

January 2009 DSG-Alabama Newsletter

YES, IT'S A "NEW YEAR", but we've still got the same problems with lack of a known cause of DYSTONIA and lack of a "cure". We remain thankful that treatments are available, however temporary, invasive or resulting in mixed results and frustration. Research progress is "slow" but moving forward. With the NIH reducing funding for Dystonia Research, 2009 will be challenging to continue many "research projects".

Much remains to be done in **AWARENESS** ---- DSG does more than most support groups but "ignorance about Dystonia is still bliss" across the Alabama medical community and patient audience.

DSG has accomplished much in the way of **SUPPORT**. Hardly a week goes by that we don't receive an inquiry from some poor soul who has been misdiagnosed, is receiving improper medical treatment, **THINKS THEY'RE THE ONLY PERSON IN THE WORLD WITH THIS MYSTICAL DISEASE**, or is seeking information about movement disorder specialists. We typically exchange multiple emails with these suffering souls..some become members but most get their information and we never hear from them again. That's OK, too, 'cause we're trying to help ONE PERSON AT A TIME.

Fund raising for **Medical Research** (or just normal DSG operating costs - It costs \$4.80 postage now to send a New Member Kit) has become more difficult than ever. We met our budget last year...barely....but it was mostly Dick Darden's influence with a local Foundation who donated \$8,000 that got us out of a hole.

Only 30 of our 71 listed members paid DSG dues last year, but we keep everyone on the distribution list and have "comp'd" some who just can't afford the \$35. Even DMRF has challenged their membership for everyone to pledge to raise or give \$1 per day - \$365 for the year. With a tight economy & a losing financial market, money is more than "tight", albeit we managed to meet our budgets last year and ended the year with a few dollars more than we began.

3 members donated \$10,000 for the 2009 Alabama Dystonia Scholars program at the Univ of AL which is handled "outside official DSG

financials" because DMRF will not earmark Medical Research donations. So, these monies don't show up on DSG's records as the donations were made directly to the Univ of AL Biology Dept (The Worm Shack). It would be nice if we could support the undergraduate students at UAB who are working summers on Dystonia research, but I've been unable to raise monies from foundations, corporations or individuals to do so. I'm sorry, but I tried my best!

Having said all the above, my own advancing years, health problems and the fact I've "tapped out most of my contacts" makes it necessary that I resign as DSG Treasurer. DICK DARDEN has volunteered to take over this role beginning with the January 2009 meeting.

I'll still function as "Volunteer Director" but will focus on the business functions; i.e. member communications, newsletters, arranging speakers (need help) and answering the poor souls who feel like they're all alone with this thing called Dystonia.

NEXT MEETING - 10 am - Sat January 19th

**HealthSouth/Lakeshore Rehab Hospital - 2nd floor classroom
Off Lakeshore Drive between I-65 and Hwy 31**

We have two (2) great speakers. It's been a long time since our last formal meeting (altho the Holiday Social had good attendance & great fellowship) so its time to reintroduce yourself to fellow members, many of whom are "new" since you last attended a meeting.

Dick Darden will lead the meeting and introduce the speakers. (Dick - I'll get you their bio's).

May 2009 be a blessed year for you and yours.

**Ken L. Williams
Dystonia Support Group of AL/Bham**