

2016 NSDA Midwestern Conference Summary

April 30, 2016 – Des Plaines, IL

The National Spasmodic Dysphonia Association hosted its 2016 Midwest Conference on April 30, 2016 in Des Plaines, IL. On Friday evening, prior to the conference, a Welcome Reception provided the opportunity for fellowship and support, when people shared their personal experiences. President Charlie Reavis started the program on Saturday morning with an overview of the mission of the NSDA. The first sessions of the Conference focused on the medical aspects of spasmodic dysphonia with Dr. Robert Bastian presenting an overview of the disorder, and Dr. Gerald Berke discussing treatment options. Several researchers, some who are funded by the NSDA, including Drs. Kristina Simonyan, Mo Chen, Michael Hammer, and Rita Patel, shared their different approaches to better understanding spasmodic dysphonia. After lunch, Dr. Laura Froeschke talked about how spasmodic dysphonia can affect your identity, and Speech Language Pathologists Jan Potter Reed and Brienne Ruel provided voice therapy tips and recommendations in break-out sessions. One person commented, “It was great meeting so many people who understood what I was going through and not being embarrassed to speak,” and another said “What I enjoyed was the variability of approaches to SD research, various treatment options, and integrating the problems of SD in our lives.”

Understanding Spasmodic Dysphonia

Robert Bastian, M.D., *NSDA Medical Advisory Board Director, Downers Grove, IL*

Dr. Bastian provided an overview of what spasmodic dysphonia is, reminding us that it is a dystonia of the laryngeal muscles. The term “dys-tonia” means “abnormal tone in the muscles.” The disorder is chronic and unremitting, but it does sometimes evolve (over a period of time sometimes getting worse, sometimes getting better). Occasionally dystonia can involve other parts of the body. Not all forms of spasmodic dysphonia have “breaks” in the voice; some voices just have an abnormal quality. Spasmodic dysphonia can be either “tonic” (stable) or more frequently “classic” (episodic and intermittent, i.e. it gets better and worse from time to time). While spasmodic dysphonia can be misdiagnosed as psychogenic, it is not so, but rather neurological. It can be confusingly task-specific. Sensory tricks can work for a time in relieving symptoms. There is short-term variability of symptoms, which aren’t necessarily tied to specific causes. The disorder could have long-term evolution (e.g., tremor often comes in later). It can get better and worse. The SD population is on the same “normal” range as the population as a whole in terms of psychological health. Diagnosis is based on history, voice characteristics and laryngeal exam. The disorder is often described by patient as “My voice catches.”

Most people with spasmodic dysphonia dislike using the telephone. For many, it is easier to laugh and sing than to talk, or vice versa. There are certain sounds and tasks that are more difficult (e.g., my name; numbers). In some cases, the condition can be temporarily relieved by vocal tricks such as, speaking in a British accent or speaking in a sing-song voice. The identification of which muscle group is in spasm is critical to treatment since there are seven paired and one unpaired muscle groups involved in moving the larynx to create speech. The larynx of most people with spasmodic dysphonia looks normal on an exam. However, you can

sometimes see the spasm when they speak if a scope is inserted. Dr. Bastian (who is a singer himself and a good voice mimic) then gave examples of the sound quality of various typical SD sounds: phonatory arrests (breaks), squeeze downs, strain, AB intermittent or continuous whisper, inhibitory spasms (a type of tremor that is dystonic, like a singer's vibrato but more insistent), essential tremor without dystonia, breathing noises (where there is some respiratory dystonia, a factor in 5% of SD patients).

The adductor form is characterized by a "grabbing" of the voice while abductor is distinguished as a "dropping away" of the voice. The "grabbing" characteristic of adductor SD may happen more at the end of the day when a person is tired. It can be mixed, both adductor and abductor spasmodic dysphonia, which can be more difficult to treat. Muscle tension dysphonia (MTD) is usually a mechanical problem, not neurological, and it can often be improved by speech therapy. Dr. Bastian concluded with the idea that a very clear diagnosis leads to clear treatment.

Treatment Options for Spasmodic Dysphonia

Gerald Berke, M.D., *NSDA Scientific Advisory Board Director, UCLA, Los Angeles, CA*

Dr. Berke began by explaining that our understanding of spasmodic dysphonia has evolved to a more spectrum-based disorder, as we've discovered that the variations do not fit neatly into boxes. One of the most helpful tests is whether or not the condition responds favorably to botulinum toxin injections. It is believed that there are various causes, or etiologies, which may include genetics and environmental triggering factors. Treatments include speech therapy, Botox® injections and several types of surgeries. Based on previous denervation (cutting the nerve), Dr. Berke pioneered the **Selective Laryngeal Adductor Denervation-Reinnervation (SLAD-R)** procedure which is generally considered today as the most effective surgical approach for adductor spasmodic dysphonia. Many people with spasmodic dysphonia do not improve much with voice therapy, but it's useful in some cases. There is a wide spectrum in terms of dosage of Botox® (1/8 unit up to about 10 units), depending on individual responsiveness, and it requires some experimentation to find the right dose. There are a variety of ways to administer Botox® including unilateral vs. bilateral, use of EMG or not, or touch and point injections. Antibodies against long-term effectiveness of Botox® have been identified, but in his experience, almost never occur in people with spasmodic dysphonia. Some of the other types of botulinum toxin (MyoBloc® and Dysport®) are not as effective for spasmodic dysphonia as Botox®. Dr. Berke explained that there is currently no cure for spasmodic dysphonia. Even with surgery, they are just rearranging the wires. The incorrect brain signaling is still occurring.

Dr. Berke identified some of the research that is currently going on to better understand spasmodic dysphonia, including several studies by Dr. Kristina Simonyan, in areas such as the role of brain networking in dystonias, genetic brain abnormalities in dystonia patients, the effect of certain drugs seen in fMRI studies and voice tremor. Some of the researchers speaking today (Drs. Chen, Hammer and Patel) will talk about the work they are doing under NSDA grants. Other research is currently underway in areas such as: life impact of SD; the pathophysiological defect in the inhibition of motor control in dystonia patients; the role of sensory feedback in speech motor control; the timing of when neural activity becomes abnormal in the process of phonation; the effect of air-flow interruption; autopsy brain study; neuroplasticity and the role of the cortex; mapping of the neuromechanism of speech.

Research Update

Kristina Simonyan, M.D., Ph.D., *Icahn School of Medicine at Mount Sinai, New York, NY*

Dr. Simonyan feels that the definition of spasmodic dysphonia has been too narrowly defined in terms of voice breaks, and rather should be considered by taking into account the full spectrum of symptoms experienced by a patient, such as harshness, strain, effort, and breathiness in addition to voice breaks. She believes that SD involves networks rather than just the basal ganglia, which had for a long time been identified as the source of the defect in SD. From her work on voice tremor in SD, she reports that 1/3 of SD patients have co-occurring dystonic tremor. (Dr. Simonyan prefers the term “dystonic tremor” to “essential tremor” since this characteristic voice tremor, so frequent in SD, is generally not accompanied by other tremors – hands, neck, etc.)

Focal dystonias like SD are far more common than generalized dystonia. SD is usually of late-adult onset (age 40-50) and impacts highly learned tasks, such as speech production. The pathophysiology includes brain abnormalities, genetics and environment. We don't yet know what the environmental triggers are. A number of possible environmental triggers have been suggested for all of the dystonias, such as blepharospasm with sun exposure; torticollis with neck injury; SD with virus or stress; writers cramp or musicians' dystonia with overuse. But these associations are still not established. (Dr. Berke and Dr. Bastian have both made the point that there are an exceptionally large number of singers with SD, making overuse a possible risk factor for SD as well.) In terms of brain organization, SD patients have abnormal activity and abnormal neural networks, leading to abnormal plasticity and loss of “inhibition” (inhibition being the mechanism that controls hyperactivity and therefore spasming in the muscles that are receiving signals from the neural network). There are abnormalities in the cortex as well as the basal ganglia. PET studies also show abnormalities in the GABA and Dopamine receptor function. These abnormalities show up, even in activities which are asymptomatic (i.e., where no symptoms are occurring). Adductor spasmodic dysphonia and abductor spasmodic dysphonia look different from each other on an FMRI. There are gray matter changes in the brain and also (though fewer) white matter changes in people affected by SD. Tremor in the vocal cords (dystonic tremor) shows similar changes, but includes more changes in the frontal part of the brain.

Spasmodic Dysphonia Research Update

Mo Chen, Ph.D., *University of Minnesota, MN*

Dr. Chen described the work being done at the Brain Plasticity Lab at University of Minnesota under an NSDA grant using non-invasive transcranial magnetic stimulation (TMS) and functional magnetic resonance imaging (fMRI) techniques to investigate the neural network difference between people with and without spasmodic dysphonia. The preliminary results show that during phonation there are few differences in how the laryngeal brain networks are synchronized when comparing healthy subjects to people with spasmodic dysphonia, but there are differences during rest. This may point to new strategies for future interventions to change how brain areas communicate with each other to help treat the disorder.

Spasmodic Dysphonia Research Update

Michael Hammer, Ph.D., CCC-SLP, *University of Wisconsin, Madison, WI*

Dr. Hammer's new research, to be supported by an NSDA grant, focuses on the "touch" receptors in the larynx that transmit information to the brain about the larynx during speech. As an example, he illustrates this concept by describing how our brain works to use information from touch receptors in our fingertips to determine how best to grip an object such as a glass of water, typing on a keyboard, or to guide movements to play a musical instrument. Most of the movements our bodies make during the day, even though we're generally unaware of it, benefit from this very delicate and elaborate feedback between the sensory receptors and the brain. Healthy voice functioning benefits from highly coordinated sensory information from the touch receptors in the larynx to the brain. Based on Dr. Hammer's previous research, it appears that the brain may process touch information from the larynx differently depending on the task. For breathing, the brain may maintain a greater defensive state and be prepared to respond to unexpected sensory input to protect the airway.

For speech and voice, the movements related to speech and voice also create sensory input to touch receptors in the larynx. However, if the larynx responds to its own self-generated sensory input every time an individual talks, the defensive closing movements of the larynx could interrupt the relatively fluent pattern of speech and voice. Based on Dr. Hammer's research, it appears that the sensory receptors of the larynx of healthy individuals become less sensitive during voice/speech tasks compared with breathing tasks. The healthy brain may actually expect to receive touch information from the larynx during speech and voice, and may maintain a less defensive state in favor of fluent speech. Dr. Hammer's findings lead to many interesting ideas related to spasmodic dysphonia. For example, during speech and voice, Dr. Hammer hypothesizes that the brain and larynx in persons with spasmodic dysphonia may maintain a more heightened defensive state where the larynx may respond protectively to the sensory input caused by its very own movements. The goal of Dr. Hammer's research is to help explain the underlying cause for the voice interruptions we commonly associate with spasmodic dysphonia, leading to improved options for voice treatment.

Spasmodic Dysphonia Research Update

Rita Patel, Ph.D., CCC-SLP, *Indiana University, Bloomington, IN*

Through use of high-speed video imaging, which captures much more detailed vocal fold motion than does more traditional stroboscopy, Dr. Patel's group, supported by a grant from the NSDA, has been able to distinguish between adductor spasmodic dysphonia (ADSD) and muscle tension dysphonia (MTD) by virtue of random spasmodic bursts and spatiotemporal disturbances in ADSD patients that don't show up in those suffering from more functional voice problems. Further, Dr. Patel's group was able to demonstrate that these oscillatory breaks on high-speed video imaging correspond to the breaks observed in specific muscles on laryngeal electromyography. By capturing these minute micro-motion and oscillatory breaks in the vocal fold motion, we can better identify the muscle group that is responsible for the voice spasms, as well as various kinds of asymmetrical and inconsistent movements that characterize adductor spasmodic dysphonia.

Reconstructing a Personal Identity with Spasmodic Dysphonia

Laura L.O. Froeschke, Ph.D., CCC-SLP, *Elmhurst College, Elmhurst, IL*

Dr. Laura Froeschke's session provided insight on how the change in one's voice is comparable to "identity theft," and discussed how to re-establish your identity. She discussed the importance of remembering that chronic conditions are tough. Society is accustomed to dealing with an illness, or a disease, as a short-term problem, but this is not the case with spasmodic dysphonia. Getting a diagnosis is helpful because it gives the disorder a name. However, it may transform the illness from something you "have" into something you "are" which gives power to the disorder. There's also the tendency of society to want to advise you to take care of your problem the way you would a short-term illness ("You should rest your voice" "You should try Botox® or speech therapy"), which has a feel of blame-shifting, even though, in spite of doing everything right, your voice still has breaks. Most often than not, war language is associated with chronic health problems, such as, "I'm fighting cancer" and "Don't surrender to..." But here too we can sometimes feel at fault if we are not winning. The voice is the fingerprint to our identity, so this loss is significant. However, it is important to remember how other things define who we are – our history, our family, our job, and what matters to us in the world. Dr. Froeschke encourages people with spasmodic dysphonia to create a wheel with a spoke and spikes. This will serve as a reminder about the many distinct characteristics that make up who we are and that the quality of sound in the voice is only one part of our identity.

Vocal Workshops

Abductor SD: Jan Potter Reed, MS, CCC-SLP, *Chicago Institute for Voice Care, Chicago, IL*

Adductor SD: Brienne Ruel, MA, CCC-SLP, *University of Madison, Madison, IL*

Two break-out sessions were offered for people with Abductor and Adductor Spasmodic Dysphonia. For those with Abductor, Speech Language Pathologist, Jan Potter Reed, presented a consonant and vowel strategy chart. For those with Adductor, Speech Language Pathologist, Brienne Ruel gave tips and techniques for the voice. She stressed the importance of having realistic expectations when it comes to spasmodic dysphonia and to try to work with a Speech Pathologist who is specifically trained in voice disorders. She also had the group practise some exercises.

Special thanks to Marcia Sterling for assisting with the compilation of this summary.

2016 NSDA Midwestern Conference Speakers

Robert Bastian, M.D. is the Director of the Bastian Voice Institute (BVI) in Downers Grove, IL. He was trained in medicine and surgery at Washington University Medical School in St. Louis, Missouri. Prior to forming BVI, Dr. Bastian completed a successful 20-year academic medical career first at Washington University, St. Louis, and then at Loyola University Medical Center in Maywood, Illinois. Dr. Bastian's passionate interest in the voice flowed initially from his own singing training and experience. He is one of the first physicians to use botulinum toxin to treat spasmodic dysphonia. The Bastian Voice Institute has attracted an extensive patient population from across the globe. He is the recipient of many awards, including the Honor Award for his teaching contributions to the American Academy of Otolaryngology. Dr. Bastian serves as the Chair of the NSDA Medical Advisory Board.

Gerald Berke, M.D. is a Professor of Surgery, and Chair of the Department of UCLA Head and Neck Surgery in the David Geffen School of Medicine and the UCLA Health System. Dr. Berke, who is a highly respected researcher and clinician, has served as chief of the department since 2012 and prior chair of the division since 1992. He also is the director of the UCLA Voice Center for Medicine and the Arts, which he founded. He performed the first functioning larynx transplant in animals and pioneered many of the procedures, including the Selective Laryngeal Adductor Denervation-Reinnervation for spasmodic dysphonia. Dr. Berke came to UCLA in 1979 to complete his surgical residency, after graduating from both undergraduate and medical school at the University of Southern California, and he became an assistant professor in 1984, and then advanced to become Professor and Chair of Head and Neck Surgery in 1992. Dr. Berke is a founding member of the NSDA Scientific Advisory Board and now serves as the Chair.

Mo Chen, Ph.D. is a Scientist and the Manager of the Non-invasive Neuromodulation lab at University of Minnesota. He received Ph.D. degree in Biomedical Engineering at Zhejiang University, China. Then he finished his postdoctoral training with Dr. Teresa Kimberley in the Brain Plasticity Lab at University of Minnesota. His research interests focus on using neuromodulation and non-invasive brain stimulation techniques to investigate pathophysiology and rehabilitation treatment of neurological disorders, especially in focal dystonia including spasmodic dysphonia.

Laura L.O. Froeschke, Ph.D., CCC-SLP joined the Elmhurst College faculty in the fall of 2015. Prior to coming to Elmhurst College, Dr. Froeschke served on the faculty of Northwestern University teaching courses in fluency, intercultural service delivery, counseling, dysphagia, introduction to communication disorders and vocal acoustics laboratory. Dr. Froeschke completed her B.A. in audiology and speech sciences from Michigan State University, and her M.A. in speech-language pathology from Western Michigan University. Following 16 years of clinical practice focused in adult neurogenics in settings ranging from acute care to hospice, Dr. Froeschke completed her Ph.D. in interdisciplinary health sciences from Western Michigan University. Her research interests continue to place a strong emphasis on interdisciplinary approaches to the management and treatment of communication disorders.

Michael Hammer, Ph.D., CCC-SLP is the Director of the Airway Sensory Physiology Laboratory and the Associate Scientist in the Department of Surgery and Otolaryngology at the University of Wisconsin in Madison, WI. He received his Ph.D. from the University of Kansas. Dr. Hammer's primary areas of interest center on understanding the mechanisms of upper airway sensorimotor control underlying airway protection, breathing, and speech, in addition to, incorporating measures of upper airway sensorimotor control into paradigms for neurorehabilitation. His current research is focused on the process of how laryngeal sensory inputs are affected by various tasks and phases of breathing.

Rita Patel, Ph.D., CCC-SLP is an Assistant Professor in Speech Sciences at Indiana University in Bloomington, IN. She earned her Masters at the University of Mumbai and her Ph.D. from the University of Wisconsin-Madison. Dr. Patel has an interest in pediatric vocal development and in the identification of the physiological factors of laryngeal function that trigger severely disturbed voice qualities. Dr. Patel aims to lay the groundwork for the development of biomechanical modeling and assessment tools to identify children who are at risk of developing voice disorders. She has a strong interest in spasmodic dysphonia. Her goal is to explore the vibratory kinematics and disturbances of muscle activity, to understand the clinical pathophysiology of spasmodic dysphonia.

Jan Potter Reed, MS, CCC-SLP is a licensed speech pathologist and is a Voice Specialist at the Chicago Institute for Voice Care. Ms. Reed has extensive experience as a speech pathologist at more than a dozen Chicago-area hospitals, rehabilitation facilities, and physician offices. She works with the Institute's patients on voice rehabilitation and coaching, bringing a unique approach, combining the science of speech pathology with techniques informed by the performing arts and integrative medicine. She earned her M.S. in Communication Disorders from the University of Wisconsin-Madison and her B.S. at Northwestern University. Ms. Reed earned a certificate in Clinical Research Methods from the University of Illinois-Chicago.

Brienne Ruel, MA, CCC-SLP is a Speech-Language Pathologist at the University of Wisconsin Voice and Swallow Clinics in Madison, WI. She attended the University of Victoria, receiving a Bachelor of Arts with distinction in Linguistics. She completed her Master of Arts in Speech Pathology at the University of Iowa, with subspecialty training in Vocology. She was the first graduate student chosen to complete an 8-week internship at the Emory Voice Center, where she obtained hands-on training in voice diagnostics and behavioral intervention techniques. She completed her clinical fellowship training at Vanderbilt Voice Center. Her clinical interest and specialty include care of the professional speaking voice, tracheoesophageal voice prosthesis management for laryngectomees, functional voice disorders, and spasmodic dysphonia.

Kristina Simonyan, M.D., Ph.D. is an Associate Professor of Neurology and Otolaryngology at Icahn School of Medicine at Mount Sinai in New York. Her main research is focused on the pathophysiology of isolated focal dystonias. Currently, she is cultivating a better understanding of normal and diseased states of the central nervous system. Dr. Simonyan received her Ph.D. in Neurobiology from the University of Hanover. Among her awards include the Fellow Award for Research Excellence, the German Research Foundation Fellowship, and the NINDS Intramural Retreat Award. She has been awarded multiple grant awards from the National Institutes of Deafness and Communications Disorders (NIDCD) focused on spasmodic dysphonia.

About the NSDA

The National Spasmodic Dysphonia Association strives to make the lives of people living with spasmodic dysphonia better through research, education, awareness and support. We are an organization made up of committed volunteers, compassionate healthcare professionals, and a dedicated staff. With your help, we will continue to fund research to understand this mysterious disorder while expanding our outreach efforts and providing support to those with SD. We encourage your involvement so that your voice is heard. *For more information about the organization, log on to www.dysphonia.org.*