



The Voice

The Voice

VOICE OF THE EDITOR

Nadine Connor, PhD

SPASMODIC DYSPHONIA (SD)

EXPLORING ASPECTS OF THE DISORDER WITH RESEARCH, CLINICAL CARE, AND PATIENT STORIES

BY NADINE CONNOR, PHD

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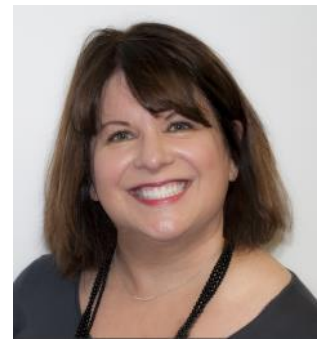
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This issue of *The Voice* is dedicated to a specific voice disorder, known as spasmodic dysphonia (SD). SD is considered a relatively rare and debilitating voice disorder that affects more women than men. The strained voice characteristic of SD, often with breaks in pitch that interfere with effective communication, tends to begin within the third to fifth decade of life. There is no cure. The road to diagnosis can be long and rocky, often with years of misdiagnosis before treatment is initiated.

In this issue of *The Voice*, we will explore different aspects of

SD, from different perspectives: from two people with this voice disorder, from a laryngologist who provides medical treatment to patients with SD, from a clinician-scientist actively engaged in research in this area and from the President of the National Spasmodic Dysphonia Association, an organization in place for over 25 years.

Thank you, Maria, Dr. Sataloff and our readers, for the wonderful experience of serving as co-Editor of *The Voice* with Dr. Kim Steinhauer over these last 4 years. This is my last issue. As I move on to other service commitments, I leave you in the capable hands of Kim and Dr. Mary Sandage.



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HORRIFIED (BUT, APPRECIATIVE)

BY MARIA RUSSO

See that look on my face? That was my initial reaction to Dr. Nadine Connor's resignation as one of two brilliant editors of *The Voice* newsletter. (Our other wonderful editor is Dr. Kim Steinhauer.) Beginning in 2010, Nadine delivered years of interesting, top-quality themes and articles. My favorite of all her issues was *Not Little Adults*, published last



TVF EXECUTIVE DIRECTOR, MARIA RUSSO, HORRIFIED TO LOSE A GREAT EDITOR.

(ABOUT TO FLY OVER MONDSEE NEAR SALZBURG)

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SPASMODIC DYSPHONIA AND ITS TREATMENT

BY SETH H. DAILEY, MD

Spasmodic Dysphonia (SD) is a brain disorder producing considerable communication impairment. It is part of the family of diseases called dystonias, literally meaning “altered (muscle) tone.” Other examples of dystonia include altered muscle tone of the neck (torticollis) and around the eyes (blepharospasm), which are conditions that can also occur with SD. Dystonias can affect different muscles groups in different people in a task-specific manner. With SD, for example, involuntary contraction of muscles in the larynx most often occurs during conversational speech, but much less so during singing or laughing. SD is estimated to affect 100,000 individuals in the U.S. and has its onset in the 30s, more often in women than in men [1].

SD symptoms are most commonly of the “adductor” type, known as “ADSD,” in which the voice sometimes (or often) sounds strained or strangled during conversational speech. ADSD accounts for approximately 80% of cases with the remain-

ing 20% being the “abductor-type” (ABSD), where breathy voice breaks occur during speech. Tremor-type SD is thought to be present with both ADSD and ABSD in approximately one third of patients making diagnosis that much more challenging [1, 2]. Symptom severity tends to be accentuated by stress and voice use on the telephone and diminished with alcohol or drugs that target anxiety, such as Valium. As with many dystonias, the patient may observe that a physical task, such as touching their own face, may produce temporary suppression of symptoms. This so-called sensory trick, however, produces only a transient effect and speaks to the inability of sensory feedback to produce a lasting benefit in this central disorder. Also important in the clinical history is a family history of dystonias and also tremor. Examination of the larynx with a flexible viewing tube (an “endoscope” specific for the larynx, called a “laryngoscope”) passed through the nose is essential in the evaluation. A flexible laryngoscope allows the observer to see motion of the larynx during a wide range of voice tasks including

conversational speech and allows tremor to be observed, if present.

Originally, SD was thought to be a psychiatric disorder, but Dedo proposed in 1976 that SD had a physical cause and proceeded with the innovative strategy of cutting an important motor nerve that supplies muscles of the larynx, the recurrent laryngeal nerve. He obtained excellent early results. Unfortunately, voice symptoms reoccurred over time for many patients with SD, which suggested that the source of the disorder was in the brain, and possibly caused by altered feedback from the larynx to the brain [3]. This thought process gave rise to the application of Botulinum Toxin type A, sometimes called “Botox” (BTX), directly to the laryngeal muscles by Blitzer in 1984 [4]. BTX temporarily quiets nerve impulses that trigger muscle actions and the muscle(s) injected are weakened, including the involuntary contractions leading to “spasms,” and possibly acts on the brain by altering sensory feedback. BTX injec-

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**“ WITH SD, FOR
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GRATEFUL APPRECIATION, CONT.

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winter. ([Click for Not Little Adults](#)). Whatever Nadine does, she does at the highest level and we have benefited from that work ethic, her research, and her extensive knowledge.

In addition to her own teaching and research, Nadine has taken on the role of Chair of the UW School of Medicine and Public Health Animal Care and Use Committee, a daunting responsibility. I’m just grateful to her for her years of service as Editor of *The Voice* and for all her work with TVF and wish her well in a new endeavors. Thanks, Nadine!



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ISSUES OF THE VOICE**

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SPASMODIC DYSPHONIA AND ITS TREATMENT, CONT.

(Continued from page 2)

tions can be done in a doctor's office with a needle placed through the neck skin, with or without guidance from muscle signals obtained through electromyography (EMG). The injection can also be performed through the mouth or even through the nose using special equipment, such as customized injectors or endoscopes with a "working channel" that allows passage of an injection needle [5]. Regardless of the route, BTX injection has a robust history of excellent safety and reliable benefit to those receiving it for SD and is endorsed as primary therapy by the American Academy of Otolaryngology [6, 7].

BTX can be injected into one or more of the small muscles found inside the larynx. Injection into the thyroarytenoid muscle(s) found in the vocal folds themselves is likely the most common technique with multiple reports supporting favorable reduction in patient symptoms [8-10]. Some reports suggest that delivery to either the left or right thyroarytenoid muscle on a side-alternating basis may reduce side effects while maintaining treatment effect [11]. Variation exists across providers, some of whom prefer to injection both sides together at one time rather than one sided injections. Regardless of approach, treatment

effect is monitored over time to maximize patient-reported benefit while minimizing side effects such as temporary coughing and choking while drinking thin liquids and/or breathy voice quality, both usually resolved within a few days after the BTX delivery. A stable dose and tolerable approach can then provide a steady platform for treatment long-term. Patients should expect to have treatment benefit for approximately three months with an approximate range of 2-6 months and side effects should not persist for more than approximately one week. It should be noted that delivery of BTX to a different muscle in the larynx, the posterior cricoarytenoid muscle(s) for ABSD is widely viewed as more technically difficult and that results are therefore less reliable [12]. In rare individuals where allergic reaction or antibody formation (and thus resistance) to Botulinum Toxin type A is observed, the use of the type B toxin can be initiated although the dosing and treatment schedule must be adjusted [13].

Voice therapy can be a useful adjunct but not as a solitary treatment. Its value is likely due to a targeted strategy of "unloading" or relaxing many of the muscles in and around the larynx that tend to be engaged when symptoms are unchecked by BTX [14]. An interesting development is the notion that sustaining

voice use right after BTX delivery may be valuable in that muscle activity may physically distribute the injected BTX within the muscles and allow voice improvements at lower doses [15].

Psychotherapy and acupuncture have no published literature to support their use as a primary intervention for SD but may be of help to reduce overall anxiety that can worsen symptoms. Medications such as benzodiazepines, anticholinergics and dopamine depleting classes also do not have a primary role but may be explored while monitoring for treatment benefit and side effects such as sedation.

Surgeons have pursued a permanent symptom reduction through operations on the larynx.

These approaches have included removing or cauterizing the thyroarytenoid muscle that makes up the bulk of the vocal folds and/or the nerve and separating the vocal folds permanently by dividing the thyroid cartilage in the midline and placing a permanent spacer (type II thyroplasty)[16-21].

Given that SD is a central disorder and these interventions are not designed to target the central input it is not surprising that to date no favorable long-term results are published to support the use of these operations. Another operation introduced by Berke

et al. is to selectively cut a motor nerve that supplies the larynx (that is, to "denervate") and then to use a different nerve to supply these muscles (that is, to "reinnervate").

Reports seem to favor use of this denervation-reinnervation procedure, but general acceptance has been hampered by the technical difficulty of the operation [22].

Despite these advances over the last decades, there is still no cure for SD. People with abductor SD (ABSD), and those patients with a superimposed tremor remain the most difficult subset for whom to achieve better voice. It is common for patients to experience a sizeable time interval from the onset of symptoms to appropriate diagnosis and treatment. This delay is multifactorial but stems from a lack of patient and primary care provider familiarity with the disease as well as a lack of available resources to find qualified and experienced professionals who routinely evaluate and treat neurologic voice disorders. This delay underscores the value of disease awareness and advocacy as espoused by organizations such as the National Spasmodic Dysphonia Association (www.dysphonia.org), which has contributed an article to this issue of *The Voice*.

Ultimately genetic

SPASMODIC DYSPHONIA AND ITS TREATMENT, CONT.

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and mechanistic studies currently ongoing will continue to shed light on this uncommon but debilitating disease. Until then patients and providers are encouraged to seek help from experienced professionals for rational and tailored treatments.

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ACCEPTING SPASMODIC DYSPHONIA

BY MATT ANFANG

My name is Matt Anfang and Dr. Seth Dailey diagnosed me with spasmodic dysphonia back in November of 2004 while I was attending UW-Platteville to obtain my undergraduate degree in Mechanical Engineering. My symptoms include a vocal component where my voice turns into a tremor that makes talking and even breathing quite difficult at times and I also have blepharospasms. My blepharospasms are eye and facial tics that increase during times of stress and anxiety. Both symptoms would make simple tasks, such as asking a stranger a question, extremely difficult and embarrassing. The results would usually be odd looks from strangers and the occasional questions. Unfortunately, back in 2004, dysphonia and other movement disorders were not well known and I, in shame, would usually opt for avoiding the truthful answer. It was only recently that I finally have been able to accept my condition and will openly talk to those who are truly interested in knowing all of the details or to those who could use help.

One of the best treatments that I have received was my first Botox shot to help with my spasmodic dysphonia. The result of the Botox shot felt like a huge burden had been lifted from my shoulders. I was able to breathe more easily and was not afraid to talk to people anymore. This joy lasted several months until the Botox wore off and I was back to where I had started with my symptoms going strong. The next few procedures we had to dial in the exact dosages because too much Botox would result in my voice being a whisper for a month, which was even more difficult. Not being able to talk to anyone because nobody could hear me definitely gave me empathy for the main star in the movie *Cast Away*. True happiness is shared and when we are not able to share things with the people we love, we feel miserable. Knowing how much relief that I could get from spasmodic dysphonia if I received Botox

injections really helped me focus on the exact timing, doses, and location of the injections. Today, we have everything nailed down to an art and things are extremely smooth in terms of my normal vocal output with minimal symptoms. I am extremely grateful for Dr. Dailey's gracious flexibility and willingness to help me overcome this challenge.

In terms of my other challenge, which is my blepharospasms, I have taken a variety of approaches to address those symptoms. Since the onset of dystonia in second grade, I have always been on a quest for some relief. I have tried hypnosis, acupuncture, EEG Biofeedback, medications, Cognitive Behavior Training (CBT), and am currently trying a gluten-free diet for at least six months. I feel that the biggest help, besides the Botox injections for my voice, have been the CBT. This training helped me to mentally separate my physical symptoms from my emotional reactions. When the dystonia would flare up, the automatic reaction would be negative reinforcement that a symptom arose versus positive reinforcement that I was able to control a reaction and/or be more accepting of myself. The simple fact that my negative reinforcement was abundantly present, was a repeating pattern that needed to change. After weeks of difficult CBT exposure training, I had gained valuable situational skills and more acceptance of my condition. My current trial of doing a gluten-free diet was after reading research about the brain and how some things such as Parkinson's disease, Alzheimer's disease, Multiple Sclerosis, Tourette's syndrome, and Epilepsy can be minimized if not cured by changing eating habits. I feel that the scientific community has much to learn in terms of the damaging effects of some foods, such as sugar, versus the positive effects of other foods such as dark leafy greens, healthy fats, and proteins.



**MATT
ANFANG**

Matt Anfang was diagnosed with spasmodic dysphonia and blepharospasms in 2004. He has learned to be more accepting of his condition while at the same time optimizing his strengths and weaknesses.

He looks forward to hearing about more advancements in Dystonia research.

Please feel free to contact Matt with any questions you may have at mattanfang@hotmail.com.

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ACCEPTING SPASMODIC DYSPHONIA, CONT.

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My Dystonia symptoms have helped mold me into the person that I am today. People all have their own challenges that they face and because my symptoms were abundantly present, I developed strong beliefs at an early age. One of my beliefs was emphasized in my first Leadville 100 Mile Ultramarathon in 2012. I believe that anything is possible with a positive attitude and persistence. This belief helped me overcome the physical and mental exhaustion I faced during the race so I could cross the finish line. The race is held in the highest incorporated city in the United States and climbs an extremely high mountain pass twice. Due to the elevation changes and the physical demands of the race, less than half of the entrants typically complete the race. Knowing this information ahead of time, I was determined to complete the race. I wanted to inspire myself

“I TRAINED FAR LESS THAN ANYONE HAD EVER HEARD OF, BUT I ACHIEVED MY GOAL BECAUSE OF THE CORE BELIEFS I DEVELOPED OVER THE YEARS DUE TO MY DYSTONIA.”

with a positive and persistent belief because we all have extremely difficult times when we want to throw in the towel and just quit. For me, the goal of wanting to complete this 100-mile ultramarathon required me to research the best ways for the human body to run, fuel, and pace for the event. I researched and contacted individuals who were successful and applied their skills and science to help me achieve my goal. During the big race, I remained organized and focused on what I had learned in order to

achieve my goal. The end of the race is a miserable five miles of ascent back up to the center of the city, this is when my belief was tested the most. However, I reached the finish line before the 30-hour cutoff and I was extremely satisfied with my success. I trained far less than anyone had ever heard of, but I achieved my goal because of the core beliefs I developed over the years due to my dystonia.

As an engineer, I always look for ways to optimize systems. I believe that if people have dystonia, then instead of sulking, their goal should be to do the best they can with what time is given to them. Life is truly a gift and I hope that others will focus on a combination of internal positive acceptance as well as being open to changes and self-improvement. Help others through your actions. I truly hope that the future of dystonia research brings clear solutions.



SUBMIT NEWS AND UPDATES

If you have an event or an update you would like to share in the newsletter, please email: office@voicefoundation.org.

Let us know what YOUR World Voice Day events will be!



World Voice Day April 16

voicefoundation.org
www.world-voice.day.org

BRAIN MECHANISMS IN SPASMODIC DYSPHONIA

BY KRISTINA SYMONYAN

Spasmodic dysphonia (SD) is a voice disorder that falls into the category of a “dystonia,” a neurological (brain) disorder characterized by uncontrolled muscle contractions causing abnormal movements, postures, or both¹. SD is a chronically debilitating condition, the effects of which extend beyond voice problems and often cause significant occupational disability and life-long social isolation. As noted by Dr. Dailley in this issue of *The Voice*, SD most often presents as an adductor type (ADSD), during which the forceful closure of vocal folds leads to the breaks on vowels and strained, strangled quality of voice. The less common form of SD is the abductor type (ABSD), which is characterized by slowed vocal fold closure, resulting in breathy voice breaks, prolonged voiceless consonants and excessive breathiness during speaking. Rarely, both types of SD occur in the same individual.

SD is a task-specific disorder, which means that it affects speech (and to some extent, singing) but not emotional voicing, such as laughing and crying. Typically, SD develops in midlife, with either sudden or gradual symptom appearance. SD is a relatively rare disorder affecting about 5.9 per 100,000 individuals in the general population². It is suggested that a large number of patients still remains undiagnosed or misdiagnosed^{3,4}. SD preferentially affects more women than men with the ratio of about 4:1⁵⁻⁸. A few cases of childhood onset, as early as 5 years of age, have been observed; however, the studies on childhood SD are largely missing.

While clinical symptoms of SD are well described, the basics of clinical management, including its detection, accurate diagnosis and treatment, are not well established². At present, speech symptoms are used for diagnosis of SD, and the outcome of the treatment with botulinum toxin injections into the laryngeal muscles frequently serves for confirmation

of initial diagnosis. Botulinum toxin injections are currently one of the few available and widely used treatments for SD. However, it is not beneficial to all SD patients. It is estimated that 90% of ADSD patients receive 90% benefit, and only 10% of ABSD patients receive 70% benefits⁹. In addition, botulinum toxin injections are relatively expensive and must be repeated every 3-4 months throughout a patient’s life, which may lead to both psychological and financial difficulties for a patient.

One of the reasons for why treatment and prevention of SD are not yet established is that its causes and brain mechanisms are not well understood. The role of different environmental factors, such as stress, upper respiratory and childhood infections, has been suggested but not yet established⁵. The presence of SD and other forms of dystonia in more than one family member was reported in about 12% of patients⁷. In addition, SD was found in patients with dystonias caused by several gene mutations, such as DYT4¹⁰, DYT6¹² and, to a lesser extent, DYT25¹³. This clearly points to the direct contribution of genetic factors to SD development. However, due to challenges with traditional genetic studies, such as the low occurrence of SD in families and clinical diversity of symptoms, no genes for this disorder have been so far identified. This is presently an area of active research, which potentially would help identify and link the contribution of genetic factors to the development of SD-related brain changes.

To this end, ways of looking at the brain (called *imaging*), such as conventional magnetic resonance imaging (MRI), show no major brain abnormalities in patients with SD. Nevertheless, recent brain imaging studies have described changes in both structure and function of the brain at microscopic levels in ADSD and ABSD patients. Using dif-

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BRAIN MECHANISMS IN SPASMODIC DYSPHONIA, CONT.

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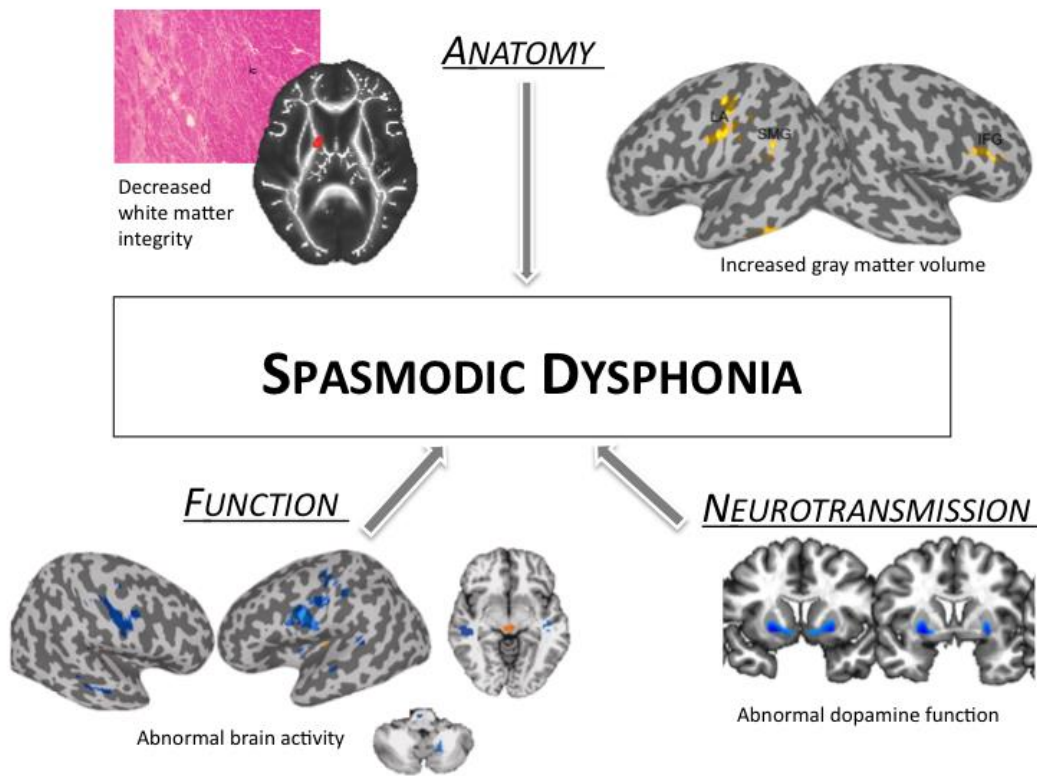
fusion tensor imaging (DTI), which measures the random “walk” of water molecules in the brain tissue, changes in people with SD in white matter were found along the pathway connecting parts of the brain that control the larynx (laryngeal sensorimotor cortex), with the brainstem region housing nerve cells that ultimately supply laryngeal muscles.¹⁴ In addition, the volume of gray matter was found to be increased in the key brain regions of speech control, including the laryngeal sensorimotor cortex, inferior frontal, superior temporal and supramarginal gyri, and cerebellum¹⁶. Substan-

tiating these findings, examination of brain tissue from deceased individuals with SD found degeneration of white matter fibers, accumulations of minerals and inflammatory processes in some of these brain regions^{14,15}.

Microstructural changes may underline abnormal function and chemical brain composition in patients with SD. Specifically, measures of brain activity such as functional MRI (fMRI) and positron emission tomography (PET) found abnormal activation in several brain regions responsible for control of voice and speech produc-

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“MORE FUNDAMENTALLY, WE DO NOT KNOW WHAT FACTORS CAUSE AND TRIGGER SD AND HOW THEY MAY DIFFER BETWEEN PATIENTS WHO DEVELOP SD AT A YOUNGER AGE VS. PATIENTS WHO TYPICALLY HAVE SYMPTOMS IN MIDLIFE.”



BRAIN MECHANISMS IN SPASMODIC DYSPHONIA, CONT.

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tion¹⁷⁻¹⁹. Compared to ADS patients, the ABSD patients showed a notably larger extent of abnormal brain activation¹⁹. Changes in brain function during tasks, which do not typically provoke SD symptoms such as whisper, whimper, coughing and breathing, were similar to the changes found during voiced symptomatic tasks¹⁷⁻¹⁹. In patients with SD, key brain regions (primary sensorimotor cortex, basal ganglia, thalamus and cerebellum) appeared to be 'disconnected' from each other and were establishing new, potentially abnormal relationships that were not present in healthy individuals¹⁹. Finally, a recent study using PET that mapped receptors for an important brain chemical, dopamine, showed reduced availability of D₂/D₃ receptors in SD patients compared to control. This was associated with decreases in dopamine release during symptomatic speaking but increases during asymptomatic finger tapping²⁰.

We have come a long way in understanding the brain mechanisms of SD, but there are still several questions that remain unknown and problems unexplored. With the first research paper by Hirano et al. in 2001²¹, which reported brain changes in one SD patient, and the subsequent studies by our group and others, it is obvious that (micro)structural changes

do exist in SD patients and that they are coupled with functional changes at different levels within the speech production system. Both contribute to SD symptom development. However, we still do not know whether these changes cause SD or are a result of other changes because human brain imaging techniques, in general, are unable to provide clear distinctions. More research combining different experimental approaches is needed to answer these questions.

Another open problem is that specific brain changes, which lead to the development of different types of SD and contribute to their symptom expression, are also not well studied. More fundamentally, we do not know what factors cause and trigger SD and how they may differ between patients who develop SD at younger age vs. patients who typically have symptoms in midlife. Most importantly, it is unknown how SD 'travels' through generations and what are the risks for SD development within a family. All these uncertainties about SD causes and brain mechanisms contribute to our limited ability to develop new treatment options that would target the brain mechanisms of this disorder and eventually help cure or prevent SD. While our own research is currently dedicated to finding

answers to some of these questions, future research would benefit from a collaborative approach between different centers and laboratories in order to unravel this mysterious disorder.

B

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PERSONAL PROFILE ON LIVING WITH SPASMODIC DYSPHONIA: SCOTT ADAMS

BY KIMBERLY KUMAN

Scott was used to losing his voice. At least once a year, he would have a bout with allergies and laryngitis resulting in this, but in 2005 something was different. It had been over a month, and his voice still had not returned. Concerned, he scheduled an appointment with his doctor and this turned into visits to multiple doctors, MRI scans, treatment for acid reflux and strep throat, and finally a referral to a psychologist. After all, wasn't it a little "crazy" that he could talk fine to his cat and to himself? The recommendation was valium to relax him, but Scott passed on that option and kept looking. He shared, "That felt wrong. I was used to speaking to large groups, and I didn't feel any more nervous in front of people."

Eventually Scott made the connection to his voice problem with his past issue with his hand, a focal dystonia called "writer's

cramp". After typing in "vocal dystonia" into Google and hearing "his" voice in a video, he discovered that his problem had a name, "spasmodic dysphonia." When he was referred to a doctor who specialized in spasmodic dysphonia, his diagnosis was confirmed within seconds of speaking. Scott tried botulinum toxin injections for several sessions but the results were limited. He later learned that one of his vocal folds was out of alignment which could have affected the response. For him though, there were too many variables with the injections, including dosage and placement. Scott was hoping to find a long-term solution to his spasmodic dysphonia and did not want the symptoms to be masked by the impact of the injections. That set him on a varied path of treatments including acupuncture, diet, certain types of cough syrup, relaxation, speech therapy, but still no definite relief of the SD symptoms.

During this time

Scott found an outlet by writing his blog. He said, "The blog became incredibly important to me because you don't feel connected to the world just because you are listening. You feel connected when you know you have been heard. Since I couldn't do that in person, the interaction in the blog became hugely satisfying and was important to my survival. I was being understood so that kept my spirits up."

Three years later Google proved most effective again in his search for answers. His alerts had been set to receive updates on "spasmodic dysphonia" and through one, he learned about a surgery in Japan. After discussing this procedure with his doctors, he was led to an option much closer to home. An appointment was scheduled with Dr. Gerald Berke, Professor and Chair in the Department of Head and Neck Surgery at University of California in Los Angeles (UCLA).

Scott jokes that it

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KIMBERLY KUMAN

Kimberly Kuman is the Executive Director of the National Spasmodic Dysphonia Association.



SCOTT ADAMS

For more than 25 years, the cartoon Dilbert has amused and entertained audiences thanks to its creator Scott Adams. "After working at Crocker National Bank, my first corporate job, I assumed that all the craziness going on there could not be going on anywhere else," he said. It wasn't until he moved to Pacific Bell that he realized everything looked the same. That freed him to create the character Dilbert with the correct assumption that his experience was common to other people. After that, the cubicle-bound engineer working for an unreasonable boss at a nameless company was born.

In his book, "How to Fail at Almost Everything and Still Win Big: Kind of the Story of My Life," the larger context of it is how to embrace and learn from failures in order to achieve success, but his struggle with spasmodic dysphonia is the narrative vehicle that brings it together in the book. Scott serves as an Honorary Board member of the National Spasmodic Dysphonia Association.

Scott Adams is an author and cartoonist, and most notably is the creator of the comic Dilbert.

PERSONAL PROFILE ON LIVING WITH SPASMODIC DYSPHONIA:

(Continued from page 10)

took about three seconds for Dr. Berke to confirm his SD diagnosis after he said “hello.” This appointment offered a new treatment option, a surgical technique called Selective Laryngeal Adductor Denervation Reinnervation (SLAD-R). Dr. Berke, who pioneered this procedure, laid out the risks very carefully. Worthwhile improvement in voice had been seen in about 85% of the cases, but he warned that 15% did not benefit. That 15% ran the risk of not being a candidate for future treatments. Scott shared, “While that was a scary possibility, the quality of my life was so affected by my inability to speak. I had to take this chance because the alternative was a life I didn’t want.” His surgery was scheduled.

A month later, Scott underwent the procedure. “The interesting aspect of this procedure is that it doesn’t

penetrate to the inner structure of your throat. He is not ‘playing’ with your vocal cords, but rather rewiring the circuitry of the nerves in the front of the neck,” Scott said. It would take about three and half months until the new nerves regenerated and the voice came back. Scott was trying to plan his follow-up visits and was told, there were none. It either works or it doesn’t, which he found amusing.

The recovery was not easy. Scott said he dreaded feeling hungry because his swallowing was affected for months. He tried to speak during those months, but his brain was still not connecting with his vocal cords. All he could do was whisper. But he was not discouraged, because he kept focusing on the final outcome. And then, three and half months after the surgery, almost to the day, his wife, Shelly said something to him, and he spoke back. In disbe-

lief, she said “You just talked.” And while weak and breathy, it was actually speech.

In the months that followed, his voice steadily improved. Scott shared, “My affirmation at the time was ‘I will speak perfectly’ if such a thing even exists. I had a weak nasally voice before I ever got spasmodic dysphonia, but after the surgery, the quality of my voice was substantially better than before SD.” Dr. Berke hypothesized that he might have had “latent” spasmodic dysphonia all his life, but ended up with a far more functional voice than ever before. Scott concluded, “And life has never been enjoyable or more satisfying. But one of my big motivations for writing this book was that I wrote it, in part, for the person in the middle of nowhere who has lost his voice to spasmodic dysphonia.”

B

(Continued from page 9)

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MAKING AN IMPACT IN THE SPASMODIC DYSPHONIA COMMUNITY

BY CHARLIE REAVIS

President, National Spasmodic Dysphonia Association

The National Spasmodic Dysphonia Association (NSDA) was established as a result of the foresight and desire to help people cope with the debilitating voice condition, spasmodic dysphonia. It was brought to reality with the help, dedication and compassion of our Founding President, Larry Kolasa and Dr. Daniel Truong. Celebrating our 25th anniversary this year, our mission remains steadfast: to advance medical research into the causes of and treatments for spasmodic dysphonia; promote physician and public awareness of the disorder; and provide support to those affected by spasmodic dysphonia. We are the only organization dedicated solely to the SD community, providing a voice for those living with spasmodic dysphonia.

The NSDA is strongly committed to understanding the science of SD and supporting research. Dr. Christy Ludlow worked with the NSDA to develop a “road map” for spasmodic dysphonia research through the proceedings of the first-ever Spasmodic Dysphonia Research Planning Workshop which was conducted in June 2005 at the National Institutes of Health in Bethesda, MD. It also helped to provide the direction for the establishment of the NSDA Research Program in 2007. Dr. Ludlow recently stepped down as the inaugural Chair of the NSDA’s Scientific Advisory Board and Dr. Gerald Berke has graciously accepted the role. He said, “It is a great honor to work with such a professional organization that is focused on impacting the lives of patients affected with spasmodic dysphonia both from a social and medical view point.”

How we support research:

- Provide research grants for up to \$50,000 per year.
- Work with and support the Dystonia Coalition, a collaboration of medical researcher, scientists, institutions, patient advocacy organizations, that is funded by the Office of Rare Diseases and National Institute of Neurological Disorders and Stroke.
- Collaborate with the National Institutes of Health (NIH) and other related organizations on innovative projects to better aid the SD community including co-sponsorship of research workshops.
- Support the Dystonia Brain Collective, a brain donation program which works with other dystonia organizations to accelerate understanding of SD.

Through outreach, education, and advocacy, we are looking forward to the day when diagnosed is achieved quicker and there is more acceptance of this disorder. Jennifer Roy shared, “My first encounter with NSDA was attending a conference in 2009, and this was prior to my official diagnosis. However, it was the result of conversations with others with SD and some of the specialists that I met at the conference that helped me to identify and articulate my voice difficulties more precisely prior to seeing the specialist who was able to diagnose the condition.”



CHARLIE REAVIS

How we raise awareness through outreach and education:

- Work with NSDA Honorary Board Members, including Dilbert Creator Scott Adams and NPR Host Diane Rehm, to raise awareness about SD in the media.
- Exhibit at professional medical educational conferences to reach out to healthcare professionals.
- Maintain a healthcare referral directory of healthcare professionals that specialize in SD.
- Host symposiums to provide a learning environment in which people with SD may enhance their understanding of the disorder, learn about the latest information on research and treatments, and network with others with SD.
- Publish the biannual newsletter, *Our Voice*, along with a bi-monthly on-line newsletter, *e-Voice*.
- Provide an educational and informative website (www.dysphonia.org) that includes voice samples, video clips, and information on treatment, listings of healthcare professionals, support, events, and the latest news.
- Work cooperatively with the Dystonia Advocacy Network (DAN) to educate legislators about SD and to participate in an annual Advocacy Day on Capitol Hill.

Support has always been the backbone of the organization and the NSDA offers a range of support options to fit the needs of affected individuals and their families. As Jan Lant shares, “The NSDA was a lifeline when I was first diagnosed with SD and continues to be. After nearly two years of

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MAKING AN IMPACT IN THE SPASMODIC DYSPHONIA COMMUNITY. CONT

(Continued from page 12)

progressively worsening voice quality to the point of only whispering at work, my job was in jeopardy. Discouragement and isolation set in, even with supportive family and life-long friends. Persistence finally resulted in the SD diagnosis, but I would need to wait three months before treatment with botulinum toxin could be scheduled. Meanwhile, my husband discovered the NSDA website and that there would be a symposium that we arranged to attend. It was life-changing. On all levels, from NSDA leadership, doctors and meeting others with SD, there was such warmth, support, understanding, wonderful people and education involved. We felt such a welcoming, caring, family feeling from the start. There is no connection like meeting others with SD for the first time and the NSDA supports us with wanting to go full circle to reach out to help others with SD in the same way. The NSDA has kept me and others afloat, encouraged

How we provide support:

Establish and maintain an international network of Support Groups and Area Contacts.

Publish and produce books, brochures, DVDs, and other resources including special tools aimed at specific issues within the SD community such as employment, disability and insurance.

Sponsor on-line initiatives including an internet bulletin board along with a presence on social media outlets including Facebook, Twitter, YouTube, and LinkedIn.

Publish a quarterly on-line newsletter called *Voices of Support* which recognizes the support activities of the organization.

and hopeful for a cure one day.”

The NSDA was there for me at a low point in my life and career when spasmodic dysphonia affected my ability to connect with the world through my voice. The people of the NSDA helped me realize that I didn't have to fight this battle alone. One thing I have learned and admire about people with SD is their perseverance, dedication and a wonderful stubbornness that anything is possible. Individually our voice is broken, but the NSDA provides us the opportunity to come together

with one, loud and clear voice to speak on behalf of everyone living with spasmodic dysphonia. This is how the NSDA has built its organization, empowering each person to add their voice to speak out about spasmodic dysphonia and be heard.

B

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MK-442 Rev. A

VOICE FOUNDATION NEWS

JOINT MEETING:

44TH ANNUAL SYMPOSIUM, CHAIRMAN ROBERT T. SATALOFF
AND
THE INTERNATIONAL ASSOCIATION OF PHONOSURGERY
 PRESIDENT, MICHAEL S. BENNINGER
MAY 26—MAY 31, 2015 PHILADELPHIA PENNSYLVANIA

Tuesday, May 26

Basic Science Tutorials
 Accent Reduction Coaching

Wednesday, May 27

Science Sessions
 Keynote Speech Frank Guenther, PhD
 Quintana Awardee Ulrich Eysholdt, MD, PhD
 Poster Session
 Special Session

Thursday, May 28

Special Session: The Aging Voice
 Speech-Language Sessions
 Poster Session
 Voice Pedagogy Sessions

Friday, May 29

Medical Sessions
 Young Laryngologists Study Group
 Vocal Workshops
 Voices of Summer Gala

Saturday, May 30

Medical Sessions
 Interdisciplinary Panels
 G. Paul Moore Lecture - Brenda Smith, DMA
 Vocal Master Class-Dolora Zajick

Sunday, May 31

Medical Sessions
 Interdisciplinary Panels Sunday

We are pleased to announce the election of
Stuart Orsher, MD as President of The Voice Foundation

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THE VOICE FOUNDATION

Advancing understanding of the voice through interdisciplinary scientific research & education

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APRIL 2015

SUN	MON	TUE	WED	THU	FRI	SAT
			1	2	3	4
All Disclosure Forms due by April 1st.						
5	6	7	8	9	10	11
12	13	14	15	16 World Voice Day	17	18
19	20	21	22	23	24	25
26 Ends Early Bird	27	28	29	30		

MAY 2015

SUN	MON	TUE	WED	THU	FRI	SAT
					1	2
The Westin Hotel Group Rate—available until May 1st.						
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
JOINT MEETING - SYMPOSIUM						
					GALA	
31						
SYMP						

SCHEDULE OF EVENTS

- February 15, 2015—Submission Deadline for the Hamdan International Presenter Award
- March 1, 2015—Proposal Submission Deadline for New Investigator's Forum
- April 16, 2015—World Voice Day
- April 26, 2015 Symposium Registration Deadline for Early Bird Discount
- May 1, 2015 Deadline to reserve room at the Westin Hotel at Symposium Prices.
- May 28—June 1, 2015 43rd Annual Symposium: Care of the Professional Voice
- May 30, 2015—Voices of Summer Gala