

**DSG-ALABAMA  
BIRMINGHAM CHAPTER**

**February 2010 Newsletter**

If you missed the DSGA meeting, Saturday, Feb 20th, it's just too bad!!!

Dr. Harrison C. Walker, one of the key neurologists at UAB's "new" MOVEMENT DISORDER CENTER, was our guest speaker. My email to him below is NUF SAID.

*THANK YOU DR. WALKER. Your presentation to our Feb 20th meeting was not only very interesting & informative, but your willingness to sit there for 1 1/2 hours and "just chat" with our members gave many the opportunity of a life-time.*

*If they didn't come away from that meeting feeling the "medical community" REALLY CARES about Dystonia patients, families & care-givers, they must have had plugs in their ears!!!!*

*Thank you again.*

*Ken L. Williams, Volunteer Director – DSGA*

The DYSTONIA SYMPOSIUM titled THE SUN RISES ON DYSTONIA PATIENTS was postponed from April 20, 2010, to a later date. Despite having a "nationally known cadre of speakers" representing all forms of DYSTONIA, but we had a hotel selected, contracts ready to sign w/the hotel, people coming from DMRF & NSDA hdqtrs, 6 different "break-out" sessions so you could talk "face to face" with the specialists in small groups of 10-15 each session.....but we were short on our fund raising efforts.....and we did not want to charge registrants a registration fee.

Bottom line was despite money committed from DMRF, Allergan, Medtronics + several individuals willing to donate a 4 figure amount, our budget had a serious short-fall between INCOME and PROJECTED EXPENSES.

Next time I'll find a "corporate sponsor"...someone like Blue Cross/Blue Shield or any good Corporate Citizen. This is why all sports, even the Super Bowl and big golf matches, all have Corporate Sponsor's to fund required guarantee's if attendance doesn't live up to estimates.

All is not lost, as we now have "great speakers" for the next 5 regular meetings which you'll hear about at the proper time.

**NEXT MEETING - Saturday, March 20, 2010..... I "know"...it's the middle of Spring Break at schools but not all of our members have children in school or are connected to an educational institution so won't be "at the beach". MORE INFO LATER.**

- A. Dr. David G. Standaert (head of UAB's major entry into the movement disorder field) announced a \$1.5 Million grant from NIH for a 5 yr study to fully research dystonia. UAB will partner with Harvard Medical & Mt. Sinai in the study.
- B. UAB announced it now treats about 300 dystonia patients at the Division of Movement Disorders.
- C. The TODAY SHOW reported on a life Deep Brain Stimulation surgery. Dr.

Snyderman, an NBC Health Editor, led the report. You can catch it "live" on:  
msnbc.com.Video/Player#35215311

D. WE MOVE completed a patient research project. Learn all about patient-physical relationship, satisfaction with overall health, understanding of the disorders and their most challenging symptoms, management options, medication side effects & much more...all from the patient's point of view>

[www.wemove.org/survey/WEMOVE\\_Dystonia\\_Research\\_Report\\_2009.pdf](http://www.wemove.org/survey/WEMOVE_Dystonia_Research_Report_2009.pdf)

I ordered a full copy of the Study Report titled UNDERSTANDING DYSTONIA and will mail you one if you can't locate the above internet link.

Next big DSGA project.....concentrate on "health & wellness programs" for dystonia patients + "Living & Coping with Dystonia" for families especially. The closest psychiatrist/psychologist I could find for the Symposium was in Toronto....

FINALLY.....Something must be done about "specialist's protectionism"; i.e.

- \* Only neurologists will treat Cervical Dystonia.
- \* If you have Blepharospasm, you have to see an ophthalmologist.
- \* If you have Dysphonia, you have to see an ENT/Otolaryngologist
- \* If you have Generalized Dystonia.....????????????????????

MAIL IN YOUR \$35 DUES TO Richard Darden, Treasurer  
Sunbelt Properties, Inc.  
2 Office Park Circle - Ste 1  
Birmingham, AL 35223

Til next time!

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