

**DSG-ALABAMA
BIRMINGHAM CHAPTER
January 2010 Newsletter**

This is the coldest January I've experienced since leaving Iowa for Alabama in 1951. It's especially difficult for dystonia patients who suffer from the byproducts of the disorder.....distorted spine, head posture, limbs, etc.

Many DSGA people were traveling, including our leader Pat Wyatt who was at the American Legion Conference with Bill, Mary Ann who was traveling with her brothers, and yours truly who "planned" to spend our usual 3 weeks in January in the sun & surf of the Caribbean but encountered the aftermath of the Haiti earthquakes that spawned large waves & turbulent seas 300 miles away as well as aftershocks (the whole Caribbean is a cluster of volcanic upheavals sitting on a "fault line") and returned "home" early.

Despite this and the freezing weather, Dick Darden conducted the regular January 16th meeting with a fair attendance and "excellent feedback" on his presentation. It's noteworthy to report attendee's included Tim & Virginia who drove all the way from Headland, Betty & OJ from Alex City and Teri from Montgomery among others.

One of DSGA's MISSIONS is AWARENESS --- something we spend a lot of money & energy on (may I cite LIBRARY BOOKMARKS, presentations at CIVIC CLUBS, the annual GOV'S PROCLAMATION OF "Alabama Dystonia Awareness Week" in June, the large numbers of our membership who'd never seen a Dystonia patient before attending a DSGA meeting, etc?).

But with spread of the internet and emergence of Blog's, Facebook, Twitter, etc. etc., there's so much news about Dystonia every day that unfortunately has contributed to much misinformation. None-the-less, the word DYSTONIA is being spread all over the globe.

I'm signed up for Google Alerts so every day I get an email from Google giving me "links" wherever the word DYSTONIA appears. About 1 out of 10 is worth reading.

There are some interesting web-sites you may wish to check out:

<http://twitter.com/beatdystonia>

<http://community.wegohealth.com/group/dystonia>(A forum on Dystonia Movement Disorders)

<http://www.lifewithdystonia.com/>

The Inside Edition TV news magazine airing the story of the Washington Redskins Cheerleader who claimed to get Dystonia from the H1N1 flu shot was one of the "hottest" piece of news in terms of how many readers responded. (Turned out she was "cured" in a couple of weeks). My favorite was the woman who wrote: "No one knows the cause of Dystonia. I got pregnant after I kissed my husband. Does that mean that kissing got me pregnant?"

My point is: Regardless of what is printed or posted or whatever they call it on the blog sites, the mere fact that they mention DYSTONIA as a neurological movement disorder is spreading awareness.

THE DYSTONIA COALITION - Not to be confused with the Dystonia Advocacy Coalition or DAC - is a recently formed collaboration of scientists, institutions and organizations recently formed to advance the pace of clinical research of dystonia.

DMRF, of course, is very active in this "new coalition" which has been successful in obtaining an NIH grant of sizeable amounts and over a period of years.

We've invited Jan Teller, Chief Science Officer of DMRF to speak to our March 20th regular meeting on THE COALITION and what it means to you, an individual living/coping with Dystonia every day of your life. **MARK THIS MEETING DATE ON YOUR CALENDAR NOW!!!!!!** DMRF is flying him all the way from Chicago just for our meeting, and we can only continue to draw this kind of speaker attention if we put bodies in seats at the meeting.

NEXT DSGA MEETING - Saturday, 10 a.m., February 20th.

Two potential speakers awaiting confirmation:

Dr. Harrison Walker - neurosurgeon at UAB who's spoke to us before and who's been influential in cutting thru some of the red-tape at UAB in getting patient appointments.

or

Dr. H .A. Jinnah, MD, PhD who was recruited by Emory from Johns Hopkins in Baltimore where he ran the Dystonia Clinic and was medical advisor to the Baltimore Dystonia Support Group. Dr. Jinnah runs a very active dystonia research program at Emory.

The Blepharospasm Support Group in Huntsville, with support from lots of doctors treating Bleph, puts on an annual SYMPOSIUM --- an all-day affair dealing with Bleph. It's very successful.

I believe DSGA is ready to take on a similar task. I've started the wheels turning by opening dialogue with the director of community relations at UAB on supporting DSGA in such an undertaking. Watch for further info but tentatively mark Saturday, April 17th on your calendar. That's a regular meeting date, BUT IT JUST MAY BECOME AN ALL-DAY SYMPOSIUM.

Program plans are:

Morning session - At least 3 doctors/researchers making formal presentations in addition to a KEY NOTE SPEAKER kicking off the symposium.

Afternoon breakout sessions - MEET THE DOCTOR - During which you will have the chance to meet in small groups with individual doctors and a choice of at least 4 different breakout sessions.

Of course, refreshments and a formal luncheon will be included. DMRF has agreed to publicize this SYMPOSIUM throughout the Southeast. DSGA members will be admitted FREE as part of your membership. Non-members will be asked to make at least a \$50 donation to DSGA. Both Allergan and Medtronic's have been asked to financially support the undertaking.

HOPE alone won't make this become a reality....but PRAYER and lots of hard work will!!!!!!

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