

May Meeting News

Question: When was the last time you had the opportunity to sit down with a movement disorder specialist for an hour and 45 minutes just discussing dystonia, the pro's and con's of certain medications, treatments including physical therapy, and get answers to whatever personal questions about the "disease" you have?

Answer: At the DSG meeting Saturday, May 16th between 10:15 am & Noon when Dr. Harrison Walker of UAB's who's passionate about treating dystonia and other neurological movement disorders and shows it.

No slide show --- no power-point presentation with difficult to understand medical terminology --- just a "sit down and talk" session shooting "straight from the hip" about Dystonia, treatments, medications pro's and con's...even physical therapy.

Dr. Harrison Walker was appointed Assistant Professor in the Division of Movement Disorders on July 1, 2008. Ironically, he completed his medical internship with the Baptist Health System in 2002 and his neurology residency at UAB from 2003-2006 and attended UAB School of Medicine from 1997-2002 where he participated in the Howard Hughes Medical Institute/National Institutes of Health Research Scholars Program.

He says his most rewarding work is in Deep Brain Stimulation (DBS) surgery. UAB now completes 2 DBS surgeries a week. He took part in the surgeries of our own Ramona, Brad and Clay.

Ramona, as you will recall, put on a dramatic presentation for those at a recent DSG meeting when she voluntarily turned off --- and then back on --- her Medtronic transmitter implant. *What a dramatic experience we all shared thanks to Ramona!*

When Dr. Walker talked about "dopamine" and it's many functions in the brain, how dopaminergic neurons can cause Parkinson's disease, adversely affect Dystonia & other movement disorders, at requests from the audience he named (and spelled) a litany of medications that adversely affect the dopamine in our neurological systems.

Evelyn, our loyal member from Cullman had 2 guests who were "awed" by the presentation, and who promptly emailed me: "*Ken. The Meeting was GREAT. Thanks for the work you do in lining up speakers that helps us all!*"

While appreciated, Evelyn, let me assure you my "thanks" comes from the good attendance we had at Dr. Walker's "sit-down discussion" which was better than all the slide shows & power-point formal presentations we've had. You filled every seat at 6 tables I'd set up for the meeting.

Thank you, Dr. Harrison Walker.

Teri came from Montgomery, Tim & Virginia drove all the way from Headland (Dothan), Brad came from Tuscaloosa, Josephine & her husband from Gadsden, Ramona & her husband from Huntsville, and Evelyn w/her 2 guests from Cullman....plus the Hawkins' from Pinson, the Wyatt's from Harpersville, while B'ham metro DSG members were in the minority.

Brenda was a little late arriving due to an auto accident she had on the drive to the meeting, but was "not injured" ...and, as Brenda said: "The car can be repaired".

Awareness update:

We hope all of you were able to watch (live or recorded) the Oprah Show when she featured Dr. Oz with 2 guests - Michael J. Fox who has Parkinson's and a young woman from Los Angeles who has dystonia.

I thought the young woman's appearance on THE TODAY SHOW gave a lot better presentation on dystonia than did Oprah's, but Michael J. Fox knows how to look at the TV camera's and command attention...even dominate the "scene".

Did any of you catch Michael Huebner's Birmingham News article March 22 about musician Leon Fleisher's new CD and his coping with focal dystonia? You can catch the article by going to:
http://blog.al.com/mhuebner/2009/03/leon_fleisher_edds_offer_glimps.html

Finally, on our own Awareness Project ---- Our leader, Pat Wyatt, again obtained a proclamation signed by Governor Riley for **ALABAMA DYSTONIA AWARENESS WEEK** the first week in June '09.



As part of this state-wide Dystonia Awareness program we reprinted 50,000 Dystonia Bookmarks, purchased another 250 counter-top literature holders and to-date have delivered, shipped or mailed bookmark kits to over 170 Alabama Public Libraries, and 12 Community College libraries. **But there's more to do. If the library in your town or county does not have the Lit Holder/Bookmark display, ask them if they'll participate, notify me as to whom I should contact and I'll either mail the supplies to you for delivery or mail direct to the library for display. The same goes for Community College libraries in your area!!!!**

Another link for you to click on and print an article about "Chronic Pain in Living With Dystonia:

http://www.aolhealth.com/condition-center/chronic-pain/feature/_a/living-with-dystonia/2009041317

Just "click on the link" and GO. Very interesting to share with others!

I'd mail you a copy but DSG has spent over \$1,800 on printing, lit holders & mailing Library Bookmarks so our "postage budget is shot". Hint: Yes, if you'd like to donate please mail a check to our Treasurer, Dick Darden, 2 Office Park Circle, Suite 1, Birmingham, AL 35223.

Thanks to Sister "K" for distributing library kits to Cullman County libraries, Tim & Virginia for handling much of S/E Alabama - Barbour, Coffee, Covington, Crenshaw, Dale & Pike counties, Josefine for Etowah County, Kim Lowe for Calhoun County, Pat for Shelby County, Janet for Elmore, Lee, Talladega & Tallapoosa Counties, Nell for Geneva County and I was able to directly contact and utilize the "central courier services" for 40 Jefferson County, 10 Baldwin County, 3 Houston County, 12 Madison County, 8 Mobile County & 11 Montgomery County libraries.

Still looking for help with 7 Walker County, 7 St. Clair County and we have absolutely no distribution for NW or NE Alabama. BUT YOU CAN HELP. JUST CHECK YOUR LOCAL LIBRARY - IF THE LIT HOLDER/W BOOKMARKS ISN'T SET UP, ASK THEM ABOUT DOING IT. DOESN'T COST THEM A THING AND IT'S A SERVICE TO THEIR PATRON'S....AND TO DYSTONIA PATIENTS EVERYWHERE.

Ken Williams