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**TRIGEMINAL NEURALGIA ASSOCIATION  
NORTHEAST FLORIDA SUPPORT GROUP**

**TIC TALK**



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**MAY 2003**



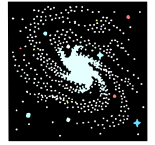
**WHY THE TEARS?** Because my friends this is the last issue of Tic Talk that your editor, Ruth Eisen, will be writing. After almost 9 years of writing it every month that we have had a meeting, I feel like I am abandoning my baby! But I know it is time for me to turn this important task over to someone else. This is the month of my 80<sup>th</sup> birthday and my body tells me it is time to sit back and relax and to have more time with my five great grandchildren and take time to indulge in my hobby of watercolor painting, I have enjoyed bringing you the events of our support group meetings, the information our speakers had for us, and the news of our fellow members while throwing in a little humor along the way. I know it is important for a group to have a newsletter and fortunately our new leader Patty Hill has said she would try and get one out even if she is not “computer literate.” I remember how unorganized my first newsletters looked, but no one cared as long as I brought them the news of our support group. We are fortunate to have Patty who is doing a great job as leader and so willing to do what is necessary to keep our group alive! Please help her all that you can! I will be seeing you at the meetings!

**REPORT OF THE MAY 3, 2003 MEETING OF THE NORTHEAST FLORIDA  
TNA SUPPORT GROUP IN JACKSONVILLE, FLORIDA**

Patty opened the meeting with a welcome to all the members present and two new members, *Loretta and Arthur Pete* from Palm Coast, Florida. Loretta spoke to the group and told the familiar story of having the excruciating pain that she thought was being caused by a bad tooth. Her dentist pulled several until it became obvious that her teeth were not the source of her pain. He told her to go to an oral surgeon who told her not to have any more teeth pulled as she had trigeminal neuralgia. He put her on Tegretol, however it made her very ill. Her children talked her into going to a pain clinic and they put her on 300mg of Neurontin that helped her and now her pain level is a 4 instead of a 10.

Loretta called Ruth Eisen, whose name she got from the internet and she sent her “The Striking Back Handbook” that she has read from cover to cover and carries with her wherever she goes. She has shown it to her neurologist and primary doctor. Loretta sent our group a generous check and we appreciate that gesture very much. We were so happy to hear Loretta’s story and to meet her

husband Arthur. Loretta said if that excruciating pain comes back they can just cut her head off! We hope that doesn't happen because we can see that this couple will be a great addition to our support group!



### **DAILY POINT OF LIGHT AWARD SHOWN TO MEMBERS**

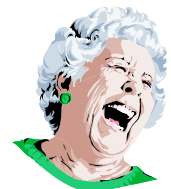
Ruth Eisen told the members that she had received through the mail the “*Daily Points of Light Award*” presented to the *Trigeminal Neuralgia Association Support Group Leaders*. A letter with it from Beth Heitman, Support Group Coordinator congratulated the Support Group Leaders and explained that The Points of Light Foundation, organized to recognize exceptional volunteerism, chose the Support Group Leaders of the Trigeminal Neuralgia Association as the recipient of the Daily Point of Light Award for Wednesday, March 26, 2003. The Trigeminal Neuralgia Association was presented with the national award by the Volunteer Center of Alachua County on behalf of the Points of Light Foundation & Volunteer Center National Network. There were also congratulatory letters along with the copy of the award from President George W. Bush and former president George bush who have endorsed the revived Daily Points of Light Award. The award we received is for Patty Hill, Support Group Leader, and Ruth Eisen, former Support Group Leader.

### **INTERESTING VIDEO ENJOYED BY MEMBERS**



A video, featuring Dr. Bradley Eli, DDS. and made from a presentation given at the 4<sup>th</sup> Conference of the Trigeminal Neuralgia Association in San Diego, California in November, 2002 was shown to the members. It included some facts about dental problems and how they affect the trigeminal nerve that shed some light on why so many who have TN believe that it is a bad tooth that is the cause of their pain. If any of the members who were not present would like to see the video they can borrow it from our Video Library and keep it for a month. Sign it out with Patty and she will bring it to the next meeting for you.

### **TIME FOR A LITTLE HUMOR**



#### Ten Top Indicators that your Employer has changed to a cheaper HMO.

1. Your annual breast exam is done at Hooters.
2. Directions to your doctor's office include “take a left when you enter the trailer park.”
3. The tongue depressors taste faintly of Fudgesicles.
4. The only proctologist in the plan is “Gus” from RotoRooter.
5. The only item listed under Preventative Care coverage is “An apple a day.”
6. Your primary care physician is wearing the pants you gave to Goodwill last month.
7. “The patient is responsible for 200% of out-of-network-charges” is not a typo.

8. The only expense covered 100% is embalming.
9. With your last HMO, your Prozac didn't come in different colors with little M's on them.
- 10 And the sure sign you've joined a cheap HMO: You ask for Viagra; you get a Popsicle stick and duct tape.

It's always so good to laugh!

**REPORT FROM RITA KELLY THAT WAS PRESENTED AT THE APRIL 12<sup>TH</sup> MEETING ABOUT A DIET THAT HELPS CONTROL HER TN PAIN**



Due to lack of space in the April Tic Talk this report could not be included in that issue. Following are excerpts from her talk.

Several copies of the diet and regiment that Rita follows had been copied by Patty and were handed out to the members. The Lemole Program for Trigeminal Neuralgia was a diet plan that cautioned the recommendations should only be used with the guidance of your physician. That you should not self diagnose!

**OPTIMAL DIET:** Basis for all health – same diet to reduce risk of all major degenerative disease – life enhancing

**DIET:** Eat a health supporting high fiber, good fats (flax seed oil/olive oil, avocados, DHA eggs) diet including vegetables, fruits, whole grains, beans and soy products. Eat cold water fish such as salmon, cod, herring, tuna and mackerel. Include ample amounts of garlic and onions. Take flx seed oil 1 to 2 Tbs. Daily on a salad or in juice or ground flax seed 1 to 3 Tbs. Daily on cereal. Keep refrigerated. Do not heat.

The other topics covered were Vitamins, Minerals, Amino Acids, Essential Fatty Acids and a Magic Drink recipe was included. There was also a Recommended Reading list: (1) The Healing Diet by Gerald M. Lemole, M.D. (2) Eight Weeks to Optimum Health by Andrew Weil, M.D. (3) The 22 Non Negotiable Laws of Wellness by Gary Anderson.

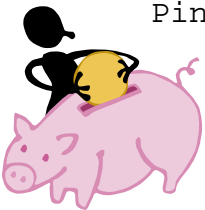
Articles on the following were also distributed to the members: Distilled Water, Meats and Soy Meat Substitutes, Recipes, and Meal Planning and Main Dishes.

**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.

Rita also shared with us her Personal Check Off Sheet that showed what she should drink, and eat through the day. Rita gave us some information pertaining to the list. She had done almost everything on the list except take Vitamin B12 so she found a doctor that would give her the shots. A nurse she knew then volunteered to give her the shots. Ruth Eisen told the group that her VA doctor informed her they could take a blood test to see how much B12 she had in her system and then they would give her the shots if she needed them. Ruth hadn't known they could do that. Rita said she had asked her doctor about perhaps getting too much B12, but he said not to worry about that because you can't get too much. Rita now gets her B12 at a health food store and they are called "Dots" and are small pills that you put under your tongue and they dissolve immediately and get the B12 into your blood stream that way. They come in different strengths. Jane Ferrier at one time took 1 cc in shot form once a day for a week, and then they reduced it to 3 times a week and now she takes it only once a week. She said it made her feel great.

Be sure you avoid artificial sugar and hydrogenated oil is a no-no because it stays in your body and never leaves it and becomes just like plastic. Rita believes this is a cause of strokes because it thickens up in your body. Other foods were discussed and then Rita told us about her nutritionist's treatment. He tested her urine and saliva and then went over the Personal Check Off Sheet with her every time she went in and would increase what she needed to be taking, for instance Rita needed more potassium. Rita is a strong advocate for the use of distilled water. Ask for these handouts at the next meeting if you had to miss the meeting as there might be some extra copies. Patty thanked Rita for her talk and for sharing her information with us. For those of us with TN it is most important to keep our bodies in the best physical condition because it helps the myelin sheath regenerate if it has been damaged and thus will be able to protect our trigeminal nerve again.

### TREASURY REPORT



Pinky says that this is a sad day **for him** cause it is the last time he will get to give you his report on our treasury. It has been fun and never fear he will still be taking care of the money in his big piggy bank for you! This last report is a good one because not only did we get a good collection from the members who attended the meeting, we received a most, most generous check from Marilyn Bain who is unable to attend our meetings but has enjoyed the newsletter. She will still receive one from our Group Leader, Patty Hill and we are most grateful for Marilyn's contribution. That calls for a 4 oink salute! OINK, OINK, OINK, OINK!

THE NEXT MEETING WILL BE JUNE 7<sup>TH</sup>! PLEASE PLAN TO ATTEND! IT WILL BE THE LAST MEETING UNTIL SEPTEMBER 2003. WE DO NOT MEET IN JULY OR AUGUST AS TOO MANY MEMBERS ARE ON VACATION AND THE WEATHER IS TOO HOT. DON'T FORGET.

**ARTICLE BY DR. DONOHUE ABOUT TRIGEMINAL NEURALGIA  
APPEARED IN THE ST. AUGUSTINE RECORD ON MAY 12, 2003.**

Dr. Paul Donohue is a syndicated columnist who answers questions sent into him by his readers. It is such good publicity for our cause because his column is printed in many newspapers throughout the U.S. and he has given information on how to reach the TN Association on the Internet and their address in Gainesville, Florida. Following is the article as it appeared:

**NERVE IRRITATION CREATES UNBEARABLE PAIN**

Dear Dr. Donohue: I was diagnosed with trigeminal neuralgia three years ago. I have taken Tegretol and it thankfully dulls the pain. Although the episodes come closer and last longer, I am coping with the pain. How do I explain this condition to a mother-in-law who thinks she knows everything and sees my pain simply as a headache? She lives with us. – N.R.

ANSWER: The trigeminal nerve is the nerve that transmits sensations from the face to the brain.. Trigeminal neuralgia is an irritated trigeminal nerve. The irritation gives rise to one of mankind's most agonizing pains. The painful episodes are brief, but patients live in constant fear that another spasm is about to happen. Brushing the teeth, washing the face, even the light touch of a gentle breeze on the cheek can spark an explosion of indescribable agony.

There are a number of medicines that can dull the pain and permit a person to cope with this affliction. In addition to your Tegretol are Lioresal, Topamax and Neurontin. When medicines bring no relief, then an attack on the nerve can often put an end to the problem. Injecting the nerve with glycerol or destroying it with a probe that emits radiofrequency current are two such procedures..

One explanation for the nerve irritation postulates that it comes from the pulsations of an artery that encircles the nerve. A skillful neurosurgeon can interpose a small sponge between the artery and nerve, and that frees the nerve from the irritating artery pulsations. If you have a computer, visit the Web site of the Trigeminal Neuralgia Association, [www.tna-support.org](http://www.tna-support.org), or write to the association for information. The address is 2801 SW Archer Road, Suite C, Gainesville, FL. 32608. The association can provide you, your mother-in-law and all trigeminal neuralgia victims an up-to-date summary of the illness and it's treatments. That ought to make your mother-in-law a believer.

REFRESHMENT TIME



Laurice Hunter brought a delicious dark chocolate cake that no one could resist! Also a blueberry coffee cake and a cheese coffee cake! Thanks so much for all those goodies Laurice! Once again there were only crumbs left and those were on Fat Cat's whiskers. He is sorry he won't be available to tell you what the refreshments were after this issue of Tic Talk, but he will be at the meetings with his knife and fork to help the members enjoy the desserts brought in by the members!

**TRIGEMINAL NEURALGIA ASSOCIATION**

**INFORMATION, SUPPORT, ENCOURAGEMENT**  
2801 S.W. Archer Road, Suite C, Gainesville, Fl. 32608  
Phone 352-376-9955  
- Patient Information (904)779-0333 Fax (904) 779-7681 e-mail: tnanational@tna-support.org

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

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Editor: Ruth Eisen – 904/471-6185 16104 Harbour Vista Circle, St. Augustine, Fl. 32080

Contacts for information about group: Local Calls: Patty Hill – 904/285-5307  
For calls to St. Augustine, Florida area: Charlie Doolittle – 904/792-2382



**JUNE 7, 2003 IS OUR NEXT MEETING DATE**



**After the June 7 meeting we will not meet again until September 6, 2003. We do not meet in July or August. Mark your calendars now so you don't show up and find no one there but others who did not get the word Or had a Senior Moment!**



**Northeast Florida TNA Support Group**  
Ruth Eisen, Editor  
16104 Harbour Vista Circle  
St. Augustine, Fl. 32080



**Good Bye from Pinky, Ruth  
and Fat Cat! We will miss you!**