

FEBRUARY 2007 NEWSLETTER

Speaker: Ricky, Brad's father

The Dystonia Support Group/Alabama Chapter met on 02/17/07 with 24 present. Those attending were, Ken, Pat and Bill, Trish, Betty and O.J., Mike and Susan, Rita and Ken, Stacy, Evelyn, Wynelle, Francine, Kim, Blake and Jack, Teri, Bettye, Ricky and Jane, Hannah, and Linda and Jay.

The meeting was opened with prayer with special requests for Rosemary's husband, Pete and the Huffs.

YOU WERE MISSED

We had several members that were not able to attend.

Sherryl – death of a family friend

Joyce- death of a relative

Mary Ann –OOT

Rosemary- family illness (for info visit web site www.dytonia-alabama.org)

Don & Betty – illness (see web site)

Virginia – prior commitment

Dave & Sewanee- prior commitment

Gerald – work

All members not attending were missed and we hope to see you in March.

WELCOME

We had four people in attendance that we want to extend a special welcome to.

Teri – most of you had heard Teri's name mentioned or read it in previous Newsletters. She has been a member of the DSG since 2005 and has generously supported our goals of support, awareness and funds for research for a cause and cure but had never attended a meeting. That changed yesterday. I told Teri I felt, as I knew her since we have corresponded for almost two years. What a pleasure and a joy to finally meet her! I think I speak for all of us when I say the group was not only inspired by her attendance but also energized. Teri we hope to see you at many more meetings.

Bettye – accompanied Teri. It was a pleasure to have you join us and to talk with you. We hope to see you again soon.

Hannah – is Brad's grandmother and has been with us before. She stated that since Brad couldn't attend she was there to support him. You are always welcome.

Wynelle – is a friend of Evelyn's. She told me after the meeting how much it had meant to her to be there. She also told me she had never heard of Dystonia and she learned from

us. Thank you for your donation to help us in our efforts to make dystonia a household word. Wynelle took "What Is Dystonia" pamphlets to place in her church. Thank you and we hope you will join us again.

WEBSITE UPDATE

Trish gave an update of our website. We had a total of 315 visits for February as of Saturday with "Brad's Page" being the most visited page. A Member Submissions page will be added to share our writings, which can remain anonymous if you so choose. We will also have business cards with our web site address provided by Sherryl for us to get the word out.

AWARENESS

"Alone we are hopeless but together we are hopeful", Pat stated. We were planning a parade for Dystonia awareness week in June but the Antique Car Club isn't willing to sponsor or work with us. Pat said that is why it is so important that each member take every opportunity to raise awareness. She had placed bookmarks in a pharmacy close to her home and handed them to everyone attending the American Legion Convention. Pat's Mother had been hospitalized for the past two weeks and Pat had noticed that the pastor sounded as if he had SD. He arrived in the room one day and Pat's Mother said, "Pat wants to ask you something." We all got a good laugh out of that. He told them he had spasmodic dysphonia and Pat told him about the support group. She also told us how the Burch's place bookmarks in their monthly statements to customers.

A DVD of the movie "Twisted" was purchased by the DSG and Ken encouraged members to show it to church or civic groups, garden clubs, etc. Email Ken if you wish to take advantage of this and the DVD will be sent fed ex to you.

DUES

We ask that you pay dues of \$35 only if you can afford to do so. We realize that each individual circumstance is different. As discussed the money is used for supplies: copy paper, ink cartridges, postage, folders, internet access, labor for printing bookmarks, (which are placed in 119 libraries in AL) etc. We provide "New Member Packets which we feel are helpful for anyone newly diagnosed with dystonia or anyone finding there is a DSG in AL. We are a pro-active group in reaching our goals of support, awareness and funds for research for a cause and a cure. The dues and donations are used to help us be successful in this venture.

IN THE NEWS

I was contacted by the Birmingham News two weeks ago and told that I had been nominated for "Good Work." I was interviewed and my picture was taken on 02/08/06. The picture and article was in the Sunday paper on 02/11/06." I didn't want anyone else

with this disease to go through the things I experienced alone” which is the primary reason I founded the group. Ken provided copies at the meeting. I had told several that the picture was huge and my article was edited and didn't have all the info I had wanted printed. Ken told us Saturday that an ad in the paper cost approximately \$3000. I had family from as far south as Mobile and Marengo County notify me they had seen it. All week I received emails, calls and comments from members, friends, co-workers and patients so this article was a blessing for us and it was FREE. My friend Mary, the SD group leader for Charlotte, NC emailed it to NSDA.

Our group will be acknowledged by DMRF in their 2006 annual report for our hard work and success. We should all be very proud of this and hope that we can encourage someone to start a group in their community or encourage other groups to work harder.

IN THE WORDS OF A FATHER

Brad missed his first meeting Saturday. His Father Ricky was our speaker. Brad was 15 years old when he developed cervical dystonia. He was an avid golfer, out going and had a wonderful personality. Ricky stated that as the CD worsened he saw Brad change. He was in constant pain and experienced the fatigue that accompanies dystonia. He was made fun of by people that don't know better and he became self-conscious. I remember the stares, rude remarks as I'm sure most of you do, but I know it must be much more difficult at 15 than at 23 or 40.

Botox didn't work for Brad and his posture became worse. After hearing Peter Cohen speak to us last April, and much research Brad decided with input from his family to have deep brain stimulation surgery, which was performed on 01/31/07 at UAB. Ricky became emotional several times as he spoke to us. He said they were asked to leave the room and when they returned Brad's head was in the halo. His family waited for six hours while he was in surgery, and 2 days as he was in NICU. “Every human needs to spend 24 hours in the NICU waiting room”, Ricky said. As serious as Brad's surgery was they observed worse cases. The family business was closed for three days. When the stimulators were turned on Thursday 02/15/07 Ricky was there. “Brad is 22 and I have been with him since the beginning and will be with him till the end.”

Ricky said this was a tough thing to go through but then he thinks of the thousands of people that live with dystonia everyday and how tough that is. He said Peter Cohen inspired Brad and he wants to speak and be an advocate for all of us battling dystonia. I have already seen Brad accomplish this, at the healthfair last spring, he does it in his job everyday and I see him doing even more in the future. Ricky said he had thanked his daughter in-law Paige for being there for Brad. He said Brad had CD when they met but it didn't bother Paige, she loved Brad and they have a beautiful baby daughter, Emily. The love and support in this family should be an inspiration to us all. They are committed to reaching our goals of support, awareness and raising funds for a cause and a cure.

As I looked around the room I saw many of you wiping away tears, I was doing the same thing. Thank you Ricky for sharing your story.

The meeting was closed with prayer asking specifically that Brad receive the results we all hope for.

We then socialized and enjoyed delicious refreshments provided by Pat and Bill. Bill is quite the cook!

Please join us in March when Stephanie the local Allergan (make Botox) rep will be our guest speaker. **Wear your green. It is St. Patrick's Day!** We will also be celebrating DSG's second birthday.

Thank you for your continued support in making our group a success. I tell all new members, my family and friend's what a special group we are. We love each other as family and I think that was very evident Saturday. You could not only feel it in the air but also see it everywhere you looked. Hugs, kisses, what a true blessing all of you are in my life!

Linda