
**TRIGEMINAL NEURALGIA ASSOCIATION
NORTHEAST FLORIDA SUPPORT GROUP**



TIC TALK

**SUPPORT GROUP MEETING
SATURDAY, MARCH 3, 2007
1:00-3:00 PM**

(Please note the new start time of 1:00 PM)

Our first meeting of the year on February 27, 2007 was well attended, with 21 people attending.

We welcomed a new member, Elaine Savitsky who was referred to our Support Group by Dr. Margaret Dennis. Elaine has been experiencing pain for about 7-8 months. She is currently on Lyrica, taking four a day. When she started Lyrica her pain went away so she quit taking the medication. The pain started to come back. Dr. Dennis advised her to not quit taking the medication and to keep some level of Lyrica in her system to control the pain. She is now able to eat, talk and get up from sleeping with little or no pain. However she was having some trouble with pain that day. We welcome Elaine our group and hope that we can provide additional support for her. And thank you to Dr. Dennis for referring her to us.

Dr. Dennis was at this meeting; she told us she has been invited to speak about facial pain and TN at a dental conference in Nashville, TN this spring. It is so important to get the dentists educated on TN and other facial pain. Educating these professionals will help to diagnose the TN much sooner and many times save the patient from having unnecessary teeth pulled. Another thanks to Dr. Dennis. Again, she is such a valuable resource for our group.

Vivian McGee is still doing quit well after her MVD surgery in late October '06. She continues to be pain free and is an inspiration and support for us all. We love good news stories.

Tory Wilcox told us that she was scheduled for sinus surgery with an ENTdoctor on February 14, in an attempt to relieve her atypical pain. This will be the first time someone in our group will be having this procedure (to my knowledge). I have a call in to Tory and hope to have an update for our Saturday meeting.

Since we had no speaker at this meeting I covered a session of the National Conference, "Ask the Nurses" (Question and Answer session with the audience) with panelists Linda Mitchell, R.N. University of Texas Southwestern Medical School and Alana Greco, R.N., TN patient and TNA Patient Representative, Gainesville, FL., with questions from the audience at the National Conference. This provided an informative discussion among our members. I will continue to pull information from the National Conference when we do not have a speaker scheduled.

Speaking of speakers, I am very happy to announce that for our April 14 meeting we will have Dr. Allison Grow as our guest speaker. This meeting will be held at the CyberKnife (CK) Center at the Memorial Hospital facility. Dr. Grow will provide a tour of the CyberKnife Center and discuss the treatment of TN with Cyberknife rhizotomy. The CyberKnife system enables the physician to deliver the dose of radiation exactly where it is needed from multiple angles.

Thank you to Mary Lou McEver for making the initial contact with Dr. Grow. More details on this meeting will follow. I will NEED TO KNOW EXACTLY HOW MANY WILL BE ATTENDING THIS MEETING. There is limited space and we will probably have to rent additional chairs if we have a large turnout for this meeting. I am also asking for a volunteer to help me coordinate this meeting, please.

Speaking of volunteering I am still asking for volunteers in the following areas: Program Speakers; Mailing/calling lists; Refreshments; Maintaining a list of doctors, dentists and other TN healthcare providers; Newspaper announcements; Support Group Information to local hospitals and medical professionals; Meeting reports to TNA National and the Newsletter.. I want to thank John Vigneaux, our treasurer and Jim O’Gallagher who keeps attendance and makes our badges, for continuing to help us out. I have not confirmed with them that they are willing to continue; so hopefully we will not need new help in this area.

Thank you to Rita Kelly and Betty O’Gallagher for volunteering for refreshments for the March meeting On Saturday.

We had an abbreviated January Newsletter (because I lost my glasses), so I will cover a few items from our December meeting:

We welcomed Richard Skinger, another snowbird from up North. Richard has been experiencing some form of TN pain for 12 years. It first started with pain after minor movement, then while taking a trip to Boston a severe shock while taking a shower. He went to an ENT and they found nothing. He had no pain for a couple of months. He was being treated by a neurologist who put him on tegretol and that seemed to help. Then on a trip to Hawaii he ended up in the emergency room with severe pain and was given codeine for the pain. He then went to Tufts Medical Center for treatment and was preparing to schedule surgery, they increased his tegretol to 200 mg and he was OK. He has TN after changes in atmospheric pressure, as some of us do. He is on five pills a day and Flonase, but not on a regular basis. He has his blood tested every three months. Richard, welcome to our group and remember we are here to support you even when you are back north.

Jean Mertans was planning to have the Gamma Knife and was unable to because of heart problems. She is currently able to cut down on her dosage of trileptal.

The December meeting was our Annual Christmas Party and once again Charlie and Eva Doolittle did an outstanding job with the program. They always come up with the best quiz questions that really keep us on our toes and again we always win nice seasonal gifts. The effort that they put into this is evident and greatly appreciated. *We won’t say a word about them being late.*

I would like to thank everyone for my Christmas gift. The musical, porcelain tree is just beautiful and was a great addition to my decorations. You all are very thoughtful.

I would like to thank all who helped me during past year and am pleased to see that our group is growing. But not pleased that we all have TN. I am mailing over 50 newsletters and e-mailing to 29. We don’t have this many attending the meetings as some are physically unable to attend and others live too far away. A special thank you to those who are able to and do attend.

I will be providing more information on the upcoming April meeting at the CyberKnife Facility at the Memorial Hospital complex. I really need to get a good idea at our meeting this Saturday on how many plan to attend the April meeting, and will definitely need help in getting it organized.

Don't forget the earlier start time for this coming Saturday's meeting. The earlier time allow the people driving from a further distance to get home at a better time and for those of us with other Saturday evening engagements to have more time. Thanks for supporting this change.

TRIGEMINAL NEURALGIA ASSOCIATION

INFORMATION, SUPPORT, ENCOURAGEMENT

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THE NORTHEAST FLORIDA TNA SUPPORT GROUP MEETS THE FIRST SATURDAY OF EVERY MONTH FROM 1:00 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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