

Dystonia Support Group - B'ham, AL Chapter
August 19, 2006

Guest Speaker : Mary Bifaro
Special Guest : Pat Bifaro, Mary's husband

Mary has suffered from spasmodic dysphonia since 1987, it entered her life abruptly as it has many of us. It took her 2 years to receive a diagnosis. She has been involved with the SDSG of Charlotte, NC since 1989 and in 1999 she accepted the leadership position. She has served on the National Spasmodic Dysphonia Association Board since the fall of 2003. She serves in the role of support which she stated is where her heart and passion are.

As I told those of you at the meeting, Mary encouraged me, guided me, was and continues to be my mentor and was very instrumental in me forming the DSG of B'ham, AL..

A perfect example of Mary's dedication and unselfishness was her offer to make a six hour trip to speak to our group. What courage, determination and compassion we saw as she told us of her personal struggle with SD and the IMPORTANCE of research. As I observed members arriving I noticed how Mary introduced herself to each of you and how receptive she was to speak with you and answer your questions. We could all see what a struggle it was for her to speak and at times how her words faltered, but she "carried on." What a wonderful example she sets for all of us with SD.

She provided us with a handout of what NSDA is doing toward research, and stressed that NSDA relies on us, its members for fundraising. The NSDA has one full-time staff member. The NSDA is committed to advancing the science of SD in order to improve the lives of SD patients. and continues to develop relationships with physicians and researchers who are interested in SD research. I want to encourage you to join NSDA for \$40 a year, the funding goes toward research and you will receive a quarterly Newsletter. We will "carry on."

IN ATTENDANCE

We had 37 members, family and friends present.

Pat & Bill
Sherryl
Francine & Gerald
Melinda & Joe Keith
Ken & Maxine Williams

**Joyce
Betty & Don
Mary Ann
Paige & Brad
Ricky
Mariellan
Sherry
Brenda & Vincent
Betty & her friend, Jane**

(I consider Jane a member, she has attended 2 or 3 meetings & worked the health fair at Brookwood Mall. She is committed to raising awareness for all of us with SD)

**Becky
Linda & Jay Mott**

SPECIAL GUESTS And New Members

Evelyn - cervical dystonia

Betty - Evelyn's friend

Christy (SD) & Robbie

(Christy has been a member for over a year but this was her first Meeting, they are from Moss Pointe, MS)

Clay

(Clay has generalized dystonia, & is Becky's son. This was his FIRST DSG meeting & they are from Texarkana, TX.)

Pat (cervical dystonia) & Charles

Kim (spasmodic dysphonia) & Blake

Dave (cervical dystonia) & Sewanee

Kellie (Parkinson's & Dystonia)

I want to personally welcome each of you and look forward to seeing you at future meetings.

YOU WERE MISSED

Nancy - prior commitment

Susie

Jane - trip to Gatlinburg with her Mother

Trisha Crain - son's birthday

Jennifer & Shelby

Susan - Susan had GD & it is difficult for her to make the trip from MS

Dennis & Mary

Virginia - prior commitment

Rosemary - brother visiting from out of town

Kellie - Kellie has not been feeling well, please pray for her

Sandy & Randy

Grace & Janet

Judy
Susan & Mike - attended a wedding
Josephine - prior commitment
Don
Janice & Steve

You were missed & hope to see you in September.

IN THE NEWS

Ken has completed his annual project for the month of August, Foundation Fund Raising. He has applied for 17 grants, made personal phone calls, delivered some grant applications by hand and once again put in many hours to reach our goal of \$30,000. Last year we raised \$15,000 & Ken is very optimistic that we will meet our goal of \$30,000. We have already received \$1000 from Blue Cross who donated \$500 last year. This is a ONE MAN operation and I am very grateful to Ken for his dedication. He states it is “ a labor of love “ for him. As he said his computer is “smoking” and I for one think he deserves some R & R. What we do now is wait and pray .

Kellie was nominated and appointed as Director of Advocacy at the August meeting but officially resigned on 08/28/06. I want to thank all members for your encouragement & understanding, apparently there was some misunderstanding between Kellie & me. She asked for possible, partial funding to DC for the Patient Summit sponsored by WeMove in September. I told her we personally pay for any meetings, symposiums we attend & she was upset & took this as a “personal attack on me.” I apologized & asked her to reconsider to no avail. As you know we need our money to operate the group & for the awareness campaigns we participate in. Kellie stated she would continue her important advocacy work for Parkinson’s but made the decision not to be a member of DSG.

Melinda will be visiting Adderholt’s office in Gadsden to tell them about the DSG and to see if anyone could attend a meeting in 2007. Becky & Clay may attend the Patient Summit on 09/18/06 & represent our group.

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Ken has made his annual trip to Staples for supplies and was able to get our folders at a discount of \$.49 each, the manger gave us 2 reams of paper also. These are used for New Member Kits and Awareness Kits. We can all go to our local Staples or Awl-Mart & ask for donations of supplies for the group, paper, ink cartridges, folders, staples, etc.

Dr. Diane Counce is a neurologist in the office where I work and she asked for Awareness Kits to give to her dystonia patients, she will also be speaking to us in 2007.

I am writing an article for Alabama Nurse on Dystonia. This could be huge in raising awareness since the nurse is the first clinical person you see when you

go to a doctor & there are MANY nurses who have never heard the word dystonia.

I want to thank Sherryl for the handouts she provided us with of news articles that were dystonia related.

Special thanks to all of you that provided our delicious refreshments.

Donations/Dues

Betty - \$20 donation

Joyce - \$35 dues/donation

Evelyn - \$35 dues/donation

*Thanks to each of you, this provides us operating funds to reach our goals of
:SUPPORT, AWARENESS & RESEARCH FUNDS.*

Our next meeting is Saturday, 09/16 /06 at 10AM. Kindly mark your calendars now. There will not be a speaker at this meeting. We have 15 new members since January of 2006 so we are going to have a round table discussion & get to know each other better.

Congradualtions to Paige & Brad on their marriage and the pending birth of their baby!!

Thanks to my dear friend Mary for sharing her story & struggle with SD, to her husband Pat for driving her to Birmingham & being so supportive of her. They toured Vulcan Park while here & I received a note from Mary stating she was not prepared for the wonderful welcome she received from the DSG of Birmingham.

“What great members you have Linda.”

I am very much aware of that and appreciate each & everyone of you.

*God bless,
Linda*