



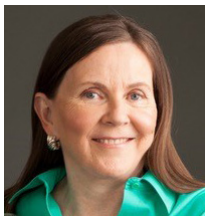
## New Beginnings

*By Dorothy Tannahill-Moran*



**“I live from one tentative conclusion to the next but the one thing I know for sure is I am confused.”**

*Notes to Myself, Hugh Prather*



Hugh Prather’s comment has summarized our life as we emerge from this pandemic (or is it a big “P” Pandemic?)

(even that has me confused). We are doing things differently across the board as the rules were rewritten in ways we haven’t yet fully comprehended.

Most of us have expectations that life will generally take shape as it once was. But we’ve changed and so has everything else. We can’t go back. The way forward is simply different, just as we are different. Now is the time to take stock in this time of emergence and re-awakening. There are three things for us to be mindful of at this time.

### 1. We are NOT THE SAME.

You, me, and your best friend have all been changed. Fear has gripped some people for a long time, and it changes who they are. Despite all of our ways of staying connected without being together in person, our social skills aren’t as robust, and we’ve become awkward. We don’t know who we can hug anymore or if shaking hands is still a good practice. We are at once hysterically happy and anxious. We’ve lost more than we may know and maybe discovering it every day. This isn’t exactly like waking up from a year and a half coma. It’s more like showing up in another country just like this one and figuring out everything, every day. We don’t communicate as effectively or execute things as well. We notice that we’re losing our temper more often, but we can’t

figure out what to do with it. At the same time, we can see and empathize with the business owners who are struggling, and we are doing our best to support them. Then, we step into a situation we haven’t been in for almost two years, surrounded by people. Lots of people. Around pre-pandemic levels of people, we are aware like never before. It makes us realize that we are different. We recognize now that our level of anxiety is going to ebb and flow like the anger from our violated expectations. We know we’re going to have to be extremely patient with ourselves and others. Only we aren’t and that’s the point.

**Key Life Lesson #1:** Our patience has to be on steroids. This is going to take a while and the only way to get through this is to have a sense of humor. The other way will only

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Our Voice is the official publication of the Dysphonia International. It is published to provide information to individuals with spasmodic dysphonia and related voice conditions, their family and friends, and healthcare professionals.

Dysphonia International, formerly the National Spasmodic Dysphonia Association (NSDA), is 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.

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# IN MEMORIAM

Remembering these special individuals who enriched our community through their dedication, generosity, and commitment.

## HONORARY BOARD DIRECTORS

### Jean Newcomer



Jean Newcomer passed away at the age of 99. She developed spasmodic dysphonia at the age of 15. She was the Director of the Ida Public Library for 38 years and worked as a reporter for the Daily Republican Newspaper in Belvidere, IL. Jean served as an email support group coordinator and was a member of the Chicago support group. In addition, she worked with Past President Dot Sowerby on writing the book, *Speechless: Living with Spasmodic Dysphonia*, which included her journey with SD, and was published in 1999.

### Johnny Bush



Country music legend Johnny Bush passed at age 85. He was a songwriter, vocalist, and performer. Johnny's career was derailed shortly after the release of his most well-known song, *Whiskey River* when he developed spasmodic dysphonia. Many years later, Johnny began performing again after successful treatment with Dr. C. Blake Simpson. He also dedicated himself to helping others with voice disorders, often accompanying patients for treatment. Johnny spoke at our San Antonio Regional Conference and performed at the 2014 Fall Voice Conference.

### Jimmie Rodgers



Singer Jimmie Rodgers passed away at the age of 87. Jimmie had a string of hits in the 50s and 60s, including, *Honeycomb* and *Kisses Sweeter than Wine*, until spasmodic dysphonia took his singing voice away in 1987. Jimmie was the Keynote Speaker at the 2005 Symposium and shared his journey and recorded a short interview entitled, *A Singer Silenced*.

## FRIENDS AND VOLUNTEERS

Mary Brady

Mariette Forberg

Bill Gross

Larry Kolasa (see page 17)

Edward J. Matushek III

Judith McKey

Janice Moses

Wilma Myers

Rev. Dr. French O'Shields, Jr

Patricia Quick

Alice Smith

Diane Truong

## HEALTHCARE PROFESSIONALS

**Dr. Herbert Dedo** | A renowned laryngologist and head and neck surgeon responsible for many new techniques, including the development of the recurrent laryngeal nerve section in the treatment for spasmodic dysphonia.

**Prof. Nobuhiko Isshiki** | A pioneer in the field of laryngology, including the development of thyroplasty surgeries for spasmodic dysphonia and other vocal disorders.

**Dr. Sid Khosla, MD** | A laryngologist and researcher in voice, vocal cords, swallowing disorders, and airway reconstruction.

make our voice worse. We have to change our expectations and realize that everything, both people and businesses, are different. We would do well to skip past expectations and act more like a tourist this year and simply “go with the flow.”

## 2. THINGS have changed.

With change comes discomfort. It's the characteristic of change we can count on. Right now, we don't know what is the same and what is different and with that level of fogginess, our best way forward is to proceed with curiosity, wonder, and a willingness to try new things. You need to be flexible each time you step foot out there, even if your foot is going into an old, familiar place. Because that old, familiar place or person has been remade into a different version of itself just like us. Just as we want to be accepted in your remade Post-COVID 2.1 version of you, so does everyone and every place. We're not great and we're doing our best, but each day life is getting better.

**Life Lesson #2:** Life is always changing, but the pandemic brought this to light in new ways. It has been uncomfortable for many of us at times and we've had to make adjustments unlike ever

before. Learn to live with the discomfort. Be curious and look at all of this as an adventure. Consider rewarding others in their attempt at getting back because for some people this emergence is very hard to do. We all need to support each other in our attempts to regain our new life.

## 3. Some GOOD things have emerged.

If anyone owned stock in Zoom before the Pandemic, they probably are out buying a new car! One of the best things to emerge in our stay-at-home time was staying connected by using Zoom and other group telecommunication services. Our organization made good use of Zoom by holding Virtual SD Support group meetings; this allowed people who were previously unable to get to a support group meeting to join in! It also brought people together from one part of the US or the world to participate in meetings they wanted to join so they could listen to a specific speaker. We also held Virtual Symposiums, and Board of Director meetings, and the list goes on. People stayed connected even though they couldn't be together for personal interactions. Home

delivery of groceries and meals from restaurants exploded, meaning the dinner take-out orders have become a new way of life. While many restaurants had to deploy new means to stay in business, these models are here to stay. People want to be able to get great meals from good restaurants without the hassle of going into the restaurant to be seated. Another emergence is dining outside. While dining alfresco has long been a European staple it's been more of an exception in the US and this too has emerged and will most likely stay in place. If you haven't noticed, many of the voice disorder researchers used the shutdown to “regroup” and have emerged with slightly expanded criteria to their studies. Good news for all of us!

**Life Lesson #3:** Not all change is bad. In fact, change is good – even if what causes it has been tinged with tragedy. Even in the worst of times, you can always count on good things to emerge. Never miss the opportunity to be grateful for all the good things surrounding you.

The pandemic has been an unusual period in the history of mankind. It has shown us many things about ourselves and while many of us may be confused, we are resilient.

## VIEWPOINTS ON NEW BEGINNINGS



### Emily Lim

**“This pandemic period has made me pause for lots of introspection, but also spurred me to seize the day. Going forward, I hope to continue getting involved in one meaningful community project a year.”**

Area Contact Leader from Singapore, Emily Lim, is an award-winning children's book author who has written over 40 picture books. She also penned her memoir, *Finding My Voice*, about her journey with spasmodic dysphonia. Emily also received the National Public Service Medal for her work in creating informational COVID-19 children's e-books for her community.



## VIEWPOINTS ON NEW BEGINNINGS *from page 3*



### **Alissa G. Yeargin, MSR, CCC-SLP**

I can think of many words to describe the pandemic: ‘challenging’, ‘frustrating’, and ‘scary’ to name a few. As we emerge from this extremely difficult time, I can’t help but focus on the positive things that have taken place. As a Speech-Language Pathologist in an ENT private practice, I have seen, firsthand, the devastation that COVID-19 has wreaked on everyone. I have also witnessed the incredible adaptability and creativity of human beings. Since 2017, our Upstate SC Support Group has met in person every other month. We have laughed, cried, sang, relaxed, reminisced, and bonded together. We have celebrated births, mourned illness and deaths, and cheered one another as we strove to achieve our goals. When the pandemic hit, for the first time in our history, we couldn’t be together in person for our meetings. It was devastating. We quickly decided that one missed meeting was one too many. We had to figure out a different way to get together. We collaborated with NSDA/Dysphonia International and switched to Zoom. There were a few hiccups along the way but eventually all of our “regulars” learned how to join. We were even able to reach new members from other parts of the state and country! Since many of our members are alone and unable to leave their home, our meetings were a shining light in an otherwise dark time. We are excited to be meeting in person again. To hug, to sit together as we always have, and to give and receive the unwavering support that our group provides. Contrary to what we may have expected, this experience has brought us closer together. In fact, we will emerge from this experience closer, stronger, and more grateful for one another.

### **B.G. Firmani**

Early in the pandemic, with New York City “on pause,” the quiet of the streets was surreal. The day my office shut down I walked the forty blocks home down Park Avenue and could have counted the people I saw on the streets. The suffering that was to come for so many was still an abstraction at that point. I could joke that I felt like Charlton Heston in Omega Man, except I was wearing heels and lugging a laptop. Everything would go virtual – via Teams, Zoom, or the old-fashioned phone – and I was already rehearsing in my mind the techniques I’d need to use to represent myself in a way that wouldn’t sink me into despair. I’d heard it in others’ tones, the question in their voices: Why do you sound like that? My SD manifests itself in different and unpredictable ways, as it does for many of us. Sometimes my voice is a whisper and I can’t project at all. Sometimes it sounds cracked, broken. Sometimes what happens is a block on certain letters – the H of Hello, the F of my last name, Firmani, both of which are not so handy if you’re introducing yourself on a videoconference call. I talk with my hands, so I found it helpful in those early virtual days to play a version of myself. I would over-articulate my gestures so that, if my voice failed to carry, my receptive face and expressive hands would show that I meant business. In the months that followed, this became normal for me: daily, over Teams, I conducted mini-orchestras. When we went back halftime into the office late in the summer of 2020, I had to relearn this talking-in-person thing. The mask in a way was helpful at first, another layer of mediation, and a handy excuse if my listener couldn’t hear me. After I got the vaccination, however, something in me changed. I realized I’d had a terror not so much of getting the virus myself as of passing it on to someone else: an at-risk friend, an elderly neighbor, a stranger. With this realization came a great sense of relief. Is it possible to have a similar unburdening with my voice issues? Or am I “protecting” my listeners from a more accurate version of myself?



### **Peter Nagelvoort**

I suspect I have had SD with essential tremor almost all my life, but I was just diagnosed eleven years ago. I have a relatively mild case, so I have been able to continue my career as a bookseller. Not a day goes by without thinking about my disorder, however, and how it will affect my interactions with colleagues and customers. At the beginning of the pandemic, all of the employees at the bookstore where I work were laid off. I was one of the first re-hired due to my ability to fill on-line orders. Because there were so few of us and social distancing was strictly followed, I often worked alone without speaking to anyone.

As the economy and the bookstore recovered, I had to adapt, playing a leadership role, and taking on training responsibilities. I discovered that long periods of time without speaking made it more difficult when I was called upon. I tried to go out of my way to be friendly, warming up my voice, and increasing my comfort level. Now, with the store bursting with customers and new hires coming on every week, I spend much of my day talking. There still are times, however, that my voice tenses up when I begin my day or when I must raise an issue with a manager. I raise my arm over my head to fool my brain into relaxing my vocal cords.



### Laura Rahuba

During the pandemic, people with spasmodic dysphonia and related voice disorders faced an additional subset of challenges. To minimize risk of infection, most non-emergency medical procedures and treatments were initially canceled or postponed, which left many of us with deteriorating voices as our symptoms returned. As weeks turned into months, treatments such as voice therapy switched to telehealth options, while in-office procedures like Botox® injections called for mandatory face masks and no accompanying visitors. For those with irregular, strained, or soft voices, speaking through a mask was yet another obstacle to verbal communication, making us feel even more isolated.

Our society was reminded of how essential social connection is to our well-being. New technology and a shift in thinking allowed us to develop creative ways to stay connected to friends and family, co-workers, and community. I'm grateful that our leadership team took swift action to adopt new technologies and switch events to remote options.

It may have started of necessity, but now it has opened doors of possibility to a new future. We carry these lessons and ideas forward, creating a community that is more inclusive and diverse, more flexible and agile. Access to support groups and events is no longer hindered by geographical location, mobility limitations, or travel expenses. NSDA/Dysphonia International has greatly increased the number of people with access to information and support. The frequency and ease with which we can consult with one another and with medical and scientific professionals now allows us to increase the scope of what we can accomplish together.



### Vicki Orazem

**“It is not impermanence that makes us suffer. What makes us suffer is wanting things to be permanent when they are not.”**

– Thich Nhat Hahn

I have had spasmodic dysphonia for thirteen years. Four of those years were spent in a deep depression. I felt as if I'd lost a very vital part of myself – the ability to express myself in the way that was always so easy for me. The accompanying loss of career and community was devastating. I felt as if I lost a limb.

All that changed when three years ago I went to a new gym. My teacher was a young woman who had lost a limb! She had been in a terrible car accident, and her right arm was amputated below the elbow. I couldn't imagine how she was going to teach. Oh, how much I had to learn from her! I learned about acceptance, adaption and learning to live my best life. When she teaches, she never mentions it, never apologizes and never makes light of it. When it is time for weight exercise, she straps a leg weight to her upper arm, when she does a plank, she uses her forearm. She doesn't miss a beat. She learned to assess what she could do, adapt how she does it and then executes. She is an inspiration every day.

*Vicki with her father*

In the past 18 months, I have experienced death and loss and grief. I have comforted the sick, welcomed family home, and cared for my father. During all these times, no one said anything about my voice, and neither did I. Sometimes, I only said a few words, and I never sounded perfect, but no one cared. What they wanted was me. Not my voice! They wanted me, and I wanted to be with them. Through this, I realized I am becoming who I always was, ME.

So, in honor of them, I'm going to find a way to live as fully as I can. I know there are days when I will grieve all my losses, but I will try to laugh, love, and be grateful for what I have and know that nothing is permanent. Life is short. Live it to the fullest.

## Reflection Question

**What changes have you experienced over the last few years? How has it impacted your life? Your voice? Are there positive outcomes that you have discovered?**



# President's Message | **New Name, Same Mission**

**Charlie Reavis**



The first thirty years of the National Spasmodic Dysphonia Association (NSDA) were primarily dedicated to improving the lives of people living with spasmodic dysphonia through

research, education, awareness and support. Three years ago, we decided to expand the Mission of the organization to include spasmodic dysphonia and related voice conditions. This change by the Board of Directors was based on the fact that our support network has been welcoming and providing for the needs of those living with other voice conditions since the organization was established. We are fortunate to be part of an organization that understands how to live and cope with a voice disorder. I believe we have the tools, commitment, and capacity to serve the broader voice patient community and we should expand our reach to help them. Our expanded Mission and name change will also better position us to collaborate with other organizations to expand our research efforts for spasmodic dysphonia and related voice conditions.

About two years ago, the Board of Directors made the decision to change the name of our organization from the National Spasmodic Dysphonia Association to Dysphonia International. The new name better reflects our expanded Mission to be more inclusive of people living with other voice conditions. The name change is not totally completed as we continue the evolution to Dysphonia International. We are still changing and updating some of our materials, but our website – [dysphonia.org](http://dysphonia.org) – has been updated to Dysphonia International.

I want to assure everyone that Dysphonia International will continue to lead the charge toward better understanding and more effective treatment options for spasmodic dysphonia and related voice conditions. That is our Mission, and we are completely committed to our core purpose. There is no group better prepared to support people with related voice

conditions than our organization – Dysphonia International. We have added and will continue to update materials and information for vocal tremor, muscle tension dysphonia (MTD) and vocal fold paralysis/paresis to our website. Much of the daily path traveled by those with these voice conditions are very similar to SD, and there is much we can do to help with the journey.

When the organization was first started, the technology allowing us to reach a world audience was not nearly as effective as today. Spasmodic dysphonia and related voice conditions are not unique to North America, leaving people in need of information and support worldwide. The blessing of today's technology is that it allows us to communicate and interact regardless of where we live. Our name and Mission change recognizes the fact that we have the capacity to support the needs of people living with these voice disorders anywhere in the world. That being said, we already have some reach into many countries. This is totally amazing when you think about it.

Our name change has not been a sudden or dramatic event but a slow, deliberate and planned evolutionary process. An example of this process was the debut of Dysphonia International to our healthcare community at the 2022 Fall Voice Conference in San Francisco. Nicole Leitner, our Program and Operations Manager and I attended this conference with more than 600 laryngologists and Speech-Language Pathologists (SLPs). Our banner, table covering, and all materials reflected Dysphonia International with our new logo. The response from the physicians and SLPs to our 're-branding' was enthusiastically positive. Many said they would encourage their patients with various voice conditions to view our website and contact us.

## **Make no mistake, our Mission is clear.**

Dysphonia International is dedicated to improving the lives of people affected by spasmodic dysphonia and related voice conditions through research, education, awareness, and support.



## **VISION**

The Vision of Dysphonia International is to ensure the ongoing viability of the organization that will continue to lead the effort to eradicate spasmodic dysphonia and related voice conditions.

## **MISSION**

Dysphonia International is dedicated to improving the lives of people affected with spasmodic dysphonia and related voice conditions through research, education, awareness, and support.

## **LOGO**

When the NSDA Board approved the organization name change from National Spasmodic Dysphonia Association to Dysphonia International, it was clear that a new logo was required which would complement the new name. The first feature of the Dysphonia International logo is the curved lines to denote a voice wave. These curved lines are interrupted to indicate a broken voice. The vertical line depicts an individual. The colors were carefully chosen as the new color palette for Dysphonia International. Altogether, the new logo represents an individual talking with a broken voice. Along with the new name and logo, is our tag line, A Community that Cares about You and Your Voice.

**People who have a voice disorder, regardless of the cause, walk a similar path, and our community is here to help support, educate, and raise awareness while we search for answers and better treatments.**



# Transitioning to Serve People Worldwide

## David Barton | Reflections from a New Zealander



David Barton

I am excited that the National Spasmodic Dysphonia Association (NSDA) is becoming Dysphonia International. This name change acknowledges our international outreach

beyond the borders of the United States, and indeed North America. We have Support Groups outside the US, and Area Contact Persons in four continents. We have members in our database from all continents except Antarctica.

All of us in the NSDA are so grateful to the medical and scientific experts in the United States who support us in many different ways; I would add though that medical advancement and scientific knowledge is a two-way street between countries. I think about Dr. Isshiki in Japan who pioneered thyroplasty Type II for SD, Dr. Jürgen Konczak from Germany who has received a research grant from the NSDA for

investigating laryngeal vibration devices, Dr. Christopher Honey in Vancouver, BC, Canada who is working in the Deep Brain Stimulation field for SD, and others, such as Dr. Kristina Simonyan who brought her skills from Armenia and then Germany to direct neurological research into spasmodic dysphonia at Massachusetts Eye and Ear. And our Founder, Dr. Daniel Truong, to whom we owe so much, was born in Vietnam. These international connections, where medical and scientific experts worldwide can collaborate and learn from each other, provide a win-win for everyone in the voice community.

As a New Zealander I have been privileged to be part of the organization's leadership for almost 25 years, and I was honored to serve as our President from 2005 to 2010. The NSDA has been a broad-based, inclusive and patient-focused group, and the only organization that has a sole focus on spasmodic dysphonia and related voice-disorders. Right from day one, I felt welcome

and was treated as a valued member of the Association. Like many SDr's I struggle with vocal communication — and I quickly realized when talking to my US-based colleagues that SD was the challenge, not my Kiwi accent! The benefits of belonging to the NSDA and the wonderful, dedicated and humble people I have met on-line and at NSDA events far outweigh my own struggles with my unreliable broken voice. I am especially appreciative of the volunteer pioneers who have given so much; I know that such outstanding service is its own reward, but let them know their influence has been felt across the oceans.

One of the most important messages the US voice community shares with new contacts is "You are Not Alone" and in return, the rest of the world says to the US, "We are in the Same Boat!" I look forward to continued progress under our new name, Dysphonia International, as we strive towards our goal of finding cures and more effective treatments for all voice disorders.

## Bringing Our Community Together One Step at a Time

When Walk for Talk was launched in 2020, we wanted a way to unite our community during the pandemic. Not only was it embraced, but it exceeded all our expectations. So many people stepped forward to make a difference, including those living with voice disorders, family, friends, co-workers, researchers, healthcare professionals, students, and even pets! It has built a greater understanding of voice conditions by empowering people to share their stories, some for the first time. It has allowed us to expand our international engagement. And it hasn't just been limited to walking. People have run, biked, golfed, paddled, and even surfed for talk!

Even more humbling is how our community has raised funds for research for better treatments and a greater understanding of spasmodic dysphonia and related voice conditions. We are so

grateful to our many individual fundraisers and generous donors. Over \$350,000 was donated in three years, exceeding all our goals. All gifts were matched dollar-for-dollar, totaling over \$700,000! With this support, more research has been funded, and the level of funding increased to attract even more investigators.

The annual Thank You videos highlight these events' camaraderie, encouragement, and strength. It also shows what a small organization can accomplish by working together. My personal thanks to our Walk for Talk Planning Committee members, Chair Mary Bifaro, James Anderson, Dennis Kaszeta, Ron Langdon, Cathleen McCulloch, Vicki Orazem, Sue Payne, Laura Rahuba, Denny Richey, and Esther Zack for their support, energy and enthusiasm.

*Kimberly Kuman, Executive Director*



We hope you will plan to join us for the 4th Annual Walk for Talk from October 12-15, 2023. No matter where you live or your voice condition, you are welcome! Together, we are raising hope for the future. Every step gets us closer to a cure for spasmodic dysphonia and related voice conditions.

**See photos from Walk for Talk on pages 18-19!**

# Expansion of Support and Belonging to Dysphonia International

*Mary Bifaro, Support Network Director*



I have served as Support Network Director for the NSDA, now Dysphonia International, since 2005. In addition,

I have been involved with the support group in Charlotte, NC, since its founding 33 years ago. As we reflect on the history of the NSDA/Dysphonia International, we look back with gratitude and we look forward in anticipation.

We, the support network of the NSDA/Dysphonia International, lift our voices in unity. We are mindful that our outreach is international and that we have expanded our mission to include related voice disorders. We have already been welcoming people with different voice conditions to our support network, so this change helps to solidify our commitment and shows the inclusivity and care that has been shared in the past.

The NSDA/Dysphonia International support network promotes leadership development and empowerment. Because of the ongoing push for further engagement and program activity, we continue to advance in our important work. On April 29, 2022, I had the privilege of chairing the 18th Annual Support Leadership Workshop for our leaders across the US and in International Regions. The enthusiasm, energy, and empathy displayed by our leaders should make us all feel grateful, hopeful, and proud.

The workshop was focused on this change and hoping to prepare our leaders, so they are more confident in providing support with the expanded mission. We also wanted to hear from them about what tools and resources that we as an organization can provide to support them and their role.

Our leaders stand side by side with one hope and one dream – to help improve the lives of people with SD and related voice conditions. All leaders in our support network have agreed to having their contact information listed on our website at [dysphonia.org](http://dysphonia.org). Today, there are approximately 40 support groups. Along with our Support Groups, we have over 100 Area Contact Leaders that serve as a vital network in locations where support groups are not yet formed. We encourage you to look on our website to see if there's a local support person in your area. They hope to hear from you as to how they might help you. If so, reach out and connect and start to build a local network. If there is not a person, please consider becoming an Area Contact Leader yourself. We are always welcoming new volunteers to help build our community.

The support pillar of the NSDA/Dysphonia International has always been constant. We want to bring hope to those we serve. Hope for better treatments. Hope for an eventual cure. Hope in knowing that everyone belongs in our community – no matter where you live, how old you are, and how your voice sounds. Hope as an acronym that might express: Helping Other People Endure.

Since the pandemic began over three years ago, we have continued to connect virtually with our community. We have been able to reach people, some who have never met anyone else living with spasmodic dysphonia or a related voice condition. It truly has connected our community. All virtual support group meetings are listed on our website. In any given quarter, there are between 10 and 15 groups which have organized meetings. If you find a time and topic that interest you, please join us regardless of your location.

Also, we found in our three global Walk for Talk events which take place annually in October that our outreach extends far and wide. Generations of people and their pets came together in support of our worthy cause, NSDA/Dysphonia International, to raise awareness about SD and related voice conditions and funds to advance research. We hope you will join us for the 4th Annual Walk for Talk on October 12-15, 2023.

Approximately 88% of the NSDA/Dysphonia International budget is dedicated to research, increasing awareness of SD and related voice conditions, and support programs and activities. This is a record that we can all be proud of. Until a cause and cure for SD have been found, our work continues. Each of you can make a difference in our organization. Our cause is worthy of our efforts.

**Every voice matters! No matter your voice condition, your age, or your location, you belong to NSDA/Dysphonia International!**



**I felt so isolated, experiencing severe muscle tension dysphonia and had not found support locally in the UK. I found the NSDA, but initially, I did not reach out as it appeared for people specifically with spasmodic dysphonia. However, as the organization was transforming into Dysphonia International to be more inclusive of people like me, I signed up for the virtual symposium. I did feel like I belonged and felt very welcomed. I've attended virtual meetings, became an Area Contact Leader, and even participated in the 2022 Walk for Talk."**

– Helen, UK



# Board of Directors UPDATES



## **Bruce Menk**

Bruce Menk from Colorado was welcomed back to the Board of Directors. He has previously served on the Board as a member in the 1990s and as President from 1995-1997, in addition to serving as Legal Counsel for many years. Bruce shared, "I am so grateful to this organization for pointing me to Dr. Daniel Truong and for his wonderful care for the last 30 years. It saved my career and allowed me to represent clients in state and federal courts until my retirement this year. Coincidentally, it also launched my daughter's career as a speech pathologist."



## **Susan Boyles**

Susan Boyles, Area Contact Leader from North Carolina, has accepted the role of Legal Counsel. She stated, "As a litigation attorney, I use my voice all the time. Being able to be heard and understood in depositions and court proceedings is essential to doing my job well. Despite the frustrations of SD, I have strived to find the silver linings in my journey with it. SD has made me a better listener. I pay more attention to non-verbal cues. I have learned to be more patient and have greater empathy for persons with any kind of disability."



## **Warren Bandel**

Warren Bandel stepped down from the Board of Directors. Warren, who plays trumpet, has hosted eleven concerts to raise funds with his quintet, Classic Brass. The most recent concert was held in a parking lot in Sun Prairie, WI. Warren continues to serve as an Area Contact Leader for Rochester, MN. We thank Warren for his years of service on the Board.



## **Dennis Kaszeta**

Dennis Kaszeta, Board member and Support Group Leader for the Greater Detroit Area Dysphonia Support Group has been appointed to the role of Area Contact Director for our Area Contact Leaders (ACL). We recently made the change of the name Area Contact Persons to Area Contact Leaders to better represent the role in our community.

## **Meet New Staff Member: NICOLE LEITNER**



Nicole Leitner joined the staff in late April, as our full-time Program and Operations Manager. She plays a hands-on role in the organization's administration to carry out and manage the operational and programmatic functions of the organization's activities. She jumped right in starting the week of our 2022 annual meetings and had an opportunity to meet many of our leaders. Since then, she has been working on new projects that will better support our volunteer leaders and help with outreach to speech-language pathology students.

Nicole shared, "Over the last 15 years I have been working in programming for a variety of nonprofits, including an adolescent homeless shelter, a community recreation center, and a mentoring organization. Additionally, I have worked at an ENT doctor's office and a hospital in the medical records office. I am looking forward to putting the skills and abilities I've gained from my previous experiences to work for NSDA/Dysphonia International. I find value in the work that I have chosen to do and find joy in helping and assisting others. I believe in empowering individuals with knowledge. In this role I will take great pride and responsibility in ensuring that resources, research, and information is available to those who need it. I see this position as an opportunity to help to build a strong community of support and to have a positive influence on individuals in need. I am grateful for the chance to contribute to the new direction and expansion of the mission of NSDA/Dysphonia International."

## **Bulletin Board Update**

Due to the decline of activity in recent years, we reluctantly closed the Bulletin Board for people with spasmodic dysphonia after 25 years of connecting people online. From the beginning, the Bulletin Board brought people together and was vital in connecting people struggling with spasmodic dysphonia. Life-long friendships developed, experiences were shared, and people knew they were not alone in living with this rare voice condition.

We are grateful to our volunteer moderators for their tremendous work maintaining the site over the years, including David Barton, Will Blum, Laurie Cermak, Pat Hill, Lynne Martinez, and Lloyd Pearson, along with webmaster Bob Campbell, who ensured it was running smoothly. The Bulletin Board was pivotal in building a worldwide community that has helped to build the foundation for our organization which has evolved into Dysphonia International.

# ANNOUNCING THE PORTER RESEARCH FUND



We are humbled to announce the most significant donation in our organization's history from Mr. Mark Porter. Mr. Porter passed away in late 2019, and his estate notified us that he had allocated a gift valued at more than one million dollars to Dysphonia International. His generosity allows us to increase our commitment to scientific research directed toward diagnosis, treatment and a cure for spasmodic dysphonia and related voice conditions.

Born and raised in Kentucky, Mr. Porter received his Ph.D. from the Massachusetts Institute of Technology (MIT). He went on to be the Vice President for Research and Development at Nuclepore. Later, he co-founded the Valley Bible Church in Pleasanton, CA, where he spent time as a teaching pastor. During this time, he was diagnosed with spasmodic dysphonia, but Mr. Porter continued serving the church for over a decade. He was a husband (of 50 years), father, and grandfather.

In recognition of his extreme generosity, the Board of Dysphonia International has established the Porter Research Fund, which will formally commit a substantial portion of this bequest to fund research. We felt that his life-long career in research made it especially fitting that this bequest become the Porter Research Fund. The remainder will be used to support and enhance our efforts in education, awareness, and support.

In our attempt to understand how our paths crossed so impactfully, we found that Mr. Porter received regular communications from us dating back to 1998. However, like so many in our community, we never met him personally at a symposium or a support group meeting.

Our goal is to provide support to those living with spasmodic dysphonia and related conditions wherever they need us in their journey. We may never know how our organization affected Mr. Porter's life, but we are honored that our mission meant something to him. His gift gives us hope that the research his legacy gift will fund will bring us closer to a cure.



## Thinking About Your Legacy

**You can make a lasting impact.** Including Dysphonia International in your will or living trust makes a final statement of your life's philanthropy that memorializes you and/or loved ones in a way that helps our community.



### What is important?

Determine who and what is important to you. Your financial resources can be applied to those you hold dear.



### Write it down.

A will can change as your wishes change. Use the beneficiary forms to define your intentions for distribution.



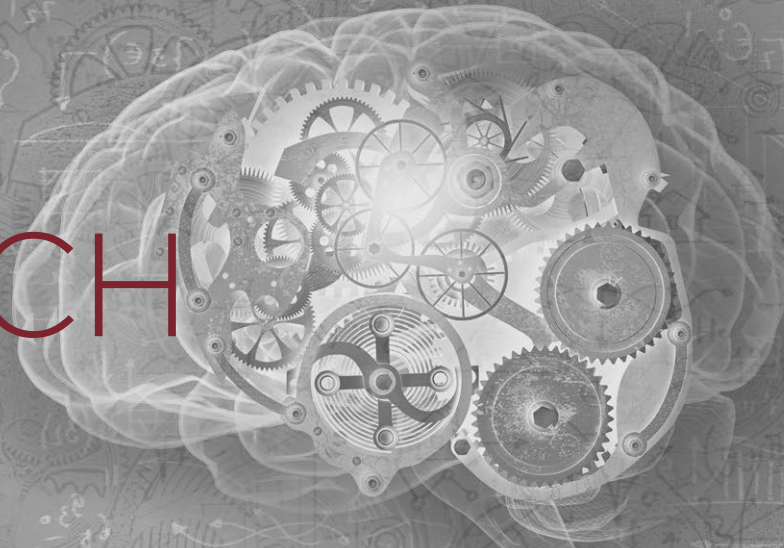
### Build your legacy!

What is truly important will be honored. Your bequest becomes an investment in the future, make a lasting impact.

### By remembering Dysphonia International in your will, you become part of our Legacy Society!

Please let us know of your wishes so that we may honor you now. Please note: If you have already included the National Spasmodic Dysphonia Association in your estate planning, we kindly ask you to update the name to Dysphonia International. We are so appreciative of your support. Go to [dysphonia.org/donate/legacy-society](https://dysphonia.org/donate/legacy-society) to learn more.

# RESEARCH Update



The most recent grants funded focus on potential new treatments, improved diagnostic tools, and identifying areas of the brain impacted by spasmodic dysphonia. In addition to funding grants and promoting recruitment for studies, our organization plays a vital role in connecting our researchers and fostering collaboration. Plans are underway for a virtual scientific workshop with our grant recipients in 2023. This is a chance for our investigators to get to know one another, share updates, and find new ways to partner. Our goal is always the same — to speed up our understanding and advance the science to find better treatments and cures for spasmodic dysphonia and related voice conditions.

## BRAIN CONNECTIVITY MAPPING STUDY

### Individual-Specific Brain Functional Connectivity Mapping of Therapeutic Response in Spasmodic Dysphonia, a form of Laryngeal Dystonia



Scott Norris, MD



Evan Gordon, MD

**Scott Norris, MD, and Evan Gordon, MD** (Washington University) are examining whether dysfunctional individual brain networks are modified by Botox® treatments for adductor spasmodic dysphonia (AdSD). The investigators are using advanced magnetic resonance imaging (MRI) to measure and compare brain activity in subjects before

and after successful Botox injections. For each subject, the team will determine whether voice-related brain regions communicate differently following successful treatment with Botox®.

This unique approach, testing for treatment-related changes in brain activity within each individual patient, is a critical improvement over previous studies that averaged data across groups. This study may enable improvements in diagnosis, participant selection for studies or treatment application, and prediction of treatment response for individuals with SD.

SD contributes to disability via abnormal, involuntary contraction of muscles controlling the voice. While Botox® targets muscles, evidence suggests that SD results from disordered brain signaling. This study aims to contribute to the groundwork in developing treatments that target disordered brain signaling. Future promising treatments might

include transcranial magnetic stimulation, deep brain stimulation, or novel medications.

Dr. Norris and Dr. Gordon expect to find an impact. Dr. Norris said, “(We will test) our hypothesis while offering additional proof of concept applications to scale potential multi-institutional collaborative studies bridging individual functional maps to therapeutic interventions, for instance. This particular line of research potentially has great potential to identify new targets for therapeutic interventions and metrics of target engagement for people with spasmodic dysphonia and possibly other forms of dystonia.”



## NEW TREATMENTS

### Stopping SD at its Source: Phase II Study of Deep Brain Stimulation



*Christopher Honey, MD*

**Christopher Honey, MD** (University of British Columbia) has studied the impact of deep brain stimulation (DBS) on individuals with SD who have received this invasive

brain surgery to treat other severe forms of dystonia, tremor, or Parkinson's disease. In six patients with severe cases of AD, the treatment was shown to be effective and safe. Patients experienced both improved the quality of voice and quality of life. A paper on this research was published in the peer-reviewed journal *Neurosurgery*.

Dr. Honey has launched a Phase II surgical trial DBS in collaboration with Stacey Halum MD and other colleagues from Indiana University. Both universities will assess ten patients with severe AD and ten with severe AB. Video assessment of the patient's vocal cords will be used to ensure they have SD. If their diagnosis is confirmed, Dr. Honey will perform DBS surgery at the University of British Columbia. In addition, the collaborators will investigate brain pathways that may cause SD.

This application of the DBS will be "double-blind" study to eliminate any possible placebo effect. The patient's DBS surgery

will be turned "on" for three months and "off" for three months without the patient knowing. Their voice and quality of life will be measured during each of these settings and then compared. The safety of this treatment will also be assessed by recording any complications or adverse events.

While studying the benefits of DBS, investigators will explore the brain pathways. This will provide novel insights into the cause of SD and may allow new non-surgical treatments in the future. DBS may be an option for those with extreme cases of SD, which are non-responsive to other therapies.

### Transcranial Direct Current Stimulation as a Treatment for SD



*Vincent Gracco, PhD*

**Vincent Gracco, PhD** (Haskins Laboratory, affiliated with Yale University) is investigating the impact of multi-electrode transcranial direct current stimulation

(tDCS), which is a non-invasive technique for neuromodulation. This technique has been given a "nonsignificant risk" designation

based on its use alone and in combination with behavioral therapy to treat a range of neurological and functional clinical disorders.

Recent neuroimaging data suggests that SD may be a network-level disorder involving multiple brain areas. In this pilot study of ten patients with AD and five controls, tDCS neuromodulation will be applied to multiple brain areas that may be related to SD. Over

a two-week period (three sessions a week), investigators will evaluate the effects of tDCS neuromodulation as a potential treatment to ameliorate the disorder. A positive outcome in this small cohort of SD participants would point to the need for a clinical trial with combined behavioral and neuromodulatory treatment, which could be more beneficial than either alone.

### Novel Application of rTMS in Abductor Laryngeal Dystonia



*Teresa Kimberley, PhD*

**Teresa Kimberley, PhD** (Massachusetts General Hospital (MGH) Institute of Health Professions) is investigating the effects of repetitive transcranial magnetic brain stimulation

devices (rTMS) on individuals with abductor SD. Prior research by this team has demonstrated improvement with this treatment in individuals with adductor SD. The study is designed to understand better how the brain activates vocal cords during phonation and to examine

the possible benefit of non-invasive brain stimulation. Prior investigations have uncovered both brain organization and connection differences in specific brain regions among people with AbSD. Speech is neuromodulated by cortical inhibition and excitement of signals to the laryngeal muscles. Dr. Kimberley shared, "We anticipate finding a decreased cortical inhibition in individuals with AbSD similar to what we found in individuals with the adductor form of SD." To address gaps in knowledge, this pilot study will use functional magnetic resonance imaging (fMRI) to better understand

brain function, including cortical inhibition. In addition, the study will apply five consecutive days of repetitive transcranial magnetic stimulation (rTMS), a safe, non-invasive neuromodulation technique, to the left side of the brain to study participants. The objective is to determine if the rTMS treatment will reduce inhibition and improve vocal function. According to Dr. Kimberley, if successful, this application might lead to an improvement, but not a cure, in voice. This might translate to the need for less frequent and/or lower doses of Botox® treatments.

# DIAGNOSTIC TOOLS

## Assessing Laryngopharyngeal Sensation in Patients with Adductor Spasmodic Dysphonia Using a Novel Tactile Buckle Aesthesimeter



Clark Rosen, MD

Clark Rosen, MD (University of California, San Francisco) is exploring a possible new diagnostic tool that may help us better understand how the vocal folds respond to stimuli in spasmodic dysphonia (SD). In addition, there is a training component for Joseph Kidane, a fourth-year medical student pursuing a dedicated research career in laryngology. Dr. Rosen will serve as his mentor, and Joseph will aid in the execution of the research study.

Dr. Rosen shared, "... there currently do not exist blood or imaging tests that can diagnose SD. One of the mechanistic theories of SD is that the larynx, or voice box, is in a hyper-sensitized state where the vocal folds contract to stimuli

that would not otherwise evoke a response in a healthy state. However, direct testing has not been formally tested before. Our research team has developed a novel, validated device to deliver consistent stimuli to different sites of the larynx. This device consists of a video laryngoscope and a "Cheung-Bearnelly" microfilament that is passed through a channel in the laryngoscope. This device allows us to visualize and record the larynx, evaluate laryngeal sensation, and see if the vocal folds close in response to the stimuli. We can assess sensation in the larynx with different monofilament sizes delivering varied strength."

He continued, "In our study, we will determine if there is a difference in the vocal fold closure between those living with SD and those without by testing three different sites within

the voice box: the lateral pyriform sinus, aryepiglottic fold, and false vocal fold. The monofilament size will be increased to strengthen the force of delivered stimuli to help approximate the threshold values for vocal fold closure in people with SD. In addition, we will ask participants to rate their perceived strength of stimuli with each tap on a scale from 1-10, comparing it between the two groups. Lastly, we will explore associations of laryngeal response with cough/gag reflex, a patient-reported outcome measure, and patient comfort level. We hope these findings contribute to our understanding of the physiological underpinnings of spasmodic dysphonia and aid in developing diagnostic tools."

## Development of a Computerized, Video-Based Measure of Severity for Laryngeal Dystonia



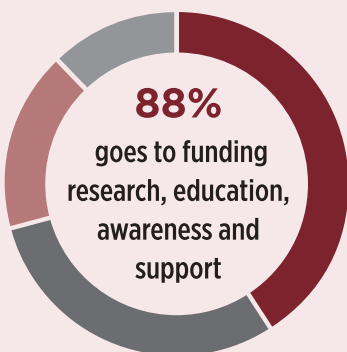
Abie H. Mendelsohn, MD

Abie H. Mendelsohn, MD (University of California, Los Angeles) is developing an advanced computer-based program to create objective measurements for outcomes of treatment.

To date, the research community has been unable to establish a quantitative scale of the severity and manifestations of SD. This shortcoming has impacted researcher's ability to measure treatment outcomes in clinical trials. Video recordings and audio-perceptual analysis of previously recorded standardized

patient examinations will be compared. The computer-based learning network will be trained by inputting expert analysis of laryngeal video and audio recordings." This grant augments the Dystonia Coalition's project led by Dr. David Peterson on objective measures.

### FINANCIAL OVERVIEW



41%

#### RESEARCH

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

30%

#### EDUCATION & AWARENESS

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

17%

#### SUPPORT

Network of over 50 Support Groups and 100 Area Contact Leaders, virtual support, and Leadership Workshop

12%

#### DEVELOPMENT & ADMINISTRATION

Support for all programs

#### RATINGS

Our organization has been awarded the Gold Seal of Transparency by Guidestar, the largest source of information on nonprofit organizations. Charity Navigator nonprofit rating is based on the amount of money spent on management and general expenses. A top score is received if that spending is between 10% to 15%. We are currently at 12% for these expenses.

# How We Support Research



## Funding Research Grants

Funding seed grants help nurture and support research into spasmodic dysphonia and related voice conditions. With these grants, we help investigators gather preliminary data so that they can apply to the National Institutes of Health for much more significant funding. This investment allows us to support multiple projects to expand our understanding of these vocal disorders. Working with our Scientific Advisory Board, led by Dr. Gerald Berke, grant applications are reviewed and recommended for funding. In addition, we are always fostering relationships with researchers and increasing collaboration among investigators. The research grants have recently been increased from \$50,000 to \$75,000 in the hope that this additional funding will help encourage more applications.



## Funding Travel Awards

The Research Travel Award program provides awards and travel funds to professional associations' annual meetings on the advancement of understanding voice. We are making connections that will help further their interest in voice conditions and ensure that this field will continue to be an area of focus for future research. This type of collaboration positions us as not only an organization for people living with SD and related voice conditions but one that works with researchers and healthcare professionals and serves as an ongoing resource to them. We partner with the following organizations: the American Academy of Otolaryngology, the American Laryngological Association, Fall Voice Conference, Sin City Laryngology, the Triological Society, and the Voice Foundation.



## Dystonia Brain Bank

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



## Global Dystonia Registry

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



## Opportunities to Participate in Research Studies

One of the most challenging parts of research can be the recruitment of patients into clinical and research trials. We work closely with researchers to share information about how people with SD and related voice conditions can participate and publicize various studies when appropriate. Our community is wonderfully responsive and eager to participate in these projects. Log on to our website for a list of research studies currently enrolling people.



# WHEN A *Thank You* JUST ISN'T ENOUGH

By Dorothy Tannahill-Moran

My big sister has always been my hero. She was the one who defended me against the neighborhood bully when I was a kid and even named me when I was born. How could you not love someone like that? But when I volunteered (for the second time) to participate in a research study on voice disorders with Dr. Kristina Simonyan in Boston, they asked me if I had an “unaffected” sibling that would also consider volunteering. The request surprised me, but I asked my sister, who said yes.

It didn't occur to me until the two of us were at the facility what the magnitude of her commitment really was. Both of us were going through a day-long battery of tests, poking, prodding, and ultimately lengthy time in the MRI. She had taken days out of her life to travel from Wichita, Kansas, to Boston. She had no “skin in the game” so to speak, other than me. She wasn't going to get anything out of it but rather had to endure all these procedures for the day.

I thanked her a few times and explained the significance of her actions for everyone with a voice disorder. She smiled and waved it off like it was nothing in her usual style—just something to do that day. I planned for us to have lunch with another Board member, Jane Gordon, who also expressed her gratitude on behalf of the entire organization. So, with my deepest gratitude, I thank my sister, Jane Bulman, for her willingness to volunteer to participate in a research study.

I'd like to add a footnote to this story.

Anyone reading this with a vocal disorder should seriously consider volunteering as part of a research study. As you know, few people have what we have, which has made it challenging to research and subsequently educate the medical community. Only when we work with the investigators will we find better treatments and cures. You are contributing to the greater good and medical advances can't take place without us. Volunteer.



*Jane Bulman and Dorothy Tannahill-Moran in Boston*

## Opportunities to Participate in Research

**Researchers need you! By participating in clinical research trials, you are helping us to learn more about the cause of, treatment for, and hopefully a cure for spasmodic dysphonia and related voice disorders. At right is a current list of trials that are recruiting. Details can be found at: [dysphonia.org/research/participate-in-research/](https://dysphonia.org/research/participate-in-research/)**



**Scan this QR code to learn more about research opportunities**

**VIRTUAL** | Staying Connected Through Communication Study

**SCOTTSDALE, AZ** | Connected Speech Voice Research Study

**NEW HAVEN, CT** | Use of Transcranial Direct Current Stimulation (tDCS) for Treatment for Spasmodic Dysphonia

**INDIANAPOLIS, IN** | Deep Brain Stimulation for Spasmodic Dysphonia / Laryngeal dystonia

**BOSTON, MA** | New Objective Measures and Treatments for Sensorimotor Disorders of Voice and Speech

**BOSTON, MA** | Brain-Computer Interfaces for the Treatment of Laryngeal Dystonia

**BOSTON, MA** | Imaging Genetics of Laryngeal Dystonia

**BOSTON, MA** | Understanding Disorder-Specific Neural Pathophysiology in Laryngeal Dystonia and Voice Tremor

**BOSTON, MA** | Multimodal Assessment of Neurophysiology in Laryngeal Dystonia (Spasmodic Dysphonia)

**AUSTIN, TX** | Auditory-Motor Control of Voice in Individuals with Essential Vocal Tremor

**SALT LAKE CITY, UT** | Sensory Trick Study

**WHITEWATER, WI** | Sensory Interaction in Voice Disorders and Laryngeal Somatosensory Evoked Cortical Potentials in Spasmodic Dysphonia

*CBS News Correspondent Jeff Pegues went public that he has been diagnosed with spasmodic dysphonia. He shared some of his experiences in this interview.*

## ABOUT YOU

### **Can you share a little about yourself?**

I currently live in Washington D.C. While I was born here in Washington, I grew up in Connecticut after spending the first decade of my life in the Philippines, Nigeria, Zaire, Ivory Coast, Zimbabwe and Paris. My father worked for the International Monetary Fund, Citibank and the World Bank at the time.

After attending high school in Connecticut, I was accepted at Miami University of Ohio where I was a scholarship football player before graduating in 1992. Miami launched me into a broadcasting career that has taken me across the country. I worked as an anchor and reporter in Illinois, Ohio, Milwaukee, Minneapolis, Miami, Baltimore, and New York City before being hired by CBS News in 2013.

During my time at CBS News, I have covered every major terrorist attack, active shooter situations, the death of George Floyd as well as the insurrection at the U.S. Capitol on January 6, 2021.

I am also the author of two books. *Black and Blue: Inside the Divide Between the Police and Black America*, is about the relationship between black Americans and police. In 2016 I wrote *Kompromat: How Russia Undermined American Democracy*, examining how the Russian government “compromised” our democracy during that year’s election.

### **Can you describe the journey from first symptoms to diagnosis?**

It’s difficult for me to pinpoint when the symptoms began appearing, but it became apparent to me that I was having a hard time speaking, which of course made doing my job as a correspondent ten times more challenging.

I was in denial for a long time. I thought it was stress related due to the relentless nature of

the news cycle or the demands of the job or maybe even the stress of going through a divorce. I didn’t know for certain until I went to see Dr. Simon Best, an otolaryngologist at Johns Hopkins in Baltimore, MD. He made the diagnosis.

### **What has helped your SD?**

I have adductor spasmodic dysphonia, which makes it difficult for the vocal folds to vibrate and produce sounds. The vocal folds slam together and stiffen leaving me sounding strained. What has helped are the Botox® injections I started over the summer. Dr. Best injected a small amount into my vocal cords and almost immediately I started to see results. What a relief.

### **What do you find to be a struggle in living with SD?**

I initially lost confidence in myself as I became more self-conscious about my voice. It was a painful and emotional struggle. I could not explain what was happening to those who would ask and wonder. Everyone has an opinion on social media and some viewers were often harsh in their assessment. I did my best to not lose hope that I would find a solution or work through it until my voice improved.

### **How do others react to you?**

People would often ask me to repeat whatever it was I was trying to say to them. That made me even more self-conscious.

### **What made you decide to go public with your diagnosis with SD?**

I’m at a point in my life where I’m grateful for what I have achieved both professionally and personally. I asked myself “Why hide what others can clearly see and hear?”

I was tired of pretending that everything was okay when it was not. It was time to be honest with myself and move forward.



Ultimately, revealing my diagnosis relieved some of the pressure and stress I was feeling. Since coming forward with my SD diagnosis, I feel so much better. I feel I’ve reclaimed momentum behind my work and overall, in my life. It’s about perspective, too. My SD diagnosis became another challenge to overcome.

### **With your career as a journalist, your voice is part of your identity. How has having SD impacted your career? What changes have been made to adapt?**

I’m optimistic it won’t impact it that much. Going through the diagnosis, I believe I’m better at what I do than I’ve ever been. I had one of the best years of my career in 2020 because, oddly enough, when I travel outside of D.C., my voice isn’t as severely impacted by SD. I spent more than a month on the road in 2020 covering social justice related stories.

Understanding and working through this adversity has made me stronger, smarter, and better. I’m bullish about the future.

### **How did your family respond to the diagnosis? Did they notice a change in your voice?**

My family and friends noticed a change in my voice. While they offered advice, they supported me through the ups and downs.

### **What advice would you give to others who meet someone with a voice disorder? What do you want them to know?**

Be respectful and supportive.



# Remembering LARRY KOLASA

FOUNDING PRESIDENT OF THE NATIONAL SPASMODIC  
DYSPHONIA ASSOCIATION (NSDA)

## In November of 2022, we lost Founding President Larry Kolasa.

Back in the late 1980s, at his dining room table, Larry launched the National Spasmodic Dysphonia Association (NSDA) — what is now Dysphonia International. He had been struggling with a strange voice problem and was searching for answers. Larry was fortunate to connect with a small group of patient advocates and medical professionals, including Dr. Daniel Truong, a Detroit-based neurologist. The rest is our organization's proud history.

Larry often retold the funny story about how he had to be convinced that he was the right person to start the NSDA. Once he did, Larry embraced his role, providing love, friendship, and support to so many. For over 33 years, he gave his time, heart, and tirelessly raised money to fund research. Larry fully supported our organization's transition to Dysphonia International, expanding its mission to include more forms of vocal disorders.

For those of us who knew Larry, the man, his loss has carved a huge void in our hearts, but his influence can be felt throughout our organization. He knew firsthand the challenges of SD. Larry made sure we have numerous resources through our website and the support network to help people navigate living with a voice condition.

He knew that education and awareness were vital in reducing the time to diagnosis so have different programs to target healthcare professionals. Larry came up with the name "Walk for Talk," our successful fundraiser that is raising awareness of voice disorders and our organization.

As one of the first people to try Botox® injections for spasmodic dysphonia, Larry knew that a successful treatment could change one's life. In his honor, we will continue to fund research initiatives, seeking new treatments and an understanding of the science so that someday a cure might be found.

Larry once said, "I have received so much more from this organization than I feel I have contributed." This beautiful sentiment reflects the power of being a part of this community. His dedication never wavered as Larry served on the Board until his death.

We grieve at the loss of this good friend whose generous spirit helped to bring us all together, but are so grateful that Larry helped to ensure that people living with SD and related voice conditions did not feel alone and could find a place of support, strength, and hope in the NSDA and now Dysphonia International.



Top Row: Stephanie Mendel and Larry | Founder Dan Truong with Larry | Charlie Womble, Dr. Valerie Levitan, and Larry | Larry with John Hunsinger | Larry with his wife Pam  
Second Row: Larry with Kimberly Kuman | Chip Hanauer, Larry, and Dr. Michael Rolnick | Dot Sowerby, Charlie Reavis, Diane Rehm, and Larry | Dennis Kaszeta, Larry, and Dr. Rolnick



# Scenes from Walk for Talk



JOIN US FOR OUR 4TH ANNUAL WALK FOR TALK | OCTOBER 12-15, 2023



# Every step gets us closer to a cure!



**OUR COMMUNITY IS WALKING FOR TALK, INCLUDING PEOPLE LIVING WITH VOICE DISORDERS, FAMILY, FRIENDS, CO-WORKERS, HEALTHCARE PROFESSIONALS, RESEARCHERS, STUDENTS, AND EVEN PETS TO INCREASE AWARENESS AND FUND RESEARCH FOR SPASMODIC DYSPHONIA AND RELATED VOICE CONDITIONS!**



# UNDERSTANDING VOICE DISORDERS

***While there are many different types of voice disorders with varying causes, the one thing they have in common is the impact they can have on your life.***

The term dysphonia refers to having an abnormal voice. Often people think of a vocal issue as a temporary problem like laryngitis. Still, there are numerous long-term voice conditions, many with no known cause, limited or no treatment options, and no cure. The symptoms can alter your voice's volume, pitch, and intonation, affecting your ability to communicate easily. Even simple things like talking on the phone or ordering at a drive-thru restaurant may become difficult.

Diagnosis of these conditions can be challenging. It is often based on the sound of your voice, a description of symptoms, and an examination of your vocal folds. While many people may have only one vocal disorder, these conditions can co-occur, making treatment even more complicated. Laryngologists and speech pathologists specializing in voice typically care and treat people with vocal disorders.

Our voice reveals much more than just words. It is an expression of our feelings, our personality, and even our identity. This diagnosis can be life-altering, affecting your relationships, employment, social activities, and even self-esteem. It is not uncommon to experience frustration or loss. Dysphonia International understands these challenges and is here to provide support and offer hope as you move forward with your voice journey. Below is a brief overview, but expanded information, helpful resources and more can be found at [dysphonia.org](http://dysphonia.org).

**SD**

## SPASMODIC DYSPHONIA

*Strained/Breathy Voice*

- Neurological
- Form of laryngeal dystonia
- Adductor: *Vocal folds spasm close causing a tight, choppy voice*
- Abductor: *Vocal folds spasm open causing breathy voice*
- Different options for treatment
- No known cause

**MTD**

## MUSCLE TENSION DYSPHONIA

*Tight Voice*

- Hyperfunctional voice disorder
- Voicing may result in fatigue and/or pain in the throat or neck
- Usually responds to voice therapy
- Commonly caused by excessive strain or tightness of the muscles around the larynx

**VT**

## VOCAL TREMOR

*Shaky Voice*

- Neurological
- Involuntary rhythmic movements of the vocal folds during speech
- Can affect other parts of the body
- Fluctuations in pitch or loudness
- Different options for treatment
- No known cause

**VCP**

## VOCAL CORD PARALYSIS

*Weaker Voice*

- Paresis: *Partial movement of folds*
- Paralysis: *No movement of the vocal folds*
- Misfiring or damaged nerves
- Can affect breathing and swallowing
- Different options for treatments
- Multiple causes



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**DYSPHONIA.ORG**

# ABOUT VOCAL CORD PARALYSIS

Vocal Cord Paralysis (VCP) refers to the impaired movement of one or both vocal cords caused by an impairment of nerve function to the larynx. VCP can affect people of all ages, from infants to adults.

## GLOSSARY AND TERMS

### Larynx

Also known as the voice box. The voice box allows us to breathe, swallow, and talk.

- Impairments of the voice box may result in one or more of these functions being affected.

### Vocal cords or vocal folds?

- Most people call the structures that move within the voice box vocal cords. Many imagine these like strings of a guitar, but they are not cords at all. They are folds of tissue, and most in the medical field will refer to these as vocal folds. These terms can be used interchangeably; vocal cords would be considered a more colloquial term.

### Vagus nerve

- A cranial nerve that exits the brainstem and skull base and supplies many structures in the body with motor (movement) and sensory innervation. Within the neck, the vagus splits into two main structures that supply the larynx. There is a vagus nerve on both the right and left sides of the body.

### Recurrent laryngeal nerve (RLN)

- This branch of the vagus nerve supplies the majority of motor signals to the larynx and the vocal cords. This nerve also carries sensory information from the larynx about and below the level of the vocal cords. The RLNs are very long and extend through the neck and into the chest before making a U-turn back up to the neck and the voice box.

### Superior laryngeal nerve (SLN)

- This branch of the vagus nerve supplies a single muscle of the voice box, the cricothyroid. This muscle aids in vocal pitch modulation and access to one's upper pitch range. The SLN also branches into two, and one branch carries sensory information from voice box and throat from above the level of the vocal cords.

### Paralysis

- Complete loss of motor nerve input to the larynx and vocal folds. Because the larynx receives information from both the right and left sides, a paralysis may be unilateral (one side) or bilateral (both sides).

### Paresis

- Partial loss of motor nerve input to the larynx and vocal folds. Because the larynx receives information from both the right and left sides, a paralysis may be unilateral (one side) or bilateral (both sides).

### Vocal cord immobility

- Often, in reference to the larynx, the term paralysis may be conflated with vocal fold immobility. Many patients with immobile vocal cords do not have a paralysis but instead, have a mechanical problem such as a scar or arthritis of the joint that prevents vocal cord movement. Your physician should be able to discern a neurologic source of immobility (paralysis) from a mechanical source.

## SYMPTOMS

*Symptoms associated with unilateral RLN, or vagus nerve paralysis or paresis include:*

### Common

- Breathless or weak vocal quality
- Decreased vocal endurance or increased vocal fatigue
- Change in power of the voice with reduced projection and loudness
- Sensation of phlegm stuck in the throat

### Less common

- Throat or neck discomfort with speaking
- Shortness of breath with speaking
- Choking or aspiration when swallowing liquids
- Swallowing difficulties

*Symptoms associated with isolated unilateral superior laryngeal nerve paralysis or paresis include:*

### Common

- Loss of vocal range, especially with higher pitches or notes
- More challenges with singing rather than speaking
- Decreased vocal endurance or increased vocal fatigue
- Change in the power of the voice with reduced projection and loudness
- Sensation of phlegm stuck in throat

### Less common

- Throat or neck discomfort with speaking or singing
- Choking or aspiration when swallowing liquids
- Swallowing difficulties

*Symptoms associated with bilateral RLN, or vagus nerve paralysis or paresis include:*

### Common

- Normal or slightly hoarse voice
- Noisy breathing (called stridor)
- Shortness of breath

### Less common

- Swallowing difficulties



## CAUSES OF VCP

*If you have been diagnosed with VCP, your physician should look for a cause (etiology). Some common causes include:*

### Idiopathic

- While frustrating, this is a very common diagnosis. This means that no cause has been identified.

### Latrogenic

This refers to a paralysis or paresis caused by unintentional or intentional injury to the nerve, typically during an operation. Any operation near or with manipulation of the vagus or laryngeal nerves can cause a paralysis or paresis. Some operations associated with vocal cord paralysis include:

- Thyroidectomy or parathyroidectomy
- Cervical (neck) spine operations performed from the front of the neck
- Esophagectomy
- Lung operations, especially on the left side
- Heart operations, especially near or including the aorta
- Skull base operations
- Zenker's diverticulum operation
- Head & neck cancer operations, neck dissection
- Trachea operations
- Carotid vascular operations

### Tumor or cancer

- Any abnormal growth in the skull base, neck, or upper chest may be associated with vocal fold paralysis. If another source of the paralysis has not been identified, it is common to order x-ray imaging of the neck and upper chest when someone is newly diagnosed with vocal cord paralysis to look for a tumor. Common tumors that can cause vocal cord paralysis include thyroid and lung tumors.

### Endotracheal intubation

- A breathing tube may be placed through the nose or mouth for an operation or critical medical illness. This is not a common reason for VCP, and the mechanism is not entirely understood.

### Diseases of the nervous system, such as stroke

- There are a variety of neurologic disorders that may be associated with VCP.

### Trauma to the voice box, neck, or skull base

### Radiation therapy or certain chemotherapy medicines

## DIAGNOSIS OF VCP

*The diagnosis of vocal cord paralysis, paresis, or vocal fold motion impairment is usually made in the otolaryngologist's office with the patient fully awake. The diagnosis is made after a thorough history and physical examination. The evaluation may be performed by an otolaryngologist and/or a speech-language pathologist.*

### Listening

- Otolaryngologists and speech-language pathologists are experts at what is called a perceptual evaluation of the voice. Aspects of one's diagnosis are made this way.

### Looking

- The voice box and vocal cords are directly evaluated with visualization to establish a diagnosis. This is typically performed with a small endoscope placed in the nose or mouth during the office evaluation. This evaluation is called laryngoscopy which may or may not include videostroboscopy.
- Videostroboscopy refers to use of special lighting that can show the vibratory characteristics and greater detail about the function of the vocal cords.

### Imaging (x-rays)

- Typically, are obtained if no source for the paralysis is identified by history or examination. Most commonly, a CT (CAT or computerized axial tomography) scan that evaluates the neck from the bottom of the skull to the mid-chest is ordered. The physician is looking for anything that may be pushing or injuring the laryngeal nerves.
- Depending on a particular situation, imaging of the brain or thyroid may be considered.
- Swallow studies
  - If there are swallowing problems, a dedicated swallow evaluation with imaging may also be obtained, typically in conjunction with a speech-language pathologist.

### Laboratory testing

- Not routinely performed for evaluation of VCP.

### Laryngeal electromyography (EMG)

- This is a specialized evaluation that may be used to assess the degree and pattern of neurologic impairment of the vocal folds. It can be used to help discern mechanical immobility from neurologic paralysis.
- Some feel this is useful both for diagnosis and for prognosticating outcomes, while others do not think this impacts or changes management in a significant way.
- This test requires placement of small electrodes (i.e. needles) into the muscles of the voice box to measure their electrical signal and infer information about nerve function.

## TREATMENT AND PROGNOSIS OF VCP

If an underlying cause for VCP is identified, it would be addressed and managed. Once injured, nerves may or may not heal, and they typically heal slowly. Spontaneous healing of the RLNs can take 6-9 months, on average.

If the nerve heals on its own, full function may recover. If it does not, the physician and speech-language pathologist's goals are focused on effective rehabilitation of voice, breathing, and swallowing. With effective treatments, most patients can enjoy near normal laryngeal function. Most people with unilateral VCP seek treatments to improve their voice, more so than swallowing or breathing.

Some patients are recommended or choose to do nothing and wait out the problem to heal. If spontaneous healing is to happen, it typically occurs in 6-9 months.

Voice therapy by a speech-language pathologist may help the patient optimize use of their impaired larynx. They can also help to avoid maladaptive behaviors that the patient may develop on their own without such intervention. Voice therapy is often recommended as an adjunct for those with severe impairment, and possibly as sole treatment for those with mild impairment.

The otolaryngologist can help rehabilitate those with unilateral vocal cord paralysis with a variety of techniques. These techniques can be used on their own or be combined. All these procedures are highly effective at improving laryngeal function.

### Injection laryngoplasty

- Material is injected into the vocal cord to augment or bulk it up such that it contacts the other working vocal cord more effectively. This procedure may be done in the office or in the operating room. Material can be injected through the mouth or through the neck depending on a physician's preference of technique.
- In the office, this technique is performed while the patient is fully awake and with local injected or topical anesthesia. Patients can

go about their day typically within a few minutes after the procedure.

- In the operating room, the patient is under anesthesia as a short case, and the material is typically injected through the mouth.
- There are a variety of materials that can be injected, some last a shorter time, and some last a longer time.
- Many of these materials used are considered 'off-label' and are more specifically made for the skin. One's own fat can also be used as a material to augment a vocal cord.

### Medialization laryngoplasty/Laryngeal framework procedures (also known as type I thyroplasty and/or arytenoid adduction)

- These are procedures performed in the operating room where a small implant and/or a suture is used to place the paralyzed vocal cord into a position where it can contact the other working vocal cord more effectively. This is a permanent procedure.
- These procedures are often performed under 'twilight' anesthesia, where the patient is somewhat awake and can talk to the physician as the implant is adjusted.

### Reinnervation

- In this operation, a working nerve from the neck may be connected to the nerve going to the voice box that is not working. This is performed under general anesthesia.
- This operation does not restore vocal cord motion. The outcome of this technique is similar to the other techniques where the rehabilitated vocal cord is made to contact the other working vocal cord more effectively.

In bilateral VCP, treatment goals are directed towards improvement of breathing. The voice is not typically the problem. Most of these treatments are surgical with a goal to make a wider breathing pathway through the voice box. These all come with risks to one's voice (making it weaker) or swallowing. A tracheotomy may be considered in some patients as well.

Some treatment options include:

### Posterior transverse cordotomy

- This operation is typically performed with a laser through the mouth. Tissue from the rear of the vocal cord is removed to widen the breathing passage.

### Suture lateralization

- Another operation performed through the mouth. A stitch may be used to pull the paralyzed vocal cord open to widen the breathing passage.

### Arytenoid abduction

- This operation is performed through the neck. A stitch may be used to pull the joint of the vocal cord open to widen the breathing passage.

### Selective abductor reinnervation

- This very specialized operation is performed through the neck. Working nerves are connected to the impaired nerves responsible for opening or widening the voice box.

### Botulinum toxin injections

- Some select patients can be managed by weakening their vocal cords with botulinum toxin. This can be performed in the office with the patient awake.

### Tracheotomy (AKA tracheostomy)

- A tube is placed directly into the trachea through the skin of the neck to allow a patient to breathe. This 'bypasses' any narrowing of the voice box.
- This may be required on a temporary basis for some patients when operating on narrowed airways.
- Some patients require this for the long term.

A speech-language pathologist may also recommend a specific type of therapy to help reduce the work of breathing.

In patients that have vocal cord immobility due to a scar or problem with the joints of the voice box, a variety of techniques, including some of those mentioned above, may be utilized. Other specialized techniques of tissue manipulation or stenting may be considered. Patients with these problems are typically managed in the operating room.

# Understanding the Impact of Vocal Cord Paralysis

with Michelle R.E. Donovan

***We talked to Michelle Donovan, who has vocal cord paralysis (VCP), for insight into what it is like to live with this disorder. She was a panel member during the 2021 Virtual Symposium on treatment options.***

## **How does VCP impact you?**

This is such a tough question for me as being diagnosed with VCP has totally changed my life on a daily basis. I was diagnosed a little over two years ago, had just started voice therapy and had my first injection when the pandemic hit. The struggles with maintaining social distancing with a voice disorder were taxing.

Talking through a mask, plexiglass, and maintaining social distances resulted in me carrying a small notepad to write down basic speech – such as an order at Starbucks. (During the pandemic, I wore a mask that called out my unseen disability with the phrase “Please bear with me. I have a voice disorder,” available from the NSDA/Dysphonia International.)

I used to take something as simple as my voice and breathing for granted. The realization that I cannot yell, scream, or sing is an ongoing grieving process. I cannot yell for my daughter in a store, sing during Mass or scream at a concert or at a sporting event. Even singing ‘Happy Birthday’ to someone is a faded memory. Most of all, I tend to sit quietly and listen more to others, whereas before, I was the

“life of the party”. I can no longer talk louder over noise in a restaurant, store, or even on a phone call to someone who is not in a quiet place.

As an attorney, the challenges with my VCP affect not only my health but my livelihood. I have to use a microphone or an amplifier in court when I never needed one. The judges and my colleagues have been very understanding with my asking for an accommodation.

For the first time in my life, I wear a medical ID bracelet identifying my unseen disability and a notation for a small intubation tube if ever needed. Living with VCP has changed my life forever, and unfortunately there is no miracle cure, magic pill or surgery that can give me back what I lost.

## **What differences do you see in your challenges with VCD versus SD?**

I’ll take the ability to breathe over being able to speak any day. The Botox® injections I take are a godsend but only provide temporary relief until the next one. Voice therapy has been a lifesaver to assist in learning breathing techniques, but everyday struggles are real. For me, aspirating is common, but I’ve learned not to panic when it happens.

## **Any tips or tricks you can suggest for people with VCP?**

The best advice is to have a wonderful medical team that not only understands VCP or SD but



can treat it! Voice therapy, rather than speech therapy, is a must!! And continue to do the voice therapy exercises. Unfortunately, this is not like rehabilitation after a surgery. VCP/SD is a lifelong diagnosis that requires daily maintenance. Find a support group, friends and family who understand when you need help. It’s ok to ask for help. If I’m with people in a loud environment, I’ll ask someone to talk for me because I know I can talk in someone’s ear in a loud place, but I cannot talk over the background noise.

## **Anything else you would like to share?**

I’ve learned that one’s voice is the very essence of who we are. It’s unique to each individual. Mental health is just as important as maintaining physical health, and faith helps too.

## **Online Support for Vocal Cord Paralysis**

Michelle is a moderator for a private Facebook group called the Vocal Cord Paralysis Support Group, where you can connect with others living with this challenging voice issue. From the group description: Whether through disease or injury, damage to the vocal cords can have a devastating impact upon the lives of sufferers. You don’t realize how precious the gift of speech is until it has been lost or has been impaired. Hopefully, this group will serve as a site of support and encouragement for those dealing with a most difficult and frustrating condition. To join this group, go to <https://www.facebook.com/groups/189179717767866> or search for the name of the group Vocal Cord Paralysis Support Group.

# You are the **EXPERT** | Tools, Tips, and Techniques for Living with Spasmodic Dysphonia and Related Voice Conditions

Living with a voice disorder presents its own challenges. We asked our community what tools, tips, or techniques work best for them to help make your life a little easier. This is a compilation of the advice that was submitted.

## TOOLS TO HAVE ON HAND

- A voice disorder card NSDA/Dysphonia International which I keep in my purse or wallet
- A visor card that I keep in my vehicle to explain my voice disorder
- A mask that says, "Bear with me, I have a voice disorder"
- Notebook and a pencil
- The speaker option on my phone helps me use a softer voice
- A whistle, in case of an emergency
- A SHIDU voice amplifier to use when I teach a class or am having a bad day
- A portable, USB waist-band portable PA system with a headset microphone
- A small dry erase board to write on. If nothing else, you'll find a kid to play tic tac toe or draw pictures with!
- A pair of ear buds for talking on the phone or on a Zoom call
- A small Boogie Board which is a reusable writing tablet to write messages

## MANAGING YOUR VOICE

- Avoid stressful situations
- Schedule my next Botox® injection as soon as I feel a spasm return
- Sometimes it is easier to use my voice in the early morning
- Drink enough water
- Alcohol seems to help too

## TECHNIQUES

- Speak three words at a time for more control before a spasm dominates
- Use baby talk to get the words out
- Try humming to activate the vocal calls before initiating speech
- Some words and phrases are easier to say than others. When you answer the phone, it might be easier to say "Yes, good morning" rather than "Hel-lo"
- I breathe in and then use a straw to breathe out slow and controlled. I find this helps me focus on relaxing the muscles
- I like to prepare in advance and slow the pace of my speaking
- I try to remember to pause and breathe as I am speaking
- I try not to interrupt others when they are speaking, and expect to be treated the same way

## PRACTICE

- Do a musical scale to warm up my voice before making a call
- The best tool for me was accepting that I had a voice disorder
- Practicing breathing exercises helps me on the phone
- Put your listener at ease by explaining I have a voice disorder that breaks up my speech; I'm not nervous or upset and am happy to repeat my message if needed. This helps me relax so my voice is better

## RELAXATION EXERCISES

- I try to smile, and look at the listener when I speak
- Anything you do must be regular and frequent to get the best results
- Take tai chi and yoga classes to learn how to breathe from the diaphragm

## WHAT YOU LEARNED ABOUT YOURSELF

- I have the courage to speak loudly
- I'm easily recognized when I speak
- I've become a better writer and my sense of humor has improved
- Realizing that when I tell people I have a voice disorder, they are very understanding and none of the outcomes I feared actually happened
- I've become a better listener
- I can help others with SD and related voice conditions
- My voice disorder is not who I am

## NAVIGATING THE JOURNEY

An unexpected diagnosis of a voice disorder can lead to many more questions. We are here to help you navigate the next steps. Explore the section on our website called, *Your Journey*, on our website. There you can find pages on relationships, employment, and socializing, along with insights on acceptance, self-esteem, managing stress, public speaking and much more!



# Communication Tips for Virtual Interactions

## USC Voice Center, Los Angeles, CA

Many of us started using videoconferencing more frequently due to the pandemic but it seems that this modality is here to stay for the long run. Video calls can be of great benefit for staying in touch with loved ones or working from home, but they can also result in voice fatigue. There is a natural tendency to talk louder when using videocalls or speaker phone (called “cell yell” effect), and this can lead to vocal fatigue or other voice problems like hoarseness, increased vocal effort, or a feeling of strain or tension in the throat. You can help prevent these by taking vocal breaks or “naps” between calls, staying well-hydrated, warming up your voice, and using good audio technology to support virtual communication exchanges. Find more tips in this handout! *Please note that the equipment mentioned is not an endorsement but rather serves as an example of a product that could be helpful.*

### Technology

#### Preferred devices should include:

- Background Noise suppression
- Live monitoring of the microphone for the voice and independent volume controls

#### Headset

- Example: Turtle Beach Recon 200 (\$60)
- All-in-one portable solution: headphones + microphone
- Good background noise cancellation with live feedback of the voice and independent volume controls.
- Best option if a quiet room is not available for interactions.
  - Available online at: [www.turtlebeach.com](http://www.turtlebeach.com), amazon or BestBuy.



#### USB microphone

##### Example 1: Blue Yeti USB microphone (\$100)

- Significantly improved sound quality.
- Best suited for podcasters/voice actors or recording artists.
- Available online at: [www.bluedesigns.com](http://www.bluedesigns.com) or amazon.



##### Example 2: Samson Go Mic Portable USB Condenser Microphone (\$40)

- Small, portable/affordable solution. However, not the best sound quality.
- Does not provide independent volume control of voice feedback.
- Best suited for meetings and virtual communications on the go.
- Available online at: [www.samsontech.com](http://www.samsontech.com) or BestBuy.



- A USB microphone will require for you to be in a quiet room for best results.
- Not an all-in-one solution: You will need to purchase headphones independently with this option or use your own headphones connected to this microphone.

#### External audio interface connected to your computer via USB

- Example: Scarlet solo studio 3rd generation (\$220)
- Preferred option for virtual voice lessons or voice therapy sessions, recording artists and individuals seeking for the best quality of sound in their work from home set-up.
- Provides the flexibility to connect an instrument at the same time.
- Includes a condenser microphone and separate headphones
- NOTE: You will need to purchase a microphone stand for this option.
  - Available online at [www.store.focusrite.com](http://www.store.focusrite.com) or guitar center.



## Additional Tips

### Optimize the environment

- Reduce background noise for all participants.
- Use a headset or headphones.
- Make your full face visible.
- Adjust lighting to avoid shadows.
- Use a simple background to minimize distraction.
- Make sure you have a stable internet connection.
- Wired connection is always preferred over WIFI to reduce latency/lag.

### Vocal Health

#### Budget your vocal dose

- Take short vocal naps during the day.
- Monitor your vocal loudness by:
  - Reducing background noise
- Using audio technology that picks up your voice clearly and can offer simultaneous feedback of your own voice

#### Warm-up your voice before voice demands

- You can use your individualized vocal warm-up routine developed in voice therapy with your clinician. If you don't have one, gentle humming for a few minutes could help.

#### Stay well hydrated

- Sip water throughout the day.
- Utilize surface hydration strategies if you feel dry or vocally fatigued such as steaming, nebulized saline, using a humidifier or using non-mentholated lozenges.

### Safe Listening

- Monitor output/volume level (Be careful. If you are turning up the volume to block out background noise, this can be dangerous.)
- Take listening breaks.
- Seek earbuds and/or headphones that fit your ear comfortably and minimize background noise.

## ZOOM TIPS

Virtual meetings have become more common place over the last few years. We put together this list of suggestions to help you and the other participants have a positive experience. We hope it is helpful and look forward to seeing you at a virtual meeting soon!

- 1 Find a private area for your call so that you are not interrupted.

Let others in your household know you are on a Zoom call. If you are interrupted by someone or something during the call, turn off your camera so that other people in the audience are not distracted by the interruption.

- 2

- 3 Adjust your screen so that your whole face is on camera. If you are using your phone or a tablet, try to have it on a stable surface.

- 4 Test your audio and video as you join to make sure everything is working properly.

- 5 Using a USB headset or microphone may help project your voice.

- 6 Mute your microphone if you are not speaking.

- 7 Turn off your camera if you need to get up from your seat during the call.

- 8 Do not eat during meetings. It is ok to have your coffee or water glass nearby though if you need something to drink.

- 9 Try to look at the camera if you are speaking.

- 10 Find Zoom meetings you can attend on our website at [dysphonia.org](http://dysphonia.org).

# 2023 Dysphonia International SYMPOSIUM April 29, 2023

After three years of virtual symposiums, Dysphonia International plans to return to an in-person format on April 29, 2023, at Embassy Suites by Hilton Detroit - Livonia/Novi in Michigan. Join us to hear leading experts in spasmodic dysphonia and related voice conditions and have the opportunity to meet others who share a similar experience.

## What can you expect if you attend this meeting?

- Attend the inaugural meeting of Dysphonia International.
- Meet others and share YOUR story about living with a voice disorder at the Welcome Party on Friday evening prior to the symposium, and, if a first-time attendee, sign up for the Ambassador Program.
- Hear updates on the latest developments, including research, on spasmodic dysphonia from experts in the fields of laryngology and speech and language pathology.
- Your questions answered during panel discussions with the medical presenters.
- Fellowship, education, and fun!

## Event Schedule

On Friday, April 28, 2023, join us for Welcome Party at 7:30 PM ET. It is a wonderful opportunity to socialize and meet many new friends. Don't miss the "pass the mic" portion, where you can share your voice journey. The Symposium will begin at 9:15 AM ET and conclude at 4:45 PM ET. An optional dinner will follow the evening. Be sure to check our website for more details.

## Hotel Information

The Symposium will be held at the Embassy Suites by Hilton Detroit - Livonia/Novi located at 19525 Victor Parkway, Livonia, MI. A special rate of \$129 plus tax for a single or double room is available until April 11, 2023, or sooner if the room block fills. Enjoy spacious accommodations in this all-suite hotel, where a separate living area and bedroom are standard. This rate includes complimentary Wi-Fi, a cooked-to-order breakfast, and an evening reception.

## Transportation

The hotel is located off I-275 in southeast Michigan, within 25 minutes of Detroit Metropolitan Airport (DTW) and downtown Ann Arbor. Downtown Detroit is 26 miles away. A taxi or a ride share like Uber and Lyft are about \$35-40 each way from Detroit Metropolitan Airport. Self-parking at the hotel is free for hotel guests and Symposium attendees.

## About the Area

Detroit is the largest city in the Midwestern state of Michigan. Near Downtown, the neoclassical Detroit Institute of Arts is famed for the Detroit Industry Murals painted by Diego Rivera and inspired by the city's ties to the auto industry, giving it the nickname "Motor City." Detroit is also the birthplace of Motown Records, whose chart-topping history is on display at their original headquarters, Hitsville U.S.A. Livonia is a western suburb of Detroit. <https://visitdetroit.com/>



**REGISTER  
HERE**

# WATCH VIRTUAL Symposiums ON-DEMAND

Over the last three years, our annual symposiums have been in a virtual format totaling over 18 hours of content. We are so grateful to our presenters for generously sharing their experience, knowledge and time. All the presentations listed below, along with recordings from a new webinar series, can be found at [www.youtube.com/NSDA300](http://www.youtube.com/NSDA300).



## 2022 VIRTUAL SYMPOSIUM April 30, 2022

### PANEL DISCUSSIONS

#### **You Belong – Your Role in Research**

*Panel Discussion with NSDA | Dysphonia International Researchers*

Dr. Divya Bhaskaran, Dr. Vincent Gracco, Dr. Christopher Honey, Dr. Juergen Konczak, *Short Video Presentation - Dr. Scott Norris and Dr. Evan Gordon*

#### **You Belong However You Communicate**

*Staying Connected through Communication: Patient and Communication Partner Perspectives*  
Dr. Carolyn Baylor

#### **You Belong | No Matter What Age**

*Panel Discussion on Living with a Voice Disorder: A Younger Perspective*  
Rachel Holtzman, Christie Deluca, and Kara Henderlight

#### **You Belong to Dysphonia International**

*Transition to Dysphonia International - Charlie Reavis*  
*An International Perspective - Video Presentation - David Barton*  
*Expansion of Support - Mary Bifaro, Support Join Us for Walk for Talk - Kimberly Kuman*

## 2021 VIRTUAL SYMPOSIUM May 1, 2021

### PANEL DISCUSSIONS

#### **Three Ways to Keep Life in Balance: Be Present, Open Up, and Do What Matters**

Dr. Amy Heard, Dennis Kaszeta, and Rev. Dr. Rebecca Cole-Turner

#### **Treatment Paths for Spasmodic Dysphonia and Related Voice Conditions**

Dr. Julie Barkmeier-Kraemer, Dr. Joel Blumin, Michelle R. E. Donovan, Erik Laurence, Bruce Menk, and Dr. Bonnie Smith

#### **Moving Research Forward to Find Answers**

Dr. Russell Banks, Dr. Divya Bhaskaran, Risa Clay, Dr. Christopher Honey, Dr. Michael Pitman

#### **The Next Chapter of an Organization and Speechless No More**

Charlie Reavis, Susan Beck, Marcia Sterling and Dot Sowerby

### RECORDED PRESENTATIONS

#### **Clinical Assessment and Treatment for Individuals with Vocal Tremor**

Julie Barkmeier-Kraemer, PhD, CCC-SLP

#### **Stopping Adductor and Abductor SD at its Source: Results of the NSDA-Sponsored “DEBUSSY” Trial**

Christopher Honey, MD

#### **Dystonia is All in Your Head: How We Know and What to Do About It**

Teresa Kimberley, PhD, PT

#### **Can Vibration of the Larynx become a Symptomatic Treatment for SD?**

Jürgen Konczak, PhD

#### **Treatment of Laryngeal Dystonia with an Electrical Neuromodulating Implant – An Update**

Michael Pitman, MD

#### **Voice Therapy for Spasmodic Dysphonia: Let’s Put it into Context**

Bonnie Smith, PhD, CCC-SLP

## 2020 VIRTUAL SYMPOSIUM May 2, 2022

### PANEL DISCUSSIONS

#### **Keynote: An Interview with Jaime Schmidt**

#### **Q&A with Healthcare Professionals**

Dr. Adam Rubin, Dr. Gerald Berke, Dr. Juliana Codino, Dr. Glendon Gardner, Dr. Ross Mayerhoff

#### **Living with a Voice Disorder Panel Discussion**

Warren Bandel, Mary Bifaro, Christie DeLuca and Scott Flanagan

#### **Q&A with Voice Researchers**

Dr. Carolyn Baylor, Dr. Michael Hammer, Dr. Juergen Konczak, Dr. Arash Mahnan and Dr. Yin Yiu

### RECORDED PRESENTATIONS

#### **Laryngeal Mechanoreceptors and Laryngeal Motor Control**

Michael Hammer, PhD, CCC-SLP

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

Juergen Konczak, PhD

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

Yin Yiu, MD and Michael Pitman, MD

#### **Understanding Spasmodic Dysphonia**

John Ingle, MD

#### **The Team Approach to the Patient with Vocal Fold Paralysis/Paresis**

Adam Rubin, MD and Juliana Codino, CCC-SLP

#### **Spasmodic Dysphonia, Vocal Tremor, and Muscle Tension Dysphonia: A Voice Therapy Perspective**

Caroline Ziegler, CCC-SLP

#### **Botulinum Toxin Injections for Spasmodic Dysphonia**

Glendon Gardner, MD

#### **Alternative Injection Approaches for SD and Vocal Tremor**

Ross Mayerhoff, MD

#### **Surgical Procedures for Abductor and Adductor Spasmodic Dysphonia**

Gerald Berke, MD

#### **Voice Techniques to Manage Symptoms of SD and Related Voice Conditions**

Christie DeLuca, CCC-SLP

#### **Develop Resilience and Master the Art of Thriving**

Dorothy Tannahill-Moran



# World Voice Day

World Voice Day is celebrated every April 16th with the main goal of increasing public awareness throughout the world of the importance of the voice and the impact of voice problems. This celebration started in Brazil in 1999 as the Brazilian National Voice Day. This Brazilian initiative was followed by other countries, such as Argentina and Portugal, and the Brazilian National Voice Day became the International Voice Day. In the United States, the American Academy of Otolaryngology – Head and Neck Surgery officially recognized this celebration in 2002 and in that year the event obtained the name World Voice.

Awareness is a critical factor that influences early diagnosis, best treatment practices, funding for research and hopefully, cures. World Voice Day helps support these goals.

Each year a different theme is chosen, and our community is encouraged to raise awareness about spasmodic dysphonia and related voice conditions. In honor of the 2021 World Voice Day theme, One World | Many Voices, members of our community recorded videos discussing the differences (if any) with having a voice disorder where they live, and what is common regardless of location. We heard from people in Canada, Japan, New Zealand, Singapore and the US. For 2022, the theme, Lift Your Voice, members of our community shared how they express themselves beyond their voice, whether it be through music, art, dance, or the written word.

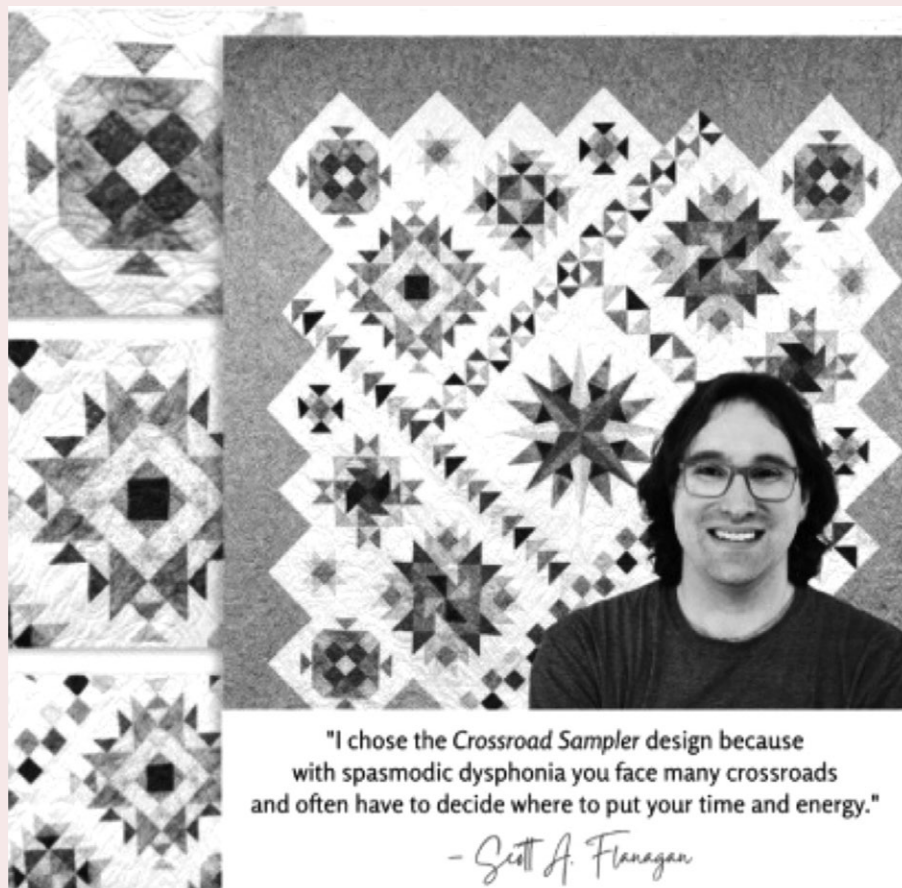
## Speaking Beyond Your Voice: Creative Outlets for Self-Expression

We were inspired to create a new program for Dysphonia International which is called, *Speaking Beyond Your Voice: Creative Outlets for Self-Expression*. This will be an ongoing project. Self-expression is about communicating your individuality – your story, your thoughts, your feelings, and your emotions. It is a basic and critical need. It helps others understand us. It highlights our personality, conveys our needs, and connects us with others. Take the voice away, and a person's primary form of expression is also

removed, but the need to be heard remains. That is why art can provide a unique and alternate form of self-expression that can be even more important to those who have lost their voice due to a vocal disorder such

as spasmodic dysphonia. Artistic expression communicates what words cannot. The creative process may also allow for greater understanding, self-reflection, and even healing. Learn more at [dysphonia.org](http://dysphonia.org)

## World Voice Day Highlight



### Special thanks to Area Contact Leader **Scott Flanagan** who uses his art to raise awareness and funds for research during World Voice Day

"One of my main missions since my SD started in 2017 has been to raise awareness and raise funds for SD research and treatment. Quilters are some of the most caring and supportive groups of people I know, so for the past couple of years I have offered a quilt pattern in return for a donation to the NSDA. In 2022, I decided to give away a quilt from my collection to one lucky person who donated to the organization. The quilt I chose to give away is my popular "Crossroads Sampler" that is 96" x 96" I chose this quilt because with SD you face many crossroads and often have to decide where to put your time and energy. Do you quit a job you love because it's too vocally taxing, or do you try to work around the SD? How do you go out and socialize in loud situations when it's difficult to talk and communicate in a quiet room? Do you make a phone call yourself or do you wait and ask for help to make life easier? A common quilt block I work a lot into my quilts is Flying Geese. For one they are one of my favorite quilt blocks to make, and also two geese use their "voice" to signal the changes in seasons as they fly south for the winter and north for the summer, much like my voice is signaling a change my life and a crossroad where I have to learn to live with an ongoing voice disorder."

# SPEECHLESS NO MORE



Available for purchase  
for \$15 at [dysphonia.org](http://dysphonia.org)



## ***Speechless No More: A Life Transformed by a Voice Disorder***

is a memoir by Dot Sowerby about her struggles with a voice disorder that rendered her speech tremulous and broken. It is a lesson

in courage and persistence during a time when the medical profession was just beginning to understand the neurological basis of spasmodic dysphonia. Dot's story, like so many, is about navigating an obstacle course of faulty diagnoses and self-doubt before she came to understand the source of her condition. Both distressing and inspiring, her quest to find answers to the cause of her voice disorder and find a treatment for it is told with honesty and spirit. This new edition of *Speechless* covers the next twenty years of Dot's life and twenty more years of progress in the treatment of spasmodic dysphonia, thanks in part to the passion and energy of all our friends and colleagues who work tirelessly to support the work of the NSDA, now Dysphonia International.

## **From the Author Dot Sowerby:**

I hope this book will mean something to you as it means a lot to me. I guess every person struggles with something in their life, but spasmodic dysphonia is no small thing. I'm pleased that I didn't let it get me down. Well, sometimes it did get me down. But I have had a wonderful life so far and I'm looking forward to a lot more fun in the years ahead. I feel like all of us in this community are family. We share so many of the same struggles. I would say this to you: Find things other than speaking that help you shine – whether that's running in a race or sharing with your grandchildren or packing up lunches for the homeless or smiling at the handsome gentleman at the next table in the coffee shop. Life is too short to miss out on the things that give you pleasure or the things that help other people. Remember, you are never too old and don't EVER give up!

## **Thoughts on *Speechless No More***

By *Stephie Mendel*

"He-ll-o," I croaked in a taut, strangled voice." Dot Sowerby wrote.

I knew I had to read this book that told it like it was, not covering up the despair a person can feel when their voice feels broken.

"*Tha t's me,*" my fractured voice tried to shout! *Tha t's me! I'm no t cra zy.*" I felt hope taking over despair. I wasn't alone. I wasn't alone anymore.

***Speechless No More*** has the same tone as *Speechless*, which I read in the 1990s when I was first diagnosed with spasmodic dysphonia. This new edition has Dot's same clarity, plus it brings us up to date on the progress that has taken place since then for both spasmodic dysphonia and for the NSDA/Dysphonia International.

A section of the book is written by Larry Kolasa, the founding President of the NSDA. Larry says, "Dr. Daniel Truong is a special person because you cannot say no to him. He told me, 'Larry, we are going to start a national organization and you are going to be the President.' I immediately said no. Soon after I said, "OK, I'll do it."

Larry said, "We have a common objective—to support people with spasmodic dysphonia. When we started, we didn't have cell phones or email. Despite what we were able to do, our early years were really difficult. We had no money and we were all volunteers. We had no office. We used my dining room table and the trunk of Rick Johnston's car. People from the local Detroit Support Group helped us by answering mail and taking requests." And, of course, you guessed it—Dot Sowerby was one of the original nine volunteer Board members.

Larry writes about the phenomenal growth of the NSDA. I'm especially encouraged by



Larry writing, "There have been more research papers on SD written since 2017 than there ever were in the previous twenty-seven years of our thirty-year history."

Also included in the book are write-ups on the recipients of the Dot Sowerby Pioneer Award: Pat Hill, Karen Adler Feeley, David Barton, Charlie Womble, Mary Bifaro, and Marcia Sterling. All dear people. I once asked if there was any research on why only nice people are able to get SD?

There is also a section providing an overview of spasmodic dysphonia. I'm also grateful to Michael Rontal, MD, for his explanation of sound production.

As a fellow SD-er and close friend of Dot Sowerby, I am honored to be given the opportunity to review this book. Dot asked me to be on the all-volunteer Board and I stayed for sixteen years while also being a Support Group Leader for seventeen years. When I stepped down from these privileges, I was sadly aware that I would no longer be meeting with my NSDA/Dysphonia International family. How many nonprofit Boards become like family? My life is fuller because of friendships I've made through this wonderful organization.

After Dot walked across the Golden Gate Bridge when she visited our local support group, we hosted a Walk across the Bridge as a fundraiser for the organization to honor her.

In closing, in addition to Dot being a close friend, she has continued to be an inspiration to me. That's the same inspiration that Dot, now 89, continues to give to the whole community. A terrific read.



# GUEST SPEAKER PROGRAM FOR SLP STUDENTS

The Guest Speaker Program for Speech-Language Pathology (SLP) Students brings the personal side of living with a voice disorder into college and university classrooms. Your voice is the best educator to help increase understanding of vocal disorders and make a long-lasting impact on future practitioners.

This program offers you the opportunity to talk about your voice experience, everything from your initial symptoms to your diagnosis and treatments and the impact it has had on your life. Through this narrative learning experience, the goals are for SLPs to:

- Better understand the impact of voice conditions on quality of life
- Gain insight into how they can better help patients as future practitioners
- Help quicken the time of diagnosis for vocal disorders by recognizing these voice conditions.

Depending on the class format, presentations can be done in person or virtually. With step-by-step instructions from Dysphonia International, you can create an impactful and meaningful experience for you and the SLP students. Contact us at [outreach@dysphonia.org](mailto:outreach@dysphonia.org) for more information.



Tampa, FL

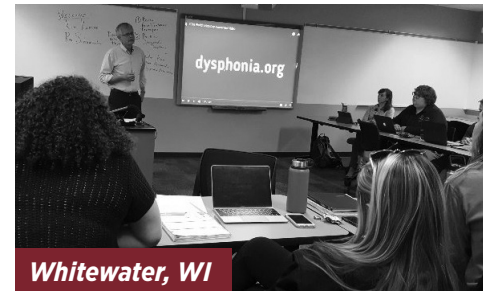


“Year after year, these presentations enhance my students learning beyond what a textbook can provide. The opportunity to hear the speaker’s personal story and their voice quality is not only informative for my students but also inspirational.”

— Nathan Waller, MA, CCC-SLP  
Northwestern University Instructor

“We are the ones usually on the receiving end of treatment and attention. Being a Guest Speaker not only increases SD awareness allows us to be teachers and advocates. It becomes one of the few places where my voice is treated with value and respect, no matter what vocal quality I am having on that day. Students are eager to hear us and learn. I always have fun and feel uplifted!”

— Victor Cheers, EdD



Whitewater, WI

## PROFESSIONAL MEDICAL CONFERENCES

In 2022, we debuted our organization’s new name and branding to our healthcare community at the Fall Voice Conference and ASHA Convention. These in-person meetings were well attended after the last few years of being virtual and hybrid. It was great to connect with so many laryngologists and speech-language pathologists and share how we can partner with them and support their patients. There was much enthusiasm around the expanded mission and being a resource for even more people living with voice conditions like muscle tension dysphonia, vocal tremor, and vocal cord paralysis. In addition, Dysphonia International funds Research Travel Awards to many professional voice conferences to help disseminate research findings and encourage collaboration among investigators. We look forward to expanding this program to international conferences in 2023.



Dot Sowerby and Susan Beck at the 2022 ASHA Conference in New Orleans



SLP Sara Davis, Charlie Reavis, and Nicole Leitner at the 2022 Fall Voice Conference in San Francisco



# AWARDS

## MIDGE KOVACS ANNUAL AWARENESS AWARD

Since 1999, the NSDA has presented the Midge Kovacs Awareness Award to recognize the outstanding efforts of one of its support groups for their work the previous year to honor the pioneering advocacy work of the late Midge Kovacs. Midge was a founding Board member of the NSDA, started one of the first support groups, and published the original *Our Voice* newsletter, to raise awareness about spasmodic dysphonia. In a note to the NSDA community in 2000, Midge encouraged all of whom are struggling with spasmodic dysphonia to think beyond our own individual voice problems.

**2022** | The 2022 Midge Kovacs Annual Awareness Award was presented to Valley of the Sun group led by Co-Leaders, Esther Zack and Vicki Orazem. This group has participated in three Walk fundraisers. Esther served on the Planning Committee of both the 2020 and 2021 Walk for Talk events. Vicki was a Virtual Leader for Montana before becoming Co-Leader for Arizona. Both leaders are active on Virtual Support Group Meetings and social media. Support Network Director, Mary Bifaro, presented the award at the 2022 Virtual Leadership Workshop.



Esther Zack



Vicki Orazem



Ilene Cooper



Cindi McCullough

**2021** | The 2021 Midge Kovacs Annual Awareness Award was presented to the Atlanta Support Group led by Co-Leaders, Ilene Cooper and Cindi McCullough, with recognition being given to past Leader, Debbie States, as well as members, Laura Rahuba and Sue Payne. Support Services Director, Mary Bifaro, presented the award at the 2021 Virtual Leadership Workshop. Some of the group's accomplishments included receiving the Mayoral Proclamation for World Voice Day; and attending the private screening of the short film *Cookie*. Laura Rahuba's artwork won for 2019 contest for Celebrating Our Voice. Sue Payne was one of the top fundraisers for our 2020 Walk for Talk, while the Atlanta group was the top fundraising team in our 2020 Walk for Talk event.



Debbie States



Laura Rahuba



Sue Payne

## DOT SOWERBY PIONEER AWARD

Since 2015, the NSDA takes great pride in bestowing the Dot Sowerby Pioneer Award honoring founding Board member Dot Sowerby to recognize her many accomplishments in raising awareness about spasmodic dysphonia and related voice conditions. The recipients follow in her footsteps making a significant positive impact on the dysphonia community.



**2022** | The 2022 Dot Sowerby Pioneer Award was presented to Board Member and Founding President from MI, Larry Kolasa. Larry is the past Leader of the MI group. He has been serving on the Board since the founding of the NSDA in 1989. The award's namesake, Dot Sowerby, presented it to her at the 2022 Board meeting. In 1998, Larry ran a marathon benefit entitled, 'Running for Research'. The Million Dollar Roundtable Foundation with which he is associated has helped fund a number of NSDA projects over the years.

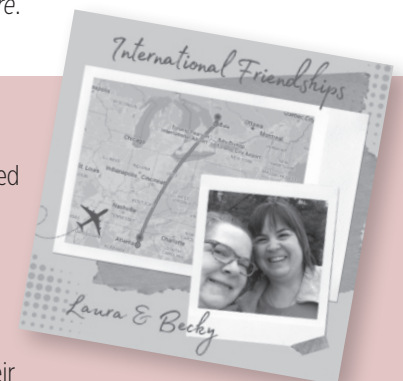


**2021** | The 2021 Dot Sowerby Pioneer Award was presented to Board Member and Silicon Valley Leader, Marcia Sterling. The award's namesake, Dot Sowerby, presented it to her at the 2021 Virtual Leadership Workshop. Marcia has led the Silicon Valley group for 15 years. She was NSDA Treasurer from 2007 to 2020. She has written a number of documents for the NSDA and is a past recipient of The Midge Kovacs Annual Awareness Award. She was instrumental in updating and publishing Dot Sowerby's new book, *Speechless No More*.

## INTERNATIONAL FRIENDSHIPS

The international friendship between Becky Lacroix and Laura Rahuba began in spring 2017, when they happened to be seated together during Leadership Workshop which proceeded the annual Symposium in Nashville, TN. Becky, who had travelled a long way from her home in Canada, was eager to share her ideas with the group. But her soft whispery voice wasn't loud enough to be heard by the whole room. Laura relayed the message on her behalf. They stuck together throughout the two-day event and stayed in touch afterwards.

Their friendship grew through conversations on Facebook Messenger, as they supported each other through their voice-related struggles. After re-locating to another state, Laura faced complications with her health insurance, resulting in a lapse of her Botox® treatment, during which time her voice deteriorated. Becky, still seeking an official diagnosis, was frustrated by the conflicting information she got from different health care professionals. Their online chats grew beyond SD, as they learned more about each other and shared bits of their daily lives. Laura was especially intrigued by Becky's pride and affection for her small, picturesque town of Bala and the surrounding Muskoka Lakes region, located in central Ontario. This prompted her to plan a trip to Canada, to visit Becky, meet her family, and be a tourist. In autumn 2018, Laura flew in from Atlanta, GA, and together the friends enjoyed a boat cruise on Lake Muskoka, a tour of a cranberry marsh, and the Anne of Green Gables Museum. Laura was welcomed by Becky's family as they celebrated Thanksgiving, which Canadians observe in October. As they approach the five-year anniversary of their friendship, Becky and Laura remain close, despite living a thousand miles apart.





## Slide Guitarist Co-Writes Song about a Broken Voice

▲ Wendy Jean Garrison | Photo Credit: Thad Lee

Slide guitarist Wendy Jean Garrison gives voice to her acoustic guitar – moving her hand up and down the frets, her pinky covered with a steel socket wrench. While her Mississippi blues sound comes easy for Wendy, speaking is harder. First noticing a change about fifteen years ago, eventually she was diagnosed with a rare neurologic vocal disorder, spasmodic dysphonia (SD). Involuntary muscle spasms impact the vocal cords, resulting in sometimes strained and strangled speech. During COVID-19, Wendy and Memphis-based Grace Askew, an award-winning songwriter and performer, joined together to co-write “I Have a Voice,” a heartfelt song about SD.

The song grew out of a request from Mary Bifaro, a longtime Board member and Support Network Director. For Mary, “It’s been a dream come true for me to unite our community through a song.” Through the organization, Wendy has found kindred spirits. She is an active member, area contact leader, support group leader, and has attended many national meetings, even performing at the symposium in Nashville, TN.

The song is part of Wendy’s musical journey. Raised in Maryland, in 1987, several years after college, she moved to Mississippi with her husband. “I was interested in the environment and Mississippi was a place where we could afford to buy land.” They put down roots on 80 acres. Wendy continued her studies and earned a PhD in biology from the University of

Mississippi. She went on to enjoy a long and satisfying career as a biology instructor there.

Along the way, music played a central role in Wendy’s life. Meeting blues scholar and harmonica player Walter Liniger at the University of Mississippi was a turning point. Liniger shared his gift with Wendy, who went on to study with blues guitarists James “Son” Thomas and Bill “Howl-N-Madd” Perry, and emulate the music of Skip James, Charlie Patton, and Robert Johnson.

Wendy said, “When I think about it, the slide is very much like a voice. Since I don’t sing, playing the slide is a way for me to communicate. That’s very appealing to me.”

Since 1996, Wendy has been a regular with local bands, including the “High Water Mark” and more recently, “Maybelle’s Lovers.” Her customized soundtracks were featured at the 2020 Tennessee Williams Festival and on the Hill County TV Network in New Albany, Mississippi, among others.

During the COVID-19 pandemic, Grace became Wendy’s songwriting coach. Grace said, “I had never heard of SD or the NSDA, so when Wendy brought this project to my attention, it was intriguing that we could write a song that could affect a whole community. When we started to write the song, the lyrics began to resonate with me. Even though I don’t have this condition, as a child, I didn’t feel heard, so I began to see myself in the song. When you write something,



▲ Grace Askew | Photo Credit: Laze L. Farm Photography

you don’t know how it will affect people from all walks of life even though it was written for a specific audience.”

Wendy added, “When I mentioned the idea of writing a song about SD, Grace was instantly on board. She asked me to explain what it was like to have a voice disorder. I tried to give some insight about what it is like day-to-day.”

The song reflects both the isolation caused by voice disorders like spasmodic dysphonia and the intense connections that can be formed through be part of the organization. “I Have a Voice” was featured as part of the 2021 Walk for Talk. This annual event brings together the organization’s community along with their family and friends to increase awareness about SD and related voice conditions and raise funds to support research to find better treatments and eventually a cure.



# Help Google Improve Speech Recognition

**PROJECT RELATE** is an Android app by Google. After providing the app with examples of your speech, you'll unlock access to 3 features: **Listen** (speech-to-text transcription), **Repeat** (repeat what you've said in a computerized voice), and **Assistant** (engage Google Assistant from within the Project Relate app). Project Relate is currently available to English-speakers 18+ in AU, CA, IN, US, and NZ, and Google is looking for people interested in trying the app and providing optional feedback on their experience. Become a tester by scanning the QR code that will take you to an interest form. Once you submit the form, Google will follow-up via email with a link to download the app so you can begin testing it.

## LYRICS

I have a voice  
But some of us don't have a choice  
To bring it out in the world  
How we want to

I have a voice  
A reason to rejoice  
But I wanna swallow my words,  
When the hollowness hurts

But I don't wish on lucky stars  
Cause' I've found that I'm not alone  
Finally, I'm building  
A place to call home  
I was never alone

May I have your attention, please  
Freedom of speech  
Ain't easy for everybody  
But we all need to reach

Out to one another  
To our sisters and brothers  
A new day is dawning  
New ways to keep talking

But I don't wish on lucky stars  
Cause' I've found that I'm not alone  
Finally, I'm building  
A place to call home

But I don't wish on lucky stars  
Cause' I've found that I'm not alone  
Finally, I'm building  
A place to call home  
My voice was never alone  
I was never alone  
I was never alone

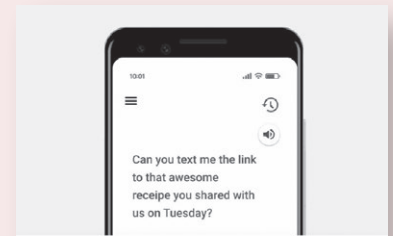
## SONG CREDITS

Co-written by Grace Askew and  
Wendy Jean Garrison

Vocals and guitar by Grace Askew

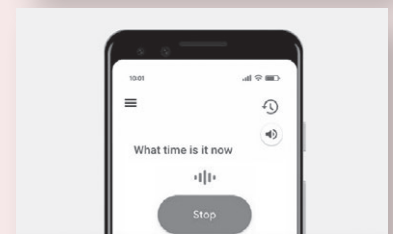
Slide guitar by Wendy Jean Garrison

Mixed and mastered by Ricky Burkhead



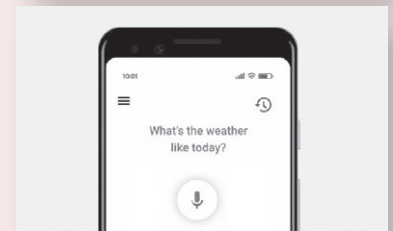
### Listen

Transcribe speech to text in the Relate app so you can use your voice to write docs or text messages.



### Repeat

Restate what you've said using a clear, computerized voice, for greater ease in face-to-face conversation.



### Assistant

Speak directly to your Google Assistant so you can take care of tasks such as setting a timer, playing a song, or asking for directions.





## DYSPHONIA INTERNATIONAL | A COMMUNITY THAT CARES ABOUT YOU AND YOUR VOICE



### RESEARCH

*Finding  
Answers*

#### To develop better treatments and discover a cure, we are:

- Funding seed grants to support breakthrough research and expand scientific understanding
- Sponsoring research travel awards to multiple professional voice conferences to increase engagement with young investigators and provide opportunities for collaboration
- Connecting researchers to our community by sharing updates and opportunities for participation in research and clinical trials
- Supporting resources, including a brain bank and a global patient registry



### EDUCATION & AWARENESS

*Building  
Understanding*

#### To share knowledge and increase sensitivity, we are:

- Organizing educational symposiums and webinars
- Publishing *Our Voice* and *e-Voice* newsletters along with educational brochures, books, articles, videos, and awareness tools
- Exhibiting at professional medical and voice conferences
- Hosting a website with an extensive repository of information
- Advocating on Capitol Hill with a focus on increasing funding for research
- Expanding awareness on World Voice Day and during Walk for Talk events
- Providing opportunities for our community to share their stories, including social media and presentations to current and future healthcare professionals, to personalize the impact of living with voice disorders



### SUPPORT

*Raising  
Hope*

#### To ensure no one feels alone, we are:

- Offering a welcoming place of compassion and understanding at in-person and virtual support meetings
- Cultivating and fostering engagement with our Support Group and Area Contact Leaders through workshops and training programs
- Expanding outreach and support internationally
- Creating new tools, resources, and programs to empower our community
- Highlighting the efforts of our volunteer support network in the quarterly online newsletter, *Voices of Support*