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**TRIGEMINAL NEURALGIA ASSOCIATION  
NORTHEAST FLORIDA SUPPORT GROUP**

**TIC TALK**



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**April 20, 2004**

Sorry for the long delay in getting a TIC TALK out to everyone. I have been having major problems with my computer. My ex IBM'er neighbor finally has me fixed. Still not the way that it used to be, I still get shut down but not as often. It took him two days. Thank goodness he enjoyed the challenge. It only cost me one loaf of my famous Russian Easter bread.

Thanks to everyone who attended the tour of the Gamma Knife center at Baptist Hospital in Jacksonville on February 21<sup>st</sup>. We had great attendance, 32 people. Dr. Douglas W. Johnson, Radiation Oncologist and Ann Klinger, RN provided a very informative program. I learned more, even though I had this procedure over 2 yrs. ago. For those who were unable to attend, I'll give a brief overview of what transpired:

We were warmly welcomed with coffee, cokes and breakfast goodies. In addition, there were nice insulated coffee mugs and pens that we got to take home.

Dr. Johnson gave a talk with slides that explained the gamma knife, how it works, why it works and then the actual gamma knife procedure. We then took a tour of the actual facilities. We saw the private patient waiting room with a bed, chairs and TV where the patient and their family wait at various times during the procedure. After the patient is prepped and fitted with a head frame a MRI, CT scan or both is performed. After these tests, the patient is returned to the waiting room while the staff prepares the personal treatment plan. The Radiologists (i.e. Dr. Johnson), Neuro physicist, neurosurgeon etc. study the patient's films and determine the actual treatment plan. This could take up to 2 hrs. or more. (The procedure is very precise and every detail must be very accurate as to the dosage (strength) and length of the gamma ray treatment.)

When the treatment plan is finalized, the patient is moved to the Gamma Knife treatment room, where they are placed on a cushioned, motorized table. A steel helmet with 201 holes is attached to the frame on the patient's head. Highly focused gamma rays will be directed to the targeted area of the Trigeminal nerve. This process could be anywhere for 30 min. to 3 hrs. Usually under 1 hour for treatment to the Trigeminal nerve. After the treatment the patient is returned to the room and briefly observed prior to being released to go home. In rare instances an overnight stay might be required.

After the tour and questions and answers with Dr. Johnson, we had a short meeting. Those in attendance decided to cancel the next meeting since it was only two weeks away.

As a result of this tour, Benny Devane has been meeting with the doctors at Baptist and is scheduled to have the Gamma Knife procedure later this month.

After the meeting some of us got together for lunch. Unfortunately the restaurant we chose did not have good parking facilities so some went on home

*Speaking of meetings*, we did have a meeting on the first Saturday in April (April 3). Attendance was not very good; we only had 7 people attend. I believe this is my fault since I did not get the newsletter out to remind everyone of the meeting. It is probably best not to change dates or cancel meetings unless really necessary. And I will try not to do so in the future. Let's mark our calendars for the following meetings this year.

**May 1, 2004** – A video will be shown, and a review of medications that we're on.

**June 5, 2004** –I am trying to book a speaker

**July & August**-There will be no meeting. This is our summer break, since many people travel during this time. Remember, even when we don't have a meeting I am ALWAYS available to receive your calls.

**September 11, 2004**- I have scheduled Dr. Cioffi, D.M.D. to come and talk with us. He is a local doctor/ dentist that specializes in treating patients with TN. Several of us go to him. He is very good and knowledgeable about TN. (NOTE: This is not the first Saturday. The first Saturday falls on Labor Day weekend.)

**October 2, 2004**-Nothing scheduled yet.

**November 6, 2004**-This will be right before the TNA National conference in Orlando. and good meeting for those who are attending the conference to make plans to meet and for those not attending to provide us with questions and areas they would like us to get information on.

**December 4, 2004**-This meeting will provide feedback from the National Conference and also be our Holiday party.

**January 8, 2005**-Note: this is the 2<sup>nd</sup> Saturday. The 1<sup>st</sup> Saturday falls on New Years Day.

These dates will not change. If for some reason they would have to be changed i.e. hurricane, you will be notified by phone and/or postcard.

I would like to welcome two new members to our organization:

Ms. Pat Alford, Jacksonville, Fl.

Myron Morgan, Jacksonville Beach, Fl

In addition I have spoken with several others that may be joining us. It is not good that there are others suffering with this same pain, but it is good that we can help them through our experiences and just listening.

For our meeting on May 1<sup>st</sup>, Myron Morgan asked that we share what medications we're on, what worked, what didn't and what combinations of drugs work for some. He has recently been diagnosed with TN and this information will help him (and us too) on knowing what to do if the pain comes back, or doesn't go away. Ruth will lead this discussion. It might be helpful to write your medications down prior to the meeting. If Ruth will collect them I can type up a sheet for everyone to refer to.

I will not be at the meeting on May 1, 2004. I will be in Ohio visiting family for a small family reunion. There is a slight chance that I can get an earlier flight out of Pittsburgh on May 1<sup>st</sup>. Ruth Eisen will be leading this meeting. She is our experienced support group leader.

I'll see you all in June. Please call me if you need anything.

**TRIGEMINAL NEURALGIA ASSOCIATION**  
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**THE NORTHEAST FLORIDA TNA SUPPORT GROUP**  
**MEETS THE FIRST SATURDAY OF EVERY MONTH FROM 2P.M.TO**  
**4P.M. IN THE MEMORIAL HOSPITAL, JACKSONVILLE, FLORIDA**

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**MAY 1<sup>ST</sup> IS OUR NEXT MEETING DATE**



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