



2024 DYSPHONIA INTERNATIONAL SYMPOSIUM OVERVIEW

May 4, 2024 | Tampa, FL

By Mary Bifaro, *Support Network Director*

The 35th-anniversary celebration kicked off at our annual meetings in Tampa, FL, from May 3-4, 2024. The agenda was packed with events, including the annual Board of Directors meeting, the 20th Leadership Workshop of our Support Network, and the Symposium. The weekend drew close to 75 participants and was filled with educational, informative, and enjoyable activities. Tampa Support Group Co-Leaders Ron Langdon and James Anderson hosted the event, extending a warm welcome to all attendees. The Ambassador Program was particularly beneficial for first-time attendees, pairing them with experienced “buddies” from previous meetings to foster a sense of connection. Friday evening featured a Welcome Party, where attendees had the chance to forge new friendships and reconnect with old ones. During the “pass the mic” session, participants introduced themselves and shared their voice experiences. For many, it was a powerful and emotional first encounter with others who share similar voice conditions.

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

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

PLEASE NOTE: The videos from the Symposium are available to view on YouTube either by clicking the title of the presentations below or [click here for the full playlist](#).

[Welcome and Overview of Dysphonia International](#)

Charlie Reavis

Charlie has served as President since 2010. He stated that over \$500,000 in research funding has been distributed in the past four years. Approximately 86% of our budget goes to funding research, education & awareness, and support. This is a record that we can all be proud of. He expressed his appreciation for the support and commitment of our Dysphonia International community, as well as our professional healthcare providers and researchers, as evidenced by their participation in our programs and activities. He pointed out that our leaders, staff, and volunteers are actively engaged in many efforts to fulfill our mission. He added that we welcome people with all voice conditions to our unique family and community.



Understanding Voice and Speech

Darla Freeman, SLPD, CCC-SLP

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

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

Darla Freeman, SLPD, CCC-SLP

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

Botulinum Toxin Injections for the Treatment of Voice Disorders

Yassmeen Abdel-Aty, MD

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

A Discussion on Challenges and Successes in Laryngology

Yaël Bensoussan, MD, MSc, FRCSC

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



Dysphonia in the Digital Age

Elijah Moothedan, MS

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

Empowering Voices: Deciphering Relevant Brain Network in Spasmodic Dysphonia Research

Scott Norris, MD

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

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

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

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

Spotlight on Communication Devices

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

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



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

Roundtable Discussions

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

Walk for Talk: Honoring the First Step with Kimberly Kuman and Mary Bifaro

Executive Director, Kimberly Kuman, shared her vision in creating the annual Walk for Talk to raise funds for research, expand awareness, and unite people across the globe. Planning Committee Chair, Mary Bifaro, talked about the excitement and empowerment that individuals and groups felt in making a difference and participating. Every step gets us closer to a cure! This October event has embodied our collective commitment to making a lasting impact. In the past four years, Walk for Talk has raised close to half a million dollars. With the match, we reached one million dollars! We are already making plans for the Fifth Annual Walk for Talk to take place from October 17-20, 2024.

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

Final Thoughts

The three pillars of Dysphonia International are: Research, Education & Awareness, and Support. Our virtual meetings continue to attract more participation with renewed energy and enthusiasm. Our support network leaders provide energy and enthusiasm in their active communication. Our educational webinar series has been well received. Our annual Walk for Talk events in October have generated tremendous excitement and have become our primary fundraising and awareness-raising campaign.

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

DYSPHONIA INTERNATIONAL

SNAPSHOTS FROM THE SYMPOSIUM



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B

C

D

E

Captions go from top to bottom for each column.

Column A: Scott Flanagan and Warren Bandel | Le'Brandon Rose and Leah Rose | Nicole Leitner, Nancy Panos, and Kimberly Kuman | Lara Bruce and Tyler Kropf

Column B: James Anderson, Darla Freeman, and Ron Anderson | Tanja Turner Bell and Antoine Bell | Akash Raj Komarlu and Joris Castermans

Column C: Linda Fetters and Sue Payne | Yolanda Leon and K. Brianlysse Nicolena Cedeño | Barb and Ron Meteyer | Carol and Roger Doles

Column D: Beverly Messinger and Valerie Handelsman | Honey Shara and Toni Gold | Roundtable Discussion | Dennis Kaszeta and Symposium participants

Column E: Board of Directors | Leadership Workshop Participants | President Charlie Reavis

2024 SYMPOSIUM PROGRAM | MAY 4, 2024

TIME	SESSION	LOCATION
9:00 AM	Welcome and Overview of Dysphonia International Charlie Reavis, President	Westshore
9:20 AM	Understanding Voice and Speech Megan Urbano, BM, MS, CCC-SLP	Westshore
9:40 AM	Evaluating and Treating Voice Disorders: Role of the SLP Darla Freeman, SLPD, CCC-SLP	Westshore
10:00 AM	Botulinum Toxin Injections for the Treatment of Voice Disorders Yassmeen Abdel-Aty, MD	Westshore
10:30 AM	BREAK	Atrium
10:45 AM	A Discussion on Challenges and Successes in Laryngology Yaël Bensoussan, MD, MSc, FRCSC	Westshore
11:15 AM	Dysphonia in the Digital Age Elijah Moothedan	Westshore
11:35 AM	Empowering Voices: Deciphering Relevant Brain Networks in Spasmodic Dysphonia Research Scott Norris, MD	Westshore
12:05 PM	Question and Answer Session	Westshore
12:30 PM	LUNCH	Atrium
1:30 PM	Neuropsychological Considerations in Dysphonia: Identity, Adaptive Coping, and Family Systems Dynamics Yolanda C. Leon, PsyD, ABPdN and K. Brianalyse Nicolena Cedeño, BA	Westshore
2:30 PM	Spotlight on Communication Devices <i>Sorenson</i> Tyler Kropf and Lara Bruce <i>Whispp</i> Joris Castermans and Akash Raj Komarlu	Westshore
3:15 PM	Roundtable Discussions Living with a Voice Condition facilitated by James Anderson, Mary Bifaro, Jan Lant, Jean McMahan, Denny Richey and Marcia Sterling Family and Friends facilitated by Warren Bandel Patrick Bifaro	Florida I & II Florida III
4:15 PM	Walk for Talk Honoring the First Step Kimberly Kuman and Mary Bifaro	Westshore
4:30 PM	Closing Comments Charlie Reavis	Westshore

2024 SYMPOSIUM PROGRAM

Welcome to the 2024 Symposium, marking the 35th anniversary of Dysphonia International. Our Mission has been clear and unwavering from the start – to improve the lives of people affected by spasmodic dysphonia and related voice conditions through research, education, awareness, and support. From humble beginnings, our organization continues to expand, committed to advancing knowledge and support for those facing voice-related challenges while striving to find answers. The evolution of our identity reflects our continuous adaptation to better serve the global community and ensure everyone's voice is heard.

BREAKOUT SESSIONS

These roundtable discussions led by our Support Network Volunteers offer an opportunity to explore different topics that impact people with vocal conditions in small groups.

WALK FOR TALK

No matter where you live, you can participate in the 5th Annual Walk for Talk, held October 17-20, 2024. Every step gets us closer to a cure!

INFORMATION ON OPTIONAL ACTIVITIES

Saturday Dinner is at 6:30 PM in the Cypress Room. The Tampa City Tour on Sunday will depart at 9:00 AM, so please meet in the lobby at 8:45 AM.

SPECIAL THANKS TO:

- Our speakers who generously share their knowledge, experience, and time.
- The Tampa Dysphonia Support Group, co-led by Ron Langdon and James Anderson, for serving as the local host for this Symposium.
- Our volunteer Board of Directors and Support Network Leaders who drive our mission and support our community.
- YOU for joining us and sharing your journey of living with a voice condition.

COMMUNICATION RESOURCES

There has been an increase in the number of tools designed to aid individuals with vocal conditions. Representatives from some of these options are available to speak with, helping you determine if these solutions could meet your specific needs.

Augmentative and Alternative

Communication Devices | Carol Doles, Eastern Regional Representative, is passionate about researching and resourcing communication tools that could be helpful to people living with vocal disorders. She has curated a wealth of information on various options, complete with a list of key considerations. Carol has also gathered a range of technologies for participants to test and evaluate firsthand.

Sorenson is a leading language service provider specializing in communication for deaf and hard-of-hearing individuals. They are currently investigating the challenges faced by individuals with voice or speech disorders to explore how their services could support during phone conversations and are interested in connecting with individuals that could benefit from having utilizing a communication assistant while making calls. <https://sorenson.com/>

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2024 SYMPOSIUM SPEAKER BIOS

Yassmeen Abdel-Aty, MD is an Assistant Professor at the College of Medicine Otolaryngology and Assistant Professor of Otolaryngology-Head and Neck Surgery at the University of South Florida/Tampa General Hospital. With specialized training in voice, airway, and swallowing disorders from her Fellowship at Columbia/Cornell and Residency at Mayo Clinic, she champions an academic philosophy centered on the integration of education, patient care, and research. Dr. Abdel-Aty's research interests focus on medical education and patient outcomes, complementing her extensive experience in resident and medical student education, mentorship in research projects, and contributions to the AAO HNS's Laryngology Education Committee. Her instructional roles span anatomy for medical students, surgical and simulation courses for residents, and airway courses for critical care providers, respiratory therapists, nurses, and military professionals.

Yaël Bensoussan, MD, MSc, FRCSC is an Assistant Professor of Otolaryngology at the USF Health Morsani College of Medicine and a fellowship-trained laryngologist with advanced expertise in voice, swallowing and upper airway evaluation and treatment. She is also an avid proponent of multidisciplinary care and has led multiple patient education initiatives around tracheostomy care. Prior to joining USF Health, Dr. Bensoussan completed her medical school at the University of Montreal and her surgical residency training at the University of Toronto, Canada. She subsequently completed a fellowship in Laryngology at the University of Southern California. Her background also includes a degree in Speech Pathology, and a

a prior career in music, which has led Dr. Bensoussan to her passion for the voice and for laryngeal disorders. She is a co-principal investigator for the NIH's Bridge2AI, a multi-institution project to integrate the use of voice as biomarker of health in clinical care. Passionate about optimization of health systems efficiency and algorithms of care, she is building bridges with to integrate technology to optimize the quality of care provided to her patients.

K. Brianalyse Nicolena Cedeño, BA is a published researcher and bilingual Psychometrist in the field of Clinical and Forensic Neuropsychology. Currently, she is the Lead Psychometrist in the Neuropsychology Division of the USF Department of Neurosurgery, Morsani College of Medicine. She holds nearly ten years of experience and expertise in research, clinical, and specialized pre-surgical neuropsychological assessments for a diverse pool of compromised patients, including those who suffer from spasmodic dysphonia. Under the guidance and supervision of her mentors, she continues to develop and define her knowledge about the robust impact of neurological disorders on family systems dynamics and other related neuropsychological manifestations.

Darla Freeman, SLPD, CCC-SLP is a Speech-Language Pathologist who's been treating voice disorders for over twenty-five years. Currently, she treats patients with voice, airway, and swallowing disorders at the Florida Center for Voice and Swallowing in Tampa, FL, where she is a scope specialist offering state-of-the-art voice and swallowing evaluations and evidence-based treatment. *continued*

2024 SYMPOSIUM SPEAKER BIOS

Darla Freeman is also an adjunct professor for ELMS College and serves on the executive committee for the Tampa Bay Medical Speech Pathology Association. She earned her doctorate degree from Northwestern University with a research focus on factors influencing successful behavior changes in adult interventions. While working as a clinical instructor at the University of South Florida, Darla started their first Spasmodic Dysphonia support group, and she continues to be actively involved with the Tampa Dysphonia Group.

Yolanda C. Leon, PsyD, ABPdN is a Clinical and Forensic Neuropsychologist who holds a Doctorate in Clinical Psychology and Board Certification in Neuropsychology. She has an appointment as Assistant Professor at the USF Morsani College of Medicine, Department of Neurosurgery and Brain Repair. She is also the Co-Director of the Neuropsychology Fellowship training program. Assessment of individuals with Movement disorders is a long-time interest of Dr. Leon and she has been a guest speaker at many Dysphonia conferences. She also incorporates Family System's dynamics in her core practice in providing care to patients as well as in her training of the next generation of neuropsychologists.

Elijah Moothedan is a third-year medical student at Florida Atlantic University. Currently, he serves as a research assistant to Dr. Watts and Dr. Bensoussan, contributing to various projects at the USF Health Voice Center, including the Dysphonia International funded initiative. He graduated from the University of Florida with a degree in Nutritional Sciences and has special medical interests related to otolaryngology and voice disorders, health disparities and public health, and disabilities.

Scott Norris, MD serves as the Head of the Movement Disorders Section at Washington University School of Medicine in St. Louis, MO, where he holds the position of Associate Professor in both Neurology and Radiology. He is a dedicated clinician, researcher, and educator. Dr. Norris earned his medical degree from the University of Missouri in Columbia and completed his residency and fellowship at Washington University School of Medicine. He utilizes advanced neuroimaging techniques to explore the connections between brain dysfunction and movement disorders, particularly focal forms of dystonia, including spasmodic dysphonia. Dr. Norris serves on the Scientific Advisory Board for Dysphonia International.

Megan Urbano, BM, MS, CCC-SLP is a Voice-Specialized Speech Pathologist at the USF Health Voice Center at the University of South Florida, specializing in assessing and treating voice and upper airway disorders. Before coming to USF, she completed a fellowship at USC Voice Center in Los Angeles, specializing in the assessment and treatment of voice and upper airway disorders. Megan holds a Bachelor of Music (Voice Performance in Opera) from Westminster Choir College in Princeton, NY. She is a classically trained singer and voice actress and has performed at Carnegie Hall and Lincoln Center for the Performing Arts. She is currently a member of the Master Chorale of Tampa Bay. She seamlessly integrates her scientific knowledge with performance techniques, ensuring that her sung and spoken voices are not only dynamic but also well-supported and healthy.