

Dear NSDA Southeast Region Support Group Leaders
and Area Contact People:

Here is the NSDA Southeast Region email newsletter for August 2008. Please forward it to the people in your area.

Regards,
Mel Dubovick

Special thanks to NSDA Regional Coordinator Corinne Liseno of California for contributing to this issue. The following comments are from Dr. Dray who is on Staff with Kaiser ENT in California. He presented to the Peninsula-South Bay SD Support Group which is led by Marcia Sterling in Palo Alto, CA. Special thanks to Mary Bifaro of Charlotte for also contributing to this issue.

PRESENTATION BY DR. DRAY, KAISER ENT, CALIFORNIA

Types are AD and AB, with usually one predominating over the other. Tremor may be evident on rare occasion.

Number of SD cases: perhaps 50,000 in US and maybe a million world-wide.

Length of treatment: varies and some patients seem to "self-cure" or go into remission.

Botox injections began in the mid-1970. Injections never completely wear-off and new nerve fibers commonly grow to replace Botox-deadened nerves.

Some medications prolong the effect of Botox. He cited anxiolytics like Klonopin and Atavan.

Dr. Dray applauded NSDA support groups for their proactive championing of research and their interaction with professionals.

Botox injections:

1. Very large variance in patient effect.
2. About 12 muscles control vocal chords, therefore injection accuracy is complicated.
3. Breathiness occurs for many patients because the muscle treated is often the one which affects breathing. Usually it takes from 0 – 4 weeks for breathiness to go away.
4. Dysphasia (choking reflex when swallowing): it takes about 0 – 1 ½ weeks to dissipate.
5. Dosage: the average is 3.88 units per patient and the range can be less than 0.1 and greater than 10.0. Again, there is very large variance among patients and there is no relationship to metabolism or body mass.
6. Note: Botox B is used widely in the Great Britain and the standard in US is the A variety. We may expect B to be used eventually in US.
7. Bilateral injections are the most prevalent area at 72%.
8. Beneficial effect: greatly improved speech for about 15.2 weeks on average; and some patients experience even greater time of effect.

To speak with SD, we can trick the brain for a time, like placing finger pressure on the throat to interrupt nerve signal from the brain, by modulating our voice, by speaking in a higher register and by positioning the head downward.

BOTOX INJECTION VOICE RECOVERY CHART

This attachment is a patient self-assessment chart. Filling this chart out for every Botox shot provides invaluable information about the effectiveness of each shot. Making this information available to your ENT will provide guidance on how often you need a shot and especially on the shot dosage.

NEWS/ANNOUNCEMENTS FROM THE NSDA

There will be a special dinner celebration in Charlotte, NC on Saturday, April 4, 2009 following the daylong Annual Symposium. The cost of the Symposium will be \$55. This includes breakfast, lunch and materials. See details on the NSDA web site at www.dysphonia.org under 'Events'. Please put these events in your budget and onto your calendar as they present a rare and unique opportunity. You will hear from SD experts and meet SD patients from across the US and around the globe. NSDA will be celebrating its 20th anniversary.

The NSDA has restocked its supply of the new book, "Easier Done than Said: Living with a Broken Voice". It can be purchased for \$15. In addition, a two-disc DVD set of our 2008 Annual Symposium is available for \$25. Please order via the NSDA website at www.dysphonia.org under 'Publications and Videos'.

ROBERT F. KENNEDY, JR'S VOICE DRAWS ATTENTION TO RARE DISORDER

Robert F. Kennedy, Jr recently appeared on Larry King Live. He hoped to gain attention for energy conservation as his passion is 'the environment'. But the public listened to his stilted, strained voice and this helped draw attention to another cause.

Following his broadcast, there was a lot of Internet talk about his voice. People wondered if he had a bad cold, lung cancer or at least something that made it sound as if he was choking up. In truth, RFK Jr. has Spasmodic Dysphonia and people on the Internet came to this discovery.

Although it was not his intent, RFK Jr's appearance on Larry King Live helped generate public awareness to Spasmodic Dysphonia.

IF YOU SHOULD CHANGE YOUR EMAIL ADDRESS

Don't forget to notify NSDA by either contacting me, meldubovick@comcast.net or the NSDA national office, nsda@dysphonia.org

Notifying NSDA is necessary in order to receive not only the Southeast Regional Newsletter but also any email broadcasts from the NSDA national office.

WANT TO MAKE THIS NEWSLETTER BETTER?

Take a few minutes and send me any articles you think will be of general interest to the NSDA community of people.

WANT TO DO SOMETHING TO HELP YOURSELF AND OTHERS WITH SD?

Become a dues-paying member of the NSDA. It is only \$35.00 per year and it will give you a sense of satisfaction that you are doing your part to help by funding medical research that may

lead to improvements in treatment and someday, a cure. Don't assume you don't need to act 'because .the other person will do it'. *Take responsibility yourself* by going to the NSDA web site and joining today!

NSDA website: www.dysphonia.org