

NSDA Southeast Region Newsletter
October 2006

Mel Dubovick, NSDA Southeast Regional Coordinator and Chairperson, US

NATIONAL INSTITUTE OF HEALTH STUDY

A study from the NIH suggests that voice rest for 30 minutes after a Botox injection can help the Botox work better. No further information is available on this.

DOT SOWERBY COMMENT ON 'JOURNALING'

Last month, I mentioned how some people write about SD in a paper notebook. Dot wrote back and said:

" I find using my computer for a journal is best suited for me. I used to write in a notebook but now find I can type away even with my eyes closed as thoughts come to me. Also it is nice to be able to use spell check!! I frequently find in writing emails, that some of what I describe or feel is something that could go in the journal. I can copy and paste some of this in my journal and then add to it there."

. . . . Dot Sowerby is Past President of the NSDA, presently is a member of the NSDA Board of Directors and resides in North Carolina.

LYRICA HELPS IMPROVE VOICE- at least for this one person who mentioned it -

A lady in PA was seriously ill with some heart problems. She also had fallen and dislocated her shoulder. Due to her illnesses, she had not had a Botox shot in 8 months. Because of her severe pain, her doctor prescribed Lyrica to ease her pain. As a result of taking Lyrica, her voice improved significantly and with no drug side-effects.

UNILATERAL BOTOX INJECTION WITH ONE CORD ON "VACATION" FOR A YEAR

A woman in SC that gets Botox shots on one side (unilateral) reports that her ENT does not alternate cords. She's been getting injections on her left cord for over one year and her right cord has been on "vacation". Using just her left cord, her voice has been "pretty darn good quality" she reports - "best it has sounded in 10 years. " She has mixed SD (AD/SD and AB/SD combined).

This is being mentioned because everyone I know who gets unilateral injections has the ENT alternate between cords, i.e. one time on left side, next time on right side.

WHY ATTEND THE 2007 NSDA SYMPOSIUM? - my personal view

Good question because unless you live within driving distance to White Plains, NY it can cost a few dollars. The answer is as follows:

The NSDA 2006 Annual Patient Symposium was a well polished, highly professional operation. It afforded attendees the opportunity to listen to some of the most prominent doctors in the country discuss various aspects of SD. The meeting rooms were comfortable; the sleeping accommodations and the meals were very good. The informal NSDA gatherings were designed to promote camaraderie among the guests and it was great.

When you go to a doctor's office, you get an opportunity to hear the doctor speak for 3 to 5 minutes IF YOU ARE LUCKY! When you attend the NSDA Symposium, you get to listen to doctors speak for HOURS!!! And all are discussing various aspects of SD. This is something that you cannot duplicate anywhere else. Don't miss it!

MORAL TO THE STORY ABOUT A WOMAN THAT STUTTERED

While the topic is not SD, the determination and inspiration of this person who stuttered is admirable!

This article was posted September 26, 2006 on www.miamiherald.com. It was written by Tom Keyser, Albany Times

Union newspaper.

ALBANY, N.Y. - Pam Mertz took a deep breath and stepped from behind the podium.

She stuck out her hand to the person sitting in the nearest chair and said,

``Hello, my name is Pam. Nice to see you tonight.''

She shook the hand of the next person and said, ''Hello, my name is Pam.

Very nice meeting you tonight.''

She walked to the other side of the podium and did it a third time: ``Hello, my name is Pam. Glad to see you tonight.''

Then Mertz settled behind the podium, took another deep breath and said, 'four little words: `Hello, my name is . . .` For a person who stutters, as I do, being able to say them can be an amazing struggle.'

For Mertz, this speech she delivered last week at a meeting of the Capital Toastmasters culminated a struggle that lasted 39 years. Born and raised in Albany, the 44-year-old began stuttering when she was 5 and spent the rest of her life trying to hide it -- until May, when she lost her job, and the secure world in which she had tried to conceal her secret crumbled.

In the past four months, Mertz has sought help by attending support groups, receiving speech therapy and joining Toastmasters, an organization that helps its members improve their communication skills.

The speech in front of 20 people was the most appropriate way for Mertz finally to acknowledge her stuttering. Her most haunting memory is of being in college and standing in front of her class. She remembers the painful look on her classmates' faces as she struggled to utter even a single word.

But at Toastmasters, she hesitated or stumbled only a couple of times. She said that for about 30 years, she took a back seat in life, and that even six months ago she was terrified of admitting she stuttered.

Mertz is one of an estimated 3 million Americans who stutter. Their stuttering varies from mild to severe; Mertz's is mild. But they've all had to face the cruel jokes and impatience of a society that can look harshly upon people with speaking

disorders.

"There's such a negative view of stuttering in our society," said Joe Klein, an assistant professor in the Department of Communication Sciences and Disorders at The College of Saint Rose in Albany. "Being able to talk is such an easy, human thing to do that I think people are really surprised when somebody can't do it as effortlessly as everybody else can."

She graduated from Keuka College in upstate New York with a degree in social work and was hired at the Glenmont Job Corps Center, working nights as a dorm advisor. Mertz remained at Job Corps for 22 years, working her way up to counselor, counseling supervisor and career-development manager. It was safe, the surroundings familiar and her co-workers supportive.

A year ago, she got a new boss, and the negative evaluations started. They led to her firing in May. Mertz said she believes it happened at least in part because of her stuttering.

She was devastated at the loss of her safe world. But things started happening that began transforming her life.

Faced with having to find a new job, and the inevitable face-to-face interviews, Mertz finally decided to get help. She searched the Internet and found the National Stuttering Association. She started attending its monthly support group at The College of Saint Rose. Mertz also joined Toastmasters.

"What I'm experiencing is such an empowerment," Mertz said. "All of a sudden

there are all these resources, and I've jumped into them all. A couple of my friends have kidded me: `You needed to be fired to find this new chapter of your life.'"

Mertz has learned breathing techniques that help her speak fluently. She's learned

to start her sentences slowly and to stay relaxed. Most important, she said, she has learned that she shouldn't be ashamed if she stutters.

"I spent all this energy trying to hide it, when it turns out I didn't have to," she said. ``I wish I'd found that out 20 years ago.'"

NEW SUPPORT GROUP FOUNDED IN ATLANTA, GA

I'm happy to announce that the NSDA has successfully re-activated an SD Support Group in Atlanta on 10/17. Dr. Christy Ludlow of the NIH was the keynote speaker. Special thanks to Concetta Griffin and Tamra Bolles who volunteered as co-leaders of this Support Group. Also sincere gratitude to Dr. Edie Hapner, Director of Speech-Language Pathology at the Emory Voice Center for her assistance in getting this group launched and supporting it on an ongoing basis.

THE NEED FOR SD RESEARCH

-Tells where SD medical research has been and where it is headed

Part of a speech by Mary Bifaro, NSDA Board Member and Support Group Leader, Charlotte, NC

Until there is a cure for SD, there will be a need for research. Since 1989, the focus of the NSDA has been in raising awareness, providing support and advancing medical research. There are approximately 50,000 people in North America who have been diagnosed with SD. Current treatments for SD reduce the symptoms of this neurological voice disorder. There is little understanding of the cause of SD. There is no specific test for the diagnosis of SD. The condition manifests

itself in the larynx although most researchers believe that the disorder stems from the brain. SD involves an abnormality of the central nervous system. It is a focal dystonia which affects communication. SD can be classified as possibly having genetic or environmental factors.

The NSDA has sponsored research in the past which looked into the effectiveness of current treatments and the effects which SD has on the lives of SD patients. In 2005, the NSDA was a co-sponsor of a Research Planning Workshop on SD at the National Institutes of Health. This was the first time that eminent researchers came together for discussions that were entirely focused on SD. Their aim was to help pave the way for future research. As a result of this program, these neuroscientists will be laying the groundwork for research and setting priorities to determine the cause of SD. This workshop was intended to serve as a help to better understand SD. Some of the research priorities coming out of this workshop include: developing accurate diagnostic tools for SD and analyzing genetic and risk factors.

Attendees of the 2006 NSDA Symposium were able to participate in the genetic marker research study by Dr. Mark LeDoux. NSDA Medical Chairperson, Dr. Christy Ludlow, is working on a brain imaging study at the NIH to gain a better understanding of SD. This study involves MRI scans. Also, a brain and larynx donation program for SD is being worked on at NIH. Another ongoing project of the NSDA is to have an SD Patient Database Registry. The purpose for this is for the medical professional to have a tool for treatment and research. Dr. Ludlow of the NIH is helping with this work as well. For the 2006/2007 year, the NSDA will be funding an SD Research Fellowship. Stephe Mendel, an NSDA Support Group Leader and Board Member, stepped forward in late 2005 to make this important donation which will launch the NSDA's research fellowship program for SD. It will take major ongoing contributions to continue the SD Research Fellowship Program.

The NSDA has only one full-time staff member. It is highly dependent on its volunteers who are SD patients in the vast majority of cases. The NSDA relies on its members for fundraising. The NSDA is committed to advancing the science of SD in order to improve the lives of SD patients. The NSDA continues to develop relationships with physicians and researchers who are interested in SD research. Several years ago, the NSDA co-sponsored the Young Investigators

Award with the DMRF. This award is designed to encourage young medical professionals to study all types of dystonia, including SD.

Since its founding in 1989, the NSDA remains the only organization in the world which is totally dedicated to SD. Over the years, it has assembled countless volunteers and many scientific advisors in its community. It continues to grow in its outreach, support and programs. The NSDA continues to strengthen its relationships with other organizations. The NSDA continues to be represented throughout the year at various medical conventions whose attendees have an interest in SD. The NSDA is working with WE MOVE in the Life in Motion campaign. The NSDA works with the American Academy of Otolaryngology (AAO) especially to commemorate World Voice Day which takes place on April 16 each year. The NSDA is part of the American Brain Coalition. This organization works to advance the understanding of the brain. The NSDA is a member of NORD, the National Organization of Rare Disorders. The NSDA maintains good relationships with other movement disorder organizations, such as the DMRF (Dystonia Medical Research Foundation). The NSDA has contacts with the Voice Foundation and ASHA (American Speech-Language-Hearing Association). The NSDA has developed a partnership with the NINDS (National Institute for Neurological Disorders and Stroke) and the NIH (National Institutes of Health) in order to support SD research. These public research institutions are leaders in research on disorders which are neurologically based.

In conclusion, the need for SD research is vital. Part of NSDA's budget goes to research, education and support. Another part goes to running our organization. Since 1989, the NSDA has been here for the newly diagnosed as well as its long-term members. The NSDA is grass roots and patient-driven. Each of us can play an important role in fulfilling NSDA's mission by contributing financially to the NSDA. In addition, the NSDA welcomes volunteers to help raise awareness about SD and to provide support to those affected by SD. When you think about the NSDA, remember it this way. Nothing Stops Determined Advocates!

Please support the NSDA

If you are not a member of NSDA, please take the time to join. The cost is \$35. per year and it is a way that you can fight back against SD, including the funding of SD medical research projects.

Go to the NSDA web site, <http://www.dysphonia.org/> and click onto the

right hand corner box, Join or Donate or write a check and mail to:
National Spasmodic Dysphonia Association
300 Park Boulevard, Suite 415
Itasca, IL 60143

All contributions are tax-deductible. The NSDA is a non-profit 501(c)3
organization and its U.S. Tax ID Number is 38-2918042.
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www.dysphonia.org

Spasmodic Dysphonia (SD), a focal form of dystonia, is a neurological voice disorder that involves involuntary "spasms"

of the vocal cords causing interruptions or straining of speech that affects voice quality.