

February Meeting News

Pat, our group leader, chaired the meeting and introduced the speaker.

Michael J. Tapley, Southeastern Rep of Medtronic, Inc. was our speaker. His company manufactures certain medical devices, including those use in Deep Brain Stimulation surgery for Dystonia. Medtronic has been a long-term financial supporter of DMRF.

Four (4) of our members have undergone DBS, the latest being Clay who has already progressed from a wheelchair to walking & even throwing a frisbee even though he has a final procedure scheduled for April 8th at UAB. You can learn more about Clay's journey from "wheelchair to walking" by going to:

www.caringbridge.org/visit/clayburns on the internet or clicking the link on DSG's web-site.

The other members who've found dramatic improvement in their "quality of life" with DBS are:

Brad, whom most of you will remember from Tuscaloosa and who has a dedicated page on our web-site. Brad attended the meeting and asked if he'd go thru it again, he said: "NO DOUBT".

Ramona, our loyal member from Huntsville, had her surgery soon after Brad. Ramona and her husband also attended the meeting. You'll recall the "drama" at a recent meeting where Ramona turned "off her device" to demonstrate how the dystonia distorted her pre-surgery and then turned it back on to return to "normal", all with a hand-held "clicker".

Kellie, who at one time was tapped as our Advocate, is the other DSG member who's living with Dystonia better with DBS.

Clay's mother, Becky, from Texarkana, TX attends all the DSG meetings she can given the distance involved. Becky recently wrote:

"The support group has meant the world to Clay and to me. The first meeting I attended was the first time I'd ever met another person affected by dystonia. Thanks again for all that DSG does."

Mike provided lots of important information about Dystonia, although at the present time DBS does not work on Dysphonia patients. After his formal presentation, Mike stayed for some time talking to individuals and groups about their particular situation, health-care specialists, etc.



If you haven't checked our web-site recently, please do so...www.dystonia-alabama.org . Our web-master, Trish, has made several changes, including consolidating what was Brad's Page into an entire "link" on Deep Brain Stimulation surgery.

Now that we're going to "tell stories" on some of our members, we'll go to smaller print! Ha! Some of these are funny ---- others are frightening ----

Sister "K" of Cullman has emailed DSG saying she's no longer able to make the trip from Cullman to attend meetings. She wants to remain "active", will distribute Library Bookmarks in Cullman county again, but just can not physically attend meetings.

Evelyn, also of Cullman, who's a regular, loyal attendee at meetings fell in late December alone in her home, laid on the floor for 24 hours before someone found her, and is now thankfully recuperating. Evelyn, we've got to have you back in attendance! One can't imagine the emotional impact of such an experience!!!! Our thoughts and prayers are with you, as expressed in the card we all signed at Sat's meeting and Pat mailed to you.

Teri of Montgomery has finally recovered from her "episode from a Botox injection gone awry" and was at our last meeting using a walker instead of a wheelchair. Terri, I can't imagine 8 months of using a feeding tube and will never understand why "bad things happen to good people". As most of you know, Terri supports her own Dystonia Foundation at Beth-Israel Hospital in New York after raising large sums of money in Montgomery several years ago for that purpose. She also supports DSG, DMRF and is a major donor to our Alabama Dystonia Scholars program! Thanks Terri for all that you do for "others"!

Amy of Birmingham recently went to a Voice Clinic in Florida seeking an alternative to the less-than-successful Botox injections many of us with Dystonia continue to experience. Amy is trying to recruit the founder of the Voice Clinic to speak to our group...probably in April '09 when she'll be visiting relatives in Birmingham.

Tim from Headland recently took a bad fall at home, splitting a gash in his head that bled profusely, and was rushed to the hospital for an MRI. No reason for the fall was found to be connected to his dystonia of the legs. When his wife, Virginia, told me of his mishap I remarked that Tim had given a new meaning to the word "head land".

Now for the story of a really loyal member. Tim was so determined to come to the February meeting even though he could not drive, so he recruited a willing wife, Virginia, into arising at 4 a.m. for the long drive from Headland (near Dothan) to B'ham so they'd be in time for the meeting. The only problem was Virginia and he drove to B'ham on Saturday, February 14th --- a week prior to the regular meeting. Virginia was so made at herself when they drove into the Lakeshore parking lot, but Tim just laughed at her and they went shopping in B'ham at Academy Sports, one of their favorite stores which they don't have in Headland.

Sequel to this story is they were first to arrive at Sat's meeting on the correct date, so they didn't have to do any shopping.

Betty of Alex City was unable to attend the Jan or Feb meetings because of problems associated with her Botox injections at Emory in Atlanta. She was due to return to Emory for further treatment recently and I haven't had a reply to my email inquiring as to her status.

Myrtis of Birmingham just had another round of Botox injections for her Dysphonia...as did Mary Ann. Mary Ann's doing very, very well w/her Botox injections. I asked her the secret and she reports that only one vocal cord is injected, something she found by trial and error with Dr. Waguspack of St. Vincents.

Your editor flew to Baylor/Houston for my regular 4 month round of massive Botox injections in my neck and jaw.....on a recent Tuesday.....then drove to Emory in Atlanta on Thursday for my vocal cord injections. My success hasn't been good with treating the Dysphonia, but Botox has saved my quality of life from Cervical & Oromandibular Dystonia. This time I had Emory reduce the Botox dosage to 1.25 units split 50% in each vocal cord compared to the 1.25 I was receiving in each vocal cord. Contrast this to the 300 Botox units I get in my neck muscles and 50 units in my jaw to give you some idea how small the vocal cord muscle really is. Even at this lower dosage in my vocal cord I've experienced some mild swallowing problems, especially drinking water.

GENERALLY, WE HAD A "GREAT MEETING" ALBEIT ATTENDANCE WASN'T WORTH THE TIME OUR SPEAKER TOOK TO DRIVE FROM ATLANTA TO SPEAK TO US. Those attending were glad they came!

NEXT MEETING --- SATURDAY, 10 AM, MARCH 21st.

I'm still awaiting a speakers commitment and have two "in the works", either one of whom will present a great program. More details later.

REMINDER: *Membership dues are due.*

Dick Darden has taken over the Treasurer's role from me and has mailed invoices to those not paying for 2009. We need your support! And you need DSG, but it is what you make it!!!!

Ken Williams, Volunteer Director
Dystonia Support Group of AL/B'ham