
**TRIGEMINAL NEURALGIA ASSOCIATION
NORTHEAST FLORIDA SUPPORT GROUP**



TIC TALK

**SUPPORT GROUP MEETING THIS COMING SATURDAY
MAY 5, 2007 1:00 – 3:00 PM**

Thank you to all who were able to attend the April meeting at the Cyberknife Center at Memorial Hospital. We had 23 members attend. Although I had hoped for better attendance, the facility was crowded with the group that we had.

Dr. Allison Grow, MD, PHD, Director Cyberknife Center, provided an excellent program. She explained the Cyberknife and its capabilities (most widely used for small brain tumors), and how it can successfully treat patients with TN. She also arranged for Dr. Ab Deshmukh from the Baptist Gamma Knife Center and Dr. Dean Lohse of the Memorial Neurosurgery Group to present also. This allowed us to get a better understanding of the Cyberknife and Gamma Knife similarities and differences, and the surgical treatments available, i.e. MVD. It was great to see these doctors present their expertise on their specialties and not touting one procedure as being better than the other.

In addition, quite by accident the neurophysicist who calibrates the equipment came in to work that day and agreed to cover the operation of the Cyberknife the equipment. (I can't find his business card to give his name). So we had four doctors presenting at this meeting.

I personally was very impressed with Dr. Grow, she is a Florida native and completed a premedical program majoring in physics and applied math at Florida State. She received a PhD in theoretical physics, taught physics at Florida A & M and then went on to Stanford School of Medicine, training in the radiation oncology program there. After ten years in California she returned to Florida as part of the launch team for CyberKnife radiosurgery in Jacksonville. Away from work she enjoys choral music, playing piano and flute, writing, baking and spending time with her growing family, a baby is due in June. I will never complain that I'm too busy to do something after reading her credentials. (Of course she's much younger than me)

We can cover everything further at our meeting this Saturday. It will be good to have everyone's input on what they got out of this meeting. A special thank you to Kathy who helped me get this meeting organized. We went the week prior to check the facilities and determine what we needed and then she came early the meeting day to help me set up everything. This is especially great since she does not have TN and Reg Maycumber was out of town and couldn't attend the meeting. She is truly a supportive partner.

Since my last TIC TALK was only a meeting notice I'll cover the highlights of our March meeting:

First it was great to see Ruth Eisen again. Ruth is one of our founding members and was our support group leader, prior to me. Ruth has had TN for 13 years and had two radiofrequency at Gainesville with Dr. Rhoton. Each procedure lasted for 3 yrs. Her latest procedure was the Balloon Compression with Dr.

Reimer at Mayo. This has lasted for 6 yrs. She has some numbness that really doesn't bother her. But bad weather does affect her TN especially the eye and nose. She takes 300mg of neurontin 5X's a day, which sometimes affects her balance. Ruth has continually supported me since she stepped down as support group leader. She maintains the email addresses, mailing lists and labels and calling lists. Ruth and her husband have had some ups and downs, more downs lately, but she always comes through with the labels. She just spent a long time verifying everything, so hopefully we have everybody's addresses and emails right. Thank you Ruth, I really, really appreciate all you do.

Other member updates:

Reg Maycumber reported that he is taking omega 3 and is experiencing less disorientation from his medications since taking the omega 3. He also asked about the use of Baclofen for the TN. There were several of us who had used Baclofen as an adjunct drug with success.

Bibi Figueroa reported that she is experiencing some tearing of the eye, her TN originally started over her eyebrow. Her good news is that her PET scan shows her lung is free of cancer, and shadows that were previously showing on her breast have disappeared. The doctors continue to monitor the lymph nodules.

Vivian McGee continues to be a good news story after her MVD last fall. She remains pain free and is a great resource for TN patients to talk to about the MVD. She has such a positive attitude based on her success and she is very encouraging to those she talks with. Thank you for doing this Vivian.

Bennie Devane is also a good news story; he continues to be pain free after his Gamma Knife surgery in April 2004. He had only two TN episodes since the Gamma, one in December of 04 & one in January 05.

Winona Unick is experiencing some pain and will be going to the dentist to have it checked, but she suspects that it's really her TN pain.

Edna Hamilton pain feels like a toothache but is afraid to go to the dentist; She had a cavity filled without having any novacaine for fear that it would trigger the TN.

Mary Griffen is doing well. During bad weather she takes extra medication to prevent the TN from triggering. She takes 400mg of Tegretol 2X and 300mg of dilantin (generic)

Mary Lou McEver continues to use the topical medication in her mouth for her pain, prescribed by Dr. Margaret Dennis.

Dr. Dennis said that she could cover this medication and procedure at a future meeting. Dr. Dennis will be presenting at a Regional TN conference on May 19 in Nashville, TN. Unfortunately I won't be able to attend this meeting but hopefully Dr. Dennis can tell us about the conference at a future meeting.

Tory Wilcox did have her surgery for a sinus infection and she is experiencing increased pain now.

Hopefully the pain will subside and she will get some relief from the surgery. Tory was unable to attend the meeting.

At this meeting we decided to donate \$150 from our funds in honor of Dr. Peter Janetta's retirement from the board of Directors of the TN organization. As many of us know Dr. Janetta was the doctor who developed the MVD surgery for TN. The donation will go to the ***Peter Janetta Initiative to develop medical educational materials and an outreach program for the treatment of TN.*** As we all know TN is hard to diagnose and many doctors are not readily familiar with its symptoms. Dr. Janetta has done so much for the treatment of TN and he will continue to do so through this initiative.

Refreshments were great at this meeting. We had originally decided to cut down with the refreshments but it was also traditional that Betty O'Gallagher make her Irish Soda bread in honor of St Patrick's Day (It is the best soda bread ever), and Rita Kelly made some good cookies. Thanks to both of you.

I would like to update you on some of our members.

-Patricia LeRoy has been ill with serious heart and neurological problems and at last information she was recuperating at the Quality Care facility in Fernandina Beach. I will try to have more information on her for our meeting.

-Rita Kelly is doing well but her husband had a serious case of the shingles and is still recuperating. They are our snowbirds and are usually back in Pennsylvania by now but are still in FL.

-I'm sad to report that Bernice Hudson passed away on April 22. She and her daughter Maggie Coyner would attend our meetings together. The last time Maggie attended her mother was not able to attend. Her health had been failing and unfortunately she was still experiencing the TN. I hope that she was able to get some relief. Maggie was such a good support for her mother.

I will have cards for us to sign for these families at our meeting.

Special Thank You:

Marilyn Bain made a donation of \$100 to our support group. She's been on our mailing list but can no longer come to the meetings. She stays updated with everyone and the new medications and treatment procedures through our newsletter.

Also, a special thank you to Marsha Brown who made a \$50.00 donation to our local support group. She too is on our mailing list and has not been able to get to meetings.

Thanks for your support and for reading our newsletter TIC TALK to stay involved.

Please try to attend our meeting this coming Saturday. Some new members have indicated that they would like to attend this meeting. It's important that we are there to help them with to manage their TN pain.

TRIGEMINAL NEURALGIA ASSOCIATION

INFORMATION, SUPPORT, ENCOURAGEMENT

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THE NORTHEAST FLORIDA TNA SUPPORT GROUP MEETS THE FIRST SATURDAY OF EVERY MONTH FROM 2:00 P.M. TO 4:00 P.M. IN THE MEMORIAL HOSPITAL, 3625 UNIVERSITY BLVD, JACKSONVILLE, FLORIDA

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Northeast Florida TNA Support Group

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