RESEARCH INSIGHTS: Kristina Simonyan, MD, PhD

Multimodal brain imaging.
Neuropathological evaluations.
Genetic analysis.

Not your typical conversational terms unless you are spasmodic dysphonia researcher Dr. Kristina Simonyan.

With over 15 years of experience, Dr. Simonyan has been dedicated to understanding the neural mechanisms of normal and diseased speech motor control and other complex voluntary motor behaviors. She has authored over 55 peer-reviewed articles on neuroscience of voice and speech control and served on various National Institutes of Health (NIH) study sections, including the working group on National Institute of Deafness and Communications Disorders (NIDCD) strategic plan for 2017-2022. Dr. Simonyan was recently recruited to Massachusetts Eye and Ear, a teaching hospital of Harvard Medical School, as Director of Laryngology Research. Her research team will continue their quest to unravel the pathophysiology of spasmodic dysphonia so that patients have a better understanding of their disorder and hopefully a better treatment.

continued on page 4
Spasmodic dysphonia is a neurological voice disorder affecting over 70,000 people in North America. It is a focal form of dystonia that involves involuntary spasms of the vocal cords causing the voice to break up or to have a tight, strained, or strangled quality. SD affects both men and women of all ethnic groups with the onset of symptoms usually between the ages 30-50.

Founded in 1989, the National Spasmodic Dysphonia Association (NSDA) is a not-for-profit 501(c)3 organization dedicated to advancing medical research into the causes of and treatments for spasmodic dysphonia, promoting physician and public awareness of the disorder through outreach, and sponsoring support activities for people with SD and their families through educational materials, annual symposiums, support groups, and internet resources. The NSDA is the only organization that is dedicated entirely to spasmodic dysphonia.

Spasmodic dysphonia is a neurological voice disorder affecting over 70,000 people in North America. It is a focal form of dystonia that involves involuntary spasms of the vocal cords causing the voice to break up or to have a tight, strained, or strangled quality. SD affects both men and women of all ethnic groups with the onset of symptoms usually between the ages 30-50.

Our Voice

It is the editorial policy to report on developments regarding spasmodic dysphonia but not to endorse any of the drugs or treatments discussed. We urge you to consult with your own physician about the procedures mentioned.

©2017 National Spasmodic Dysphonia Association
Printed in the U.S.A.  •  11/17
Imagine being alone in a recording studio booth with just a microphone and a 304-page book that needs to be read out loud and recorded. And you have spasmodic dysphonia. That is what Dilbert creator, Scott Adams, faced when he sat down to tackle the audio version of his new book, *Win Bigly: Persuasion in a World Where Facts Don’t Matter*.

When his last book came out in late 2014, *How to Fail at Almost Everything and Still Win Big: Kind of the Story of My Life*, Scott felt he was not up to recording it himself. His voice had recovered greatly as a result of the surgical operation called Selective Denervation-Reinnervation performed by Dr. Gerald Berke at UCLA in 2008, but it was not quite there yet.

With the new book, Scott said, “I knew the question of whether I would read it or not was inevitable. It is always more effective when the author reads the book.” He explained to his publisher that frankly, he didn’t know if he could get through it. Scott was anxious, wondering what would happen if he could only get halfway through the book, but they agreed to take the chance. A recording schedule was prepared: four hours of continuous reading per day over four days.

Working with an audio engineer, Scott sat in the booth reading out loud. Then re-reading sentences as needed. At the end of each day, he could feel some fatigue in his voice, but it recovered overnight. “Amazing” is what Scott said when asked how he felt when it was completed. “When the audio director told me it was a wrap, I didn’t expect the emotional impact it would have on me,” he shared. The end result is an audio version of his new book that is just over 9 hours long.

Scott also does daily live broadcasts with a robust following. He shared, “It is impossible to describe that type of social interaction. I just love connecting but the irony is not lost on me. This is my previous world in reverse – I can talk and all these people watching can’t. They can only text me.”

Scott’s goal was not just to recover from spasmodic dysphonia, but rather to have a better voice than even before the symptoms of SD appeared. He repeated the affirmation ‘I will speak perfectly’ and today, people tell him how much they like his voice. He also attributes that to the vocal training he had prior to surgery. He developed tools and techniques to help, especially when there are high vocal demands.

Serving as an Honorary Board Member for the National Spasmodic Dysphonia Association, Scott is helping to raise awareness about SD. He wants people to hear the degree of his recovery and share his message of motivation of what is possible. Recording an audio version of his book seemed out of reach for him just a few years ago and being able to achieve that is one of his proudest accomplishments.
In this interview, Dr. Simonyan shares her journey on how she became interested in voice research, and more specifically, spasmodic dysphonia. We thank Kristina for her dedication and passion to help the SD community understand this complex voice disorder!

Can you share some of your background and your early interest in research?

I have been interested in science as long as I can remember myself. My first experience with clinical research came at the time of my medical studies at Yerevan State Medical University in Armenia, where I used every opportunity to get involved and assist with the research projects of various backgrounds. During the first years of my medical school, I was very interested in neuropathology and worked on a research study exploring the causes of sudden infant death syndrome. Later on, I became fascinated by the field of otolaryngology, both clinically and scientifically. Ultimately, after graduating from medical school in 1998, I entered the otolaryngology residency program, also in Armenia, where I was trained as an ear, nose, and throat surgeon and started working on research projects examining disorders of hearing and laryngeal functions.

The pivotal moment came when I was applying for a one-year clinical fellowship program in Germany. One of the places I had applied was Georg-August University in Göttingen. The head of the ENT Phoniatrics department, Prof. Dr. Eberhard Kruse, wrote back a very nice letter and informed me that, unfortunately, there were no vacancies at that time, but that he would keep my application in mind. I, of course, paid little attention to his promise, especially that I was already accepted to more than ten other university clinics and was chosen as one of the two DAAD (German Academic Exchange Service) fellows from Armenia. I was already preparing to spend my one-year fellowship at Ludwig-Maximilians University in Munich, when a letter arrived from Dr. Kruse informing me that, if I would consider joining the PhD program instead, he would arrange for my interview. Somehow, I even did not think twice and agreed to switch tracks and start the PhD program instead of my clinical fellowship. I was overexcited to join the research ENT team and at the same time to have an opportunity for a clinical involvement.

However, there was one more twist in the story. When I arrived to Göttingen for my interview, Dr. Kruse informed me that between him sending his invitation and my arrival, he had already chosen another candidate for his graduate project. But, he suggested that I meet with Prof. Dr. Uwe Jürgens as he still had a vacant graduate student position. Ignorantly, knowing nothing about Dr. Jürgens and his work, and being quite disappointed that I was not going to be a student of Dr. Kruse, I headed to the German Primate Center to meet with a potential graduate advisor. After spending a few hours talking to Dr. Jürgens (or Herr Jürgens as he wants to be called), I was convinced that this is what I wanted to do, not only for the period of my graduate work, but pretty much the rest of my research life. His research involved not only understanding the voice control but, even more fascinating for me, he was studying how the brain controls voice production.

As you know, I have continued to study brain mechanisms of voice control to this day. Herr Jürgens became a life-time mentor, and I cherished my time spent in his lab — to the point that after obtaining my PhD degree in Neurobiology from TiHo University of Hannover and the German Primate Center in 2003, I continued working in his lab for my Dr. med. degree, which I received from Georg-August University of Göttingen in 2004. Together, we mapped the full spectrum of cortical and subcortical connections of the laryngeal motor cortex in the rhesus monkey using neuroanatomical tract-tracing techniques, which laid a solid foundation for the future studies in humans.

I also worked with Dr. Kruse in the clinic to fulfill my residency requirements, which I completed in 2001. I remained in the ENT clinic on a part-time basis until 2004, and that’s where I started seeing patients with different voice disorders, including spasmodic dysphonia, voice tremor, and muscle tension dysphonia. As it gradually became clear to me that I wanted to pursue a research career over clinical practice, I sought to expand my knowledge of the field of voice and speech control. I spent one month at the RIKEN Brain Science Institute in the laboratory of Dr. Neal Hessler studying the vocal learning in birds and two months as a guest researcher in the laboratory of Dr. Christy Ludlow at National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health (NIH). She ultimately offered me the opportunity to return to her lab as a postdoctoral fellow. So, in 2004 I moved to the US and began my studies on brain mechanisms of voice and speech control in healthy and diseased states. Having worked with rhesus monkeys and songbirds in the lab and human subjects in the clinic gave me a great perspective and understanding of the important questions that are still not answered and the problems that we still need to tackle to resolve the mysteries of neurological voice disorders.

After spending five and a half years at NINDS and securing independent extramural NIH funding, in 2009 I moved to a faculty position at Mount Sinai School of Medicine where I rose to the position of a tenured Associate Professor. During my time at Mount Sinai, I developed a rigorous research program on spasmodic dysphonia and
other dystonias, which was and continues to be supported by three major NIH grants. Among our major accomplishments are the mapping of the large-scale neural networks controlling speech production as well as identification of potential imaging biomarkers of spasmodic dysphonia and delineation of a novel oral medication for the treatment of this condition.

Just recently, I was recruited to Massachusetts Eye and Ear, a teaching hospital of Harvard Medical School, as Director of Laryngology Research, where my team will continue our quest to unravel the pathophysiology of spasmodic dysphonia so that patients have a better understanding of their disorder and hopefully a better treatment.

How did you get involved in spasmodic dysphonia research?

My involvement started in the ENT clinic at Georg-August University in Germany where we saw and evaluated patients with various voice disorders, including spasmodic dysphonia. My research involvement goes back more than a decade ago to my time at NIH, where I led two research studies examining brain structural, functional and neurochemical alterations in spasmodic dysphonia. It is also at NIH that I established the brain tissue repository, which is an active collection of patient volunteers willing to donate their brain and larynx after death. It is an extremely valuable and probably unique collection that should ultimately allow us to examine the brain tissue and understand the cause of alterations we observe using brain imaging techniques, such as MRI and PET.

What is the focus of your current spasmodic dysphonia research and how do you hope that it will impact the lives of people with it?

My focus remains on continuous deepening of our understanding of SD-causative pathophysiology. I work in close collaboration with Dr. Laurie Ozelius at Massachusetts General Hospital (MGH) who is well-known to the dystonia community for her outstanding discoveries of four out of six known dystonia genes. Together, we are examining imaging and genetic underpinnings of this disorder, which we hope will shed light on causes of SD and the risk of development of this disorder in unaffected family members. My other studies deal with validating the clinical benefits and central effects of sodium oxybate, the new oral drug for treatment of alcohol-responsive SD and voice tremor. Finally, another study encompasses other focal dystonias in addition to spasmodic dysphonia, and this aims to identify the common and disorder-specific features of different task-specific dystonias. This study also incorporates the evaluation of postmortem brain tissue in conjunction with brain imaging, which I am conducting with a long-time collaborator, the neuropathologist Dr. Alexander Vortmeyer. Just recently, we completed a major study at Indiana University in collaboration with Dr. Mark Hallett at NINDS that identified a missing link of dopaminergic alterations via the direct basal ganglia pathways. This paradigm-shifting study gave a much clearer understanding of basal ganglia pathology in spasmodic dysphonia and suggested that both D1 and D2 receptors are abnormal in dystonia. Hopefully, we can use this information in the near future to try to modulate these pathways for finding new treatment options for SD and other dystonias.

What has surprised you the most in working with spasmodic dysphonia?

If I could paraphrase, the selectivity of this disorder in predominantly affecting speech production still fascinates me to this date. I think understanding this aspect may not only solve some of the mysteries of SD but also explain how the brain is organized during production of normal speech.

Can you tell us about your new lab and your team?

My lab is currently relatively small and consists of two postdoctoral fellows and three research assistants. As we settle in at Massachusetts Eye and Ear and MGH/ Massachusetts General Hospital (where I hold an appointment in the Department of Neurology), we will bring in more researchers interested in brain mechanisms of normal and diseased voice and speech production. We are part of the larger MGH dystonia research group that includes Drs. Laurie Ozelius, Nutan Sharma, Cris Bragg and Xandra Breakefield. I am also continuing my long-standing clinical collaborations with Drs. Andrew Blitzer at Mount Sinai, Steven Frucht at NYU, Drs. Phillip Song and Ramon Franco at Mass Eye and Ear, as well as a speech-language pathologist in the University of Queensland, Australia, Dr. Anna Rumbach. In collaboration with our Irish colleagues, Drs. Richard Reilly and Michael Hutchinson, we are examining the impact of temporal discrimination abnormalities in dystonia; with Dr. Mark Hallett at NINDS we continue our work on neurotransmitter alterations in task-specific dystonias, and with Dr. Alexander Vortmeyer we are evaluating the correlations between imaging and neuropathological changes. Our multidisciplinary and diverse team of investigators brings the necessary breath of knowledge and expertise so I hope we will be able to offer better treatment options for patients with spasmodic dysphonia.
Each person’s experience with spasmodic dysphonia is different, yet there are common threads that can connect one another. “Real Life” is written from the point of the view of the author. This issue features Iris Miller Stetson who shares her personal experience with spasmodic dysphonia including having SD at a very young age, and writing and publishing a book about living with SD. Iris also leads the NSDA Oakland Spasmodic Dysphonia Support Group.

While most people with spasmodic dysphonia (SD) are afflicted as adults, it started for me in 1960 when I was twelve years old. At the time there was no internet, no phone answering machines, no email or texting, and no one who knew why I suddenly couldn’t speak normally. I was undiagnosed for the next four decades and during those years I spoke as little as possible due to the shame I had about my broken voice and the physical pain I usually felt when I tried to speak.

As a teenager, my speech condition exacerbated the difficult relationship I had with my mother. Derogatory remarks from her and others about my speech stung, and I isolated myself. However, those remarks also lit a fire in me, a determination to be strong and never give up on myself or my search to learn the truth about my dysfunctional voice.

Interestingly, during the forty years that I was undiagnosed, I was an accomplished singer. I had no idea why I could do one thing with my voice so well but not the other. I was attractive, good in sports and music but I was challenged in school, in finding a good job, and in intimate relationships. I wanted to reach out to people but, since it was such a struggle to speak normally, it was hard. Fortunately, music gave me a way to connect but only to a point. Wanting to improve myself, I spent years in psychotherapy as well as in learning various forms of meditation, yoga, and similar techniques. Nothing ever changed my speech but my heart and mind strengthened, helping me to become more positive, better adjusted.

In December 1999 I was finally diagnosed with a severe case of Adductor SD. Once I learned the truth about my voice I wanted to write my story, had wanted to for years. I had waited so long for a diagnosis and it was wonderful to know the truth but it brought up old and painful emotions that I had to sort out. I wasn’t ready to tell my tale.

Still, I began jotting down notes and I began learning how to speak again. Botox® injections were working but it had been so long since I spoke properly that I didn’t know how to do it anymore. I slowly progressed and, after years of speech therapy, I was able to speak normally most of the time. I still wasn’t ready to write my story but began a blog for the speech disabled, The Princess Frog: A Voice for the Speech Disabled at http://princessfrogspeaks.blogspot.com, sharing some of my personal experiences, insights, and ways of coping.

The more I got used to speaking without pain or much effort, the more I thought about the other voices I had relied on over the years. I had sung professionally, had worked in the publishing industry where I honed my skills with the written word, and had learned American Sign Language.

Now I could no longer sing due to the Botox® injections but, with that great loss, I became even more aware that I could never lose my most precious voice — my voice within, speaking as clearly as ever, pushing me to write my story.

In April 2016, my memoir, The Voice of Acceptance: A true story about abuse, disability, and the pursuit of happiness, was published. It felt like I was standing naked. I was baring my soul to the world but I knew I had to in order to educate and bring awareness about what life can be without a functioning voice. I soon heard from family and friends but then began hearing from strangers who wanted to understand and learn more. Most were interested in my inner journey, how my courage and resolve strengthened along the way.

After living with SD for over fifty years, I see how much my attitude towards my speech condition has changed, from something I was ashamed of and hated to what I now view as a gift. Having SD has taught me so many hard life lessons about patience, perseverance, and hope. I have learned that a cure for SD or cancer is possible, that life is full of miracles and I am thankful for mine.
NEW BOARD MEMBER PROFILE

Warren Bandel

Warren started having symptoms of spasmodic dysphonia when he was in 6th grade. At first, the teachers thought maybe he was developing a stutter, and he started speech therapy. Warren said, “No one made a big deal about it. They would just say ‘That’s Warren,’ especially when I was younger.” Finally, in high school he received a diagnosis of spasmodic dysphonia by Dr. Arnie Aronson at the Mayo Clinic in Rochester, MN.

It took time for Warren to accept spasmodic dysphonia. He calls his 20s, his lost decade. Outwardly, he was happy go lucky, but internally, he was coping with anger and frustration of having SD. It wasn’t until his aunt sent him an article about Botox® injections in the 1990s that he started treatment. The injections worked for a while but became less effective. Then in 1996, a surgical procedure was performed to remove some of the muscle around his throat. The SD symptoms remained but the tension was reduced and speaking was no longer as physically demanding. With the combination of time and treatment, his acceptance of SD grew. And that led him to take up music again.

Warren held his first NSDA benefit concert in 2015 in Rochester, MN. The year prior, he and his fellow bandmates in the Brass Quintet performed at the 25th anniversary dinner for the NSDA. It was with their help that Warren organized this first concert. Warren tried not to have any expectations. He said, “If it raised a couple hundred dollars, that is more than we had before. We are having fun and playing music.” Warren still gets emotional talking about these events. He said the support from friends and family has been tremendous from the posts on Facebook, to attending the concerts, and making generous donations to the NSDA when they “passed the plate” during each concert. That their first event raised over $3,000!

The benefit concert in Rochester, MN, has become an annual event and continues to grow. This year, Warren took the Quintet on the road and hosted a concert in conjunction with the local SD Group in Mankato, MN, and he hopes that too will be an annual event. Warren says, “Music speaks louder than his words. And it’s a great gift to give back to the NSDA.”

When asked why Warren wanted to serve on the NSDA Board, he shared, “It goes back to the original thought I had at the Orlando Symposium. Knowing I wanted to do more, and this allows me to do that. It has been a six-year journey, but I knew if this opportunity ever came up, I would say yes.”

Warren said, “I feel that it might be worse to lose your voice mid-life than early. I don’t really think about it anymore, but for others they are just starting their journey with SD and I want to make sure people have support.”

Warren shared that the support of his wife, Anjanette, has been so important. Ironically, they met three months prior to the Orlando Symposium, and she has been supportive of him ever since. He could not do what he does for the NSDA without her support. Recently, Warren and Anjanette went to New York to participate in a research project by Dr. Kristina Simonyan. Also, Warren’s sister participated in a genetic study as a control participant.

With a focus on fund-raising, Warren put together a map to see where the NSDA is hosting fund-raisers and there are some large gaps. He will be working to get more people involved and finding the right type of fund-raisers for them. We thank Warren for all the work he has already done and look forward to having him on the NSDA Board!
By the time I was diagnosed with spasmodic dysphonia, I was already used to finding “a path less taken” to achieve my goals. As an introvert, I often found that much of the advice on how to effectively manage my career did not work for me. I didn’t know it at the time, but we live in an extrovert-oriented culture and our ideals are based on that personality-driven behavior. I’d rather eat a bug than go work a room as a means of meeting new people. So, when someone told me advice like “go work the room” as a means of meeting people, I knew I had to find a way that worked for me. Common advice doesn’t mean it works for everyone.

I tell you this because I’ve noticed many people with SD get their career derailed because of their voice. Sometimes the derailment was done to you and for many, you made a reluctant decision to stop doing what you were doing. Letting your career get derailed for any reason is dispiriting at the least and depressing for most. I urge you to find another path to career fulfillment. There is ALWAYS more than one path to every goal including your career. Since I recognize what you are, or have probably gone through, I’m not going to give you just a pep talk. You need some practical guidance on how to deal with both the dent in your self-esteem and how to put your career onto another meaningful path.

Mending the Self-Esteem

Your Self-Talk

The message we give ourselves is the most powerful of all. If your self-talk disparages you in anyway, you have set yourself up for a self-fulfilling situation. A negative mindset cannot lead to a positive life. It is possible for you to stop or minimally reduce the negative chatter going on in your head. Like working out a muscle, you do have to continue to do this long enough for it to take effect but you can do it.

Here’s how:

1. Notice when you say internally, or even out loud, a negative thought about yourself. No, you won’t catch all of them all of the time but the more you catch, the more you will catch over time until there’s almost nothing to catch. You could also ask those closest to you to point this out simply to assist with your awareness.

2. Replace what you said with a positive statement. The point of this isn’t to stop your self-talk but to train your self-talk to be positive. What you say has got to be something you know and believe. In other words, if you say an affirmation that you don’t believe, it won’t help. You also need to be careful to not use a negative in your statement. Example of a correct replacement: “I’m worthy of success.” Example of incorrectly using a negative: “I’m not stupid.”

Thought for you to consider: Whatever you believe about yourself on the inside is what you will manifest on the outside.
“Prime” Yourself

In her book, Presence, Amy Cuddy tells you about restoring your personal power. She and others have studied various aspects to being self-confident. Basically, they found in a series of studies that when a person is “primed” negatively or positively before tackling a problem, it impacts the outcome in the same direction.

To Prime yourself, you think of a situation where you were your most powerful. It would be a time that you were being consistent with your personal values, skills and character and produced an outcome that was positive and meaningful. You could write this down to reinforce the thinking and how that situation felt. That’s it. Apparently, we are easily shifted by our own thoughts. I’d suggest priming yourself daily if your self-confidence is still suffering.

Help someone

You’d be shocked at how good you can feel when you get out of your own head and shift into service to others. This can be anything so get creative or use some of those skills you’ve amassed at work. Helping someone else will really boost your spirit.

Making a New Path

Tweak your Career

A good alternative to the career you had is to tweak some of the conditions of your work. My own sister was a bank auditor for years and eventually became a consultant that did bank auditing when most of the corporate auditor positions moved out of her city. I once had an attorney as a client who didn’t want to keep working as an attorney. I was able to Google “careers that use law degrees” and found a list of 100 careers other than being an attorney but needed the background and education. Capitalize on your background and skills.

Brand a New Identity

Katherine Hepburn never shied away from acting when her voice started shaking. In fact, it became her trademark and personal brand. You’ll notice there are many people out there with disabilities will make that the centerpiece to their work. Rather than shrinking with your SD, live it large!

Resurrect Your Dream

One way to look at the momentary blip in your career path is that it’s a signal for you to pursue your dream or to create a new dream. I can just hear a few of you more “mature” readers already dismissing this idea because of your age. Shame on you! It’s never too late and you’re never too old to have a big audacious goal. Keep in mind that Colonel Sanders didn’t launch his chicken empire until he was 70.

Retool

It may be time for you to retool your education and skills. Use this as an opportunity to do something fun and exciting. Go back to school or pursue a program to test your interest.

Reset your Perspective

Don’t settle for “just” any job that allows you to shrink from exposure to speaking. Have fun exploring a new path. Be bold. Be willing to risk. Decide how you want to be going forward and go be that!

Most people with SD talk about the negative impact it has had to their career and life. It’s not fun – I know from experience. I also know you can turn the situation around and make it the best time of your life.

Additional Career Articles by Dorothy Tannahill-Moran available at www.dysphonia.org

Interview with the Experts: What You Need to Know about ADA and Your Career Support

Figuring Out a New Career Now That You Have Spasmodic Dysphonia

Own Your Voice Professionally but Don’t Let It Define You

Are YOU Guilty of the 3 Introvert Career Killers?

Two Ways Introverts and People with SD Impact their Career Goals (and what to do)

Your Voice: Your Personal Brand
I am a 71-year-old clinical psychologist in part-time private practice in Kelowna, BC, Canada. Kelowna is located 250 miles East of Vancouver. Following viral pneumonia when I was 24 years old, I began to notice my throat becoming rather itchy with throat clearing but nothing more. After my doctoral training as a psychologist I taught college classes, did workshops and had many attendances as an expert witness in Court all while developing a busy private practice. By mid-1991, however, my voice became so difficult that I had to quit teaching (although I was able to keep my private practice) and seek help. I had an understanding family physician who arranged for me to see Dr. Murray Morrison, the only spasmodic dysphonia specialist in Vancouver at the time. My first visit with Dr. Morrison, my diagnosis of adductor spasmodic dysphonia, and my first Botox® treatment were all on the same day in January 1992.

My first Botox® shot actually lasted about 10 months, much longer than the usual three or four months thereafter, and it provided much needed relief. With the passage of time, however, I realized that my professional life did not allow me to take two weeks or more off every four months to wait out the breathy periods. The injections did give me a useful voice when I took the shots but, again, I found the process too disruptive of my professional calendar. As a result, I began exploring virtually EVERY traditional and alternative approach known to humankind – i.e. chiropractic, massage therapy, physiotherapy, hypnosis, acupuncture, naturopathy, allergy testing and treatments, mainstream speech therapy, biofeedback, Feldenkrais, the Alexander technique, yoga, meditation and others – none of which produced significant or sustained benefit. I even had my silver-mercury dental amalgams removed! Neurontin 200-300 mg per day and clonazepam, as well as voice practice, benefited me to some degree. I found that, in my case, the vocal exercises didn’t readily generalize to everyday conversation.

Prior to my surgery, my vocal spasms (aside from Botox® injections) were noticeable to family, friends and clients alike. I was able to maintain my professional practice, imperfectly, by attending to my breath and voice placement, keeping my neck and shoulders relaxed through various relaxation strategies, and the aid of the above mentioned medications. My counselling clients would, at times, question my vocal spasms, and I would explain that I had a voice disorder, and that it was neither painful nor infectious. My clients seemed to find that explanation acceptable, it never became a “big deal”, and I do not believe that I lost any clients because of it. On the contrary, I was able to draw parallels between my own voice problems and their psychological or medical difficulties, as a way of demonstrating that all of us, sooner or later, are given challenges in our lives that can either defeat us or provide opportunities for self-improvement.
Given the up-down nature of Botox®, and my failure to find any other way of relief, I decided to have the SLAD-R surgery with well-known ENT and surgeon, Dr. Gerald Berke, in Los Angeles in January 2007. I returned to work 10 weeks post-op, starting with only two hour-long sessions per day, increasing to four sessions per day, and then full time in mid-April. My Kelowna speech therapist analysed my speech (when reading sentences and paragraphs) with her voice analysis program and found it to be in the normal range within about four months. My voice continued to strengthen, eventually plateauing about six months post-operation.

Since then I have been using Dragon NaturallySpeaking 9, voice recognition software, to do my letters, reports and emails (as well as this article); that would have been impossible prior to the surgery. I suspect that I have lost the top two or three pitches in my upper range but consider that loss a very small price to pay. Very infrequently (once or twice a week or less), I have a bit of spasming on the order of 1 to 5 seconds but am able to control it. I am not breathy. I would consider my voice to be functionally 98% or better and, frankly, I do not think about it much anymore.

I am very satisfied with the outcome. I am on no medication, whether Botox® or any other prescribed medication, to help moderate vocal spasming. I have been back to work as a clinical psychologist on a full-time basis since April 2007, going to part-time practice several years ago of my own accord as a move towards semi-retirement. My reduced schedule was completely unrelated to my voice quality.

As was the case pre-op I remain vocally sensitive to the flu/colds and certain foods such as caffeine, dairy products, chocolate, citrus, nuts and spicy dishes; the theme remains but it plays out at a different, more manageable, level. No one ever asks now if I am having voice problems. Conversely, from those who knew me pre-op, I have had many compliments on my voice.

While spasmodic dysphonia can clearly challenge our social, psychological and occupational well-being it is my view that, “if one has to have it,” it is better to have it now, for example, than 50-100 years ago when no one had even a basic understanding of the disorder, and there was no relief to be had at all. We are blessed to have knowledgeable physicians and speech therapists now who can help guide us through this challenging disorder, not to mention the NSDA and its Spasmodic Dysphonia Bulletin Board which have proved to be an invaluable resource and support to me, and many others, over the years.

Having to explain to others what spasmodic dysphonia is, and how it affects you, can be exhausting. The NSDA asked people with SD to share their thoughts on what you wish others would understand about living with this voice challenge. We had great feedback and compiled the responses. Some will undoubtedly resonate with you. Our thanks to all those who participated.

Here are few of them:

• I am not sick. I am not anxious. My spasmodic vocal sounds are not contagious. Please do not be afraid to treat me as a normal person.

• Me not talking doesn’t mean I’m not interested. It probably means I’m tired from trying to talk. Talking takes a lot of energy. I hate it when people say “It’s ok. Don’t talk.” I have things to say too.

• I appreciate when you treat me just as you would anyone else. Lastly, be patient. I may speak slowly but I need to say what’s on my mind just like anyone else.

Log on to the NSDA website, www.dysphonia.org, to download the full list along with other “You Are the Expert” articles including advice on social situations and being newly diagnosed with SD.
Myofascial release (MFR) is one of many manual therapies used as interventions for pain and dysfunction-related issues, though use of it in the treatment of dysphonia is newer. Myofascial release is derived from osteopathic techniques from the early 1900s and became more popular from the 1960s onward. Fascia is connective tissue that separates and connects much of the body’s internal structure. Historically, it was thought that tightness or restriction of the body’s fascia, due to trauma, injury, surgery, could cause tightness, pain, and patterns of dysfunction throughout the body and it was believed that with the application of myofascial release treatment these restrictions could be eliminated.

Science has more recently cast doubt on these fascia-specific claims, by challenging the belief that one could selectively blame one specific tissue for such problems and that therapists could singularly target one tissue to the exclusion of all others for treatment. However, the hands-on techniques can still be useful for the remediation of a wide range of dysfunctional issues, including dysphonias, as there are now more accurate explanations for the results seen in myofascial release and other manual therapies, that align better with current pain science and neurology.

Myofascial release is a rather broad description of manual therapy and although variations exist, most rely on slow stretching, most often performed without lubricants or oils. While many forms of myofacial release rely solely on the perceived expertise of the practitioner to detect problems and determine a course of treatment, newer models rely more strongly on a patient-directed model; one where treatment decisions are made from a collaborative agreement between practitioner and patient. In the case of dysphonia, this is accomplished by a slow and gentle graded palpation through the neck region, where the practitioner attempts to locate areas that, with light pressure/stretch, replicate familiar aspects of the patient’s symptoms. If the pressures/stretch replicates familiar aspects of the dysphonia and is felt to be potentially helpful by the patient, treatment follows until the symptoms lessen.

Goals of myofascial release treatment include targeting more permanent lessening of symptoms and vocal exertion, improving voice quality, assisting in providing more efficient breathing patterns, etc. Treatment sessions may run from 30-60 minutes and occur at intervals determined by collaboration between the patient and practitioner. If, during an evaluation session, myofascial release treatment shows promise, I believe that the patient should note some form of lasting improvement within 3 sessions. Myofascial release should not be painful. Your therapist may bring any pain and other dysfunctional sensations to your awareness, but only to determine relevance. Treatment may be reimbursed by health insurance, depending on the provider and your insurance. Rather than dictate a strict pre-determined protocol of treatment, a skilled practitioner should work to connect you with a range of familiar aspects of your condition, allowing you to make the determination whether or not the sensations are tolerable and potentially helpful. To many it may sound odd that you might feel your spasmodic dysphonia symptoms without attempting to speak, but this is a common aspect of a patient-directed model of MFR. It may be quite unlike other manual therapy or massage that you have had in the past. While there are aspects of my version of myofascial release that may have similarities to manual circumlaryngeal treatment, which has proven efficacy, myofascial release will be a slower and less abrupt form of intervention, making it better tolerated by most. Once the patient has been taken through the evaluation and treatment process, home self-stretches should be provided, using the identical process used during treatment sessions. The current scientific literature (see links) shows that manual therapies, including myofascial release, are effective in reducing
I first noticed a change in my voice at the age of 19. I thought that I was causing this strain in my voice. I convinced myself that I had lost my confidence and that some form of chronic stress must have taken over my voice box. Ten years later, I was diagnosed with adductor spasmodic dysphonia. Receiving this diagnosis brought both relief and despair. Relief, because I can now stop blaming myself for not having a “normal” voice. Despair, because my options seemed very limited.

At the time of my diagnosis, I had just enrolled in Massage Therapy School. It didn’t take long for me to notice a difference in my voice after receiving massage. I came across “Walt Fritz Foundations In Myofascial Release Seminars” when researching manual therapy for voice disorders. I wanted to know what helped my voice during a massage. I wanted to understand the science and technique behind the alleviation. I wanted options.

I attended Walt’s seminar for neck, voice, and swallowing disorders in October in Bellville, NJ, as both a recent massage graduate and an undercover patient. I was extremely hesitant to volunteer for one of the anterior neck demos, but I am so happy I did. Walt was able to safely reproduce the familiar feelings of suffocation and tightness in my throat, which are prerequisites to establishing relevance for treatment. These sensations brought tears to my eyes, but also an immense sense of relief. I was afraid that the work would feel too intense and invasive, but I felt safe and relaxed. I felt and heard a clearness in my voice for the rest of the day, and noticed an improvement in my breathing. I am not looking for a “cure,” just help. I don’t know if manual work is capable of providing long term impact on my voice, but I am 100% okay with incorporating it into my treatment.
Botulinum toxin treatment of false vocal folds in adductor spasmodic dysphonia: Functional outcomes

C. Blake Simpson, MD1, Christopher T. Lee, MD1, Jeanne L. Hatcher, MD2, Joel Michalek, PhD3

Laryngoscope. 2016 Jan;126(1):118-21

Dr. Blake Simpson and his colleagues performed a retrospective case series of patients with botulinum toxin injections of the false vocal cords with Botox® in the treatment of adductor spasmodic dysphonia. The conclusion is that it is a viable treatment and may have advantages over other techniques due to avoidance of the “breathy phase” that is commonly seen. They have published the results of this work and below are the abstract and lay summary.

Abstract

Objectives/Hypothesis: Supraglottic injection of botulinum toxin (Botox®) has been described as an effective treatment for adductor spasmodic dysphonia (ADSD). Anecdotal evidence suggests that the patients have little to no breathiness after injection, but no formal longitudinal studies have been carried out to date. The purpose of this study was to examine the voice outcomes in patients with ADSD after supraglottic Botox® injection.

Study Design: Retrospective case series.

Methods: Patients with ADSD who were treated with supraglottic Botox® injections completed a qualitative self-evaluation of voice function after injection using the percentage of normal function (PNF) scale, a validated, quantitative scale from 0% (no function) to 100% (normal function). Post-treatment voice improvement after injection was determined using a Voice Handicap Index-10 (VHI-10) questionnaire.

Results: A total of 198 supraglottic injections were performed between July 2011 and October 2014. Twenty-five questionnaires were completed. Mean post-injection PNF was 95.0% ± 8.4% and was significantly increased from the pre-injection mean PNF (62.5%) ± 22.6% (P < 0.001). The mean best VHI-10 for all injections was 7.23. In 19 of 25 patients (76%), there was no reduction in vocal function after injection, indicating that the “breathy phase” commonly experienced in the first several days after the typical Botox® injection was not present in the majority of patients. In those patients that did have a decline in their voice after injection, the decline was only 9.2% of vocal function, and this normalized within two weeks. Our study suggests that injection of the false vocal cords with Botox® in the treatment of adductor spasmodic dysphonia is a viable treatment and may have advantages over other techniques due to avoidance of the “breathy phase” that is commonly seen.

Conclusions: Supraglottic Botox® injection is an effective treatment for ADSD. Post-injection voice is significantly improved, and the majority of patients do not experience breathy voice/decline in vocal function after injection.

Lay Summary

Botox® injection in the vocal cord muscles is a well-established and effective treatment for adductor spasmodic dysphonia. There are a number of approaches that a physician can use to perform these injections, including guidance with electromyography and direct visualization with a flexible laryngoscope. A well-known side effect of these treatments is the “breathy phase” experienced after the shot, that may last days to weeks, and limits the amount of time that the patient spends with a “good” voice. Our study looks at a specific method of Botox® injection where the main target is the false vocal cords, instead of the true vocal cord injection approach which is traditionally utilized. This method has been shown to have minimal breathy voice after injection.

Our procedure uses a flexible laryngoscope placed through the nose to guide the needle placement. The needle is placed through the mouth or the neck under local anesthesia in the office setting. The target of Botox® injection is the false vocal cords, and the doses to this structure are typically higher than the doses used in the true vocal cords. In this study, roughly 200 injections were examined over time, looking at the patient’s “percent normal” vocal function following Botox® injection. The findings showed that the average percent normal function was 95% following injections, indicating that most patients achieved a very good voice after treatment. Also, in 76% of patients, there was no “dip” in their vocal function after injection, indicating that the “breathy phase” commonly experienced in the first several days after the typical Botox® injection was not present in the majority of patients. In those patients that did have a decline in their voice after injection, the decline was only 9.2% of vocal function, and this normalized within two weeks. Our study suggests that injection of the false vocal cords with Botox® in the treatment of adductor spasmodic dysphonia is a viable treatment and may have advantages over other techniques due to avoidance of the “breathy phase” that is commonly seen.

1Department of Otolaryngology-Head and Neck Surgery, University of Texas Health Sciences Center at San Antonio, San Antonio, TX

2Department of Otolaryngology-Head and Neck Surgery, Emory University, Atlanta, GA

3Department of Epidemiology and Biostatistics, University of Texas Health Sciences Center at San Antonio, San Antonio, TX
POSSIBLE NEW TREATMENT OPTION FOR SPASMODIC DYSPHONIA: IMPLANTABLE ELECTRIC STIMULATOR

Michael J. Pitman, M.D.

Dr. Pitman is the Chief of the Division of Laryngology and serves as the Director of the Voice and Swallowing Institute of Columbia University Medical Center. He is an expert in voice restoration, conservation, and swallowing and airway disorders.

Dr. Pitman and his team have been researching an implantable electric stimulator for the treatment of spasmodic dysphonia and other focal dystonias. When stimulating the nerves in the larynx, they have discovered that by modulating the neurologic activity they can improve the voice in patients with spasmodic dysphonia. The stimulation is thought to reset the muscle spindle, normalizing the proprioception of the laryngeal muscles, resulting in a smooth voice.

With a small five-patient pilot trial completed, they have discovered that after inserting an electrode into the vocal fold, stimulating for an hour, five days in a row, all the patients received an improved voice quality. Ultimately, if the stimulator works as planned, whenever a person feels like they need a treatment, they would turn a battery on, and, after about 25 minutes, they would turn it off and go on with their day.

Overall, the preliminary research investigation shows that if the patient undergoes this treatment for a week or so, they will experience a good voice quality for about 3-4 weeks. In addition to this, every time they complete the treatment, the carryover should last longer and longer.

Will this treatment be used for all forms of spasmodic dysphonia? We think it could be used for any form of spasmodic dysphonia and other focal dystonia. Therefore, it would not be used for just for people with abductor and adductor spasmodic dysphonia, but for people with writer’s cramp and torticollis.

When will you be enrolling patients into a clinic trial?

We are hoping to start within the next 6-12 months with the goal of enrolling approximately 20 patients. At that point, we would have a better understanding of what the stimulating parameters should be. The patients will likely undergo a functional MRI to evaluate brain physiology before treatment.

They will then receive one week of treatment and have the MRI again to check for changes in brain physiology associated with spasmodic dysphonia. This will be in addition to the typical outcome measures: how good is your voice, how many spasms have you encountered, etc.

What type of device will be used?

MED-EL is the company that is funding this project, and they are one of the top cochlear implant companies in the world. They have modified their cochlear implants so the stimulating lead can be safely placed in the larynx. They have implanted these nine times already for bilateral vocal fold paralysis. Fortunately for us, because of this bilateral vocal fold paralysis research, they have already worked out many of the issues of laryngeal stimulation. As a result, we are already 10-15 years ahead of where we would be if we were just starting.

Can you talk about symptom improvement?

Right now, our knowledge is preliminary. But in the patients that we stimulated, they tended to have a little bit better voice quality immediately after the stimulation. Interestingly most of them tended to have much better voice quality hours after the stimulation. In addition, after the 5 days the improvement lasted from 3-14 days.

We think the more cycles of treatment, the longer the carryover will be. Theoretically, after you become a user of this and treat yourself for a week, it may last for a month or so.

What kind of procedure would be involved?

Currently, it would be a surgical technique under anesthesia. Everything is moving toward being minimally invasive. Our ultimate goal is to do this procedure in the office and have it be as minimally invasive as possible.

For some reason if it didn’t work or the patient wanted to have it removed, is it removable?

It is completely removable and there should also be no long term side effects from the lead in the larynx.

Anything else you’d like to share?

I think this is very exciting! We are in the early stages but we are keeping our fingers crossed that this will come to fruition over time. Hopefully, it will fulfill our dreams of better care for our patients.
THE NEUROSURGICAL TREATMENT OF SPASMODIC DYSPHONIA:
THINKING OUTSIDE THE VOICE BOX by Dr. Christopher Honey

The National Spasmodic Dysphonia Association is funding a grant investigating the effectiveness of Deep Brain Surgery (DBS) for the treatment of spasmodic dysphonia. This research is being led by Dr. Christopher Honey. Dr. Honey is a Professor of Neurosurgery at the University of British Columbia. He obtained his medical degree from the University of Toronto and his doctoral degree from Oxford University as a Canadian Rhodes Scholar. He completed his Royal College training in neurosurgery in Vancouver. Dr. Honey’s team includes three nurses dedicated to DBS, a research coordinator, and a clinical fellow (neurosurgeon studying DBS).

Why did you decide to study Deep Brain Stimulation for spasmodic dysphonia?
Our Center at the University of British Columbia has one of the world’s largest experiences with deep brain stimulation (DBS) for the treatment of a variety of neurological conditions including Parkinson’s disease, dystonia, and tremor. We were surprised and delighted when two of our patients who had had routine DBS for their limb tremor subsequently reported that their spasmodic dysphonia (SD) had unexpectedly improved. We investigated these patients and discovered what we believe to be the brain pathway involved in SD. Our research has now continued with funding from the NSDA to a phase 1 trial to determine the safety and effectiveness of DBS for SD. This trial will test how DBS affects the voice and quality of life of six patients with SD. The recruitment for the trial is now closed and we expect to be able to report our results next year.

How do you expect this research to be helpful?
We hope that this new therapy will offer another treatment option for patients with SD and specifically will help those who do not get a good benefit from current medical management. For the last 30 years, treatment for spasmodic dysphonia has focused on the resultant abnormal muscular movements of the vocal cords. Treatments such as botulinum toxin injections are designed to weaken those muscles rather than to fix the underlying problem and thus, when the Botox® wears off, the problem comes back. Our studies are directed at the underlying cause of SD. Our research has also provided a unique opportunity to study how the brain produces speech. Our team is grateful to the National Spasmodic Dysphonia Association for their support of our research.

SPASMODIC DYSPHONIA RESEARCHER UPDATE:
Teresa Kimberely, PhD, PT
Dr. Teresa Kimberley, whose pilot spasmodic dysphonia grant was funded by the NSDA, has moved from the University of Minnesota to Mass General Hospital Institute of Health Professions (MGH IHP) in Boston, MA. She will be leading the Brain Recovery Lab at the MGH Institute of Health Professions and continuing her work in focal dystonias, including spasmodic dysphonia. “The opportunity to collaborate with the wealth of expertise in the Boston area and the world-renowned imaging facilities at MGH were big drivers for the move,” said Dr. Kimberley. She looks forward to connecting with area spasmodic dysphonia support groups in New England. Her new NIH R01 project will continue to recruit patients with focal hand dystonia, adductor spasmodic dysphonia, and healthy control participants with a goal of understanding the brain dysfunction in focal dystonia and developing novel treatment options.

Be Part of the Dystonia Brain Collective
The NSDA, working with other organizations of the Dystonia Brain Collective, is proud to partner with the Harvard Brain Tissue Resource Center to help solve the mystery of spasmodic dysphonia and other dystonias through brain donation. The Harvard Brain Tissue Resource Center is responsible for collecting, preserving, and distributing human tissue to qualified scientific investigators who are conducting SD research. Help us find the answers to spasmodic dysphonia by enrolling in this program which will benefit future generations. Learn more about the program at www.dysphonia.org.
Can you tell us about the focus of this new research grant?

Many people with SD also have another disabling condition called vocal tremor (VT). Unfortunately, standard therapies for SD (e.g., Botox®) are less effective for VT. There is thus a great need to develop new treatments, which begins with a better understanding of VT. Towards this end, in our research project, we will use brain imaging to look at neural activity in patients who have both SD and VT. We will compare what we find with neural activity seen in patients with only SD. This will show us what abnormal brain activity is uniquely associated with VT. The results will reveal what brain area functioning goes awry in VT, which will be a major advance in our understanding of this condition.

Patients will undergo three different sessions as part of the study. First, in a one-hour session, we measure subjects’ voice characteristics at the UCSF Voice and Swallowing Center. Second, in a two-hour session, we run subjects in a brain imaging experiment at the UCSF Biomagnetic Imaging Laboratory. The brain imaging experiment uses magnetoencephalography (MEG), which non-invasively and silently records the minute magnetic fields generated by the brain as subjects vocalize. In the experiment, subjects first have electrodes pasted on their throat to monitor muscle activity in their larynx. Then subjects lie on their back with their head in the MEG scanner, and speak vowels while the scanner records their brain activity. As subjects speak, their voice is picked up by a microphone and returned to them via earphones. Third, after the MEG experiment, in a 30-minute session, we image subjects’ brains using a magnetic resonance imaging (MRI) scanner at UCSF Mission Bay. From the MEG scanner data, we look for differences in brain activity between SD patients and SD/tremor patients just before and just after they begin to vocalize, and in response to perturbations of the pitch they hear as they vocalize.

Who is working on your research team?

The research team consists of myself, Prof. Srikantan Nagarajan, Prof. Katherine Yung, Prof. Sarah Schneider, and Prof. Mark Courey. As Director of the Speech Neuroscience Lab at UCSF, I have been collaborating for many years with Prof. Nagarajan, who is Director of the Biomagnetic Imaging Laboratory at UCSF. Prof. Yung is the laryngologist of the UCSF Voice and Swallowing Center, and Prof. Schneider is the Center’s principal speech language pathologist. Prof. Mark Courey, who will be a consultant on the project, is Chief of Laryngology at Mt. Sinai Medical Centers in New York. Together, our research team has a long history of collaboration on various voice disorders, including spasmodic dysphonia.

How did you get involved in research?

I have always been interested in how the brain works. In graduate school, I studied models of learning in neural networks and then began studies of how auditory feedback (i.e., how we hear ourselves as we speak) affects speech production. When I moved to UCSF, I found a very collaborative environment that enabled me to work with many other researchers on studies of the neural basis of speech production, not only in healthy speakers, but also in several patient populations, including patients with impairments of the voice.

What drew you to SD research?

My speech research has always concentrated on the role of sensory feedback in speech motor control. I was drawn to studying SD because it is often theorized to be a disorder affecting feedback processing of speaking: A number of studies suggest that the laryngeal spasms of SD are a hypersensitive response to the auditory and somatosensory feedback speakers experience when phonating. Once I began studying SD, I was also motivated by the desire to help the patients who I got to know when they were subjects in our experiments.
NSDA VOLUNTEER SPOTLIGHT
ROBIN HOCHSTATTER

WomenOnCall is a non-profit organization that creates opportunities for professional women to volunteer in a more meaningful way by aligning skills, expertise and interests with short-term, high-impact volunteer projects. As a small non-profit, we are always looking for ways to expand. When NSDA Executive Director, Kimberly Kuman, tapped into WomenOnCall by posting a volunteer opportunity for editing video content, she was introduced to Robin Hochstatter.

Professionally, Robin spent over 33 years at Kraft Foods in video production. “When I started at Kraft, corporations were just starting to utilize video production for training and internal communication. It was a great time to be part of the team, as we grew from three to 15 people fairly quickly. We operated like an agency within the company and it gave me great training to understand the clients and their needs. Once Heinz bought Kraft, it was an opportunity to retire and start my own business, Brown Dog Productions.”

In 2015, Robin discovered WomenOnCall after a Google search for local volunteer opportunities. What appealed to her was how they matched capabilities to requesters’ needs. She was a perfect fit for the NSDA’s video project. The goal was to take over four hours of video interviews and pare it down into small segments of personal stories, compilations of experiences, and educational videos through interviews with doctors. Telling stories is Robin’s passion and video is a powerful way to do that. Multiple people talking about the same topic, in this case living with SD, is compelling.

“At first, I was amazed and a bit intimidated by the nature of the content. There was so much material to go through on such a variety of issues that people with spasmodic dysphonia were dealing with. Working on the “Ask the MDs” videos helped greatly to understand SD and the journey people go through for diagnosis and treatment,” Robin explained. The staff at NSDA simplified the process by outlining the video content and putting together themes and content that flowed together.

Robin loved the energy of the people who were interviewed and how they choose to respond to challenges of living with SD. She enjoyed learning about the role the NSDA plays to bring people together. “It was fascinating to learn about the different forms of SD and the variety of responses to the same treatment. I also found a new appreciation for Botox®, beyond wrinkles,” Robin said.

In addition, none of the people seemed nervous and were very open to the experience of being interviewed. She was most impressed that they were using their voice, the very topic that is the focus of their journey, to share their story.

Working with WomenOnCall, Robin has been exposed to a broad spectrum of non-profit organizations and is enjoying giving back through her gifts. Robin jokes, “I am just happy not to be just shooting videos for Velveeta® Cheese anymore.”

The NSDA thanks Robin for her time and talent for editing these videos. To view them, log onto NSDA’s YouTube Channel at www.youtube.com/NSDA300.
Support Group Co-Leaders, Ron Langdon and James Anderson, in conjunction with the Tampa SD Support Group conducted their 6th annual Walk on World Voice Day, April 15. A total of over $2,500 was raised for the NSDA. In North Carolina, Board Member, Mary Bifaro, and the Charlotte SD Support Group conducted their 4th Annual Walk & Cookout on April 1. Twenty-four people attended and a total of over $2,400 was raised for the NSDA.

Board Member, Warren Bandel, brought his Classic Brass Quintet to Mankato, Minnesota to perform a benefit concert on April 7, and a total of nearly $2,000 was raised for the NSDA. According to Mankato leader, Steve Jaeger, “It was a team effort sponsored by Bethany Lutheran College, the Mankato SD Group, Thrivent Financial, Poburka Design, and the Classic Brass Quintet”.

We are so thankful to share in the birthday celebration of NSDA Board Member, Stephie Mendel. Organized by her sons, David and Doug, donations in honor of her birthday were made to the NSDA, and she received the “gift” at a family party. She was overwhelmed by the number of people who contributed. Over $37,000 for NSDA research was donated from over 25 families plus Sophie (her adorable dog). To say she was touched is an understatement. “There is not a gift I would have rather received. I was just stunned. I appreciate my family so much and am so proud of my sons,” shared Stephie. We appreciate the family’s generous support!
2017 Dystonia Advocacy Day

As a member of DAN (Dystonia Advocacy Network), the NSDA comes together with other dystonia organizations in order “to speak out with a single, powerful voice on legislative and public policy issues which impact the dystonia community.” Dystonia advocates from around the US gathered in Washington, DC for the 2017 Advocacy Day in March. The event culminates with a trip to Capitol Hill so that participants can meet with the offices of their Members of Congress and Staff to urge support for legislative issues affecting the Dystonia community. Representing the NSDA were: DAN Chairperson, Emma Mattes, from Florida; DAN Steering Committee Member, Brian Leugs, from Colorado; NSDA Executive Director, Kim Kuman; Dorothy Tannahill-Moran from Kansas; Teresa Dunn from Missouri; Vickie Orazem from Montana; Susan Beck from Tennessee; Deb Lindsey from New Hampshire; Dennis Richey from Iowa; Karen Feeley from Virginia; Dick Stuart from New Hampshire; James Anderson from Florida; Laura Rahuba from Tennessee; and Dea Zugby from Maryland. A number of our volunteers also attended the DC Metro Support Group meeting which is led by Lois Jackson. Dates for 2018 will be announced soon.

SD Awareness Tools Available

Order online at www.dysphonia.org

BUTTONS: This button is a creative way to let others know about spasmodic dysphonia. It measures 1.75” x 2.75” and was designed by Andrea Butteworth who has spasmodic dysphonia. Andrea shared that the goal of these buttons is to help many feel more confident and open the door for conversations about SD.

BUSINESS CARD: Explaining that you have a voice disorder can help make a situation less stressful. Three business-size cards provide an easy way to explain to others about spasmodic dysphonia and raise awareness.

CAR VISOR CARD: This visor card (5.5” x 8.5”) will help explain what spasmodic dysphonia is, especially in stressful situations. Keep one in your car! Special thanks to NSDA Advocate, Deb Lindsey, who suggested this idea to the NSDA.

Educational Outreach

Members of the Dayton, OH, Spasmodic Dysphonia Support Group conducted their annual visit to Miami University speech-language pathology class (pictured right). According to past Leader, Mary Ann Keller, “It was such a wonderful time of sharing with Dr. Renee Gottliebson’s class. We came away with such an uplifted spirit – like we had really done something special in our own individual way to move information about SD along to those who were so interested in learning about it.”
2017 NSDA Leadership Workshop

The NSDA was pleased to host its 13th annual Leadership Program in Nashville on Friday, May 5, 2017. Thirty people gathered (pictured above), including Board Members, Support Group Leaders, Area Contact Persons, Advocacy Leaders, special guests, and staff. We wanted our half-day workshop to be informative, interactive, and inspirational. Attendees were asked to bring in their media devices, as well as a fundraising or awareness ideas that they wanted to share. Each attendee received a notebook of materials which covered support, awareness, an overview of the NSDA, and information on key components of our on-line reference library. The NSDA staff gave a demonstration of the new NSDA database and website, as well as social media tools. Small groups discussed fundraising and awareness ideas and gave individual presentations on topics shared. Through their tireless activities, NSDA leaders breathe life into our organization. They are ambassadors of the NSDA and they carry our banner high. They continue to make a difference in the lives of those affected by spasmodic dysphonia. They are dedicated to the important work of the NSDA mission. NSDA leaders motivate, inspire, challenge, encourage, and equip people with SD through their work. When they come together as leaders, there is power and strength in their unity, friendship, and fellowship.

NSDA Leadership Reflections

“As leaders within the NSDA, we are one family. When someone asks you a question about the NSDA, speak up as a spokesperson. We are one community that is educating and supporting those who need us. Be heard and speak up for yourself and others.”

Pat Hill, Area Contact Persons Coordinator

“It is always beneficial and rewarding when a new member comes – not only for them to realize that they are not alone and to become educated about SD, but for the group to also share their stories and lend support.”

Jan Lant, Leader of the Sacramento Valley SD Support Group

“I totally need to not allow SD to hold me back or steal my joy. I need to never give up and allow SD to rule my life. I need to be thankful for the new friends I’ve made through the NSDA.”

Mary Foster, Area Contact Person

“Working through my spasmodic dysphonia for many years caused me to be deeply introspective, especially about communication styles. It also forced me to be a better listener, albeit driven by my reticence to speak freely. This allowed me to develop a deeper appreciation that everyone has a voice – no matter how low, how high, how full or how strained. Ultimately, it has served me and allowed me to explore the world differently than I might have.”

Victor Chears, NSDA Ambassador
Support & Awareness

SUPPORT GROUP SCENES

Valerie Hidalgo, a member of the Knoxville Spasmodic Dysphonia Support Group, commented on the value of the NSDA Support Groups: "The Leader, Susan Beck, did a masterful job of gathering us in and creating a setting that had us relaxed and glad to meet one another. Sharing was awesome."

Congratulations to Martha Murphy, Leader/Founder of Dystonia Support & Advocacy Group of San Diego County. The Group celebrated its 30-year anniversary at their meeting in November with over 50 people attendance. Dr. Joseph Chung presented his unique perspective on the importance of movement.

REPRESENTATION AT CONFERENCES

Board Member, Dot Sowerby, hosted the NSDA booth at the conventions for the American Academy of Otolaryngology (AAO) in Chicago, and the American Speech-Language-Hearing Association (ASHA) in Los Angeles. Volunteering with Dot at AAO was Chicagoland leader, Cathy Jacobs, and her fiancé, Jim Mangan, Howell (Chip) Evans, and Dot’s son, Jim. At ASHA, Scott Lautanen, Area Contact Persons Coordinator, Pat Hill, along with new Los Angeles Support Group Leader, Toni Gold, joined Dot.

Special Thanks to Fred Hosier

In May, Fred Hosier stepped down from his position on the NSDA Board of Directors. We thank him for his years of service on our Board. Among Fred’s many accomplishments, he hosted the 2017 NSDA Education Conference in Philadelphia, PA, and he helped craft the Values Statement for our organization. Fortunately, Fred will continue to serve as Co-Leader of the Southeastern PA Spasmodic Dysphonia Support Group and remain active in other NSDA activities. We appreciate Fred’s commitment and dedication to the NSDA and the SD community.
Dot Sowerby Pioneer Award

Past President/Board Member Dot Sowerby had the pleasure of presenting her namesake award, the 2017 Dot Sowerby Pioneer Award, to NSDA Immediate Past President, David Barton. David is an extraordinary, dedicated, and tireless NSDA leader and this award honors his many contributions to the NSDA as President, Bulletin Board Moderator, Executive and Support Committee Member, International Communications Director – using his writing and leadership skills to support, educate, and raise awareness about spasmodic dysphonia.

Since 1995, David Barton has supported the NSDA, traveling from his home in New Zealand in order to attend as many NSDA meetings as possible. He served as the seventh President of the NSDA from 2005 through 2010. David was one of the founding Moderators of the Bulletin Board in 1997. This on-line forum allows those affected by spasmodic dysphonia to ask questions and seek advice. It has had well over 40,000 posts since its inception and has more than 5,000 people registered as part of its community.

David shared, “I am humbled and grateful to accept this award from my NSDA colleagues. As Dot says, “when we meet together at an NSDA symposium, it feels like we are with family!” Like so many of us with SD, when I was first diagnosed, I felt my struggle with speaking was unique to me, and it was a huge relief to discover there were others with SD. But wait, there’s more ... I found there was an organization for us, and the original SD pioneers had put this in place for all of us with SD!”

Read more about David's many contributions to the NSDA at www.dysphonia.org

Midge Kovacs Annual Awareness Award

Circle City, Indiana Support Group Leader, Bev Matthews, was presented the 2017 Midge Kovacs Annual Awareness Award by Board Member and Support Services Director, Mary Bifaro. Bev shared, "I was so surprised and honored. I never expected to get an award for something that I enjoy doing. There are so many dedicated volunteers in the NSDA who make tremendous efforts to raise awareness of SD and develop fundraising campaigns for SD research. I feel humbled by this fantastic group of people, and lucky to be considered a partner in the great things being done."

Since 2015, Bev Matthews and the Circle City, IN group have hosted three successful SD Workshops. In her welcome remarks in 2015, Bev said: “I wanted you to see that I may look like a normal person, but my voice, the first thing you hear from my mouth, is not normal and is not reliable. I have spasmodic dysphonia and it affects me every day of my life.” The workshops were designed to educate people with SD, along with students, educators and physicians who treat affected persons or research the disorder. It is our hope that we will all have a better understanding of the effects and treatment of spasmodic dysphonia after a few compressed hours of the workshop.

This award is named after Midge Kovacs from New York who started one of the first SD support groups. She began writing a newsletter called Our Voice to share information about SD as well as experiences of people living with SD. She encouraged all of us with SD to think beyond our individual voice problems. In her honor, the NSDA adopted this name for its current newsletter.

Read more about Bev's contributions to the NSDA at www.dysphonia.org
Overview of the NSDA
Charlie Reavis, NSDA President

President of the NSDA, Charlie Reavis, opened the 2017 Symposium by highlighting the mission of the NSDA. He described how the NSDA’s aim is three-fold; to educate the community, to provide support to those affected by SD, and to advance the medical research that focuses on SD. Reavis continued by describing how the NSDA’s purpose is to help everyone with SD to lead a better life. The NSDA’s vision is to ensure the ongoing viability of the only organization worldwide, which will continue the effort to eradicate SD. Charlie encouraged the NSDA community to share their stories with one another as a way to show support for others. He closed by highlighting the fact that 88% of the NSDA budget is dedicated to SD-specific programs and services.

The Vanderbilt Experience:
Overview of SD Treatment with Botox® Injections and Current Research
Gaelyn Garrett, MD and David Francis, MD

In their presentation, Drs. Gaelyn Garrett and David Francis from the Vanderbilt Voice Center discussed their practice and the overall patient experience. The Vanderbilt Voice Center, which began in 1990, has grown to become one of the largest centers for SD, as they see over 800 patients. Out of all of their patients, 85% of them have adductor SD. Drs. Garrett and Francis touched on the techniques to properly diagnose SD. They stated that when diagnosing patients, there are a number of passages that patients are asked to read. This allows the healthcare professional to determine what type of SD is present.

Drs. Garrett and Francis went into detail about the various differences between spasmodic dysphonia and muscle tension disorder (MTD). One way to differentiate between SD and MTD is that MTD improves with voice therapy. MTD is also more commonly diagnosed, while SD remains to be a rare disorder and can still take between 4-10 years to be properly diagnosed. Distinguishing factors include whispering, which is commonly seen in a person with SD, but not in someone with MTD. In addition, singing is easier to accomplish for a person with SD than it is for someone with MTD.

The most common treatment options for SD include: voice therapy, medications, botulinum toxin injections, and surgery. Regarding botulinum toxin injections, Drs. Garrett and Francis stated that about 70-80% of adductor SD patients report that they receive beneficial results with Botox® injections. The average bilateral injection that is given at Vanderbilt is 1.25. However, both doctors stressed that one size does not fit all in terms of botulinum toxin injection dosages.

Surgical Options for Spasmodic Dysphonia
Gerald Berke, MD

Dr. Gerald Berke, who pioneered the SLAD-R (Selective Laryngeal Adductor Denervation-Reinnervation) procedure, presented on the various surgical options that are available for SD patients. Prior to his in-depth description of the surgery, he touched on how botulinum toxin injections have the potential to improve the lives of many SD patients. They act on the neuromuscular junction and may take a few days to begin working. He also described how after several years of administering botulinum toxin injections, they do have the potential to make the surgery more difficult for the doctor because of the build-up of scar tissue. However, for those that exhibit complications from the botulinum toxin injections, surgery may be a viable option.

Overall, the SLAD-R surgery usually results in having three to six months of breathiness after the procedure. It is important to note that those with abductor spasmodic dysphonia or mixed dysphonia are not candidates. He also described that even with surgery, incorrect brain signaling is still taking place within the body. Lastly, he pointed out that nerves don’t reinervate well after the age of seventy; therefore, he does not recommend the surgery after this point. Along with the SLAD-R surgery, other available procedures include laryngoplasty, myomectomies, and thyroplasty.
The Role of the Speech Pathologist in Spasmodic Dysphonia

Melissa D. Kirby, MS, CCC-SLP

Speech-Language Pathologist, Melissa D. Kirby, spoke about how the human body is open to a wide range of variability. She described how SD is a journey and that patients with SD are the best diagnosticians. Ms. Kirby touched on how voice therapy is an adjunctive treatment option for SD that can be combined with botulinum toxin injections and surgery. She described how Speech-Language Pathologists do not have a lot of “fancy” equipment. Instead, they have specially trained ears for listening during the initial evaluations. This can be explained by their education, as Speech-Language Pathologists are taught to assess both the emotional and physical state of the patient.

Overall, there are a number of exercises that a Speech Pathologist uses with SD patients. Ms. Kirby described how several sessions in voice therapy have the potential to teach SD patient various ways to work around the issues they may face. A couple of tips that many have benefited from are to speak more slowly and softly and massage the larynx.

Along with therapy, Speech-Language Pathologists also help SD patients with insurance issues, letters to Human Resource departments, and guiding patients and family members through the decisions of treatment options. In her closing remarks, Ms. Kirby stated that there is a high value in attending SD support groups, as they provide patients and their families a chance to meet others with SD and learn how they can cope.

Spasmodic Dysphonia Research Overview

Gerald Berke, MD

Dr. Gerald Berke provided a background on the SD research that is funded by the National Institutes of Health and the NSDA. He touched on how the NSDA is committed to understanding the science of SD, which can be seen through their constant support of research. The current areas of research that are being examined include environmental risk factors, pathophysiology of central nervous system dysfunction in SD, novel treatment approaches, and diagnostic tools for SD.

Dr. Berke described how there are multiple research studies being conducted across the country. In San Francisco, researchers are looking into how SD affects brain activity during speaking. In Minnesota, researchers are examining the structure and excitability of the brain between healthy subjects and those with SD. Lastly, in New York City, researchers are examining genetic risk factors and brain changes in SD patients.

The NSDA is constantly looking for research applications from new startup grants to post-doctoral studies that are focused on research aimed at increasing the understanding of spasmodic dysphonia.

Beyond the Snapshot: Your Brain and Spasmodic Dysphonia

Teresa Kimberley, PhD, PT

Dr. Teresa Kimberley provided an overview on how her team at the University of Minnesota is using non-invasive magnetic neuroimaging to gain a better understanding of the abnormal central nervous system networks that are involved in spasmodic dysphonia. This involves measuring the excitability of portions of the brain. Their goals are to understand the brain network dysfunction that is involved in SD and to find the best ways to modulate brain connections in order to improve symptoms.

Dr. Kimberley touched on one of her main passions, which is the study of neuroplasticity. This involves an examination of the brain’s ability, which is subject to change. Overall, neuroplasticity helps the brain find new pathways to recover lost function. Due to the fact that speaking is a complex activity, especially for an SD patient, Dr. Kimberley aims to determine how vocalization brain areas are connected to each other and with the rest of the brain, with regards to patients with SD.

Dr. Kimberley encourages everyone to support the NSDA, as the organization provides direct funding for research and makes it possible for people who are interested in SD to learn more and network with others. Currently, Dr. Kimberley and her team are actively seeking research participants for their study.
Unconditional Well-Being Through Mindfulness
Christie Bates, LPC

Contemplative therapist, Christie Bates, presented on the topic of mindfulness and how it involves non-judgmental awareness and attentiveness, which may allow the individual to be able to face and/or change the chaos in their life. This contemplative practice involves getting past the difficulties in life.

In order to raise the individual’s level of mindfulness, praying, journaling, and meditating are suggested. Ms. Bates stressed that it is crucial to keep in mind what is most important, what is of value, and what truly interests the individual. With this in mind, the individual will be able to work on collecting their attention to reach a level of concentration.

She described how when an individual is under stress, their attention becomes hijacked. Due to this, self-care is important, as the individual should aim to be kind and respectful to themselves and others.

When awareness, acceptance, and action are heightened, they have the potential to help the individual achieve harmony with reality. Ms. Bates stressed that mindfulness is a process and takes time and practice to achieve. Overall, everyone owns their actions and their consequences. Bates ended with the thought that although there is no cure for SD, individuals can still live creatively with it.

Voices in the Land of Crazy Horse
Keynote Speaker: Kevin Hancock

Kevin Hancock, the 2017 NSDA Keynote Speaker and author, presented a compelling speech that had everyone on the edge of their seat. Hancock is CEO of Hancock Lumber in Maine, a 6th generation family business. His experience with SD began back in 2010 when his voice began to spasm and felt as if it were being squeezed. Even though Kevin went through a rough patch, he spoke about how spasmodic dysphonia changed his life.

Kevin stated that he was blessed and grateful for SD and would never want to give it up. According to him, we are all here to find our own true voice and share it with the world. Kevin did just that on a South Dakota Indian reservation, which he visited multiple times, while he was struggling with his newfound SD. During his time there, he searched for his voice in a community where no one’s voice is heard. He learned how to really listen, which enhanced his leadership style. Kevin brought this skill back to his company, which allowed for him to invite others to lead and share the stage, where he was able to listen and lead more effectively.

Through his experience, Kevin learned to strengthen the voices of others, especially those who feel unheard. After his journey, Kevin began to envision a community where every voice is felt, respected, trusted, and empowered — a place where everyone would be able to lead. He shared that SD helped him learn how to listen, to himself and to others, which helped to save him and his family business. According to Kevin, “It took losing my speaking voice to find my soul’s voice.” Toward the end of his presentation, Hancock posed the question, “Have you ever considered that SD picked you for a reason?” Overall, Kevin strongly believes that our true voice still lives within us. He ended his speech with a quote from E.B. White, “The world is full of talkers, but it is rare to find anyone who listens. And I assure you that you can pick up more information when you are listening than when you are talking.”

Final Thoughts

Overall, many found it inspiring to hear all that is being done for SD and to hear the stories of people who are living courageously with SD. One attendee stated, “I was very inspired by meeting and listening to those who came to the symposium in Nashville. Every one of you sounded so beautiful to me when you were talking. I felt like I could finally hear myself, and it sounded amazing! I can’t explain to you how inspiring it was to hear you all speak the way I speak and plug away and be happy, or sad (for a moment) but be you.”

SAVE THE DATE: NSDA Symposium
May 5, 2018 | Irving, TX
Since 2013, NSDA President, Charlie Reavis, and NSDA Executive Director, Kimberly Kuman, have exhibited at the annual Fall Voice Conference. This Conference is designed to encourage and educate professionals on a multi-disciplinary approach to the management of vocal difficulties. This includes the clinical care of patients with voice-related problems and how clinical and basic science research can guide patient care. This year’s meeting was hosted in Arlington, VA, from October 12-14, 2017, and has grown in size, with close to 400 people attending. Local NSDA volunteers included DC Metro Spasmodic Dysphonia Support Group Leader, Lois Jackson, and Special Projects Manager, Karen Feeley, attended to help distribute information to participants. Charlie Reavis spoke to over 75 laryngology fellows and early-career laryngologists to share information about the NSDA and how we can help partner with them in education and support of their patients.

Lois shared her perspective on attending the conference:

Thank you for the opportunity to participate as a NSDA representative at the 2017 Fall Voice Conference. Not only was I proud to be a representative voice of spasmodic dysphonia/tremor, I also appreciated the opportunity to attend sessions with medical professionals including several that treat members of local SD Support Group. Some highlights included:

1. Meeting and networking with the broader voice community (otolaryngologists; audiologists; speech-language pathologists; speech, language, and hearing scientists; audiology and speech-language pathology support personnel; and students) and to learn of the organization’s rigorous certification process and high standards set for its members.

2. Seeing medical professionals and researchers (international) who are dedicated to raising awareness, treating and pushing the boundaries on speech and hearing disorders, and striving for cutting-edge solutions to ease the burden for their patients.

3. Learning about current research in communication sciences and disorders and the requirement that presenters and researchers be non-commercial or full-disclosure by speaker if otherwise. Poster presentations that complemented the program were also quite extensive, informative and practical. The broad spectrum of disorders, range of diagnosis, and treatment of voice, language, disorders was on display.

4. Being pleasantly surprised at the interest and the research projects underway and presented that directly related to SD, MTD, and tremor (rare ailments with no known cause or cure) as well as the focus on new technologies in trials. Dr. Pitman’s work with electro-magnetic stimulation was particularly exciting and will be followed closely in future.

5. Loved the idea that NSDA gave travel grants to attend this meeting to several professionals and researchers who presented their findings and research at this conference and who each sought out NSDA leadership and expressed their appreciation. This is a great way to stimulate interest in SD/tremor research and raise awareness of SD among medical professionals.

To encourage research in spasmodic dysphonia, the NSDA sponsored four travel grants for researchers to attend the Fall Voice Conference. Congratulations to the 2017 Recipients and thank you for your continued work!

**Rohan Bidaye, Fellow**
Deenanath Mangeshkar Hospital,
Mumbai, Maharashtra, India
**Thyroarytenoid Myoneurectomy in the Treatment of Adductor Spasmodic Dysphonia**

**Linda Carroll, PhD, CCC-SLP, ASAHF**
Montefiore Medical Center,
Bronx, NY
**Does Botox Make Me Look Better or Sound Better? The Effect of Botulinum Toxin on Aerodynamic Measures in Adductor Spasmodic Dysphonia**

**Christina Cerkevich, PhD**
University of Pittsburgh School of Medicine, Pittsburgh, PA
**The origin of cerebral cortical output to laryngeal muscles**

**Ann Rooney, MS, CCC-SLP**
Montefiore Medical Center,
Bronx, NY
**Spasmodic Dysphonia versus Muscle Tension Dysphonia: What’s in the air?**
Being connected.
That is what we hear the most when people are asked what the National Spasmodic Dysphonia Association means to them.

- Being connected to other people living with SD through NSDA-sponsored symposiums, local support groups, and on-line resources.
- Being connected to the latest updates on research.
- Being connected to resources on how to live with SD and educate others.

Ironic, really, since often times, our voice does not connect. It is those broken or breathy words that make it so challenging at times. When I was first diagnosed in 2001, it was through the NSDA that I found relief and understanding through the connection of meeting others who had the same voice as I did.

Read more in this issue about the two new grants the NSDA has funded as we are making new, exciting connections through research.

We want to find new options and new answers and this research is possible because of YOU! Not only through your generous donations but your willingness to participate in research. Now more than ever, there is interest in spasmodic dysphonia research and we want to continue funding these grants with your help!

We invite you to be part of our 2017 Challenge Grant! Generously matched up to $75,000, your donation will help us make more connections and propel us forward. You can help everyone with SD through your generous contribution.

We hope you will donate online at www.dysphonia.org or mail your gift to the NSDA using the enclosed donation envelope.

Together, we are working to find answers and connect people affected by SD through research, education, and support. We need your continued help to support the only organization solely dedicated to understanding spasmodic dysphonia. Please make the connection and support the 2017 Challenge Grant today!

Thank you for your support!

SAVE THE DATE
2018 NSDA Symposium
May 5, 2018
Embassy Suites by Hilton
Dallas DFW Airport South
Irving, TX

Join us for an engaging day focused on spasmodic dysphonia!

- Meet others and share YOUR story about living with spasmodic dysphonia at the Welcome Party on Friday evening prior to the symposium, and, if a first-time attendee, sign up for the SD Ambassador Program
- Hear the latest developments on spasmodic dysphonia from experts in the fields of laryngology and speech and language pathology
- Have your questions answered during panel discussions with the medical presenters
- Find support, information, and connections to help empower and live better with SD

Log onto www.dysphonia.org for more details!