

DYSTANCE4DYSTONIA EVENT - Oct 2010 DSGA newsletter

Rebecca Sharp, daughter of Tim & Virginia Hornsby definitely deserves a reward as DSGA MEMBER OF 2010 for her leadership, perserverance and hard work as lead co-chair in the 5k run & 1k walk event held last Saturday, October 9th, in Dothan.

The event attracted 60 runners and walkers (including 1 in a wheelchair), raised something like \$10,000 for DMRF Medical Research and increased "awareness" about Dystonia throughout SE Alabama, SW Georgia & NW Florida.

In addition to "kudo's" for Rebecca, I can't say enough about all of the work, time and effort put into this event by many of the SE Satellite Group members, including co-chair Chrissi Brannon.

DSGA B'ham representatives included Pat & Bill Wyatt, Sandy Kibler and myself. Rebecca Sharp, her husband, Tim & Virgina Hornsby, Pat & Bill and myself were at the kick-off point of the event at 5 am Saturday morning setting up registration tents, display booths, food tables, water stations and mapping the chosen route in advance of the beginning of registration at 7am and the run beginning at 8 am. Several even "prepped" on Friday afternoon.

Allergan (Breck Barlow of SE AI and Sandy Kibler of B'ham" was the major sponsor with a \$2,500 donation and Mike Tapley of Medtronics donated \$1,500 for food, supplies, etc. In addition there were many donations from \$100 to \$1,500 by DSGA members in both the B'ham & Dothan groups and, of course, the registration fees of the runners & walkers.

Lissa Salvatierra of DMRF deserves "kudo's" for the assistance she gave to Rebecca in planning and pulling off the successful event following DMRF's template, which was followed by many Support Groups throughout the USA.

Please click on the link to view the slideshow: [DISTANCE4DYSTONIA](#)

If anyone has trouble opening the albums, Sandy will send the pics as simple jpegs. She's already looking forward to next year.

Sandy also "created" a FACEBOOK page for DSGA on the internet. If you are already in "Facebook", click on "groups" and type in DYSTONIA SUPPORT GROUP OF ALABAMA to be listed therein as a DSGA member. If you are not on FACEBOOK, you are invited to set up your "page" today by going to www.facebook.com and follow the simple registration instructions....no charge...and as part of our AWARENESS effort we need exposure on FACEBOOK.

DMRF is already on line at the following web-sites. You can gain useful information about Dystonia on those connections:

www.dystonia-foundation.org
twitter.com/dmrf
myspace.com/thedmrf
www.youtube.com/user/cemiwire
facebook.com(keyword: dystonia friend)
the.dmrf.ning.com

Nat'l Spasmodic Torticollis Ass'n was instrumental in publishing a book: LIVING WELL WITH DYSTONIA - A PATIENT GUIDE. Mike Tapley of Medtronic's is looking into the possibility of a group purchase of the book for distribution to all DSGA members to share with their families. I've read the book and found it

quite interesting and very insightful to the struggles of living with dystonia in all of its many forms. MORE NEWS ON THIS LATER!

Dick Darden, DSGA's treasurer, has been in conversations with Dr. David Standaert, Yuqing Li and Mike Ford at the behest of Tom Brannon, UAB'S Public Relations Director, about Tom's idea of pursuing an on-site seminar showcasing the movement & neurology center at UAB. The plan is to show facilities at 7th Avenue South Sparks Center and at Spain Rehab Center. Making these buildings and doctors available probably calls for a Friday afternoon session instead of one of our regular Saturday morning monthly meetings.

Dick Darden has volunteered to host a finger-food buffet and cocktail event following the tour and UAB's on-site presentations. It'll be like spending a half day with a Dystonia doctor...and not have to get an appointment, wait or get 5 minutes attention.

All of DSGA's directors voted in favor of the plan. Now its up to the DSGA members as to how many would attend such an event. I know the date is still undecided, but "first" we need to know the extent of the interest among membership. Please RSVP me as to your "interest" in attending such a UAB event depending of course on the date selected when the facilities and doctors would be made available for a "DSGA Tour". RSVP to Klwmgw@aol.com now!

Janet Heishetter, Ex Director of DMRF, has asked me to enlist the support of DSGA members in contacting their Senators and members of Congress as well as the key committee members of the Department of Defense's research funding. Dystonia was one of the medical conditions DOD included their funding last year for military personnel, and several of the medical centers we use for our Dystonia treatments benefited in 2010 from such research grants. For ease of providing sample draft letters & instructions on who to contact, I'm forwarding separately Janet's email to me.

Please participate in this ADVOCACY program. Your member of Congress could be the tipping point in extending such Dystonia Research funding by DOD through 2011 & beyond.

A reminder that DSGA combines its Nov-Dec meetings into a Holiday Social scheduled for 11:00 am, Saturday, December 4. This change in meeting dates avoids conflicts with Thanksgiving & Christmas. The turkey & ham will be donated...all you have to do is bring a covered dish and your family members to the event.

I'm working diligently on a schedule of topics and speakers for 2011 beginning with the January 2011 meeting. If anyone has any suggestions, please share same by email to Klwmgw@aol.com.

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