



2011 Central Regional Symposium Summary

September 17, 2011, Milwaukee, Wisconsin

Prepared by Bev Matthews, *Circle City SD (Indianapolis, IN) Support Group Leader*

Charlie Reavis, the NSDA President, opened the symposium by reading the NSDA mission statement. He said the NSDA currently has about 70 support groups and 200 area contact people. The NSDA is supporting a couple of research projects and next year will put \$40,000 to \$50,000 toward a new project.

NSDA is a donor-supported volunteer organization which currently only has one full time staff person, Kim Kuman, the NSDA Executive Director. It is the only organization totally focused on spasmodic dysphonia (SD) and the SD community. There are some 70,000 persons with SD across the U.S. 85% of the NSDA funds go to directed programs like this symposium, the National symposium and research. The NSDA website can be found at www.dysphonia.org and its Bulletin Board is at www.dysphonia.bb.org/forums/sd/. Charlie then introduced each speaker.

Defining Spasmodic Dysphonia

Robert Bastian M.D.

Bastian Voice Institute, Downers Grove, IL

Spasmodic dysphonia is a neurological disorder known as a dystonia. A dystonia is a syndrome of abnormal muscle tone, manifested in a sustained muscle contraction.

The incidence for a genetic connection seems to have low penetrance, but it could take an illness or something else to trigger the onset of SD.

One in 20 persons with SD has a family member with SD and it can skip generations.

The case-history of SD in a patient includes typical features:

- It is unremitting once established
- The symptoms are complex (“voice catches, breaks”)
- Variability of symptoms with stress, alcohol effects, etc.
- “Hate” the telephone
- Difficult sounds, tasks (task specificity)
- Easier to sing or laugh than to talk
- Many are misdiagnosed, with a history of failed treatments

It is possible for the Adductor form of SD to evolve to Abductor and vice versa.

Surgical Option for SD

Joel Blumin, M.D.

Medical College of Wisconsin, Milwaukee, WI

The SD disorder is most likely neurological but it hasn't been proven yet. Doctors are not even sure what part of the brain to target. They have made more progress with Parkinson's (Deep Brain Stimulation). Currently, there are no treatments for SD which are directed at the central nervous system. Speech therapy doesn't resolve SD but sometimes it can help.

To date, the best treatment is botulinum toxin injections. However, even with botulinum toxin injections there are limitations:

- It is not a permanent treatment/cure.
- Roller coaster experience from one injection to the next.
- Not every doctor has the training or expertise to administer botulinum toxin injections
- Insurance may or may not cover the cost.

The main purpose of the surgical approach is to try to achieve permanent treatment. The first surgical methods (RLN surgery, 1993, UCLA) basically did what botulinum toxin does today. Symptoms would often return to these patients.

In the late 1990s Dr Berke at UCLA developed a new form of surgery, known in full as Selective Laryngeal Adductor Denervation-Reinnervation (SLAD/R). This surgery is now offered by several doctors at various centers in the US. After surgery for SD, patients often still have a breathy voice for about 4 months before the voice gets better, but sometimes the patient totally loses volume. Experience with the SLAD/R surgery over 10 years has found that 90% of the patients are happy with the outcome. However, they typically still can't yell or hit high notes and surgery can't help with tremor.

A myectomy, which involves cutting some of the muscles that spasm, can be performed through the mouth with a laser. Dr Blumin couldn't recommend this treatment because while the treatment seems to go well, 100% of the patient voices eventually return to their original state.

The Type II Thyroplasty involves separating the vocal chords that spasm from each other. This procedure has mainly been done in Japan. The benefit may be short-lived (average 20 months) and patients can have trouble breathing. Dr. Blumin said he couldn't recommend Type I Thyroplasty or PCA Myoplasty.

In summary, botulinum toxin injections are an effective treatment. An operation can be a reasonable option for some (SLAD/R) but can cause permanent damage. Plus, all treatments currently treat the symptoms, not the cause.

Treatment Options in SD: Botulinum Toxin Injections

Seth Dailey, M.D.

University of Wisconsin School of Medicine, Madison, WI

Dr. Dailey said that botulinum toxin type A comes in a vial of 100 units so once the bottle is opened, it needs to be used quickly. This is why so many physicians set up clinics which group patient treatments together. Botulinum toxin has a safe track record and allergic reactions are rare. The downsides to Botulinum toxin injections are:

- Type A is FDA approved for blepharospasm and cervical dystonia but not for the treatment of SD
- It is used "off-label" for SD
- Botulinum toxin injections is can be refused by insurance companies when used to treat "hoarseness"
- Injection sites can calcify
- A person may develop antibodies to the botulinum toxin injections and may have to change the type.

Methods of Access:

- Mouth
- Neck/skin – Above the vocal chords or below
- Nose using nasal scope

Approaches:

- Point touch (by feel)
- EMG guidance during vocalization tasks
- Direct visualization – see where the tip of the needle goes
- Indirect visualization

Living with SD Discussion

Panel Participants: Charlie Reavis, Adam Wilcox and Cathy Jacobs

Charlie Reavis, NSDA President – Never go anywhere without the NSDA (3-fold) card. “The King’s Speech” is a movie which you can use to explain SD to others. He also said that when you have SD, only those with SD can truly understand.

Adam Wilcox – Adam was 7 years old when people first would say he had a “shaky voice”. Other kids called him “stutter voice.” At 14, he was diagnosed with SD with tremor. He said that people generally become introverts when they can’t talk. At 19, he had the SLAD/R surgery, and afterwards his voice was good. Then after one year, the stilted began. A couple of years later, he went to try botulinum toxin injections. It worked, but he still had the tremor. Adam started up a Facebook site called Spasmodic Dysphonia and he now has some 500 friends from all over the world.

Cathy Jacobs – Cathy said “I don’t have to worry about sales calls anymore because after saying “Hello” a couple of times, they hang up on me!”

Speaker Responses to Audience Questions

Placement of the botulinum toxin injection makes the difference between how effective each treatment is. A good hit is typically most effective.

When to consider having botulinum toxin injections re-administered: It’s best not to wait until you’re at the bottom. There’s a rhythm you fall into. The idea is not to compete to see how long you can go between treatments.

Typically, the larger the dosage, the more side effects can occur. There is a learning curve for each patient.

Speech therapy is typically better for tremor than for the SD.

It is not unusual to have multiple focal dystonias.

Dystonias can evolve for the worse or for the better. Some symptoms become less severe over time.

There has not been much success in getting dystonias listed for a Social Security disability.