

Newsletter

Dystonia Support Group-Birmingham, AL Chapter

February 18, 2006

Quote: *The day you become silent about matters, then those matters no longer matter-do they?*

Dr. Martin Luther King

There were 21 present at our February meeting. Those in attendance were: Ken Williams, Pat & Bill, Josephine, Sherryl, Francine & Gerald, Rosemary, Don, Mariellan, Brenda & Vincent, Jennifer & Shelby, & Linda & Jay Mott.

THOSE THAT WERE MISSED

Susie

Ricky, Jane, Brad & Paige

Trish

Mary Ann

Brenda

Mike & Susan

Susan

Virginia

Joyce

Don

Sandy & Randy

Janice & Steve

We extend our deepest sympathy to the Burch & McBrayer families in the death of loved ones last week. Please remember Sandy as she goes to Vanderbilt Voice Clinic on 02/22/06. We also hope that Betty & Susie feel better soon.

ACKNOWLEDGEMENT of NEW MEMBERS and SPECIAL GUESTS

1. We welcomed *Janet* from Auburn who brought her mother *Grace*. Grace has suffered from ASD since 1997.
2. *Judy* referred by Kathleen, who is responsible for our wonderful meeting facility. Judy has been diagnosed with essential tremor but there is a possibility that she has been misdiagnosed & may have generalized Dystonia.
3. *Susan* accompanied her Dad, Don Susan attended the first meeting on 03/21/05 at the food court in Brookwood Mall.
4. *Becky* from Texarkana, TX. was a special guest. Becky's son Clay is 27 years old & has generalized Dystonia & Spasmodic Dysphonia. He developed GD when he was 11. This was the first time Becky had met others with Dystonia. I think she felt as we all did the first time we attended a support group meeting, relief to meet others & hear their stories. She was kind enough to share Clay's story with us & the roller coaster ride they have been on.

IN THE NEWS

Jennifer has volunteered to work with Mary Ann on AWARENESS. She contacted the Cullman County Public Library System for us & got the name of someone willing to deliver

bookmarks to the 9 libraries located there & Ken has mailed them. Jennifer made the statement, *"I can be an advocate for the group and for myself."* **GREAT work Jennifer!**

I spoke with Lindsay at Governor Riley's office and have mailed a letter & information for a proclamation declaring June 4th thru 11th **National Dystonia Awareness Week** for our state.

WHERE IS THE SPEAKER???

I apologize for Dr. Goynes not speaking to us. I wasn't notified that she would not be in attendance.

We had an informative round table discussion with good interaction between all members.

DISCUSSED

- Local doctors vs. out of state doctors
- Neurologists vs. Movement Disorder Specialists
- Medications & side effects
- Procedure for Botox for SD at Vanderbilt Health Clinic & Baylor in Houston explained to us by Francine & Ken
- Frustration of lack of awareness regarding Dystonia and MISDIAGNOSIS for many of us
- 2 perspective NEW members contacted by Pat Wyatt
- REMEMBER the result you receive from Botox depends on the correct dosage & the correct muscles being injected. Ken reminded us all that we will NOT get better with one treatment; it can take 1 to 2 years
- Frustration of dealing with Medicare

Kindly mark your calendars for 03/18/06 when Dr. LeDoux will be joining us again. Please bring your informed consents & medical records if you wish to participate in the research study.

YOU DON'T WANT TO MISS THIS!!!

DMRF chose 3 support groups for a special meeting & we are fortunate enough to be one of them. This is in part due to our accomplishments as a "New Group." Peter Cohen a 41 year old attorney from Maine will be speaking to us on **04/15/06 at 10AM**. Peter has a remarkable story to share with us. At the age of 11 he developed generalized Dystonia. He used to eat lying on his side & also was married while lying on his side... to be continued by Peter.

We want to **FILL THE ROOM** at this meeting so feel free to bring family & friends. This is an amazing story for anyone to hear. Does your treating physician want to hear about DBS surgery, ask them?

Thanks to Ken for providing our refreshments.

There are still a few of you that have not paid your \$5 membership dues to help with costs for this Newsletter, New Member Kits, postage etc. The postage for a New Member Kit to be mailed is \$2.25. I kindly ask that you pay in order for us to continue to help others.