge Kovacs Award and the Dot Sowerby Awareness Award
- Published the quarterly online newsletter, *Voices of Support*, highlighting the work of the volunteer Support Network

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