

---

# TRIGEMINAL NEURALGIA ASSOCIATION NORTHEAST FLORIDA SUPPORT GROUP



## TIC TALK

---

### Support Group Meeting Saturday March 1, 2008 at 1:00 PM

---

Our regular Support Group Meeting will be held on this coming Saturday. This will be a very important meeting, as the final planning for our “CELEBRATION” on April 5th will be made. Cindy Ezell and Ruth Eisen will be there to work with everyone to finalize all the responsibilities

Invitations to this special event were mailed out late last week. I worked with Cindy to update our mailing list but it’s quite possible that I did not get everyone on the list, especially those of you who receive the TIC TALK by E-mail, so if you DID NOT receive the invitation by now please let me or Ruth know. My number is (904) 285-5307 or Ruth at (904) 797-5345.

I will not be at this March meeting, and Reg Maycumber has graciously volunteered to lead the meeting. Again we are having trouble getting a speaker but he is still trying. If not, we will still be prepared to have an informative meeting. And with the Celebration planning there will still be plenty to do.

Our February meeting was held on February 2. We got off to a rocky start; we could not get into our meeting room. There was a fire alarm at the hospital, but no fire, so security couldn’t get down to open the doors. I continue to not understand this since I schedule the doors to be open one hour before the meeting time, it never is. (Can’t complain too much they are nice enough to give us the room.) Then the video I planned to show was eaten by the tape player, the tape is ruined.

The good news about the meeting is that we had a new member, Ellen Gilbert. She read about our support group in the newspaper. And we all got to meet her informally in the hallway, as we waited for the door to be opened. (I promise you Ellen our meetings usually run more smoothly)

Ellen was one of the fortunate ones who went to a doctor that knew about TN and was diagnosed immediately. She was diagnosed by her family doctor in Panama City, FL four years ago. She started having a slight pain and then it hit with a vengeance. She was put on Trileptal immediately. She moved to Texas and saw a neurologist there; he was amazed that her country doctor in Panama City could diagnose and properly treat her TN. Most of us realize how amazing this is.

She would go several months without pain and then suffer excruciating pain. She was tried on several medications and found she was allergic to sulfur. She was put on Tegretol, since her insurance wouldn’t pay for Trileptal. Once back in Jacksonville her doctor was able to get her on Trileptal. Her CVS pharmacist is very familiar with TN, again a rare finding. She takes 150mg 3X’s a day. If she misses she starts to get twinges about 4:00 AM. She has lived in several areas of the country and has now settled in our area. Welcome to our group Ellen, we hope that we will provide good support for you.

Cindy Ezell talked a little about the formation of our Support Group (She, Ruth and Mary Lou are our founders). The first meeting had 35 people attend. There are now over 300 names in the data base for the Northeast Florida area. Cindy has recently been named TNA Support Group Coordinator for TNA National Headquarters in Gainesville, FL. Our congratulations to Cindy. Cindy recently talked to a mother of a 14yr. old girl from Ethiopia who suffers from TN. You can see how valuable our National Organization is to everyone everywhere.

Charlie Mae said that she was so happy at the first meeting to finally find someone who would understand the pain of TN. And, our Charlie Mae, who makes all my phones calls for the meetings for me, will be undergoing knee replacement surgery in early March. So please remember her in your prayers.

I don't know about everyone else, but this weather has not been kind to my TN, I'm back on Neurontin 300mg 3X's a day. I will stay on it now because I see Dr. Cioffi on Tuesday. Mary Lou told me that Dr. Cioffi had referred a patient for the cyber knife treatment. I will try to find out how that patient is doing.

Please try to attend this coming Saturday's meeting and work on the planning for the reunion. I know that as hosts we want it to be really special. I have arranged to have the two rooms next to our regular meeting rooms also, so we should have plenty of space. And remember in the planning to be sure to have some things for me to do.

I'M SURE THE HIGHLIGHT OF THE MEETING WILL BE BETTY O'GALLAGHERS IRISH SODA BREAD. SHE ALWAYS MAKES IT FOR US IN MARCH, HER LAST NAME WILL GIVE YOU THE HINT AS WHY. IT IS SO..... GOOD. I WILL REALLY, REALLY MISS IT.

I spoke with Laurice Hunter, she had the gamma knife last month and is doing well. She still has some pain and is on medication. But we know that the Gamma takes a little longer.

A special thanks to Marsha Brown who made a donation of \$50.00 by mail to our local support group. Thank you Marsha, these donations really help.

I need to apologize to you all for forgetting to thank you for the lovely Christmas present. The Lennox dish goes with my other pieces, even my china. Thank you so much, but you really, really shouldn't do this.

**TRIGEMINAL NEURALGIA ASSOCIATION**  
**INFORMATION, SUPPORT, ENCOURAGEMENT**  
925 NW 56th Terrace, Suite C, Gainesville, FL 32605-6402  
Phone 352-331-7009 800 923-3608  
Patient Information –Alana Greca 352 376-3608 Fax 352 331-7078  
e-mail: [tnanational@tna-support.org](mailto:tnanational@tna-support.org) website : <http://www.endthe pain.com>

**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**

Leader Patty Hill --904/285-5307 106 Overlook Dr., Ponte Vedra, Fl. 32082  
Contacts for information about group: Local Calls: Patty Hill – 904/285-5307  
For calls to St. Augustine, Florida area: Charlie Doolittle – 904/797-2382

Northeast Florida TNA Support Group  
**Patty Hill, Editor, 106 Overlook Dr, Ponte Vedra Beach, FL 32082**