
**TRIGEMINAL NEURALGIA ASSOCIATION
NORTHEAST FLORIDA SUPPORT GROUP**



TIC TALK

SUPPORT GROUP MEETING THIS COMING SATURDAY

December 2, 2006 1:00 PM - 3:00 PM

PLEASE NOTE THE CHANGE IN TIME FOR THE MEETING TO START AT 1:00 PM



THIS MEETING WILL ALSO BE OUR ANNUAL CHRISTMAS PARTY

What an exciting meeting we had in November. A real good news story and a wonderful new addition to our meetings. Kathy Taylor (for awhile at least).

I'll start with our good news story. I mentioned in our last Newsletter that one of our newer members, Vivian McGee, was going to have the MVD in Gainesville. Well she did on Friday, October 27; and guess who was at our meeting Yes it was Vivian and she was pain-free, it was so exciting to have her attend the meeting only one week after her surgery.

Two years ago Vivian had the Gamma-knife and the positive effect only lasted 6 months. Her pain continued to get worse and she finally was referred to Dr. Freedman in Gainesville, for consideration for a radiofrequency (RFD). Dr. Freedman did not want to do the RFD and recommended the MVD. Vivian agreed to the MVD, but was very scared.

Fortunately Vivian has a very good friend, Anita, a registered nurse. who came down to be with Vivian during her surgery and recovery. Anita also attended our meeting.

Vivian and Anita told us a little about the surgery. The doctors made a quarter size hole in her skull behind her ear, he took a small part of her brain out (yes that's right) and found the problem, put a piece of Teflon pad between the artery and nerve and closed the hole up. The actual surgery lasted only 15 minutes, from 10:30 to 10:45. The surgery was on Friday and she was released to go home on Sunday. Her friend Anita watched her closely for complications, i.e. for infection, swelling or stroke. Fortunately Vivian had none of these. Anita would not let her do anything during this recovery time. **WHAT A GREAT FRIEND.**

Anita has been a nurse for 23 years and had never heard of TN. She said that this was a learning experience for her. We sent her home with the book "Striking Back" so she can become an advocate for TN patients. What a good news story. I should add that Vivian is only 50 years old, which made her a good candidate for the MVD.

News about some of our member that were in attendance:

Richard Bernhardt has had the balloon surgery at Mayo and is doing well. **Mary Lou McEver** is seeing Dr. Margaret Dennis for her TN pain. Dr. Dennis has prescribed a compound that Mary Lou applies to a denture device and uses about two hours a day. This compound settles the nerve and within a week was free of pain.

Dr. Dennis attended our meeting and is a great asset to our group. In addition to being a dentist she has completed a fellowship at the University of Kentucky Orofacial Pain center, one of only three degreed programs in the country. Her practice is now focused on the diagnosis and treatment of facial pain disorders. She works with compounding pharmacist to prescribe medications that can be applied topically for the treatment of pain. We are so fortunate to have Dr. Dennis take such an interest in TN and our support group.

Dr. Dennis said that she is treating George Farrell for his anesthesia dolorosa. She has been able to alleviate his pain by working on his neck.

Now for our next good news story: **Kathy Taylor** will be attending our meeting and providing support to our group until May. Kathy is currently attending the University of North Florida and is working on her masters degree in Rehabilitation Counseling Kathy has suffered from TN and expressed the desire to her professors to do her internship in the field of TN. Kathy's TN was a result of jaw problems. She found a doctor in Minnesota that was able to restructure her jaw and relieve her TN. She has since this meeting made a return trip for some fine-tuning on her jaw and is doing well. She works (for no salary) at the Gainesville, National TNA Headquarters. She loves what she does and says who else would pay to drive to Gainesville every day to work at the TNA office. She works with Alan Greco regarding the medications and treatment for TN.

She encourages us all to use the National office as a resource. She says she has never seen so much compassion as these folks have. There will be times when we don't always get along with our doctors, or we have an allergic reaction to our medications, or what works for one TN patient will not always work for another. These are times when we can use our National Organization for help; everyone there is so trustworthy. Fear accompanies facial pain. We need to have courage to get the treatment we need, and it sure helps to have a friend like Vivian's, ANITA. Many times is not a question about our medications. There are the social issues, depression and isolation. We need to take risks, step out and take control of your life and illness. There are ways to become whole again.

Kathy covered a few of the topics from the National Convention in Portland:

New Medications -Namenda is a new drug that is being tried on TN patients. It regulates the calcium in the system. Naturally, with the newer drugs it is very expensive. Kathy had a handout on this medication and it's the one I'm trying to get more information from my nephew, the pharmacist.

Treatments -Pulse Radio-frequency (PFR) is showing some success, it's minimally invasive, done on an out patient basis and the treatment lasts from 1-2 months. I will also try to have more information on this for you.

ONDAMED-biofeedback therapeutic device is also being tested for TN. Again, more info to follow.

Dental Issues

Kathy said there was a lot of coverage on dental in relation to TN. Dr. Henry Gremillion, DDS, who spoke at the conference, stated that if the dentists actually listened to their patients the diagnosis is there. Many times the pain is not true TN but travels along the Trigeminal Nerve pathway, i.e., atypical TN, TMJ and/or the need for a root canal. There is no definitive diagnostic criteria for TN. He warns beware of having a tooth pulled, when it may not be necessary. Make sure that your dentist understands TN and gives the anesthesia that does not affect the Trigeminal nerve. Your doctor and dentist should confer before any major dental procedure. Before a procedure see about getting and anti-anxiety medication, and work with

your neurologist to increase your meds before dental work. Your dentist should be flexible with your schedule for when your TN is OK.

Dental Hygiene:

-Avoid any product with alcohol, lubricate your mouth, use a soft toothbrush (Crest is hard, Oral B is good, infants toothbrush is good). Biotene products are good for mouth hygiene. *Dr. Dennis agrees that they are excellent products. The new generation of electric toothbrushes is good. Dr. Dennis said that if you can't brush at least use a washcloth to get the plaque off your teeth.*

Dr. Joanna Zakrzewska spoke at the conference and talked about Anesthesia Dolorosa. A few key points were to keep a pain diary to assist in minimizing amount of medication and achieve maximum cognition. She recommends cognitive behavioral therapy to help individuals become "expert Patients" and to regain control of their lives.

We will get more information on these subjects as the Conference material becomes available. I will have copies of the handouts at our December meeting.

Thank you Kathy for all this information. I was amazed at how quickly Kathy has become an expert on TN. She will be a great asset to our group while she is completing her work on her masters.

Mary Lou McEver talked briefly about the new Cyber Knife that Memorial Hospital is getting. It is a laser therapy and is said to be more accurate than Gamma. Mary Lou and I are working to have a presentation on the Cyber knife for either our January or February meeting.

I hope that the time change to a 1:00 P.M. for this next meeting will work for everyone. Kathy and I both have functions to attend later in the day, plus it allows those traveling further to get home before dark. At this meeting we can talk about the best time to start our meetings and when to schedule them. I have not reserved the meeting rooms for 2007 yet.

This meeting is our annual Christmas celebration so I will be preparing at the goodies as my gift to you. Please try to attend. Charlie will provide the entertainment, what would we do without him? I will also have some handouts for you to make the meeting be productive.

HOPE TO SEE YOU ALL THIS SATURDAY!

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THE NORTHEAST FLORIDA TNA SUPPORT GROUP MEETS THE FIRST SATURDAY OF EVERY MONTH FROM 2:00 P.M. TO 4:00 P.M. IN THE MEMORIAL HOSPITAL, 3625 UNIVERSITY BLVD, JACKSONVILLE, FLORIDA

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