

MEETING NEWSLETTER - SEPT 2007

DYSTONIA SUPPORT GROUP OF ALABAMA

When Alabama and Auburn are both playing football at home, most everything else stands still. Given that, we still had 15 attend the regular Sep't 2007 DSG meeting Saturday, 9/15/07.

In addition to our speaker, I also introduced a guest, Emily Burns, daughter of member Becky of Texarkana, TX who's not only attended several DSG meetings but who has been a "great" fund-raiser for us. Emily's brother, Clay, who came to one meeting has Generalized Dystonia. Emily is a senior Pharmacy Student at Samford and is writing a paper on Dystonia which she hopes to present at an upcoming Chicago meeting and then get published in Medical Journal's. *Emily will be back in January or February '08 as she has a survey we will urge all DSG members to complete as part of her project!*

Trish reported on her successful Dystonia Awareness presentation to Rotary Clubs of Homewood/Oxmoor (45 attended) and Vestavia (96 attended). I also mentioned Kim who spoke 9/13th at the Rotary Club of Gadsden (25 attended), traveling all the way from Pell City to represent DSG. Linda had already spoken to Alabaster-Pelham Rotary.

Mary Ann mentioned her volunteering to "work" the DSG Display Booth at the Shelby County Fair (*even though she's not from Shelby County*) which runs 9/17 thru 9/22 in Columbiana. Ken & Rita had their truck loaded by Ken after the meeting with the Display Booth, my wife's fold-out buffet table, a card table & 2 chairs which they transported from the meeting to Columbiana (alho they live in Pell City *which is St. Clair County*) and set up the display Saturday afternoon. Pat, Director of Awareness, arranged for the display space and is "in charge" of the display & having people there to bring awareness to patrons of the Shelby County Fair. **VOLUNTEER.**

NEXT UP ---- The loyal Cullman "group of 3" volunteered to have the Display Booth at an upcoming Health Fair. As soon as I get the booth materials back from Columbiana, I will deliver it to Evelyn and Betty in Cullman. *The BOOTH has been a great investment and probably one of our more productive Awareness efforts.*

Speaking of "DSG investments", in addition to the overhead projector & portable screen used in the Rotary presentations (& hopefully many, many more), I got an "in" at Long's Electronics and purchased a wireless microphone & amplifier for 50% of retail costs. It got a good first workout at Saturday's meeting.

PATIENCE IS A VIRTUE...

except when dealing with government officials. That was the message that came thru loud & clear from Kellie Ellison, Alabama Legislative Coordinator, our speaker from PAN -- the Parkinson's Action Network in Washington, D.C. Kellie, who lives in B'ham with her 16 year old "ordained minister" son, 13 year old daughter and an

adopted now 2-yr old baby and husband, has undergone 2 DBS surgical procedures for Parkinson's and Dystonia (she has both). She's heading for a 3rd surgery soon as the 2nd was --- "can I say BOTCHED?"

PAN, with offices in Washington, DC, works "eyeball to eyeball" with elected officials on pending legislation.....*such as the horrible proposals (1) by CMS to reduce the reimbursement by Medicare/Medicaid for BOTOX, (2) refuse to pay for EMG's used to find the proper place to inject Botox into muscles and (3) force hospitals to "bundle" all charges related to one injection session into one figure.*

We all know what that will do IF the proposal passes --- whatever Medicare & Medicaid do in reimbursement schedules is almost immediately followed by all doctors & hospitals for non-Medicare or Medicaid patients. It will only force more doctors to "quit" giving Botox injections and with non-payment of the EMG machine to guide them to the proper site of injection they may as well shoot the toxin in the needle up in the air for all the good it will do.

BY THE WAY --- How many of you wrote CMS and/or your legislators prior to 9/14th deadline as requested in the Email Alert I sent to each of you???????

Kellie very clearly explained how a "unified legislative front" must be presented for Dystonia patients, just like PAN is doing for Parkinson's.

EDITORS NOTE: When I inquired of DMRF why they did not have a "point & click" link on their web-site for members to use as a quick & simple way to send a message to CMS or legislators, the response was....we're budgeting for doing that in 2008. DUH???????

It's very clear we have a splintered approach to Advocacy among the many Dystonia organizations, albeit efforts are being made to change this w/formation of the new Dystonia Advocacy Coalition which DMRF, NSTA, NSDA, Torticollis/Dystonia, Care4Dystonia, Bleph Ass'n, Musician's w/Dystonia Ass'n, and on and on...*but there are a lot of ego's there to "salve" before I expect them to put forth a "united front".*

My new project is producing an ADVOCACY DIRECTIONS KIT for all members helping you "make your voice heard" in Washington and in Montgomery. Question #1 - Will you use it? YOU HAVE AN OBLIGATION TO MAKE YOURSELF HEARD. Silence isn't Golden!

Kellie also described what was involved between PAN, the Michael J. Fox Foundation, and others in getting an \$8.5 million NIH grant which recruited Dr. Standaert from Harvard to UAB to form & be Director of the CENTER FOR NEURODEGENERATION & EXPERIMENTAL THERAPEUTIC'S at UAB. FYI - Dr. Standaert will speak to a DSG meeting in March 2008. But, mark my word...if it had not been for PAN & the Michael J. Fox Foundation, Dr. Standaert would be at Emory in Atlanta instead of UAB in Birmingham.

FOUNDATION FUND RAISING PROJECT:

I prepared 12 different Grant Applications and sent to local Foundations for receipt prior

to Sept 1st (the deadline for 2007 funding). So far, Protective Life Foundation turned us down (they gave \$10,000 in 2005), THE CARING FOUNDATION of Blue Cross/Blue Shield of AL sent a \$1,000 DMRF check, and EBSCO Industries, Inc. sent a \$1,000 DSG check.

I have good vibes from the Daniel Foundation and the Drummond Companies, but as we've discovered in 2005 & 2006, this Foundation Grant Application business is almost a

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Lottery and we have to be grateful for whatever we receive. DSG's given it's budgeted amount to NSDA and NSTA, but only \$4,650 of the \$10,000 pledged to DMRF research.

CLEANING UP LOOSE ENDS:



The Caldwell Research Lab Fund - When I challenged 8 of my friends that I would "match" their collective donations (See Aug Newsletter for details), they mailed DSG checks totaling \$2,350 + another promised \$150 later, so what I had intended as a \$2,000 minimum personal donation has become \$2,500. The total of \$4,850 + DSG members sent \$1,000, \$100, \$100 and \$50 in response to the Aug newsletter, and \$500 pledge from an anonymous donor totals \$6,600 raised to-date toward our \$10,000 goal.

I'm maxed out so PLEASE HELP BY WRITING LETTERS LIKE KEN'S SAMPLE IN THE August newsletter. Look - Collectively you only have to raise \$3,400 and we've hit our \$10,000 goal to pay summer salaries of 3 undergraduate Univ of AL students working in *The Worm Shack*. *A bus trip to visit the Caldwell Lab next June is already scheduled!*

NO OCTOBER MEETING - Cancelled on account of FOOTBALL:

Due to Linda's involvement in a special flu vaccine research study in Sept & Oct, and the conflicts with many members going to football games in this period, Linda asked me to announce that the October meeting is cancelled.

HOLIDAY LUNCHEON:

The November-December meetings as usual are combined in a Holiday Social to be held the first Saturday in December. Please mark it on your calendar, get yourself there and bring your family & friends. For the last 2 years, it's been a SPECIAL EVENT.

Unfortunately, I'll be out-of-the country so that's one less mouth to feed and I won't be there to bug you about fund raising....???

GRATEFULNESS E-CARD:

The left-over refreshments I brought to the Sept meeting were donated to the Benedictine Sisters of Sacred Heart Monastery. Sister K.C. surprised me with a Gratefulness e-card saying.....Thanks for all that you do and thank you too for the yummy goodies that you sent our way after Saturday's meeting.

"Sister K.C., you mean so much to all of us and we are blessed to have you in our midst."

UPCOMING SPEAKERS:

January 19, 2008 - Still awaiting confirmation of a speaker.

February 16, 2008 - Thanks for Mary Ann Culotta, Dr. Waguespack and his speech therapist, Dan Thomas, from St. Vincent's will be our speakers.

March 15, 2008 - Thanks to DMRF, Dr. David G. Standaert, MD, PhD the Director of the newly created "movement disorder treatment & research center" will be our speaker and tell us all the things he's already accomplished at UAB and what's on the horizon.

*LET ME BE THE FIRST TO WISH YOU & YOURS A BLESSED HOLIDAY SEASON
AND A HEALTHY, HAPPY & FRUITFUL NEW YEAR. Ken L. Williams, Treas.*