
**TRIGEMINAL NEURALGIA ASSOCIATION
NORTHEAST FLORIDA SUPPORT GROUP**



TIC TALK



Annual Christmas Party/Meeting this coming Saturday, December 1, 2007. 1:00-3:00 PM. at Memorial Hospital. We will have our regular meeting with a guest speaker, Brenda Starr Walker an instructor on Yoga and Shiatsu Therapy. Please try to attend, we always like to have good attendance for our guest speaker and this is an important topic for alternative therapy for our TN pain.

Of course we will have Charlie and Eva Doolittle presenting the Annual Quiz and prizes. This is always so much fun, especially with lovely Eva presenting the prizes.

I will provide all refreshments as my gift to you. So don't eat lunch, we can start eating when you arrive and be able to get everything done and be out on time.

Our November meeting was well attended with 21 members.. Our guest speaker Dr. Timothy Sternberg was very informative. He is such a Gator fan, that we kept the game on the TV with the sound down so we could inform him of the score. He got so in to our group that he soon forgot about the game (of course the Gators were leading). He stayed well after his presentation to answer questions.

I have attached a write up on his presentation that Tory Wilcox prepared. She did such a great job on this document that we can now use it for reference material. THANK YOU Tory for doing this. Tory arranged for Dr. Sternberg to come and also arranged for our guest speaker for our December meeting. This has been such a help to me. Speakers are not easy to get to come especially on a Saturday and to arrange two in a row is a wonderful feat. THANK YOU, THANK YOU!

Since I didn't get a full newsletter out in November I will now cover our October meeting in this newsletter.

We had several new people to our meeting, one I had talked with over the phone for about a year.

It was good to meet and hear the good news story for **Svitlana** and **John Drougas** from Orlando, FL. I had talked with John many times and not with Svitlana, she was in too much pain to talk. Svitlana is originally from the Ukraine, and that is where she started having TN pain. Her pain started with tooth pain and she had a crown

taken off. The pain felt like it was going right to the brain. The periods without pain became shorter and shorter. She was a teacher and had to quit teaching and wouldn't go out. In her country there are no support groups and you are told to "live with it"

She later moved to New Jersey with her husband and found a support group in Philadelphia. She was scared to have the MVD surgery, afraid of being paralyzed. They then moved to Florida where she was in constant pain for three years. She had few hours of sleep; she tried Neurontin, tegretol and Lyrica nothing was helping. She found a pain doctor in Orlando who prescribed narcotics, nothing worked. Svitlana said that everyone has joy in their life her only joy was her husband. She had emotional and physical pain. She said in her country you only smiled if you know someone: in the US everybody smiles...and it hurt her to smile. In January her husband called me about Svitlana, how she was suffering and how she was scared of the MVD. I referred her to Vivian McGee, one of our support group members, who had a very successful MVD in Gainesville. She spoke with Vivian and was then willing to try the MVD.

She spoke with Dr. Freeman at University of Florida in Gainesville, who did Vivian's surgery. Dr. Freeman didn't promise her anything but said he would try. He was so kind and nice to her. He did find a vein and artery that was resting on the nerve. Her surgery was very successful.

She said that she was born here in the United States a second time. She and her husband were able to go back to the Ukraine this summer and her family was finally able to see her without pain. What a blessing.

The support she received from her husband was obvious; he helped her through all the pain and her cure. Also what helped was having a support group to refer to and being able to talk to someone who has had a procedure done. Let us not forget how important our support is, whether its family, friends or support group members.

Also, Reg Maycumber brought two new people to this meeting **Vivian Carpenter** and **Pat Luckie**. (See how important support group members are)

Vivian first had pain in 2002, she had no idea what was happening. Her pain lasted ½ a day then went away. Then a year later it came back full force and she was given morphine and then Neurontin. In 2005 it was back again. She was in agonizing pain and on the floor in the waiting room at St. Luke's, the pain was so bad. Her primary doctor referred her to a specialist who diagnosed TN. She was put on Trileptal two 300 mg daily and has had no pain since.

Pat has had TN since the mid eighties; she's had pain and numbness for over 22 yrs. It first started with numbness and then the electric shock pain. She had a MVD in Atlanta by Dr. Garcia and four days later her pain was back. Her doctor said he thought it would go away. In '95 she had pain again for three months. Tegretol had quit working for her. She had the radiofrequency and her pain was gone and she is now numb on the her right side of her face. She said she is a survivor, although she feels like she's just stepped out of the dental office all the time.

We welcome Vivian and Pat and hope to see them at future meetings. And thanks to Reg for bringing them.

Cindy Ezell, from TN National Headquarters, spoke to our group on the membership campaign. She asked that we offer TN Memberships to our friends and family. The membership is \$35 for the year of which \$33 would go to National and \$2 to the local support group. Our National Organization receives no government funding and is dependent on donations to survive. This is really no different than contributing to the Cancer and Heart Funds: the big difference is that Trigeminal Neuralgia is a rare illness with no real cure. We need to get the word out and ask for support from friends so that our organization can survive and research can continue. Unless we get the word out no one knows.

Cindy and Ruth Eisen also talked about the starting of our Northeast Florida support group 13 years ago and would like to have a reunion of all current and old members. The first meeting had 13 people in attendance, and then they advertised in the paper for the next meeting and had 35 in attendance. We know that there are more people suffering out there and we need to help find them. Some who have been “cured” don’t come to the meetings and it would be good to see them again and hear how they are doing. We have tentatively scheduled this reunion for February. Ruth and Cindy will be in charge of the mailing lists and contacting people. Reg Maycumber and Kathy Brown have volunteered to be in charge of refreshments. We volunteered Charlie Doolittle (in his absence) to be program chairman. Thanks to everyone for volunteering. We will need more volunteers.

Speaking of volunteering, thanks to Ruth for pointing out the importance of volunteering. Many times I feel overwhelmed with all that needs to be done for our group, and all the things that could and should be done to make us more effective. I always need help. I want to thank all those who stepped up to help in the recent months, it really, really helps. I want thank Jean Mertens for volunteering to help with the treasure and funds of our organization. John Vigneaux has done this for many years and a break from this task is well-deserved. Thank you for doing this for so long.

A special thank you to Elda Brontoli for sending a donation of \$25 to help with the postage costs.

I hope to see you all at our meeting this coming Saturday. Remember I’ll be working really hard so that we all have a nice party.

And for those of you who can’t attend, I wish you a very nice, peaceful, painless and blessed holiday season.

HOPE TO SEE YOU SATURDAY!

<p style="text-align: center;">TRIGEMINAL NEURALGIA ASSOCIATION INFORMATION, SUPPORT, ENCOURAGEMENT 925 NW 56th Terrace, Suite C, Gainesville, Fl. 32605-6402 Phone 352-331-7009 or 800 923-3608 Patient Information –Alana Greca 352 376-3608 fax 352 331-7078 e-mail : tnanational@tna-support.org e-mail :tnanational@tna-support.org website : http://www.endthepain.com</p>

THE NORTHEAST FLORIDA TNA SUPPORT GROUP MEETS THE FIRST SATURDAY OF EVERY MONTH FROM 1:00 P.M.TO 3:00 P.M. IN THE MEMORIAL HOSPITAL, 3625 UNIVERSITY BLVD, JACKSONVILLE, FLORIDA

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Northeast Florida TNA Support Group
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