
**TRIGEMINAL NEURALGIA ASSOCIATION
NORTHEAST FLORIDA SUPPORT GROUP**

TIC TALK



SEPTEMBER 2004

Hurricanes, hurricanes go away—our TN Support group wants to meet. (Remember when we were children and we used to sing, “Rain, rain go away my brother and I want to go out and play----- I’m old enough to remember this song). Right now there is nothing stirring in the ocean so we should have good weather for our meeting this coming Saturday, October 2.

I hope that everyone is well and did not feel the effects of hurricane Jeanne too much. Again, I was very fortunate, no damage, not too much rain or wind. It’s really hard to believe that we’ve been so fortunate since our neighborhood is across the street from the ocean. I hope that all of you were as lucky. Hopefully this will be the last of the season.

Gerald Cioffi DMD offers his apologies for missing our September meeting. As we suspected, his practice was affected by hurricane Frances. They lost power in their area, so computers, etc. were down and his staff was busy rescheduling appointments and failed to remind him of our meeting. We rescheduled for our October meeting, but they called last week and asked for November instead.

Dr. Cioffi is now definitely on schedule for November 6. He was upset that he missed the meeting, but I assured him that we thought his absence was due to the hurricane and knew that he wouldn’t just forget about us.

Since Dr. Cioffi will not be able to attend our October meeting, and many of you missed the September meeting, I thought that we could again update on how we are doing. Also, I have talked with two other new TN patients that will try to make this next meeting.

There are also some committee items that we need to work on. Like refreshments, my fault, I forgot to get the list around. I will do the refreshments again this month and then I’ll get the volunteer list around. Also I would like someone to volunteer to work with me to get information out to our local dentists, neurologists and neurosurgeons about our organization. There was a good article about the Gamma Knife at Baptist hospital and it’s use on TN patients. Previously, I asked that they refer these people to our organization so that we can offer continued support after their treatment. I don’t think that they are doing this. I would like to work more closely with their staff and other doctors and medical facilities so that all TN patients can receive our support. I will bring this newspaper article. I think that we will have enough items on the agenda to give us a good meeting.

I did hear back from our TNA headquarters about being able to attend just one day of meetings at the TNA Fifth National Conference, Nov. 11-14, 2004, in Orlando. These requests are being handled by Shelley Wilson, Phone: 817 416-7202, E mail:kayser-wilson@charter.net She will accommodate all those that she can, and on a first come first serve basis. She must coordinate all the activities for the day, i.e. continental breakfast, lunch and maybe dinner on some of the days. So she must know in advance

who wants to attend. I will bring copies of the schedules of the day's events for the conference for you to look at and decide if you want to attend a portion of the conference. I will be attending all of the days, except the Sunday wrap up.

It was great to see Bennie Devane back to our meetings. Bennie had a successful Gamma Knife treatment at Baptist earlier this year. He is off tegretol and is taking only 3 neurontin a day. It is good to see him doing so well.

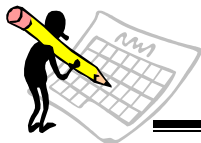
We had a new member Bonnie Lawton and her husband attend from Georgia. Bonnie has had several procedures and is still incurring pain. She's had the glycerol treatment that did not work. Four years ago she had the MVD. For three months she had no pain, but her eye went numb. During her procedures they cut one nerve and nicked 2 other nerves, leaving her face and tongue numb. She is currently on 300 mg of neurontin 2 pills 4 times a day, and sometimes darvocet for the pain. Our hope is that we will be able to give her support and help her find some relief.

Mike Morgan was on 400 mg of tegretol and reduced it down to none. He then started to incur a new different pain and is now back to 100mg of tegretol. A new MRI did show a problem with the myelin covering on several of his nerves.

Betty O'Gallagher is able to increase her tegretol by 1/2 of a pill to manage her pain.

Ruth is still on Dilantin, but her liver counts were up.

My thanks to Ruth for sending me our mailing labels. With all the hurricane scares and my house repairs, the month slipped away from me. I thought that I had one more week to get this newsletter out. I realized about 3:00 A.M. Monday morning, that our meeting was this coming weekend, not a nice way to wake up. Thanks again to you all for your patience with me.



Hope to see you all this Saturday, October 3, at 2:00 P.M.

**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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**Northeast Florida TNA Support Group
Patty Hill, Editor**