

Dystonia Support Group/Birmingham, AL Chapter

April 21, 2007

*Guest Speaker: Dr, Mark LeDoux*

We had 26 in attendance:

Pat & Bill

Betty & O.J.

Rita & Ken

Pat

Josefine & Ted

Ken

Stacy

Terri

Betty

Trish

Jane & Ricky

Brad, Paige & Emily

Mary Ann

Evelyn

Betty

Jay

Linda

## WELCOME NEW MEMBERS

I want to extend a personal welcome to our new members Melanie and Richard. We hope that you were provided with support, education and left knowing that you are not alone in living with dystonia on a daily basis.

## GUEST PRESENTATION

Dr. LeDoux is a movement disorder specialist and a professor at UT in Memphis. He is actively involved in research for a cause and cure for dystonia. In 2006 many of us participated in his *Genotype Research Trial*.

Thanks to the new members that participated at this meeting.

Dr. LeDoux spoke to us on Botox and had a slide presentation. He stated that Botox injections are a “skill and art more than a science.” He chooses to use an EMG machine when injecting, he can hear the activity of the muscles and tell which are in spasm. This allows correct placement of the needle in

the muscle rather than fat or tissue. Some patients experience flu like symptoms after injections for approximately 48 hours, and you may have slight bruising and soreness.

Dr. Andy Blitzer was the first physician to treat spasmodic dysphonia. Dr. LeDoux told us what a small target there is to inject for SD. He also discussed injections on one side versus both sides and injecting the folds by the vocal cords versus the cords themselves.

There are six forms of dystonia and Writer's Cramp is the most difficult to treat. The six forms are spasmodic dysphonia (voice), cervical dystonia (neck), blepharospasm (eyes), writer's cramp (hand), oromandibular (jaw) and generalized dystonia (entire body).

Botox is a powder that is reconstituted with 1 cc of saline and must be used within 4 hours once mixed. 100 units/2cc per vial. This is why some physicians have "Botox Injection Days." Botox is not FDA approved to be frozen and reused.

## COMMERCIALY AVAILABLE BOTULIN TOXINS

- 1. Botox – manufactured by Allergan**
- 2. Dysport - Botox Type A – Made in Europe & UK**
- 3. Xeomin – Type A manufactured by MERZ in Germany; not FDA approved in USA yet but in clinical trials which Dr. LeDoux is participating in. Thought to be a cleaner product. (Anyone interested in participation can contact me)**
- 4. Myobloc – Type B manufactured by Solstice Neurosciences (Burns more and has more side effects)**

He stressed the importance of **not** receiving booster injections due to the risk of immunity. Botox should be injected every 12 weeks/3 months and not before. 400 units should be the maximum injected. If you develop head drop with chin to chest it is an indication that you received too much. It is important to remember that once you decide Botox injections as your treatment it will take several months to adjust dosage.

On a personal note I thought once I got my first series of injections I would have no more pain, my head would be straight as an arrow and no shaking. I was expecting a quick fix. Remember to be patient, in my case after 12 months/ 4 series my dose had been perfected. For someone that went 16 years misdiagnosed I am 90% improved and that amazes me.

Having FDA approval for Botox manufactured by another pharmaceutical company would hopefully drive the price down.

Dr. LeDoux told us to ask our physicians questions: what muscles are you injecting, how many units are you injecting, are you using Botox A or B, etc.?  
If you feel something isn't right, get a second opinion.

I feel that we play a very important role in our treatment and along with our physician we are a team.

Dr. LeDoux was kind to answer questions by many of our members.

## **YOU WERE MISSED**

We had several members that could not attend. All of you were missed and hope to see you at the next meeting.

## **THIRD ANNUAL SUMMER LUNCHEON**

**Please join us on 06/16/07 for our third annual "Summer Luncheon." Pat & Bill are providing the meat this year and we are asking that each member bring one or two covered dishes or a dessert. We encourage you to bring family and friends.**

**This is an opportune time to socialize and get to know each other better. REMEMBER WE MEET AT 11 rather than 10!!**

*I look forward to seeing all of you on the 16<sup>th</sup> and thanks to all of you for making DSG Birmingham a success.  
Linda*