

Dystonia Support Group - Alabama August Regular Meeting News

GOOD NEWS! Under the strong leadership of Rebecca Sharp & her co-chair Chrissi Brannon, everything is coming into place for the upcoming DMRF DYSTANCE4DYSTONIA 5k RUN & 1k WALK.

The Date: 8:00 am, Saturday, October 9, 2010 in Dothan, AL. The Hornsby's are working with several nearby motels for a group discount for those of us who will be traveling to help work or take part in what is DSGA'S MAJOR FUND RAISING EVENT of 2010....as well as our MAJOR DYSTONIA AWARENESS project.

Allergen donated \$2,500 and is the Official Sponsor.

Medtronics is funding \$1,200 for beverages, refreshments, & other such needs for the volunteer workers and for the event participants.

A number of S/E Alabama businesses, several DSGA individual members & family friends have made cash donations in amounts ranging from \$250 to \$1,000.

DMRF is to be applauded for the design & production work on the printed materials, registration packet for sponsor's & runners/walkers. They have been of major assistance to Rebecca & Chrissi and will continue to offer assistance until the event is completed.

If you wish to donate, offer to work at the event or anyone wishes to register as a runner or walker, it's not too late. Email me for registration forms that Rebecca has provided or contact her direct at rsharp@centurylink.net

REPORT ON D.S.G.A. MEETING HELD IN B'HAM SATURDAY, AUGUST 21, 2010

Since I did not attend due to a last minute reaction to pain medication I'd taken for a pulled muscle in my neck, I'll defer with THANKS to the report made by Nell of Geneva, AL who's been a long time DSGA supporter & member but unable to attend B'ham meetings until the SE Satellite Group was formed. Nell rode from Geneva to B'ham with Tim & Virginia Hornsby.

*In her words: **"This was the best, most informative program I have ever attended on Dystonia, and well worth the 8 hours of travel"**.*

Dr. Erwin B. Montgomery, Jr., M.D. - Division of Movement Disorder Center at UAB was MOST informative during his slide presentation as well as the following Q&A period. Dr. Montgomery spoke generally about his training & research. He was recruited to UAB by Dr. Standaert (whom we all know is establishing a first-class Movement Disorder Center, including research on dystonia). Dr. Montgomery's research focuses on understanding how the brain controls movements and what goes wrong when a person develops Dystonia. His clinical practice focuses on neurological and psychiatric disorders. He is the recipient of the Dr. Sigmund Rosen Scholar of Neurology Award and has been involved in this effort for 30 years.

Dr. Montgomery was accompanied by Tom Brannon, Director of Development, Strategic Planning and community relations. Mr. Brannon distributed his personal contact cards from the Dep't of Neurology and assisted in the Q&A period.

There were 26 persons in attendance and interest/attention was great as evidenced by the fact the Q&A period went so long the meeting did not adjourn until 12:40 pm (instead of noon).

Details of Dr. Montgomery's comments as understood by me were:

- 1. There is some difficulty recognizing Dystonia from X-Rays. The Dystonia patients brain appears normal on the X-Ray unlike the Parkinson patients brain which shows the deterioration of the brain cells.**
- 2. There seems to be multiple "causes", albeit we have yet to definitively determine the cause(s).**
- 3. Certain oral medications help some forms of Dystonia.**
- 4. Dystonia seems to run in families and Dr. Standaert was one researcher that identified the DYT1 gene which is now the focus of much research.**
- 5. Dystonia could be an accident of nature.**
- 6. Many studies have resulted in a few therapies now used in treatment. Among the therapies are Deep Brain Stimulation (DBS) and Botox toxin injections. A number of "off label" medications are sometimes prescribed. This means a medication designed for something else is used as a trial and should be under the careful supervision of a knowledgeable medical practitioner who carefully monitors the experiment.**
- 7. DBS is ONE of the most promising treatments for Dystonia. The treatment is reasonably safe, 97-98% effective with only 2-3% having any difficulty with the procedure. Compared to BOTOX injections which are 70-80% effective in improvement of the condition leaving 20-30% of dystonia patients who aren't helped by such treatments. Also, 4% of Botox patients develop an immunity to the injections. The injections must be made in the right dosage and in the exact spot in the muscle(s) that spasm. This requires a great deal of training, experience & knowledge by the medical practitioner.**
- 8. There is no known cause of Dystonia, however, neuroleptics may develop dystonia from some medications like Reglan, for example. Statins may also be the cause of muscle spasms resulting in pseudodystonia.**
- 9. Physical Therapy & Exercise are important in treating dystonia as it keeps joints loose & limber.**
- 10. Stephanie Guthrie is a nurse practitioner at UAB who can put people together to share their experiences, which (of course) is something DSGA also provides.**

Dr. Montgomery spoke generally and specifically about his training and research. He stated that UAB, post Dr. Standaert's arrival, now has a number of people involved in research projects. He referred to his group as a "team" and believes sharing of information between and among members of the medical practitioner and research group is critical to the achievement of good results. There are more than a dozen highly skilled and experienced professionals now at UAB who are involved in treatment and research of Dystonia and other neurological movement disorders.

Refreshments were provided by Mary Ann Culotta and Janice Hawkins. As stated, the meeting did not adjourn until 12:40 pm and was well worth my 8 hours of travel to attend.

Pat Wyatt chaired the meeting.

Editor's comments: Nell was chairman of the Geneva Library System and one of the first libraries to participate in DSGA's long running program of distributing Dystonia Awareness bookmarks through Alabama public libraries. Nell has also been a generous donor of money, especially in individuals within DSGA raising \$10,000 every year for 5 years straight to fund the Alabama Dystonia Scholars program. Albeit not an official DSGA project (since monies flowing thru DSGA must go to DMRF which do not earmark specific funds in Medical Research but leaves this to their official committee), the Alabama Dystonia Scholars program has been important to Alabama dystonia medical research efforts. Incidentally, we do not have the funds for the summer of 2011 as yet so do invite volunteers like Nell to participate NOW. Personally, I'd like to expand this program to include undergraduate students at UAB working in the Dystonia Research lab's full-time during summer when school is not ongoing. The program currently only involves research at THE WORM SHACK at the University of Alabama in Tuscaloosa, and most of you have met the great young men & women who are or have been recipients of the award.

Such donations should be made by check to the University of Alabama Biology Dep't under their tax exempt ID, which I would provide.

Hope to see you at the September meeting....and also in Dothan for the DYSTANCE4DYSTONIA event October 9th.

IN DEFERENCE TO THE DOTHAN EVENT ON 10/09/10, DSGA WILL NOT HAVE A MEETING THE FOLLOWING SATURDAY, SO AFTER THE SEPTEMBER MEETING & THE DOTHAN EVENT, OUR NEXT MEETING WILL BE OUR HOLIDAY SOCIAL ON SATURDAY, DECEMBER 18TH AT 10:30 AM.

Ken Williams, Volunteer Director
Dystonia Support Group of Alabama
Chptr of DMRF