

NSDA Southeast Region Newsletter
February 2007
Mel Dubovick, NSDA SE Regional Coordinator and
Chairperson, US/Canada

Preface: I typically publish this Newsletter later in the month. However, I have quite a few articles and particularly wanted to send you the first article without delay.

Taiwan, China Headlines:
**CHANGGUNG KAOHSLUNG TEAM DEVELOPS
WORLD'S FIRST CURE FOR SPASMODIC
DYSPHONIA**

source:

<http://www.taiwanheadlines.gov.tw/ct.aspxItem=60254&CtNode=9>

special thanks to Mary Bifaro of Charlotte, NC for making this article available through her Support Group Newsletter

" The majority of treatments worldwide for spasmodic dysphonia involve injections of botulinum toxin and are ineffectual in curing the disorder. *Now, Kaohsiung's Changgung Throat Beauty Center team has developed the world's first laser thyroaretoid muscle nerve vaporization treatment, already demonstrated on 17 patients at the center.* A noted United States otorhinolaryngology journal will be publishing this medical breakthrough in its January issue.

Center physician Su Chiying says that the cause of spasmodic dysphonia is still unknown. Suffers experience over-contraction of the muscles in the voice box making them unable to phonate smoothly, and leaving them with urgent, shaky and broken voices when speaking. The difficulty patients have

in speaking can lead to anxiety or even depression, the inability to make friends, hold down a job, or even suicidal thoughts.

In the past, ENT specialists have suggested that patients take injections of Botox in the muscles of the vocal apparatus, creating a temporary paralysis of the nerves and muscles and alleviating the spasms. Unfortunately, this treatment lasts only three to five months, and some patients have reactions to the treatment and have to abandon it.

Kaohsiung's Changung Voice Center [has developed a revolutionary new microlaser surgery for the throat that uses a microscope attached to a lens in the throat. A laser is used to vaporize the feedback nerve cell receptors deep inside the thyroaretenoid muscle.](#)

Dr. Su says that this laser surgery truly treats the causes leading to spasmodic dysphonia. Currently, the treatment has been attempted on 18 patients, and after 1 to 3 years of tracking their progress, 94% (17/18) have experienced clear improvement in their condition. More than half of the patients have almost no symptoms remaining. The procedure lasts just an hour and requires only a short hospital stay. At present, no complications or aftereffects have been reported."

Please ask your doctor to look into this so we can all learn whether this procedure is credible. I would suggest that SD patients who receive feedback on the article from their healthcare professionals would post onNSDA's general Bulletin Board to further the discussion on this topic.

(<http://www.dysphonia-bb.org/forums/sd/>)

MORE ON GETTING HELP FROM YOUR US SENATOR or REPRESENTATIVE ON SOCIAL SECURITY DISABILITY INSURANCE

Per Senator Mel Martinez (FL) web site:

"The Senator cannot offer legal advice and cannot intervene on matters that are pending before the courts. The Senator does do not have the authority to overturn a decision already given by a federal agency." - - - clearly there are limits to what the FL Senator can do. Here is a further clarification from someone who worked in government:

US Senators and Representatives tor can help with a broad range of inquiries that constituents may have with the Federal government -- everything from getting a passport to inquiring about social security disability findings. The key is that a Senator's/Rep's power is limited in the adjudication of any claim one has with the Federal government. The agencies follow strict legal guidelines (laws and regulations) and thus, Congress has limited power over a matter in adjudication by an individual agency. Our representatives can, however, assist in facilitating paperwork and/or explaining the process, etc., to a constituent.

I just would not want to give false hope to anyone that their representative can actually sway an agency in its decision-making, because each decision is governed by law, regulations and agency policies.

A VOICE FOUND

Here is a poem written by Linda Barnette, a member of the Greensboro, NC Support Group. Linda gave permission to share poem with others. You may want to share this poem with your support group.

She spent her last 5 years of her teaching career with the use of a little microphone and a lot of writing and help from her students. She retired in

2003 and decided to run for the Board of Education in spite of her disability. She won and is now in her third year of service.

A Voice Found

On the surface I am a person without a voice,
Straining to speak, to communicate,
to get people's attention...

It would be easier to retreat into the silence,
But I have a mission in this world
which fate will not ignore.

Though the physical is only a whisper,
my spiritual voice is strong.
It speaks for the weak, the disabled, the gifted,
for all the children...

IN ITS SILENCE IS ITS STRENGTH
as it shouts for justice and equality for all.
It is a voice found--a voice for all the people.

GREAT FUND RAISING IDEA

Kay Lentini of XXXXXX mentioned:

Here is an idea that I got great success from. I called it: 'Silent Night a fundraiser for Spasmodic Dysphonia.' I held the event in December to reflect the "Silent Night" song and to offer people year-end tax deductions. I sent a letter to all of my friend's husbands announcing that if they would make a donation to NSDA (directly) that their wife had vowed to remain Silent for 24 hours. Let me tell you what...it was greatly received. Especially by the men! I must say, no one was able to be Silent for 24 hours. They all had great excuses. It did give my

friends an appreciation for what I go through with SD. The local newspaper even interviewed me and put my picture in the paper. The husbands loved it. The next week, I had all of the participants over for chocolate fondue and champagne to thank them. If anyone wants further info, email her at partyrentalsource@yahoo.com

SEEDS OF HOPE by author, Steve Goodier

“We cannot live only on hope. But neither can we live without it. Nobody knew this better than John Chapman.

John Chapman was a man of great hope. He was born in 1774 in Massachusetts. In the early 1800s he got in on the opening of land in the Northwest Territory (as it was then called) of the new United States. He found small plots of land suitable for farming and cleared them by hand. He bought fruit seed in Pennsylvania every year and carried it to his many apple orchards, usually on his back.

When the trees were large enough to transplant, he sold them to settlers homesteading the West. Eventually, he had little apple orchards spread around what would become the states of Ohio, Michigan, Illinois and Indiana. Most people forgot, or never knew, his real name and took to calling him Johnny the Apple Man or Johnny Appleseed.

Johnny was a gentle man with a big vision. He was liked by most people who knew him, the native Indians and white settlers alike.

His vision was to spread the goodness of apple trees everywhere people settled. Apples, he believed, gave the promise of harvest and hope that the wilderness would become home. Every tree he grew was a symbol of hope.

Johnny had another curious habit. He loved books, but did not have the means to carry more than two, usually books of inspiration or theology. Because Johnny wanted to share his books, he carefully cut chapters out of whatever inspirational

book he had available and loaned one or two chapters to families that wanted to read. He's later swap those chapters for others when he came back through. In this way he left hope and encouragement wherever he traveled.

His grave can be found today in Fort Wayne, Indiana. It says, 'Johnny Appleseed (John Chapman). He lived for others.'

Johnny understood his greatest task in life to keep hope alive. When we keep hope alive, then hope keeps us alive."

ROBERT F. KENNEDY, Jr. INTERVIEW IN O' MAGAZINE (Oprah)

Special thanks to Stephe Mendel for making this article available.

Quoting Robert Kennedy, Jr. from an interview with Oprah in her magazine called *O*, the February issue.

Oprah: I know that you have a genetic neurological condition called spasmodic dysphonia, which is straining your speech. Does it hurt when you talk?

Bobby: No, but it's an effort. The disease didn't hit me until I was about 43. I used to have a strong voice.

Oprah: So you just woke up one day and your voice was different?

Bobby: It began as a mild tremble for a couple of years. After people would hear me speak, I'd get all these letters, almost always from women: "I saw you on TV and you were crying—it was so good seeing a man share his feelings!" I'd think, Oh God. I knew for every woman who wrote, there were ten men saying, "Look at this friggin' crybaby!" [Laughs]

Oprah: Did your voice worsen?

Bobby: I've been told that it's not supposed to, but I think it has. There's a treatment for it: Botox shots. They put a needle into your voice box every four months. They still haven't gotten my dose right. Then they went on to talk about Global warming

note: There was mention that RFK, Jr. might run for the US Senate from the State of New York if the present Senator, Hillary Clinton gets elected President (vacating her Senate seat). Politics aside, if someone as visible as RFK, Jr. ran for the US Senate, it is inevitable that his vocal condition would be mentioned, at least to explain why he sounds the way he does. That would greatly boost public awareness about SD.

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.

Spasmodic Dysphonia (SD) is a neurological voice disorder that involves involuntary "spasms" of the vocal cords causing strained or interruptions of speech affecting voice quality.

Save the Date: May 5, 2007 NSDA Symposium