

August 15 Meeting Report



We had a GREAT meeting. 23 members attended. Yuqing Li, PhD at UAB who's a Dystonia researcher and one of his graduate assistants put on the program and handled Q & A.

Dr. Li and his UAB research staff has a Medical Research grant from DMRF, among others. One of the projects they're working on is testing the chemicals successfully used by The Worm Shack at Univ of AL Biology Dep't using mammals (mice) to duplicate successful results of Drs Guy & Kim Caldwell's lab with their worms. This newly discovered chemical combination of existing generic drugs has already been licensed by the Univ of AL Biology Dep't to QX Pharma of Australia where its in Stage 1 and 2 research.

Dr. Li and his staff also are using Artane in mice. They induce dystonia in the mice using human cells....then administer Artane....to gauge results. We all know the side effects of Artane and this research is dedicated to trying to improve the results w/o the accompanying side effects.

They had slide presentations "in motion" showing the mice w/dystonia trying to walk across a "small bridge" and falling off ---- which was funny to watch ---- but not so funny when we consider the affect Dystonia has on human's!!!!

THANK YOU, DR. LI.



The audience was "very much into" the presentation and soaked up information like a sponge, asking great questions and getting answers where available.

Ramona from Huntsville brought her adopted Chinese-born daughter, Kathryn, who speaks Mandarin (as does Dr. Li) and her adopted son, Shawn, who's considering the medical research field when he graduates.



DSG member Sandy Kibler who's the N.AL rep for Allergan (mfgr of Botox A) will speak to our group at the September 19th meeting. She has loads of information on "new toxin's" like Botox to share with us. Sandy also has Dystonia and she has a passion for helping dystonia patients. We're fortunate to have an Allergan rep in our midst. Sandy also "knows" area doctors!!!!

It's still being confirmed, but Dick Darden, our treasurer, will give a book report on a new book THE DYSTONIA PATIENT just off the press. *(This is tentatively scheduled, unless when he finishes the book Dick thinks there's sufficient information to consume an entire meeting in which case we'll schedule Dick for the October meeting).*



Tim & Virginia of Headland, AL held a Dystonia Support Group meeting in Dothan for SE Alabama dystonia patients who simply can't drive 4 hours each way to attend DSG meetings regularly. They had 8 patients and 12 family members attend the informal get-together....which is an indicator of how much of a "desert" the Dothan area within a 75 mile radius has been for dystonia patients. Tim said "They soaked up information like a sponge".

Tim inquired about DSG setting up a satellite group who would meet probably every 2 months and 3 times annually would rent a van to bring area members to attend a B'ham DSG meeting. I've worked matters out with DMRF to rename us **Dystonia Support Group of Alabama** with permission to operate a satellite group by DSGA naming Tim

and one other SE AL member a **Director of Outreach**, which empowers them to operate under the corporate umbrella of DMRF just as we do; i.e. tax exemption status, a corporate charter, availability of necessary personal liability, auto liability, employers liability and employee fidelity insurance...all of which is required in today's liability & tax climates.

That way DSGA becomes a state-wide organization, can have local meetings in SE Alabama on a scheduled basis yet give everyone an opportunity to attend the DSGA meetings in Birmingham at least 3 times annually by providing transportation facilities for the 4 hour each way trip. Tim & Virginia are already doing great **awareness & support** work in the area and now DSGA can broaden our horizon's to serve even more dystonia patients and their families. We already have a member in Ft. Walton, FL, one in Samson, AL and one in Geneva, AL who are "members" but can't attend meetings due to the distance & lack of transportation....now we'll have even more thanks to Tim & Virginia's grass roots efforts.



Please go to <http://www.caringbridge.org/visit/clayburns> (Just click on this link) and get updates on the trials and tribulations of Clay Burns with his DBS surgery and now his dysphonia problems. Clay and his parents (you all know Becky of Texarkana, TX who's been a DSG supporter from the beginning) are in Birmingham now where Clay is scheduled for further procedures and possible new surgery. We all should keep them in our prayers! And you can post a personal note by signing the guest book on the Caring Bridge web-site.

Thanks for reading! For those who missed this meeting, please try to attend future meetings and show gratitude for these speakers we recruit to give of their Saturday to keep us informed and current on Dystonia and treatments therefore.

If you haven't sent Dick Darden your SUPPORT GROUP PROFILE & THERAPEUTIC HISTORY, or you've lost your copy, email me and I'll send you another. The more information we can collect on doctors treating dystonia, types of treatments, types of dystonia suffered by each member, etc. the better we'll be able to serve you.

**Ken L. Williams, Volunteer Director
Dystonia Support Group of Alabama**