

November 2008

DSG-Alabama Newsletter

NEWS FROM DYSTONIA SUPPORT GROUP - AL/Birmingham

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by Ken L. Williams, Volunteer Dir/Treasurer

THE WORM SHACK

For the latest on Dystonia research progress in which the Alabama Dystonia Scholars are involved click on this link: <http://uanews.ua.edu/aneews2008/nov08/moody111808.htm>

WE MOVE NEWS

If you want to receive regular email bulletins from WEMOVE.ORG click on this link to their website: www.wemove.org

You can become a member of WEMOVE, an organization funded by educational grants from the Medtronic Foundation (manufacturer of the implants used in DBS & some Parkinson's patients) at no charge.

Their latest bulletin of interest to Dystonia patients tracks the advice DSG has been spouting; i.e. **TAKE CHARGE OF YOUR OWN TREATMENT!** Quoting from a recent bulletin:

IMPROVING PATIENT-PHYSICIAN COMMUNICATIONS - ASK QUESTIONS

If you don't understand what the doctor tells you, keep asking questions and discuss his/her answers. Talk until you do understand!

Every time you're given a prescription for a new or changed dosage in medication be sure you understand everything about the prescription...dosage, possible side effects, etc.

If a question comes up while you're at home, write it down for your next visit.

NEWS FROM NAT'L SPASMODIC DYSPHONIA ASS'N

Quoting from OurVoice, quarterly membership publication by NSDA: (slightly paraphrased)

Q & A by Robert W. Bastain, M.D., NSDA Medical Advisory Board Chairperson:

Q - I have just been diagnosed as having Adductor SD and am considering trying BOTOX injections. Can you give me some information on how you decide upon the dose for use the first time and what is the "optimal dosage"?

A - Before the first botulinum toxin injection, I try to make it clear that it is impossible to know your personal optimal dose until we've gone through two or three injection cycles? The "average" or "typical" dose in my practice is approximately 1.25 units split between the 2 vocal folds. I have a few patients who routinely get 0.25 units (half in each vocal fold) and 1 patient who gets 8 units (half in each vocal fold). 80% of my patients fall somewhere between 0.7 units and 2 units (half in each vocal fold), however.

There is no correlation between dose and any patient "characteristic". A tall, muscular, young man may need a tiny dose, while a petite or older woman might need double or quad-triple his dose. It requires a "trial" to find the dose that gets optimal benefits.

My first dose is between 0.7 or 1.0 unit (half in each vocal fold). At this dose, almost everyone has some effect/benefit. 1 or 2 out of a hundred will call a week later and say nothings happened. To that rare individual I say: *"I'm sorry, but you are apparently not highly sensitive to botox and we'll boost your dose significantly at your next injection"*.

On the other hand, 1 out of 5 will call and say:

"My voice is much too breathy; I'm tending to cough on liquids; when will this go away?" I will answer: *"I'm so sorry as I know this is really unpleasant, but I won't do this to you again. We have now learned that you are extremely sensitive to botulinum toxin and we'll drop the dose on your next injection"*.

BOTOX therapy must be tailored to the informed patient's needs and concern, and not only to the doctor's strategy! I find the best dose to be in the range quoted above: i.e. 0.7 to 2 units (50% in each vocal fold) which is why I begin with 0.7 to 1 unit (50% in each vocal fold) to decrease the number of patients who have an unpleasant experience and long duration of breathiness.

Editors comments: I only know a handful of DSG dysphonia members who are satisfied with their Botox dosage/results, so I found this very, very enlightening>

I've now been to 4 "voice specialists" over a span of 5 years. The first started with 10 units in "one" vocal cord. *I couldn't talk for 4 months.* On my next visit, I asked to reduce the dose and inject both vocal cords. He did reduce it to 7 units but ignored my request to split it between both vocal cords. *I couldn't whisper for 3.5 months.*

I gave this history to Doctor #2 who injected 4 units (half in each vocal cord). *I couldn't talk for 2 months. I didn't go back.*

I gave my history to Doctor #3 who injected 3 units (half in each vocal cord). *Success: Now I couldn't talk for 6 weeks!!!* I complained on my next "cycle" so he reduced the dose to 1.25 units in each vocal cord - total 2.5 units. **BIG DEAL!** *Now I couldn't talk for 5 weeks!!!!* I waited 9 months before going back and my voice got so bad I forced myself to return. I asked for a lower dose, but the doctor had 2 Brazilian specialists visiting him and watching so he talked more to them than to me. **Result:** *He gave me the same 1.25 units in each vocal cord and I had 2 weeks of swallowing problems plus 6 weeks later I'm just regaining some strength in my voice.*

Now, in reading this article I understand. What do you suppose the current doctor will do when I go back in January '09 and "tell him" I want a lower dose?

It's easy to preach "talk to your doctor". The "trick" is getting them to "take the time to pay attention".

**REMEMBER THE HOLIDAY SOCIAL - 10:30 AM, SATURDAY,
DECEMBER 6**

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