

**DSG-ALABAMA
BIRMINGHAM CHAPTER
MARCH NEWS**

Other News:

These days, deadlock in Congress seems to be dominating the political headlines. However, there is one issue area where Members of Congress have shown some signs of "working together" to create meaningful progress by bolstering dystonia research.

The National Institutes of Health (NIH), the nation's foremost leader in federally supported medical research, is hosting a robust dystonia research effort via several projects. But...this funding will only come from "the wheel's that squeak the loudest" which is why ADVOCACY with your elected officials in Congress about Dystonia research funding is so important. The 2010 Dystonia Advocacy Day in Washington, DC has been set for May 4th and 5th at the St. Gregory Hotel in Washington, DC. This two-day event brings dystonia affected individuals from across the country together on Capital Hill to educate legislators about Dystonia and enlist congressional support behind add'l research funding. DMRF is the driving force behind the Dystonia Advocacy Coalition, a network of several national movement disorder organizations all with one common cause.

Dr. Li, the lead researcher at UAB's movement disorder center, is our April 17th meeting speaker. He'll talk more about the \$1.5 Million NIH Grant UAB rec'd to participate in a research project with Harvard Medical College and Mt. Sinai Medical Centers. Dr. Standaert got the grant.

Drs. Guy & Kim Caldwell of THE WORM SHACK (dystonia research center at Univ of AL-Tuscaloosa so-called because they use "glow worms" who have a 17 day life span as their experimental subject" are co-publishers of a Research Article published by The Company of Biologists. The article describes how "glow worms" make such good research subjects because (a) the biologist can see thru the whole body and (b) their life span is so short that they can actually view 3 or more generations at one time (grandpa, father & son or grandma, mother & daughter) to see the progression of their research so quickly. Remarkably, humans share some 34 of the gene's found in glow worms.

The "Worm Shack" is where our Alabama Dystonia Scholars work thru summer months on scholarships paid for by a handful of DSGA "donor's" for summers of 2007, 2008, 2009 & 2010. IF YOU WOULD LIKE TO BE A DONOR TO THE \$10,000 TOTAL WE COLLECTIVELY GIVE EACH YEAR, LET ME KNOW AS WE NEED TO BEGIN ON 2011 FUNDING SHORTLY.

Thanks to a "Community Grant" Sandy Kibler helped me apply for from Allergan in the amount of \$750, + matching donations from Tim & Virginia Hornsby and myself, WE WILL PRESENT TO TIM & VIRGINIA OF THE SE SATELLITE GROUP AN EXACT REPLICA OF OUR "TABLE-TOP DISPLAY" COMPLETE WITH DUPLICATION OF ALL THE SIGNS AND A CARRYING BAG at the March 20th meeting. The SE Satellite Group will use this for displays at local fairs, civic club gatherings, etc.all in the interest of RAISING AWARENESS ABOUT DYSTONIA....just like we've made good use of ours for the past 4 years.

We managed this w/o any funding by DSGA or the use of any of your membership dues & other donations to DSGA.

DSGA on the other hand is going to have to fund the purchase of an LCD projector so our speakers can use their laptop's to make power-point presentations to us. Our February speaker (Dr. Harrison was able to borrow one from Sandy Kibler) and our March, April & May speakers have all requested we provide one. They rent for \$125 and we can purchase one for something

south of \$600, so it doesn't make sense to rent. 4 of the 6 DSGA directors have already approved the expenditure and I'm going shopping tomorrow "on line" so we'll have one by Sat March 20th.

DON'T FORGET.....R.S.V.P. about attending the March 20th meeting to Klwmgw@aol.com.....yea or nay! We owe good attendance to our invited speakers less it become difficult to recruit "good" speakers like we've had.

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