
SUMMARY OF 2022 VIRTUAL SYMPOSIUM

Prepared by Mary Bifaro, *Support Network Director*

The 2022 Virtual Symposium took place on Saturday, April 29, 2022. There were four live sessions, each lasting around an hour, and were presented on Zoom webinar. Presenters were visible to participants, and participants were able to ask questions and give comments using the chat function. The sessions were recorded and [available for viewing here](#). The theme of the program was: **YOU BELONG** and the sessions were designed to share how you are an important part of the **National Spasmodic Dysphonia Association (NSDA)/Dysphonia International** community no matter what your age, location, or voice condition.

Session I: Panel Discussion with NSDA/Dysphonia International Researchers

We funded four grants during the fiscal year which ended 3/31/22. One is a study by **Drs. Scott Norris and Evan Gordon** at Washington University in St Louis, MO. The pilot grant is called 'Individual-Specific Brain Functional Connectivity Mapping of Therapeutic Response in Laryngeal Dystonia'. Drs. Norris and Gordon recorded a brief video which was shown during the 2022 Symposium. They will be looking at how dysfunctional individual brain networks are modified by Botox® in AdSD (adductor SD). They have as a primary goal to obtain data to bridge efforts in understanding functional network dysfunction at the individual level in patients with spasmodic dysphonia. This line of research may be important in identifying new targets for therapeutic intervention and metrics of target engagement. MRI (magnetic resonance imaging) will be used to measure and compare brain activity in individuals pre and post Botox® injections. This approach allows researchers to test for treatment-related changes in brain changes within individual patients.

Another research panelist was **Dr. Christopher Honey**, Neurosurgeon and Professor at the University of British Columbia. He is working with **Dr. Amanda Hu**, Laryngologist from University of British Columbia, **Dr. Stacey Halum**, Laryngologist, Indiana University School of Medicine, and **Dr. Rita Patel**, SLP, Indiana University. Their study is called, 'A Phase 2 Randomized Controlled Trial of Deep Brain Stimulation (DBS) for both adductor and abductor SD'. They are looking at a new treatment that blocks the cause of spasmodic dysphonia, is performed only once, and can be successful for adductor, abductor, and mixed spasmodic dysphonia. All patients will be assessed at two university voice centers (Vancouver and Indiana) and will receive video assessment of their vocal folds to ensure patients have SD prior to the DBS procedure. Patients will have DBS surgery and their stimulation will be turned on and off for three months without the patients knowing. Their voice and quality of life will be measured during each of these settings and then compared to see which is better. This study will investigate the brain pathways causing spasmodic dysphonia and the benefits of the therapy.

Another research panelist was **Dr. Vincent Gracco**, Senior Scientist, Haskins Laboratories, New Haven, CT. His study is 'Network Targets Transcranial Direct Current Stimulation as a Treatment for Laryngeal Dystonia'. The project uses transcranial direct current stimulation (tDCS) which is a non-invasive technique for neuromodulation with a 'nonsignificant risk' designation that is being used alone and in combination with behavioral therapy to treat a range of neurological and functional clinical disorders. Recent neuroimaging data suggest that spasmodic dysphonia is a network-level disorder involving multiple brain areas. This project will apply tDCS neuromodulation to those multiple brain areas over a two-week period (three sessions per week) and will evaluate the effects of multi-electrode tDCS as a potential treatment to improve the disorder. A positive outcome in the small cohort of 10 participants would point to the need for a clinical trial with combined behavioral-neuromodulatory treatment that could be more beneficial than either alone.

Another research panelist was **Jurgen Konczak, PhD**, from University of MN in Minneapolis. With him was his colleague, **Dr. Divya Bhaskaran**. They are working on an NSDA/Dysphonia International funded grant called, 'Wearable Non-Invasive Neuromodulation Technology for the Symptomatic Treatment of Spasmodic Dysphonia'. They are testing the effectiveness of vibrotactile stimulation (VTS) among individuals with abductor SD. This non-invasive neuromodulation delivers stimulation directly to the larynx muscle through a collar around the neck. This team has demonstrated voice improvement using this technique on people with adductor SD. The conclusion was made that this is an exciting time for people living with a voice condition. There is a significant increase in the number of researchers working on voice. There is a collaboration across voice centers in the US and international regions. Researchers are going down more than one road to try to understand the cause of spasmodic dysphonia and look for better, more effective treatments. The NSDA/Dysphonia International continues to draw more attention to our rare disorder as we fund research.

Session II: Staying Connected Through Communication: Patient and Communication Partner Perspectives

Dr. Carolyn Baylor, SLP, at the University of Washington is working on a research study entitled, 'Staying Connected through Communication: Spasmodic Dysphonia'. This is a research opportunity for people with spasmodic dysphonia, and their family and friends. The study wants to hear from people who live with communication disorders and other people in their lives about how they communicate with each other. Surveys will be sent. The goal is to plan for a future larger study by giving feedback on methods and materials based on your experience of living with SD. Polls were conducted during the presentation. Dr. Baylor spoke about the barrier of having a communication disorder. She added that a communication disorder affects our physical, mental, and social well-being. She talked about developing communication skills and the impact of having shared decision-making with family and friends. The ability to communicate with the environment is important. The behavior of your communication partner makes a big difference. Respect and patience are pivotal. Family members, close friends, and co-workers also live with the consequences of having a chronic voice disorder. It is important for them to know how they can provide social support to the person with a communication disorder.

Session III: Living with a Voice Disorder: A Younger Perspective

This panel of three people gave a fascinating discussion on living with SD at a young age. They continue to be active in their personal and professional lives despite voice challenges. **Rachel Holtzman** founded the Facebook Group, Young SDers, and is pursuing a dual degree in law and public policy. **Christie DeLuca** is a speech-language pathologist who has SD and her work involves helping voice patients and training other SLPs about spasmodic dysphonia. **Kara Henderlight** works in outdoor recreation and is the Leader of the Milwaukee Dysphonia Support Group.

These women gave their personal SD stories and the treatments they take or have decided not to take. Kara talked about the lack of confidence she had due to the sound of her voice; she has now evolved into becoming an advocate. She discussed having a core group of friends and support from a husband. Christie talked about once being in customer service and having to talk on the phone all day. She found a profession, being a speech-language pathologist, that she is passionate about. She said that the SD journey is filled with challenges. The positives of having SD are how you develop empathy and humility. Rachel discussed the challenges of dating with SD. Normally, young people can project. She has found that young people with SD want to talk about dating, careers, and are looking for social and emotional support. She refuses to let SD control her, and she plans to show up with confidence. The young women concluded that education is empowerment and that the NSDA/Dysphonia International has many resources. They recommend becoming fully familiar with the information on NSDA/Dysphonia International website at dysphonia.org.

Session IV: You Belong to Dysphonia International

NSDA/Dysphonia International President, **Charlie Reavis**, discussed that we are evolving into having a new name but that our mission remains the same. We are the only organization dedicated to improving the lives of people living with spasmodic dysphonia and related voice conditions through research, education, awareness, and support. We have expanded our mission to include related voice conditions. We have always been welcoming those living with other voice disorders. We understand how to live with and cope with a voice condition. We believe that we should expand our reach since we have the tools and capacity to serve a larger community through expanded outreach.

Although we will change our name to Dysphonia International, we will always be entirely dedicated to our core purpose, spasmodic dysphonia. We have begun to add information and tools for tremor, muscle tension dysphonia, and vocal fold paralysis to our website as well as training for our support leadership. We now have the technology that will allow us to reach a worldwide audience. We know that spasmodic dysphonia and related voice conditions are not unique to North America. We already have relationships with individuals in many countries of the world. We shared a video of David Barton from New Zealand who is past President of NSDA/Dysphonia International. He gave his perspective on having an international point of view.

NSDA/Dysphonia International Support Network Director, **Mary Bifaro**, discussed the vibrant support network which has always been a constant. We realize that our outreach is international and that we have expanded our mission to include related voice conditions. This demonstrates the inclusivity that has been shown in the past. At present, we have about 45 support groups across the US and in international regions. In addition, we have about 100 Area Contact Leaders. All our support leaders are listed on our website at dysphonia.org. They hope to hear from you as to how they might be of service. 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.

Since the COVID pandemic began over two years ago, we have continued to connect virtually with our community. By launching the virtual support meetings, we have been able to reach people, some who have never met anyone else living with a chronic voice condition. All our virtual support meetings are listed on our website. If you find a time and topic that interest you, please join us! Until a cause and cure for SD have been found, our work continues. Each of you can make a difference in our organization. Every voice matters!

NSDA/Dysphonia International Executive Director, **Kimberly Kuman**, talked about the huge impact that our two successful Walk for Talk events have had. She shared that generations of people walked together to raise awareness and funds for research – both in October 2020 and October 2021. People gathered family, friends, co-workers, and healthcare professionals. They posted videos, shared photos, and told their SD stories. They wore Walk for Talk swag and walked behind our banner. They walked united for our worthy cause. This year, we will have our **2022 Walk for Talk** from **October 20-23, 2022**. Please make plans to join us and do your part to further our important mission goals. Kim shared a thank you video from the 2021 Walk for Talk event which had been just launched.

Kim reflected that the pandemic has transformed how we operate as an organization. The changes made have ensured that we are even more connected to our community and able to provide more services than ever before. This will serve us well with the expansion under our new identity as Dysphonia International. There are new opportunities available to us. With a more inclusive name, we have a greater ability to raise general awareness of vocal challenges, support more people with voice conditions, and fund more research with the ultimate goal of finding a cure.