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**TRIGEMINAL NEURALGIA ASSOCIATION  
NORTHEAST FLORIDA SUPPORT GROUP**

**TIC TALK**



OCTOBER 2004

**NEXT MEETING, Saturday, November 6, 2004**

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At our next meeting we will have **Gerald Cioffi DMD**, as our guest speaker. As I have mentioned in our previous newsletters and meetings, Dr. Cioffi specializes in the treatment of TN patients for both dental work and control of the TN pain. This will be a very informative discussion. Please come prepared with any questions that you might have.

Our last two meetings have not been well attended; I am concerned that we might not a good attendance for Dr. Cioffi's presentation. If Dr. Cioffi had been able made it to the August meetings as originally scheduled, we would have been embarrassed by our lack of attendance. Please make every effort to attend this meeting.

Prior to our September meeting I received calls from the following: **Lillian Byers**-Lillian is currently having a bad time with her TN she is on 2100 mg of neurontin and not getting any relief. She let me know that due to her problems she will not be able to call people for meetings nor take care of the refreshment assignments. **Mary Lou McIver**- She was unable to attend this meeting. **Bennie Devane**- Bennie is still doing well, but was going to attend a retirement party for a close friend. **Phil DeStefano**-Phil called and said that his wife Phyllis had a heart attack and would be unable to drive him to our meetings. As most of us know she has been taking care of Phil and he now has to take care of her. She is doing well but must take it easy. Phil also will not be able to do the calls for our meetings now. We pray that they are both doing well. I will try to see if there is some way I can get them to our meetings. **Charlie Doolittle** let us know at the last meeting that he would not be able to attend. He had a "Black Tie" symphony function to attend. That's our Charlie!

Laurice Hunter has volunteered to help in the calling our members for our meetings. Ruth will make the calls for those in the St. Augustine area. Thanks to you both for this. We could still use some more volunteers for this, since you know how last minute I always am on everything.

Dr. Cioffi rescheduled from October to our November meeting so we were again without a speaker for our meeting. However we were able to fill our meeting time with updates of how we are doing and reviewing the upcoming National Convention if Orlando held in November.

Elaine Campbell is a new member to our group and this was her first meeting. Elaine reported that she had been treated for dental problems, resulting in 2 root canals and still experienced pain. She has seen both an oral surgeon and medical doctor before being diagnosed with TN. She is currently on 1200 mg. Of neurontin 600mg 2X's a day. She is scheduled to see a neurosurgeon in November for the possibility of having a MVD. She was not familiar with all the procedures available. I sent

her some articles on the procedures available, so that she would have more information prior to her meeting with the neurosurgeon.

We were out of our supply of “ Striking Back” to give her. We have been providing them to our new members free of charge. This book is very helpful to us all in understanding TN. I have since ordered a new supply for us from National.

Since Elaine is new to our group and unfamiliar with all the procedures. Several of our members reviewed the procedures they had and their current and medications.

Ruth Eisen has had two radio frequencies, that each lasted 3yrs.and the balloon procedure by Dr. Reimer from Mayo Clinic. She has damaged nerve pain and is currently on 300mg 4X's a day of neurontin and is not rid of all the pain. She has had TN for 10 yrs.

John Vigneaux has had three radio frequencies and has been on many different medications. His pain is steady at the eye at 3 to 4 minutes in duration. He is currently on 1-neurontin 2X's, 1 tegretol 2X's and 3 Dilantin.

We then talked about massage therapy, anodyne therapy and reflexology. With many of the nerve endings in the hand is there is some belief that this therapy can help TN pain. I told of a small article that I read that told of putting an ice cube at the skin web between the thumb index finger for treatment of migraine headaches. I keep forgetting to try this for my TN pain.

Judy St. Martin has had no procedures. She was first tried with neurontin and Dilantin and couldn't function. (We all know that feeling). For the last 3yrs. she has been on neurontin and trileptal and has been weaning off all meds for the last year.

Laurice Hunter is still on depakote and added neurontin in January. She is on 1500mg depakote, 1 in the AM and 2 @ night. Her pain has recently started back especially when chewing and brushing her teeth.

Phyllis is numb on one side but has gotten used to it; and I forgot to write down what else she said.

Sometimes it's hard for me to listen and write, and I'd rather listen, but I have no memory. :(

We were pleased to see Clem Dowling again. Clem has not been able to attend our meetings since he and his wife moved to an assisted living facility. His wife has been diagnosed with Alzheimer's and he has given up driving; so it has become hard for him to attend. He was able to taxi to the meeting and I drove him home. I was glad to do this just to see him again and hear how he is doing. He is doing very well, after 2 glycerol treatments (the 2<sup>nd</sup> one successful); he has been pain free for 6 years and is off all medication. We hope that he will be able to arrange to come to future meetings.

We talked about the National Conference to be Held in Orlando Nov.11-14. I handed out copies of the agenda for the conference and asked that all of you unable to attend to please review and identify the sessions that you would like me to attend. I will make every effort to bring back as much information that I can. The attending one day's sessions only is doable but arrangements must be made with Shelly Wilson prior to the conference: her number is 817 416-7202.

At our November meeting please let me know of your interests. I do know that there will be a lot of coverage on alternative treatments for TN.

A few weeks ago, I received E-mail from Rod Lawton, Bonnie Lawton's husband. Bonnie has been in a lot of pain lately. The pain is now in her right arm the same side as her TN, they were unable to determine the cause of the pain or to relieve it. Also her son had emergency surgery and will be requiring some care. They were scheduled to go to the conference but now may not be able to attend. I do hope that they will be able to attend the conference and our meetings. Bonnie and Rod are also new members. They are from Georgia. We all wish Bonnie well.

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**PLEASE** try to attend our November meeting. If you are unable to attend, please call me and let me know. I want us to have good attendance for Dr. Cioffi.

By this next meeting we will all know who our next President will be. This has certainly been a heated campaign. I hope that our state of Florida is not in the limelight again. I hope that you all got a chance to vote. I know that I always vote. I need to do this to cancel out my husband's vote. One of us will be happy

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

Leader Patty Hill --**904/285-5307** 106 Overlook Dr., Ponte Vedra Beach, Fl. 32082

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For calls to St. Augustine, Florida area: Charlie Doolittle – **904/797-2382**



**NOVEMBER 6, 2004 IS OUR NEXT MEETING DATE**



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