
TRIGEMINAL NEURALGIA ASSOCIATION
NORTHEAST FLORIDA SUPPORT GROUP

TIC TALK



FEBRUARY 2003



Hope you had a Happy Valentine's Day full of warm fuzzy hugs and kisses! It's *love that makes the world go around* don't you agree? And it is caring for each other that makes our support group members come to our meetings even though they have found a solution to stop the pain of their TN they want to help those who are still having the horrendous pain of TN to find their solution. They don't just walk away and they are blessed because of their compassion! Give a friend a Big Hug today!

FOLLOWING ARE TWO ANNOUNCEMENTS THAT ARE MOST IMPORTANT FOR YOU TO KNOW AND REMEMBER!



1. THERE WILL BE NO MEETING IN MARCH BECAUSE OF THE TRIP TO THE McKNIGHT BRAIN INSTITUTE MARCH 5TH.
2. THE APRIL MEETING WILL TAKE PLACE THE 2ND SATURDAY OF THE MONTH ON APRIL 12TH INSTEAD OF THE 5TH AS ALL THE CLASS ROOMS IN THE MEMORIAL HOSPITAL EDUCATION WING WILL BE FILLED ON THAT DATE.

THE FEBRUARY 2003 MEETING PRESENTED VARIED AND INTERESTING INFORMATION AND EVEN A FEW SONGS



Ruth Eisen, Co-Group Leader opened the meeting by greeting all the loyal members who attended. A new member, Bill Peed, was introduced and asked to tell us about his history with Trigeminal Neuralgia. It turned out to be a most unusual story that he shared with us.

Bill was taking a nap when he had an excruciating pain that felt like someone had hit him with a baseball bat and it made him jump up feeling dizzy. He told his



wife something was wrong with him so she took his pulse and it was 30 (60 or over is normal.) They went to the ER where they gave him an EKG, stress test and a MRI. Next his doctor thinking he had a heart attack ordered a heart catheterization that was very painful. The pain then went away for a month, but came back the same way it did the first time. Then they were back at the doctors and hospital again seeing four eye, nose and throat doctors, dentists, oral surgeons, pain management doctors and nobody knew what it was.

Bill happened to have a friend that he explained the pains to and his friend said that his Mother had something like that, why didn't he compare notes with her? Bill did and called her on the phone and told her about the stabbing, pulsating, burning pain that was in his jaw and that it was so excruciating he didn't want to live. She said, "Bill, you have Trigeminal Neuralgia!" He was amazed that she could tell him over the phone what it was when all the doctors he had seen couldn't tell him what it was. She explained that she had also gone through all the same range of doctors and that finally her neurologist figured out what she had. That is how he got on Tegretol when he went back to his pain management doctor and explained to him he said, "Yeah, you're probably right, let's try this" and put him on Tegeretol He has been on it 3 weeks now and is up to 800mg, but so far it has not helped.



He heard about our Support Group when he was visiting a friend in the hospital who had been in an automobile accident and while there he met his friend's mother and in their conversation he started telling her about his condition. To his surprise she said, "You have Trigeminal Neuralgia." He asked her how she knew? How could a stranger walk up to me and tell me what I have? She gave him Rennie Manning's telephone number and he called and she told him what her symptoms were and they were exactly the same as his. Rennie gave him Patty Hill's number who told him where we meet, etc. and that is what brought him here today. Thanks Rennie!



Ruth told him we were very glad that he came and hopefully we can help him find a solution for his pain. His story was unusual in that we had never heard of TN being diagnosed as a heart attack before. It points out how very much this excruciating ailment needs to become known to all the doctors in every field of medicine. Our Association is working on that, and we need to do our share.

Pru Virtuoso our member who has not been with us for some time reported that her TN had come back with a vengeance. It hit her so bad that her sister wanted to take her to the emergency room. She is now on 1,800 mg. of Neurontin and Baclofin. When she first had the pain her kids thought she was having a stroke. She had to have work done on her car and while she was talking with the mechanic she mentioned the pain she was having. He said that sounded like the pain another of his customers had, and that turned out to be our long time loyal member, Charlie Mae Walton! Pru did go to her family doctor the next day and he fortunately knew what it was right away. So, as she summed up, the way she got started with our group was through Charlie Mae's mechanic that worked on both of our cars. Don't they call that "Serendipity?"



Pru tried Tegretol as she was on 3,600mg. of Neurontin and she said she was "going bananas" on it. Dr. Boggs put her on the Tegretol and she took two doses and had a bad allergic reaction to it. She went back on Neurontin and Baclofin with

the “Sleeping Tiger” feeling that it would hit her again at any time and it did hit her the night before our meeting and she agreed with Bill who said he felt like he would rather be dead than endure the pain of TN. She plans to go back to Dr. Boggs and perhaps have a Glycerol Injection.

Ruth then welcomed back the Kellys, Rita and Richard who are “Snow Birds” from Butler, PA that spend part of their winter in St. Augustine. Rita told us that she hadn’t been taking any Neurontin for months until a few weeks ago she would get just a little jab now and then so her Neurologist said just to go back on one or two a day. Rita says it works for her to put ice packs on her face when the pain hits. When she goes off her strict diet it will come back. She always stays on B-12 and uses what is called “dots” that she gets in health food stores that go under your tongue. Their nutritionist does not believe in pharmaceuticals and believes anything that can be cured by drugs can be cured by nutrition. Rita is going to bring a list of things that comprise her diet at the next meeting.

(The next meeting will be April 12th, please don’t forget!)

RUTH EISEN IS STEPPING DOWN AS CO-SUPPORT GROUP LEADER AFTER 8 YEARS OF SERVICE



This announcement was made by Ruth who explained that after eight years she was “burned out” and that her health and her husband’s health had been of some concern in the past several months so with mixed feelings she decided it was time to turn the reins over to Patty Hill who volunteered to take on the position of Co-Leader some months ago. Ruth will continue to write Tic Talk and come to the meetings. She will also help Patty as much as she can while she is learning what her duties consist of. The membership owes Patty a vote of thanks because it is a job that has a lot of responsibility attached to it. It can be time consuming and although it is rewarding knowing you are helping so many people find solutions to their pain, a lot of help and support is needed from the members to accomplish all the jobs that have to be done. A Co-Leader is really what is needed!



Ruth then entertained the members by singing two songs in honor of St. Valentine’s Day. Phyllis DiStefano accompanied Ruth on the piano. The songs were “My Funny Valentine” and “With A Song In My Heart”.



The meeting was then turned over to Patty Hill who told the group that Laurice Hunter had already offered to help her in her duties as Co-Group Leader and she was grateful to her for that. Patty then showed the video she had made of the program that had been on TV January 31st called “Life Moments” that had a segment of 15 minutes concerning an MVD operation performed by Dr. John Alksne a neurosurgen from the San Diego Medical Center on a lady who had TN and had been in pain for 7 months. It was very good publicity for the TN Association’s Goal to acquaint more people with what TN is and to give hope to those that have it by letting them know there are procedures for it.

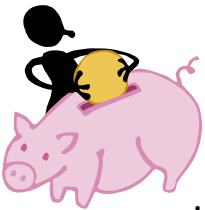
After the video Patty passed out copies that she had reproduced of the handouts that were given to those attending the Conference in San Diego. Most of them were testimonials of things that people had found that helped them. Some of them are nutrition based and B-12 kept coming up and the role that opiates play in helping you. Some of our members have used a morphine patch and have been able to function while on it. Every one was appreciative of Patty doing this for the group!

The meeting was adjourned and it was Refreshment Time! It was a good meeting with 18 in attendance.

REFRESHMENT TIME !!! YES !!!



Betty O'Gallagher was responsible for making us all about 10 lbs. heavier than we were when we came to the meeting! She had an out-of-this-world Strawberry Cake that melted in your mouth! Brownies to die for, and oatmeal cookies, all homemade! She also had cheese and crackers and candy for us. You see why we gained all that weight? But it was worth it! She also furnished the drinks! Thanks very much Betty.



TREASURY REPORT

We had a super collection this meeting as one of our members paid for the rest of the year in one lump sum. Thanks to Nick Vetro and his wife who live in Flagler Beach that is a good distance from us. They can't always make the meetings, so by paying ahead he feels he has contributed his share even if he can't be here. That's what I call Loyalty and Support! Thanks to the rest of our members also for their generous contributions. This collection deserves a 5 oink salute! Oink, Oink, Oink, Oink, Oink

APRIL 12TH MEETING will include a report about the trip to the McKnight Brain Institute by the members who made the trip. If time permits one of the shorter videos may be shown also. Your Editor hasn't conferred with Patty about her plans for the meeting, but I will put them in the March edition of Tic Talk.

DISCLAIMER: This newsletter is not intended to diagnose, prescribe, or to replace the services of your physician. We offer information about our member's experiences, medicines and procedures for TN. This Support Group is not advocating any particular course of action for anyone and our speaker's opinions are their own.

ABOUT SUPPORT GROUPS

This is an excerpt from an article in the San Diego Support Group's newsletter, "Tic News" that is written by Kay Holiday.

Dr. Ken Casey who collaborated with George Weigel on writing the basic book on Trigeminal Neuralgia called "Striking Back" spoke at the TNA Conference at San Diego the first night of the Conference. One of the outstanding characteristics of Dr. Ken Casey is his warmth and understanding of our problems. He started by saying that many doctors in the United States are uneasy about support groups for various reasons. They are afraid of the interchange of ideas and information at support group meetings that might not include the whole picture for a patient but admit an informed patient is a better patient. Of course, some don't like anyone "treading on their turf" and with others it is just a financial problem when patients change doctors and procedures. He also talked about many support groups now in Germany who get together once a month to exchange ideas of how to improve Support Group meetings.

The characteristics of a good support group are that they are supportive and educational; have many willing volunteers to do the many tasks involved; complete confidentiality is important; shared leadership, non-profit and commitment to personal change. They touched briefly on "leader burnout" which happens all too frequently.

At support group meetings it is important to have greeters at the door to meet new people who are feeling shy and insecure at their first visit to a group. It is also good if the greeters can sit with newcomers to make them feel comfortable and introduce them to others who have TN. One of the most important things many people seem to get from the meetings is to learn that they are not the only ones who have this awful pain. People can help people with understanding, warmth and information.

Dr. Casey stressed that you should never give up HOPE – You are in charge of your own body and you should do something to help stop the pain. The support groups help you to go from being a victim to getting information that will put you in charge of your problem. You will have to learn the names of many new medications for TN as well as the names of various procedures that may help you. But, at least, you will be able to understand what the doctor is saying to you.

Ask the doctor why he picked that particular medicine and what side effects it might have and what to do if you miss a dose, how long before the medicine takes effect and you will be out of pain. Most Americans don't pin their doctors down to answer their questions in words they can understand. Patients should also ask doctors how many of the procedures they have done, what percentage was successful and how many deaths have occurred from that procedure. It is also important to keep your personal doctor informed of what medications and/or procedures other doctors have ordered for you.



Editor's Note - Thank you Kay for letting us use the above article. Your newsletter always has good information in it! Keep up the good work!

**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

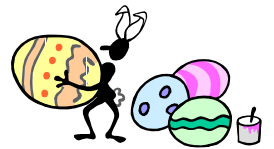
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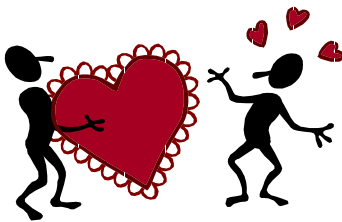
APRIL 12, 2003 IS OUR NEXT MEETING DATE



Report on trip to McKnight Brain Center in Gainesville, Fl. will
be given by members who made the trip. The remainder of the program
will be printed in the March edition of Tic Talk. Note the date change from the
1st Saturday to the 2nd Saturday of the month. This is only a temporary
change.



Northeast Florida TNA Support Group
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*Happy Valentine's Day to all
Especially The many Support Group
Members who are truly Participants
And not just Spectators! Bless You!*