

## September 19 Meeting Report – Dystonia Support Group - Birmingham

James and his wife drove from DeFuniak Springs, FL.  
Tim & Virginia drove from Headland, AL (near Dothan).  
New member, Chrissi and her husband drove from the Dothan area.

**Our scheduled speaker, Sandra Kibler from Allergan (mfr of BOTOX), dispatched her husband to deliver refreshments but could not be the speaker 'cause she came down suddenly with the flu.**



When I went to Lakeshore Rehab hospital Friday nite to "set-up" for the meeting, I found the meeting room already set up for nurses continuing education which ran Friday thru Saturday. Somehow they overlooked the "double booking" as DSGA has the "Classroom" reserved for the 3rd Saturday of each month except June & November. But "panic" quickly led to "taking the easy way" when I summoned the night supervisor who offered to relocate their Saturday teaching session to the "cafeteria" if (?) she could get in touch with the Director of Nursing, who didn't answer her phone.


**I decided it best for we, as non-paying guests" of HealthSouth/Lakeshore, volunteer to have our meeting in the cafeteria & eliminate the problem...since I knew Sandy didn't need the power point presentation equipment only located in the classroom. So my helper and I set up the Dystonia Display, rearranged the cafeteria tables & chairs to accommodate our Sat morning meeting.**

 **Mary Ann Culotta** stood in for **Pat Wyatt** as Meeting Chair, since Pat's not only recuperating from shoulder surgery, but her 92 year old mother was just operated on for a broken arm that required a pin and her husband **Bill** is still recuperating from his latest bout with cancer.

After the typical exchange of "who had what treatments lately"....and "how did they perform", we went straight to a business meeting ---- the initial plan to open the meeting. Directors (Awareness, Leadership, Support & Treasurer) have been working w/Tim & Virginia (Virginia, by the way is also recovering from shoulder surgery) on establishing a SATELLITE SUPPORT GROUP to meet each month on a non-conflicting date because S/E Alabama has many, many DSG members & other dystonia patients who simply won't do what Tim & Virginia do to drive 4 hours or more each way to attend DSG's regular meeting. In fact, one of our "more generous" financial contributors lives in Geneva, AL and has never attended a meeting due to the transportation problem.


***The idea of a "satellite" operation meeting in Dothan, AL was widely distributed to members in my meeting invitation and RSVP request....with no stated objections. We had DMRF's approval prior to the "directors" voting! So here's the results:***

  We "approved" a name change from DSG of B'ham to **DYSTONIA SUPPORT GROUP OF ALABAMA**. (There is an informal group in Mobile who meets once annually but otherwise we have members from throughout the state (and TN, GA, FL & TX as well))

 We elected two new Co-Directors of OUTREACH...previously unfilled. **Tim Hornsby & Mrs. Chrissi Brannon** were nominated & elected with authority to establish & operate a satellite support group for S/E Alabama & the FLA Panhandle dystonia patients. Their email address is: [dothandystoniasupportgroup@gmail.com](mailto:dothandystoniasupportgroup@gmail.com) .

They will meet monthly in Dothan, **except they'll pick 3 regular B'ham meetings when we have prominent speakers** (defined as having national or regional impact on DYSTONIA plus 1 of DSGA's B'ham social's for which a 12 or 15 passenger van will be rented so they can meet at a central location & van-pool to the meeting joining all of us for whom B'ham is a more central meeting spot not requiring 4-6 hours of car travel each way for a 2 hour meeting.


Anyone joining the "satellite" must pay the regular DSGA membership dues and be as active as the choose in fund raising for medical research and DSGA "operations". **WE WILL BE ONE ORGANIZATIONAL SUPPORT GROUP UNDER DMRF'S CHARTER & "Umbrella of Tax Exempt status, Public Liability, Auto Non-Ownership or Hired Car Liability, Employers Liability, Fidelity Bond & Umbrella excess Liability insurance....for which we hold Certificates of Insurance that protects every volunteer while on DSGA projects.**

 Clay Burns, the young man from Texarkana, TX who's mother has attended many DSGA meetings and Clay has attended several, goes back into UAB for "new" DBS surgery 9/30/09.


After initially getting good results, they've had a continuing saga of "adjustments" and now have decided the implant is too deep into the brain. So-o-o-o, Clay has had a "taste" of being able to walk and drive a car so he's agreed to a "new DBS" surgery with intent to place the implant in a different location of the brain...despite all the risks surgery always involves; i.e. excess bleeding in the brain, infection, etc. Keep Clay, his mother Becky, father and a sister (*who also attended a meeting doing a paper at Samford*) in your prayers. For up-to-date info on Clay's saga go to


<http://www.caringbridge.org/visit/clayburns>


and read all the past postings and watch for the new ones post 9/30's operation.

 Evelyn is home from the hospital & rehab but is still recovering. You'll recall she fell some time ago, was not found for 24 hours, then hospitalized and into rehab. We miss you Evelyn. To top it off, the person that drives her to & from meetings is also ill.

 Long-time member Rosemary who lost her husband many months ago and has no other family in the area is entering an Assisted Living Facility in Mississippi nearer some relatives. We'll miss you Rosemary.

 Long-time member Myrtis was unable to attend Sat's meeting because in her words "her back's just worn out". We pray she'll get proper treatments and return as a regular attendee. We miss you!

 DSG has been invited to give a presentation to the Sylacauga Rotary Club. Dick Darden, our director/treasurer has accepted the assignment and will utilized our "canned" overhead projector presentation we used at some 12 other Rotary Clubs by various volunteer members.

 I spent yesterday afternoon driving to Columbiana and setting up DSGA's DISPLAY BOOTH with hand-out materials conveniently placed for pick-up at the Shelby County Fair which begins this evening and runs all week. Last year, Pat arranged for the space and had volunteers help her "man" the booth. Due to Pat being a homebound care-giver for her mother, she and I decided this year just to reserve the space and set the booth up to be "unmanned". I'll go back next Sunday afternoon to disassemble it and recover whatever materials haven't been picked up or otherwise is missing.

😊 **Sandy Kibler**, our member who's an Allergan rep and was unable to give her presentation at last Sat's meeting, reports she's relieved to find she just has a stomach illness and not the flu or the swine flu which she first feared. Hopefully, we can give her at least 15 minutes of our October 17th meeting to give a "condensed" presentation. Our regular speaker will be **DICK DARDEN** who will give a "book report" on the new book **LIVING WITH DYSTONIA**. I'll send out a meeting notice the 2nd week in October as a reminder.

😊 We still have only 1 answer to the 6 Fund Raiser proposals I sent out to corporation and foundations who've donated to DMRF's Medical Research Fund in prior years. So far, only the 1 rejection I reported in the last bulletin...but no money either. I don't know whether that's "good news or bad news".

**Ken L. Williams, Volunteer Director**

**Dystonia Support Group of Alabama  
Chptr of DMRF**