

**NEWSLETTER for may meeting  
05/20/06**

*Guest Speaker: Peter Cohen*  
*Special Visitors: Dr. Cheryl Goyne, local neurologist*  
*Phillip Paulk, local Medtronic rep*

**23 Members Attended**

Josefine  
Susie  
Mike & Susan  
Bill & Daw (Jennifer's parents)  
O.J. & Betty  
Sherry  
Gerald & Francine  
Rosemary  
Shelby & Jennifer  
Don & Betty  
Brad & Paige  
Mary Ann  
Vincent & Brenda  
Jay & Linda Mott

**YOU WERE MISSED**

Ken Williams  
Trisha Crain  
Nancy  
Ricky & Jane  
Becky  
Brenda  
Susan  
Dennis & Mary  
Virginia  
Joyce  
Kellie  
Randy & Sandy  
Jane & Grace  
Mariellan  
Judy  
Don  
Bill & Pat  
Steve & Janice

---

\*

Peter, who is now 41, knew something was wrong at the age of 15 when his right hand would cramp while trying to play the cello making it impossible to hold the bow. He quit

playing which was the first of many forced resignations. Something was wrong although he continued playing tennis in high school; he was experiencing twinges & severe muscle cramps in his legs. Dystonia attacked him muscle by muscle, slowly & resolutely for 20 years. The circuits in his brain were stuck, like a CD when it is scratched playing the same notes over & over. When he was a teenager, a doctor had said Dystonia may be the cause of the symptoms he was experiencing. At age 35, Peter had graduated from law school, which proved to be more physically challenging than academically. He was working for a law firm but his life had turned horizontal. He could no longer work & spent hour after hour, day after day on the floor in his apartment. He ate, watched TV, peered up at his friends to talk from the floor with his 6 foot 4 inch body twisted & contorted in an abnormal position. In November of 2002 three months after marrying from a chaise lounge, he & his wife attended a Dystonia conference in Florida. Dr. Mahlon DeLong a neurologist from Emory School of Medicine in Atlanta told of promising surgery called deep brain stimulation. Lying on the floor in the back of the room Peter was not able to ask the questions he wanted to.

Peter saw a woman he had met at a Dystonia symposium in Chicago whose symptoms were almost as bad as his. She walked upright & her tremors had stopped. This was a turning point in his life. He said, "What the hell, I'm going to do it." This was his only hope of returning to a somewhat normal life.

This was only the beginning of a long road filled with uncertainty for Peter.

**Answers to Questions and Information**  
**Thanks to Peter, Dr. Goyne & Phillip Paulk for an Educational Panel Discussion**

1. There are no guarantees that DBS will work, it is NOT a cure, and it is a symptomatic treatment
2. There should be in depth discussions with you treating physician
3. You can not do enough research via internet, communication with people who've had DBS
4. TRAVEL to hospitals & physicians where DBS is done
5. There were 4 surgeries which lasted 6 to 8 hours each (only 2 required now)
6. Recovery period after each surgery before the next can be done
7. His head in a halo with screws in his skull, prepared for surgery his head still jerked from Dystonia
8. Before the batteries (placed in chest) can be turned on to regulate stimulator that controls spasms you have to recover & heal from surgery (a few months)
9. Batteries have to be changed; requires anesthesia, surgical procedure
10. More pain after surgery because for 20 years he had not been in an upright position
11. He had to learn to walk, sit, etc. again
12. He experienced severe headaches & vomiting after surgery (he told us the physician thought perhaps this was due to air entering the brain during surgery)
13. He had a TIA (trans ischemic attack: lack of blood) & couldn't answer the question or move which was very frightful for him
14. He was over adjusted which caused a speech impediment
15. Adjustment is by trial & error & different for each individual

16. There is not enough data to know what the future holds for Peter but he has continued to improve

17. DBS surgery is FDA approved for Parkinson patients

18. There is no long term data on patients who had DBS surgery (only 3 to 4 years)

Please remember that DBS is an invasive surgery & doesn't work for everyone. This should be researched in depth before a final decision is made. For those of us with CD, Botox only works if we receive it every 3 months on a regular basis. It took 18 months for my body to adjust to Botox & it took 9 months for my physician to get my dosage correct.

When looking at Peter I could tell he had Dystonia but compared to the picture of him prior to surgery & now was truly remarkable. He told us that he lives in fear because of the uncertainty of his future. "I live each and everyday to the fullest."

Thanks to modern technology Peter was able to tell his story & he remarked, "For this we should all be thankful." He opened by saying how very important it is for us to raise money for research and wanted to know what we had accomplished. **I am going to comment on how successful the "letter writing campaign" can be. Ken put much effort & time into this project & I know it works. Last year I received over \$500 & this year over \$1200 from relatives, friends & business acquaintances. Once again I encourage all of you do this.** (I will provide anyone interested, a copy of the letter I use; it tells of my struggle with SD & CD for the last 31 years)

Peter is a remarkable, friendly man with an educational, inspirational story to tell. He is not presently practicing law. He lives in Maine & serves on the Board of Directors of the Disability Rights Center of Maine. He is the Chairperson of the Junior Advisory Council, on the DMRF's Public Policy Committee, & a new member of the Board of Directors. Peter is featured in the film **TWISTED** (we will have more info on this at a later date) & has a wealth of media experience including an appearance on the TODAY show in 2004. **\*Some of the info in this Newsletter came from an article from The Atlanta Journal Constitution provided to us by DMRF** (I can provide you with a copy)

## SUMMER SOCIAL

06/17/06

We've had speakers for all but one meeting this year so it is time for us to reconnect with each other. In lieu of a meeting we will have BBQ & "fixins" on **June 17, 2006 at 11 AM.**

The BBQ will be provided by Ricky, Mary Ann & I. **Please call or email me with the dish you can bring no later than 07/10/06.**

Ken – Potato Salad

Stephanie (Susie's daughter) – Milo's Tea

## ACCOMPLISHMENTS TO RAISE AWARENESS

1. Article in Senior Living
2. Article in Shelby Co. Reporter
3. Governor Riley's Proclamation for Dystonia Awareness Week June 4<sup>th</sup>- 11<sup>th</sup>
4. Health Fair at Brookwood Mall on 05/31/06 (see below)
5. Bookmarks in bags distributed at state American Legion convention in Mobile June 3<sup>rd</sup> - 5<sup>th</sup> (courtesy of Pat & Bill)
6. Bookmarks placed in Books-A- Million at Brookwood Mall (courtesy of Ricky)
7. Bookmarks to be placed in every pizza delivered in Vinemont by Papa John's during National Dystonia Awareness Week (courtesy of Jennifer & Shelby)
8. "National Dystonia Awareness Week is June 4<sup>th</sup> -11<sup>th</sup> "& web sites listed on the billing statements mailed out, reaching 150 People (courtesy of the Burch's)
9. There will be an article in Dystonia Dialogue about Peter speaking to DSG/B'ham; "People on the Move"
10. 4 new members in 2 weeks (courtesy of NSTA, Jennifer Molski, Mel Dubovick & health fair)

## DONATIONS

I think it is time to acknowledge members who give or raise money for the important work we do as a support group. This will allow us to see on a monthly basis what is accomplished & hopefully inspire us to do more. After speaking with a couple of members who volunteered at the health fair I don't think they were aware of the cost of our participation. The space was \$500 & an additional \$300 for our display. I feel it was money well spent because we reached a large number of people in a short period of time. We don't have a Michael J. Fox to speak on our behalf so the responsibility rests on our shoulders. I know many of you have donated money prior to this Newsletter & it is captured in a printout Ken will provide. (this will be a monthly addition to the Newsletter)

Josefine - \$25

Susan - \$50 (Josefine's relative)

Gerald & Francine - \$50

Mike & Tammy - \$50 (Linda's relatives; letter writing campaign)

Billy & Denise - \$500 (Linda's relatives; letter writing campaign)

## BROOKWOOD MALL HEALTH FAIR

Our first health fair was a big success, we reached approximately 500 people. 85% of them were very interested in what we had to say & the most common comment of the day was, "I've never heard of Dystonia." We had the opportunity to provide both verbal & written definition & facts about Dystonia. I want to personally thank Ken Williams, Betty, her friend Jane, Joyce, Sherryl, Trisha Crain, Ricky & Brad, Susie & Jennifer & Shelby.

This awareness campaign could not have been accomplished without you.

## FUTURE SPEAKERS

Struggling on a daily basis with SD for 31 years myself & with 50% of our members suffering from SD, I feel we have been short changed. I have failed to have a speaker address SD. I invited a speech pathologist but she didn't respond to my invitation. I am excited to announce that on August 19<sup>th</sup>, Mary Biarfo will speak to us. She has SD, is a support group leader from North Carolina, serves on the Board of NSDA, is dedicated & works diligently to raise awareness & make a difference for all of us with SD. **Please mark you calendars now for what will be an educational & inspirational meeting.**

*Thanks to all of you who make the DSG of Birmingham a success.*

*Linda*