

Theme: **BACK TO BASICS**

The DSG of Alabama met on 01/20/07 with 15 in attendance, Pat, Bill, Sherryl, Brenda, Vincent, Paige, Emily, Brad, Jane, Ricky, Trish, Jay and Linda.

Special Welcome

I want to extend a special welcome to our newest members Rita and her husband, Ken. Rita suffers from writer's cramp and was misdiagnosed for many years. Josefine, she is looking forward to meeting and speaking with you in February. Rita is our first member to find the **DSG** through our new web site. Her friend Helen found the website and referred Rita. Thank you Helen and please join us for a meeting.

You Were Missed

All of you who had prior commitments, were out of town, had to work, or have family illnesses were missed and we hope to see you in February.

Special Prayer

As all of you know we start each meeting with prayer. We had special prayer for Brad, his family, and his doctors. Brad is scheduled for deep brain stimulation surgery on 01/31/07 at UAB hospital.

I had received a call from Rosemary stating that her husband Pete is not doing well and requesting that we lift him in prayer. Pete suffers from cancer. We lifted them in prayer and ask that you continue to do so in the days ahead. Rosemary you were missed, give our best to Pete.

Website

Trish updated us on web site visits and we are averaging nine to eleven per day. We hope to see this number increase in the future. The most common viewed pages are: ***Upcoming Events, Join Us and Newsletters***. Rita's husband, Ken suggested that we provide our doctors with the web site address to provide to their dystonia patients. We agreed as a group this is an excellent idea. I feel it important that local doctors know Alabama **has a support group and a web site.** I had emailed it to Dr. LeDoux and when I saw him on 12/01/06 he told me he thought it was great and that Trish had done a good job.

Care4Dystonia which is Beka Serdan's site has a link to our website. This is a great networking opportunity. The VA hospitals, your place of business, a friend that perhaps has a business with a website. A great way to raise awareness and reach more people with dystonia.

Trish asks that all members contact her with suggestions of how to improve the web site.

AWARENESS

Pat told us she received a great response from the State Board of Directors for Veterans Affairs. She provided them with the letter to watch "**Twisted**" and a bookmark. The director stated he would post this on the Veteran Affairs website. A lady that was attending a meeting of twenty-five also took the information with her. There was a man in attendance who spoke about his friend that suffers from cervical dystonia that was passing the information on to her and was excited to find out there is a support group in Alabama.

Pat also stated that she had a good response from the council meeting of homemakers. She said they were very interested in learning more about dystonia and one couple stated they would record "**Twisted.**"

We discussed raising awareness and **we all do it in our own way.** There is not one of us with dystonia that doesn't raise awareness. The Burche's do it everyday in their business, Sherryl does it everyday by passing out bookmarks and telling others about her battle with dysphonia, I tell my patients and business associates, etc. The fact is we all do it.

We agreed to have one big awareness campaign a year.

Ricky stated he was disappointed that the "*Ride and Run for Dystonia*" did not happen in 2006 but it will happen. He is disappointed more than any other member. There were personal circumstances that prevented this and it is a big undertaking for any one of us. We need to remember it was Ricky's effort and idea that started our Books- A- Million campaign in which our bookmarks are displayed by the cash register in many Books-A-Million stores in Alabama. This includes some cities in Texas, thanks to Becky's effort.

We have to realize that as important as the DSG is to us, we all have other priorities and obligations. Whether it be full-time jobs, family, aging parents, church, school or personal adversities, this is life and reality. We all must make a conscious effort to be respectful of each other. I have not done this in the past but after some confidential emails and conversations I realize I am not the only one with problems.

We are still a "new group" and I am very proud of each of you and what you have accomplished in raising awareness in your own individual way. I think we all agree what we do have is time and I am excited about our commitment to continue to fulfill our goal of raising awareness.

Apology

I apologized to those in attendance and want to extend that apology to those of

you that could not attend. I know from emails and conversations that many of you have felt pressured to raise awareness, money, and take positions. The fun of attending meetings got lost along the way, many felt there was too much business and not enough support. I also know that many of you have lost interest in the group for this or perhaps other reasons. I take full responsibility for this and I am sorry. I assure you there will be **no more pressure**.

Meetings

I've always shared my thoughts with you and will continue to do so. As some of you may know I was thinking about not conducting monthly meetings anymore. This has been very difficult for me and I have continued to pray for guidance since July. In the beginning I prayed that God let me know if starting this group was His will for my life and He did.

Rita made a comment yesterday, " I am so glad to know I am not alone." Brad stated that the monthly meetings were what sustained and encouraged him, Ricky stated that being able to be with the group, which is family to him is so important, Sherryl said, "We volunteer and do what needs to be done as a group rather than a select few attempting to do everything," a member commented that the fun of attending the meetings was gone ... WOW, that is the reason I wanted to cut back meetings I wasn't having fun anymore, it was a second job for me. I have allowed us to drift from our path and get away from basics ... and here within is the answer to my prayer for guidance. God works in mysterious ways but I do know He ALWAYS works and in His own time.

Meetings

We discussed that we will continue with monthly meetings. **It is apparent to me that we must get back to basics which is: support and sharing our experience of living with dystonia.** That is what the group was formed for and what you as members have voiced that you want. We will review treatments and have open forum discussions of living with dystonia beginning on 02/17/07.

We will have 3 to 4 speakers a year with Dr. LeDoux speaking on 03/24/07.

We will have our annual "Summer Luncheon" in June and "Holiday Luncheon" in December. We will break from meetings in July and November.

Business

Ken was out of town and could not attend the meeting. We told Rita and her husband Ken what "our Ken" accomplished in fundraising for research. He took it upon himself to learn to apply for grants. Every person in the room voiced their respect and admiration for Ken. As all of you know he is much more than our

treasurer and devotes 20 to 30 hours a week to DSG efforts, not because he has to but he wants to. He is a clever businessman with important contacts. We all agree that Ken is in his element doing what he does best and I don't know of anyone that can fill those shoes. He is accomplishing what we all want to accomplish, to leave a legacy that we made a difference for all of those with dystonia and to make it easier for those that come after us.

A. There will be **no further solicitation** of members to raise money for the group by writing letters; if a member needs donation envelopes they will be available at each meeting on our display table. Members will continue to receive a packet when there is something as important as the film "Twisted" being aired and you will make a **personal decision** as to how, or if, you choose to raise awareness. I respect that we are all different and what I choose to do may not be what you choose to do. **No one will be ostracized for any personal decision made.**

B. **There will be no future listing of members names and monies raised or donated to the group.** We have single parents, members on fixed incomes, members caring for aged parents, and members with different financial situations. No one will be made to feel alienated from the group because of this.

C. **I trust Ken completely to continue to make business decisions** for the group. He notifies me of all decisions prior to carrying them out.

My question to you as members: Do you want to have a vote or say so in these matters or do you want Ken and I to make the decision? Please email me your response ASAP and this will be another business decision handled.

Refreshments

Thanks to Linda and Jay for providing refreshments yesterday. A calendar will be provided at February's meeting so each of you can sign up for a meeting. Pat and Bill are providing next month's refreshments. (Pat I know you were providing March but someone else will cover that)

In Closing

As I told you yesterday I have learned by trial and error how to become what I hope to be: a better leader. Did I make mistakes, sure I did, but all I know to do is "carry on" as my dear friend Mary would say? I hope to learn from my mistakes.

*I made a decision in January of 2005 to start a DSG **BUT** it is not my group, **it is our group.** We will do things on a volunteer basis and have group feedback at each meeting to alleviate problems in the future. If you have a gripe you got to*

have the guts to voice it. I can assure you there will be no criticism of you We are all adults that can agree to disagree for the best of the group.

I encourage you to chair a meeting if you wish to do so, hey I have heard many of you speak out and I know you are capable of leading a discussion. Brad, Sheryl, Trish, Ricky, Pat, Bill I overheard Jay speaking with Ken yesterday and not only was I surprised, I was extremely PROUD. That man knows much more about dystonia, my treatment and me than I thought he did. I am going to try and get him to lead a meeting: "Living with a Wife Who Has Dystonia". I have planted the seed.

*I am so excited about 2007. My passion to help all of those with dystonia is as strong as it ever was. Thank you for allowing me to lead you and for your continued support. For those of you that have been offended or lost interest I ask for a second chance to: **Get Back to Basics.***

*God bless,
Linda*