

## **2017 NSDA Symposium Summary**

### **May 6, 2017 | Nashville TN**

Over 100 people attended the 2017 NSDA Symposium in Nashville, TN, on Saturday, May 6, 2017. On Friday night, attendees were greeted by the bluesy sound of a slide guitar played by NSDA Support Group Leader Wendy Garrison. That was followed by the sharing of personal stories at the Welcome Party, where there was opportunity for everyone to be heard. Saturday included presentations from SD medical experts, utilizing mindfulness as a tool, and several breakout sessions which focused on living with SD, the impact of SD on family and friends, and abductor SD. Keynote Speaker Kevin Hancock delivered an inspired talk sharing his experience of living with spasmodic dysphonia, and how this seeming liability turned out to be a blessing for him. This summary touches on the many aspects of the presentations, which are available for viewing on the NSDA's YouTube channel at [www.youtube.com/user/NSDA300](http://www.youtube.com/user/NSDA300).

#### **Welcome and Overview of the NSDA**

Charlie Reavis, NSDA President

Charlie Reavis, President of the NSDA, opened the 2017 Symposium by highlighting the mission of the NSDA. Our aim is three-fold; to educate the community about SD, 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. Charlie 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 reinnervate well after the age of seventy; therefore, he does not recommend the surgery after this point. Along with the SLAD-R surgery, other 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.

Ms. Bates 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 6<sup>th</sup> 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 developed 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 EB 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."

# 2017 Symposium Program

May 6, 2017 ♦ Nashville, TN



**Welcome to the NSDA Symposium!**  
We appreciate you joining us and hope you find this meeting informative, supportive and fun. We have an excellent program

that is designed to include plenty of opportunities to interact with one another and have your questions answered. We encourage you to talk to as many people as possible – don't be shy – this is one place your voice will be heard. Special thanks to all of our speakers and panelists who generously share their knowledge and experience to support the spasmodic dysphonia community.

## **Keynote Speaker: Kevin Hancock**

We are pleased to welcome Kevin Hancock as the Keynote Speaker. Kevin is the President of the Hancock Lumber Company. He was diagnosed with spasmodic dysphonia in 2010. Five years after, he published his book "Not for Sale: Finding Center in the Land of Crazy Horse" about his personal experience with SD. Kevin is a recipient of the Ed Muskie 'Access to Justice' Award, the Habitat for Humanity 'Spirit of Humanity' Award, the Boy Scouts of America 'Distinguished Citizen' Award, and *Timber Processing Magazine*'s 'Man of the Year' Award. He is an advocate of strengthening the voices of all individuals through listening, empowering, and shared leadership. Kevin will be selling copies of his book at the Symposium with proceeds going to the NSDA.

## **Musical Performance by Wendy Garrison**

Since we will be in Music City, we will hear from one of NSDA's own! Greater Memphis Support Group Leader Wendy Garrison has been playing slide guitar since making Mississippi her home in 1987. She is a member of the 4-piece Oxford band "Maybelle's Lovers" playing their original ghostly country, and new takes on cover songs. Wendy has had abductor spasmodic dysphonia since 2005. Wendy will play for us on Friday evening and during the breaks on Saturday. <http://msslideguitar.com>

## **Break-Out Sessions**

The three break-out sessions offer a chance to meet others with specific interests. They will provide an opportunity to share experiences, not only about the challenges of living with spasmodic dysphonia, but also the successes.

## **Symposium Extras**

### ***Friday Night Welcome Party***

On Friday evening, join us for the Welcome Party at 7:30 p.m. in the Kentucky Ballroom. It is a wonderful opportunity to socialize and meet many new friends and share your story. Light appetizers will be served and there will be a cash bar.

## ***Ambassador Program***

For first-time attendees to NSDA Symposiums, we host an NSDA Ambassador Program. We will try to match people of similar backgrounds with another experienced attendee to help answer questions and be a "point-person" at the symposium. If you signed up for this program, you will have a special ribbon and we will have participants meet by the registration desk at 8:30 a.m. on Saturday.

## ***Optional Programs***

Join us for an optional dinner after the Symposium at 5:30 p.m. On Sunday morning, we will meet in the lobby of the hotel and depart for a 10 a.m. Walking Tour of downtown Nashville. The tour will last 90 minutes. For more information or to sign up for either of these events, stop by the registration desk. There is an additional cost for each of them.

## **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. With your help, we will continue to fund research to understand this mysterious disorder while expanding our outreach efforts and providing support those with this disorder. We encourage your involvement so that your voice is heard. For more information log on to [www.dysphonia.org](http://www.dysphonia.org).

# NATIONAL SPASMODIC DYSPHONIA ASSOCIATION

## 2017 Symposium Speaker Profiles

### **Christie Bates, LPC**

Ms. Bates is the Program Director of Mental Health and Contemplative Services at The Ranch, a treatment center for trauma, mental health and addictive disorders just west of Nashville. A Licensed Professional Counselor in Tennessee, Christie has extensive background working with individuals and families facing chronic stress and acute trauma. She earned a Bachelor's degree from Rhodes College, as well as a Masters in Mental Health Counseling with the support of a Career Development Grant from the American Association of University Women. Her training has included secular mindfulness, Buddhist meditation and contemplative Christian practice. Her intention is to help participants move beyond the view of mindfulness as mere stress reduction.

### **Gerald Berke, M.D.**

Dr. Berke is 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 techniques now used by laryngologists to treat patients in an office setting. 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, 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.

### **David Francis, M.D.**

Dr. Francis is the Assistant Professor of Otolaryngology at the Vanderbilt Voice Center. He received his medical degree from the University of Rochester School of Medicine and Dentistry and completed his Residency at the University of Washington Medical Center, and did his laryngology fellowship at Vanderbilt. Dr. Francis has over 12 years of experience in his field.

### **C. Gaelyn Garrett, M.D.**

Dr. Garrett the Senior Executive Director and Professor of Otolaryngology at the Vanderbilt Voice Center. She specializes in laryngology and directs a fellowship program at Vanderbilt. Dr. Garrett received her medical degree from the University of North Carolina at Chapel Hill School of Medicine. She has served as the President of the American Laryngological Association and has helped treat singers ranging from Johnny Cash to Martina McBride.

### **Teresa Kimberley, Ph.D., PT**

Teresa Jacobson Kimberley, PhD, PT is an Associate Professor in the Department of Rehabilitation Medicine, Divisions of Physical Therapy and Rehabilitation Sciences and member of the Institute of Engineering in Medicine at the University of Minnesota in Minneapolis, MN. She is a clinical science researcher with dedicated focus to understand the neuropathophysiology of motor impairment and develop novel interventions for neurologic motor disorders. She is co-director of the Brain Plasticity Lab which has helped to pioneer the use of neuroimaging and non-invasive brain stimulation and in the investigation of rehabilitation-related research. She is currently funded through the National Institutes of Health and several foundations, including NSDA. She serves on the Foundation for Physical Therapy Scientific Review Committee and is an Associate Editor for the Journal of Neurologic Physical Therapy and Restorative Neurology and Neuroscience.

### **Melissa Kirby, MS, CCC-SLP**

Mrs. Kirby is a speech-language pathologist specializing in the evaluation and treatment of voice and resonance disorders in both children and adults. She graduated with a B.S. from Abilene Christian University and a M. S. from Vanderbilt University. Melissa has spoken on many voice-related topics at numerous national, regional, and state conferences. She regularly holds training seminars for music educators, worship leaders, choirs, and other organizations. Melissa currently offers speech and singing voice therapy through the St. Thomas Health system in Nashville and in her private practice.

# NATIONAL SPASMODIC DYSPHONIA ASSOCIATION

## 2017 Symposium Schedule

May 6, 2017 | Nashville, TN

Time	Session	Room Location
9:00 A.M.	<b>Welcome and Overview of the NSDA</b> Charlie Reavis, NSDA President	Kentucky/Mississippi
9:15 A.M.	<b>The Vanderbilt Experience: Overview of Spasmodic Dysphonia, Treatment with Botulinum Toxin Injections, and Current Research</b> C. Gaelyn Garrett, M.D. and David Francis, M.D.	Kentucky/Mississippi
10:00 A.M.	<b>Surgical Options for Spasmodic Dysphonia</b> Gerald Berke, M.D.	Kentucky/Mississippi
10:30 A.M.	<i>Break</i>	Foyer
10:50 A.M.	<b>The Role of the Speech Pathologist in Spasmodic Dysphonia</b> Melissa D. Kirby, MS, CCC-SLP	Kentucky/Mississippi
11:10 A.M.	<b>Spasmodic Dysphonia Research Overview</b> Gerald Berke, M.D.	Kentucky/Mississippi
11:30 A.M.	<b>Beyond the Snapshot: Your Brain and Spasmodic Dysphonia</b> Teresa Kimberley, Ph.D., PT	Kentucky/Mississippi
11:50 A.M.	<i>Question and Answer Panel</i>	Kentucky/Mississippi
12:30 P.M.	<i>Lunch</i>	Atrium
1:30 P.M.	<b>Unconditional Well-Being through Mindfulness</b> Christie Bates, LPC	Kentucky/Mississippi
2:30 P.M.	<b>Break-Out Session: Impact of Spasmodic Dysphonia</b> <i>Personal Journeys: Living with Spasmodic Dysphonia</i> <i>Rarest of the Rare: Abductor Spasmodic Dysphonia</i> <i>Spasmodic Dysphonia Impact on Family and Friends</i>	South Carolina Georgia Alabama
3:15 P.M.	<i>Break</i>	Foyer
3:30 P.M.	<b>Voices in the Land of Crazy Horse</b> Keynote Speaker: Kevin Hancock	Kentucky/Mississippi
4:25 P.M.	<b>Closing Comments</b>	Kentucky/Mississippi
4:30 P.M.	<b>Adjourn</b>	
5:30 P.M.	<b>Cocktails / Dinner (optional – additional fee)</b>	Virginia