25th Anniversary NSDA Symposium Highlights

The 2014 NSDA Symposium celebrated the 25th Anniversary of the organization. Taking place on Saturday, May 3, over 130 people came together in the Chicagoland area, for a day of education, sharing, and inspiration. A new feature this year was the NSDA partnership with Multivoice Dimensions, to offer Continued Medical Education credits to Speech Pathologists. On Friday evening, old SD friends reconnected and new friendships quickly formed at the Welcome Party. Always a highlight, it offers SD people the opportunity to socialize and share their story with the full group.

The presentations on Saturday were designed to engage both the presenters and the audience in discussion. The Chair of each panel gave a brief introduction to the topic and then questions were taken from the audience for the panel to answer. The first panel was moderated by Robert Bastian, M.D., with Christy Ludlow, Ph.D., Seth Dailey, M.D., and Brent Richardson, M.D. providing an overview on spasmodic dysphonia. The doctors clarified some of the history and misconceptions and reminded the audience that every treatment works or fails for someone, so what works for one person may not work for another. Spasmodic dysphonia is very uncommon, often difficult to diagnose and treat, and can have other conditions associated with it (e.g. tremors, reflux, muscle tension). The cause remains unknown, and currently doctors only treat the symptoms. All that is really known is that the disorder is somewhere in the brain. Earlier it was believed that it was in the basal ganglia, but now that theory is evolving. Currently the treatments can include psychotherapy, medications, voice therapy, botulinum toxin injections, and surgery, with botulinum toxin injections being the standard treatment.

Some highlights of the discussion included:

- Spasmodic dysphonia has no effect on health or how long people live.
- The voice changes over time: it is usually stable once established, but the voice can develop more strain.
- Some people can have times when their voices sound good and other times when symptoms are more pronounced.
- For some people, when they use voice less they do improve.
- The more stress and fatigue one has, the worse the voice can be. However, think of stress and fatigue as affecting SD as it is not a stress, psychological, or fatigue disorder.
- The broken-up or strained quality of SD can be erratic or sustained.
- Sensory tricks such as tapping on the head can sometimes work.
- It is possible to change forms of SD such as going from abductor to adductor. It can also get milder or a voice tremor can develop.
- An expert voice doctor usually diagnosis SD by studying the patient's history, listening to how they sound and examining the vocal cords.
- Every treatment works for someone, but not for everyone, with SD. Treatment has to be varied by patient as everyone is different.
- Essential tremor is NOT related to an SD tremor. An essential tremor is a more regular tremor.
- Some people’s baseline changes with the use of botulinum toxin injections.
- Acid Reflux can exacerbate symptoms, but it doesn’t cause SD.
- Video examples can make all the difference to someone trying to understand what an SD voice sounds like.
Julie Barkmeier-Kraemer, Ph.D., CCC-SLP, moderated the second Treatment Panel on Voice Therapy with Kate DeVore, M.A., CCC-SLP, Julia Edgar, Ph.D., CCC-SLP, and Jan Potter Reed, MS, CCC-SLP. They discussed treatment through voice therapy. The SLPs primarily work with resonance and breathing to enhance voice quality and make people with SD more understandable. The presenters demonstrated proper breathing techniques and encouraged people to use Voice Therapy in conjunction with other treatment such as botulinum toxin injections. There are currently only two research studies and publications on the effect of Voice Therapy on SD and Botox® treatment, so more studies are needed.

Some highlights of the discussion included:

- Speech therapy can address what the problem is and how we have maladapted to it. It can provide strategies to use to better communicate.
- Voice therapy may help with ease of speaking.
- There is a lack of evidence or basic research for voice therapy and SD so there may have to be tweaks to determine what the best form of therapy is. It may be helpful if the patient is open to trying new things.
- Exercises may help relieve stress and connect the voice with breath. There are many techniques in an SLP’s “bag of tricks” to increase breathing correctly.
- SD patients can help spread the word about SD by inviting students to a Support Group meeting. There are two sentences or tasks that some experts can analyze to tell whether a patient has ABductor or ADductor SD. The experts listen for the breaks or the breathiness on certain syllables. The Diagnostic sentences to elicit symptoms are:
  - "We eat eels every day", or counting from 60 to 69. These connected words or numbers can reveal AB patterns.
  - "The puppy bit the tape", or counting from 80 to 89. These connected words or numbers can reveal AD patterns.
- When breathing is shallow, it is not good for the voice; instead try to breathe from the belly.
- It is common for people not to use their respiratory system well when they have SD. However, they need the air stream to get their voices going.
- Treating Muscle Tension Dystonia through voice therapy may be extremely helpful.

The Treatment Panel on Botulinum Toxin was moderated by Andrew Blitzer, M.D., DDS, along with Drs. Bastian, Dailey, and Richardson. They discussed botulinum toxin injections at great length, outlining the pros and cons such as the roller-coaster of changes, breathiness, swallowing and aspirating problems, along with the variety of ways the toxin can be injected. They agreed that botulinum toxin is not the best treatment for tremor, so if a tremor is associated with SD, then oral drugs may need to be used in conjunction with other therapies.

Some highlights of the discussion included:

- There is no single 'right treatment' for SD.
- We need to find out how to unscramble the faulty nerve system to and from the brain when we move vocal muscles. It is not known how to do this yet.
- Long term use of Botox® does not seem to have a negative influence.
- Effectiveness of botulinum toxin can depend on if a person has bilateral or unilateral injections.
- Some people have mini injections.
• For abductor SD, the treatment needs to balance the competing demands of breathing and speaking because of the muscles involved.
• Injections will treat symptoms, not cure SD. The long-term aim is for doctors to treat the origin of disorder in the brain.
  There is a need for consistency in dosing and placement. (needs bullet)
• It is important for the patient to discuss with the doctor what his or her expectations are so that both are on the same page.
• Alcohol can help relieve SD symptoms in some people.

Dr. Joel Blumin, Medical College of Wisconsin, chaired the Treatment Panel on Surgical Options. He indicated that not much has changed in ten years. Dr Blumin reiterated that is because the problem is in the brain, and the treatment is currently carried out elsewhere. The panel discussed the SLAD/R surgery (denervation-reinnervation) which he and others have been performing since 1993. It is currently the best surgical procedure for Adductor spasmodic dysphonia. They also discussed Myectomy (removing an affected muscle) and Thyroplasty (inserting a barrier in the larynx). Both of these options are less desirable; they are not good for the elderly, and have been done on only a few patients, and good results are mostly short term. Even though Dr. Blumin does these surgeries, he made it clear that all of the surgical options are invasive and destructive, irreversible and difficult to perform. Following surgery, sometimes botulinum toxin injections may have to be used to reduce effort. Symptoms may return and some cases are considered "failed" because the brain doesn't adapt. These doctors are seeking long term treatment without long term problems. Deep Brain Stimulation (DBS) is probably the best long term hope, but the correct neural pathways are currently unknown. DBS is in its infancy. The panel agreed that the best therapy is a strong doctor/patient relationship with good communication. They teach other doctors to "Listen to your patient. He is trying to tell you what is wrong with him."

Some highlights of the discussion included:
• Doctors don’t really know which part in the brain is causing SD, but if discovered, brain surgery may be possible. At this time, SD does not improve enough with DBS.
• SLAD/R has been largely successful for people with Adductor SD.
• Don’t approach the surgery casually. It may reduce strain in talking.
• The right evaluation is what is most important. The professionals need to watch the evolution of disorder also.

During the afternoon, attendees had the opportunity to attend simultaneous break-out sessions on **Voice Therapy Group Sessions** for Adductor, Abductor, and Tremor) led by Dr. Julie Barkmeier-Kraemer

**Mindfulness, Meditation and Progressive Relaxation** led by Kate DeVore

**Living with Spasmodic Dysphonia** led by Jim Anderson, Fred Hosier, and Karen Feeley

**Spouses and Caregivers Session** led by Richard and Ruth Stuart and Warren and Anjanette Bandel

**Abductor SD Discussion** led by Mary Bifaro, Victor Chears, and Charlie Womble

The day ended with Dr. Christy Ludlow, discussing Research Milestones over 25 years along with the Drs. Blitzer and Blumin. Dr. Ludlow spent 30 years at the National Institute of Health (NIH) and has just retired as the first Chair of the NSDA Scientific Advisory Board. She is a long standing friend of the NSDA. Dr Ludlow provided a brief overview on the history of SD research and reported on current research.
Some highlights of the discussion included:

- SD is a central nervous system disorder.
- There is some current study of possible risk factors, including dust, mumps, rubella, a lot of voice use, and many more items might lead to SD.
- SD is an "orphan" disorder in the dystonia family, very rare.
- There are no rats or other animals who have SD because speech does not occur in other animals.
- Research on dystonia genes DYT6 and THAP1 have been studied, but there is not anything leading to only SD.
- More brains for the Brain Bank at Harvard are needed. We need to know what parts of the brain are involved with SD.
- Clinical trials are needed.
- The goals are simple: Find the cause, Treat it, Prevent it!

The day wrapped up with an optional dinner to celebrate the 25th Anniversary of NSDA. Balloons bobbed, cake was laid out, and music filled the room. Area Contact Person, Warren Bandel, performed at regular intervals with his bandmates from Classic Brass Quintet. Special guests along with the leadership of the NSDA were recognized including President Charlie Reavis for his dedication and leadership. Dr. Christy Ludlow was honored for her years of service as the NSDA Scientific Director by her peers, both in person, and by video from Dr. Mark Hallett and incoming Scientific Director Dr. Gerald Berke. When reflecting on the 2014 Symposium meetings, Executive Director, Kimberly Kuman, commented: "Thank you for creating and building this wonderful organization that empowers and inspires people. Thank you for the leadership, dedication, and energy you contribute in your own personal and unique way to make this an amazing organization."

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