

2016 NSDA Eastern Educational Conference Summary



From left, Bridget Rose, Yolanda Heman-Ackah, Kevin Leahy, Joseph Spiegel, Amanda Hu, and Fred Hosier

Over 70 people attended Eastern Educational Conference hosted by the National Spasmodic Dysphonia Association on November 5, 2016, in Philadelphia, PA. The first four sessions of the conference focused on the medical aspects of spasmodic dysphonia (SD). After lunch, participants heard from a speech language pathologist, two support group leaders (**Cathie Leister** of the Southeastern PA SD Support Group, and **Lois Jackson** of the DC Metro Spasmodic Dysphonia Support Group), and a doctor with her own life-changing condition who uses mindfulness meditation and teaches it to others. Special thanks to **Fred Hosier**, NSDA Board Member and Co-Leader of the Southeastern PA SD Support Group, for moderating the conference and preparing this summary.

Understanding Spasmodic Dysphonia

Yolanda Heman-Ackah, M.D., *Director of the Philadelphia Voice Center*

Dr. Heman-Ackah kicked off the medical sessions with an overview of what SD is. SD is a focal dystonia of the larynx. A dystonia is a neurologic disorder characterized by involuntary muscle contractions and caused by repetitive movements or abnormal constriction. A dystonia can happen in any muscle in your body. Some people with SD happen to have dystonias in other places in their bodies as well. But most people just have it in their larynx. SD produces movements in the larynx that you can't control.

In most cases the cause of SD is unknown. This is what happens during speech: There are four different sets of muscles on both sides of your voice box. The vocal folds are two light ligaments that are the primary source of sound. The muscles perform the movements of the vocal cords.

Nerves send the signal from the brain (the basal ganglia region) to the muscles that tell the muscles how and when to move. The brain is where the signal starts, and then it goes down the nerves to the muscles. The muscles are connected to the vocal cords so when the muscles contract, the vocal cords move in a coordinated fashion. We add articulation through the tongue and lips to form speech.

In the most common type of SD, adductor (AD), the vocal cords spasm closed. Normally when you start to speak, your vocal cords are open. When you had AD SD, your vocal cords are shut which gives speech a tight sound.

With abductor (AB) SD, the muscles that normally open your vocal cords are the ones that spasm. This happens more in voiced speech (vowel sounds like long e, long a, short a), and you get a breathiness in your voice where you would otherwise get a sound.

In mixed SD, people have spasms in both types of muscles. Spasms in SD can vary from mild to severe.

Some other variations of SD: You can have a dystonic tremor along with SD. When you try to hold a sound, the vocal cords start to tremor. When you have a tremor with SD, Botox® doesn't help the tremor. However, medications can help the tremor. This is one of the hardest types of SD to treat. You can't always get the tremor to settle down.

Non-speech sounds usually come out normally because they're not controlled by the basal ganglia region of the brain. For example: laughing and crying can be normal. Singing can be normal. When you imitate another type of speech, such as an accent, that can be normal.

Sometimes a speech pathologist can help someone with SD by teaching them to use a slightly different-sounding voice.

Treatment Options for Spasmodic Dysphonia: Botulinum Toxin Injections

Kevin Leahy, M.D., Ph.D. *Assistant Professor of Clinical Otorhinolaryngology: Head and Neck Surgery, University of Pennsylvania School of Medicine*

Botox® is the brand name for botulinum toxin. It's a treatment, but not a cure, for SD.

Why do we use it for SD? In SD, the muscles that control the vocal cords spasm. We want to use something that's going to relax the muscle.

How does it work? Within the nerve, a neurotransmitter has to be released to start a muscle contraction. The Botox® prevents the release of the neurotransmitter. The end result is paralysis of the muscle because the nerve signals don't stimulate the muscle contraction.

Why is it important to know how the Botox® works? After your Botox® shots, you may find that you get a breathy voice. This may not happen for two to four days because the Botox® has to diffuse through the muscle. Then the breathy voice lasts 5 to 14 days. Initially the muscle is completely paralyzed. But the body has a quick way of overcoming that. It starts to break down the Botox®. Then the muscle function starts to come back.

Why do some people have difficulty swallowing after Botox®? Part of the swallowing mechanism involves vocal cord closure. When the vocal cords are weakened by the Botox®, they don't close as quickly. When you drink something, it might sneak down the wrong pipe.

How do we give Botox®? There are a few different ways it's administered. It has to be injected into the muscle so it gets to the nerve.

The original technique was using an EMG machine, and it's probably still the most common. Electrodes connect you to an EMG machine via sticky pads. The EMG picks up electrical signals produced in the body. When the Botox® needle enters the muscle, you get a change in the sound. During the injection, you start

with a loud sound when the needle is in the air column, then it's quiet again. When it begins to pop, you're in the right place.

Another technique is video-assisted. A camera goes in your nose or mouth. It's looking at the larynx using similar landmarks, and you can see the needle go into the muscle.

There's also the point-touch method. Feeling the Adam's apple, you work your way down, pushing through the cartilage. For some men the cartilage is more boney, so you have to slide the needle under the cartilage instead of passing through it.

The trans-oral method uses a long needle that goes into the mouth and down to the vocal cord to deliver the injection. Another person besides the doctor administering the shot has to hold the camera, and the patient has to hold their tongue.

No matter which method is used, we like to have consistency when we do the shots: the same amount and time of breathiness, so you can predict your life around the timing of your shots.

There is no set amount of Botox® that any patient gets. Everyone has their own unique dose. There's no way to tell how much to give the first time. Breathiness can last longer with the first shot. It's the side effects and duration of the effectiveness of the shot that helps measure what dose to give. We try to keep the side effects low and short and the duration of the good effects from the Botox® shot as long as possible. Three to four months duration is optimal. Dr. Leahy gives about one unit or a little less for the first time someone with AD SD gets their shot. The dosage for AD ranges from 0.2 to 2.0.

Some patients get their shots for AD SD one side at a time, with the shots spread out about two to three weeks.

With abductor SD, it's a somewhat larger muscle that's affected, so you have to give a bigger dose, usually starting at 5 units per side. The dosage ranges from 1 to 10 units.

Everyone gets a scope the first time you see the ENT, and that's usually the last time Dr. Leahy does the scope unless the patient is having an issue.

Factors that Predict Patient Perceived Hoarseness in Spasmodic Dysphonia

Amanda Hu, M.D., *Assistant Professor of Clinical Otorhinolaryngology: Head and Neck Surgery, University of Pennsylvania School of Medicine*

Dr. Hu presented her research on hoarseness versus dysphonia in SD patients.

In Dr. Hu's work with SD patients, she noticed two scenarios:

1. Patients sound severely hoarse, but it isn't affecting their quality of life.
2. Patients sound mildly hoarse, but it has a more profound effect on their quality of life.

The objective of Dr. Hu's research was to determine what factors affected patient-perceived hoarseness in SD patients. The study examined 145 patients from five states, and 86% had adductor SD. About 15% of patients were professional voice users (teacher, lawyer, singer, actor, etc.).

Dr. Hu's research found there were four variables that were significant in determining the perceived hoarseness for an SD patient:

- Female gender
- Clinician-perceived dysphonia
- Older age, and
- Higher anxiety.

Professional voice use, disease duration and depression weren't significant factors.

"Hoarseness is a very personal symptom," Dr. Hu concluded, "And many factors determine personal perception."

Treatment options for Spasmodic Dysphonia: Surgical Procedures

Joseph Spiegel, M.D., *Professor of Otolaryngology and Medical Director of the Jefferson Voice and Swallowing Center, Philadelphia*

SD diagnosis is confirmed by successful use of Botox®. Some patients, a small percentage, will inquire about surgery because they can't continue to get Botox® injections or they want to stop getting them. Sometimes it's the discomfort of getting the injections. Sometimes it's the logistics. Perhaps their

career makes the ups and downs of Botox® shots inconvenient. Or they may live far away from a medical facility where they can get the Botox® shots. Sometimes it has to do with the Botox® dosing. Some patients have very difficult dosing and acquire a sensitivity. They may get too long a period of breathiness.

There are a few different surgeries that have been done for SD:

Recurrent laryngeal nerve ablation: cutting the recurring laryngeal nerve. This paralyzes the vocal cord. The surgery isn't done anymore.

Thyroid retinoid myomectomy: This destroys some of the muscle, therefore it can't be dysphonic. The largest number of these operations have been done in South America. The problem: The procedure doesn't last very long. At least half of patients go back to getting Botox® six months afterward.

Thyroplasty: This surgery drives the vocal cords farther apart for people who have AD SD. A cut in the middle of the thyroid cartilage is made, and it's held apart with blocks made of metal. However, if you wait long enough after this surgery, the dysphonia eventually comes back. Some patients returned to getting Botox® in three to five years.

SLAD-R (Selective Laryngeal Adductor Denervation-Reinnervation): This is the most common surgery done for SD in the U.S. In this procedure, part of the nerve going to the muscles of the vocal cords is cut.

The patient is asleep under general anesthesia. An incision is made in the neck, and a little hole is made in the thyroid cartilage to see the muscles and the nerves. The nerves to the two main adductor muscles in the vocal cords and the branches of the nerves are cut. A nerve from the neck which is normally a sensory nerve that goes to other muscles is sewn into the main branch. This prevents other nerves from growing in so dystonia can't get started again. The process for the voice to return can take up to a year.

The results from SLAD: 26% say they still don't have a great voice afterward.

Doctors don't perform a lot of surgery for SD. The reason is because over the years we've become good

at the Botox® injections. Most people find a lifestyle that fits into the Botox® injection schedule, and we've been able to help most people in that way. But it's important for people to know there is a surgical option and that there is a pretty good chance they'll have a good voice afterward.

Every Breath You Take: Understanding the Role of Voice Therapy in SD

Bridget Rose, MM, MS, CCC-SLP, *Philadelphia Ear, Nose and Throat Associates*

Bridget Rose, a speech language pathologist (SLP) sees a lot of nervousness, tension and anxiety in patients with SD, and it can be greatly reduced after voice clinic sessions.

At Philadelphia ENT Assoc., after a patient sees the ENT physician, they see a speech language pathologist. The SLP wants to be able to provide the tools that can be used with the everyday voice. The SLP does this as an adjunct therapy to Botox® injections. Usually it's a couple of sessions before the patients receive their first Botox® injection, and again after they get their Botox®.

What does the SLP do? We get to know the patient's functional needs and the severity of their vocal limitations. We're there to educate the patient, too, about SD and the vocal anatomy. We also want to explain why we have you do certain vocal drills.

We have diagnostic tests to differentiate between muscle tension dysphonia and SD, between AD and AB, and to see if there's also a tremor. Some assessments tools include:

- Counting in the 60s and 80s (60 to 69, 80 to 89) using one breath
- Sentence readings with voice and unvoiced and mixed consonants
- Singing
- Speaking with a higher pitch
- Whispering
- Laughing.

We find out: if there is strain and effort in speech; are there hesitations when the voice can't quite get out; is the phonation breathy or does it have a choked, strangled sound; are patients shorter of breath while speaking; are they holding their breath

while speaking; is there a lot of fatigue from speaking?

The 80s series is difficult for someone with AD SD. The 60s series is difficult for someone with AB SD.

For AD SD, voiced sentences are very challenging. Example: Albert eats eggs every Easter.

For AB SD, voiceless sentences are more challenging. Example: Harry hit the hammer hard.

The goals for speech therapy are to reduce negative compensatory tension or strain; coordinate a synchronicity among respiration, phonation, resonance and articulation; reduce vocal fatigue; and increase the ease of voicing.

The sessions: Patients learn how to do stretching and massage themselves. We also do abdominal diaphragmatic breathing. Some patients can learn to convert singing into speech using a higher pitch. Using shortened voice segments and shorter phrases also helps.

The abdominal breathing tasks can increase body awareness. Patients place their hands in their abdominal area while they're performing various tasks. They can develop a pattern of inhalation and exhalation that is gently supported. Smooth phonation through breathing can help with voice onset. Patients can hold a tissue in front of their mouth and nose to see that they have a continuous airflow.

Imagery can help some people. For example: Imagining you're floating along a calm river.

After receiving Botox® injections, it's important to use the techniques you've learned. Why? They can help extend the time between Botox® shots beyond three months.

We can also work with an SLP who is closer to where the patient lives if they travel a long distance to get their Botox® injections.

Mindfulness and Spasmodic Dysphonia

Bidi McSorley, M.D., *Pediatric Behavioral Medicine & Mindfulness Teaching*

Using Mindfulness, Dr. McSorley teaches children, teens and adults skills to live with less stress, less anxiety and increased vitality and health. Dr. McSorley has a condition that robs her of part of one of her senses. So we asked her to not only speak about mindfulness, but how that has factored into having a life-changing condition. This is an adaptation of her talk to the attendees in Philadelphia:

One thing I've observed is an increase in anxiety and stress in our culture.

Meditation has proved profoundly helpful to me personally. I share a challenge, too. About 20 years ago, I was diagnosed with pediatric macular degeneration. I was at the peak of a professional career with two little kids. Like many of you, I had a misdiagnosis, because when you have something that people don't know a lot about, you can get a misdiagnosis. So I was told at 38 that I was going to go blind. They weren't sure when I was going to go blind, but it was pretty soon. So you add in uncertainty.

Because I'm a doctor and I have medical resources, I found out it wasn't true and got information pretty quickly. I'm not blind. But then I began a journey of living with a deteriorating condition and learning how to be with it. And that's where I found meditation so powerful because I was at a time of my life where, not only did I have this diagnosis, I had a career, and I had kids.

You don't just have SD, you have family, kids, financial stresses, work, parents, in-laws. It's not only SD that you live with, it's all these other stresses. And honestly, if I didn't figure out another way to be in life, I was going to have my head explode or it was going to twirl off my body into outer space because of stress and anxiety.

What I found is that meditation has allowed me to be in the world in my life as it is in a different way. It doesn't mean my life is perfect. It isn't. I have lots of stresses. But I'm able to be with that stress in a different way.

And so with many of you with your journeys with SD, you've discovered that. You've discovered a way to be with your SD with a diagnosis many people don't understand, or people say stupid things.

With my eyes, people would say to me, "You need a different pair of glasses."

Wow, I hadn't thought of that!

I'm sure there's an equivalent of that in your lives.

So be with that in a different way: That's what meditation can offer.

What is mindfulness? Mindfulness is paying attention, on purpose, in the present moment, without judgment, with kindness and a curiosity. It means being with whatever is, whether you like it or not, with an attitude of non-judgment and openness, allowing what is already here to be, because it's already here, and all that goes with it.

This means being with SD, or for me, with macular degeneration, with all the complicated feelings that come with it, like, no one of us asked for this, with these unexpected, unwanted visitors, and to be with that with an openness and curiosity, and to be with all the complicated feelings that come with that: the anger, the disappointment, the frustration.

A side about frustration: One thing that I've learned from my eyes, is that a physical disability is a very different frustration. You can be frustrated because your computer isn't working, or because your children aren't doing what you think they should. A physical disability is a very different frustration. And I've really come to appreciate that. When your body doesn't do what you want or expect it to do, or what others expect it to do, there's a different level of frustration.

With mindfulness, it's being with what is, including that frustration, not pushing it away. Saying some days, I really don't like having this voice. Or I really don't like having these eyes.

I was thinking recently, OK, I've done this for 20 years, I've done pretty good with it, now it's time to give me back my eyes. But that's not the deal we get.

Mindfulness is paying attention on purpose. What do we pay attention to? We pay attention to how we interact in the world in three arenas: thoughts, emotions, and our body. Our body has five senses and other body sensations too, which this group is particularly aware of. When we pay attention, we pay attention to those three arenas.

Meditation is brain training. It's training your brain to come back again, and again, and again, to a focus point. In mindfulness meditation, we use our bodies or our breath. By doing that, we keep ourselves in the present. And by doing that, we're more alive.

We spend so much of our time in inner chatter. In the past: I should have done this; what about this, this memory, I can't believe she did this, etc.

In the future we think about, I have to go home, read emails, etc.

We spend very little time right here, in the present. And part of our inner chatter is that we're not very nice to ourselves. We're usually very critical, pretty judgmental. Another part of mindfulness is this concept of loving kindness, being kind to ourselves, embracing who we are with kindness and compassion.

Especially when you live with disability, be able to say to yourself, "this is really hard". Give yourself a mental hug. Give yourself space where you can let yourself feel both the sadness and the compassion, that kindness toward yourself.

When we pay attention to these three arenas, we find amazing things. Mindfulness is really good for your brain. It increases the neurons and the energy and those parts of your brain which are calming, rational peaceful parts, and it decreases those parts of your brain that are involved in the stress reaction. You feel more integrated. By increasing those parts of your brain, you increase emotional regulation, and you're able to tolerate more difficult emotions in an easier way.

The emotions don't go away. I'd love to tell you that I meditate, my life is wonderful, no one stresses me out, it all worked out. But that's not the way it goes. I still have all those stresses in life, but there is a

spaciousness around my life and stress, around my disorder.

One of the things that happens with our thoughts – that constant chatter that happens – we do this wonderful thing of believing our thoughts, we get anxious, these thoughts spin around and they get more crazy.

I'm sure with many of you when you first got diagnosed, you thought, what's going to happen to me, who is going to hire me, how am I going to find a partner, how are my kids going to hear me? All those thoughts come. And then more thoughts come: This is never going to work out. This is going to be really bad. I'm never going to find another job, because I got fired. All these thoughts go around and around and around and create more anxious thoughts.

What would it be like to be able to step back and say to yourself, these are my thoughts; not all of them are true, I don't need to get stuck on them; I can step back and see my life in a different way.

In those thoughts and emotions, we react in very habitual patterns. We get stress and we react in that habitual way, whether it's screaming, crying, getting a headache, whatever.

What mindfulness can do is create some space. Instead of reacting, you respond. Sometimes the reaction is your own thoughts such as worrying about the future. What if you could step back from that, instead of getting caught in that reaction, create a space and then respond. What would it be like to step back and respond in the face of chaos? That's what meditation can offer.

So I'd invite you to investigate this, the thought of taking care of yourself in this way. You can spend five minutes a day. Give yourself that space of kindness and tranquility in the midst of chaos.

Pictured: Fred Hosier and Bidi McSorley



Living with Spasmodic Dysphonia Session

During the Living with Spasmodic Dysphonia session, which was facilitated by **Lois Jackson** and **Cathie Leister**, many great ideas and resources were shared. Listed are some of items discussed. *Please note that is not an endorsement for any products by the NSDA but rather a sharing of information.*

Voice Amplification Systems

Hisonic - <http://hisonic.net/wired-pa-system.html>

Sonivox - <http://www.harriscomm.com/sonivox-speech-amplifier.html>

Relay Systems

The Maryland Relay system was discussed for phone communication (<http://doit.maryland.gov/mdrelay/Pages/default.aspx>) You can google Relay System and your state to find similar programs.

Phone Equipment Program

<http://www.tedpa.org/StateProgram.aspx>

The Telecommunications Equipment Distribution Program Association (<http://www.tedpa.org/>) has information on amplified phones and individual state programs. Often equipment is distributed free or at low cost.

Jobs Accommodation Network

www.askjan.org

The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues. This is both for employees and employers.

Vocational Rehabilitation

<http://www.dli.pa.gov/Individuals/Disability-Services/ovr/Pages/default.aspx>

Many states have a program that provides vocational rehabilitation services to help persons with disabilities prepare for, obtain, or maintain employment. Below is the link for program in Pennsylvania, but you can also google vocational rehabilitation and your state for local resources.

Tips

- Use a whistle to get someone's attention and communicate
- Take a deep breath between words, especially on the phone
- To go around voice recognition, try hitting 0
- When someone is being rude because of your voice, especially on the phone, "I have a voice disability, do you have an issue dealing with someone with a disability?"

Links to Articles

Siri and Voice Disorders - <http://bit.ly/2dJWjiu>

Voice Exercises - <http://bit.ly/2bSUvSb>

NSDA Support Groups - <http://www.dysphonia.org/support-groups.php>

This summary is published by the National Spasmodic Dysphonia Association
For more information, log on to www.dysphonia.org