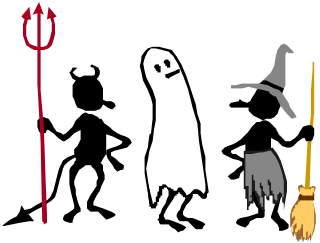

TRIGEMINAL NEURALGIA ASSOCIATION
NORTHEAST FLORIDA SUPPORT GROUP

TIC TALK



OCTOBER 2003



Better watch out for all spooks because that is your former Editor, Ruth Eisen, in that sheet come back to haunt you! Seriously, your Leader Patty Hill, is making a trip to Germany and Italy and will not have time to get a newsletter written. So I volunteered to do it for her this month.

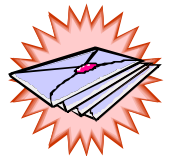
NOTICE: OUR NEXT MEETING WILL BE NOVEMBER 1, 2003

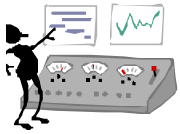
**NORTHEAST FLORIDA SUPPORT GROUP MEETING OF
OCTOBER 4TH, 2003**

Patty Hill opened the meeting with a warm greeting to the members, and welcomed a new member, *Dorothy Lederman*, who told us of her TN history later in the meeting. Patty then read correspondence from the Association office that covered several topics that are listed below.

CLAIR PATTERSON: Excerpts from a letter written by Roger Levy, Chairman of the TN Association Board of Directors about Claire follows;

From the humble beginnings of a kitchen table assembly, Claire Patterson has taken TNA to the status of a national organization, respected as an agent for change by its broad constituency of supporters. Now after almost 13 years of continuous growth and success, TNA, the agent for change, is to undergo changes of its own. As you know, Claire, as our founder, has served as President and CEO since inception. She established our Mission, initial goals and objectives and, with the aid of those she gathered around her, the vision that allowed TNA to grow and flourish. As the organization grew, she has overseen the daily operations of the Association, while continuing to further its outreach to patients, the professions and to the public at large. More recently, she has overseen the closing of the national office in Barnegat Light, the transition to our new home in Gainesville, the engagement and training of our new staff and implementation of our operational procedures.





Now it is time for Claire to focus on those aspects of TNA's affairs where her knowledge and expertise can be put to the broadest and most effectiveness use. Remaining on our Board of Directors, she will assume a new volunteer status as Director for Research and Institutional Relations. Consequently, effective July 1, 2003, Claire will cease to manage the daily operations of TNA and will no longer serve as President and CEO. As our Founder and Director for Research and Institutional Relations, Claire will act as TNA's representative with our Medical Advisory Board to facilitate better utilization of their medical expertise; expansion of patient educational materials, both through TNA publications and our website; stimulate effective use of the data available in our Patient Registry; assist in the efforts of the Medical Advisory Board special projects, such as the establishment and operation of a Dental Task Force; encourage and participate as needed in the development of clinical trials with pharmaceutical companies; assist in the development of a Scientific Advisory Board to promote research on TN and related facial pain conditions and continue our liaison efforts with NIH to promote research projects and increase awareness of TN and related conditions.



Her new role will allow Claire and Buck to return to Barnegat Light, from where she will be able to travel on TNA business, as the need arises. We are sure you will want to join with the members of our Board and the Medical Advisory Board in wishing Claire and Buck continued good health and happiness as they enter yet another new phase in their lives.

CHALLENGE GIFT PROGRAM: This program will allow a donation to be matched dollar for dollar up to \$5,000, to the extent that your new gift exceeds your previous gift. For example, if your last gift to TNA was \$150 and you now give \$225, \$75 (the extra you gave this year) will qualify for the match and TNA will receive a total of \$300. Under this Challenge Gift Program, TNA stands to gain an additional \$100,000 in matching gifts this year. Please recognize the leadership of our Founder, Claire Patterson by making your gift now!



Patty asked the members if they would be agreeable to donating \$200 from our Treasury Fund as our contribution to this program as our support groups recognition of the outstanding work that Claire Patterson has done. Because we donated \$100 last year, that means \$100 of this donation would be matched and we would be giving a total of \$300. A motion was made and seconded that we should do this, and after a showing of hands of those in favor, the motion passed.

If you as an individual usually donate each year to the Association and intend to this year, and any who want to donate for the first time, this would be the ideal time to do it. It will also assure that you will receive the TN Association newsletter, "TNAAlert" that contains pertinent information on any new developments in procedures and medicines for TN and news about your Association. Send check or Money Order and make payable to: Trigeminal Neuralgia Association, 2801 SW Archer Road, Suite C,

Gainesville, Florida 32608 In the Memo space put "Challenge Gift Program".



TREASURY REPORT: John Vigneaux, Treasurer reported that as of 09-06-03 we have \$1,103.99 in the treasury. After the \$200 donation is subtracted we will have \$903.99 balance. Thanks so much John for keeping our treasury accounts up to date for us. You are greatly appreciated!

TRIP TO BAPTIST CANCER INSTITUTE: Patty told the group that she had been in touch with one of the personnel at the Institute about the Gamma Knife machine that is now in operation there. She was invited to visit them and they would show her the facility. Patty was impressed with their set up and asked if they would have a speaker available to speak to our group. She was told that they could furnish a speaker, or if our members would be interested in visiting the Institute they could arrange for us to take a tour of the facility.

The group was interested in the tour and Patty is going to see if we could do it on a Saturday, or if not, what day would be available. Patty will let us know as soon as she receives that information. If this can't be worked out we will arrange for a speaker from the Institute to speak to us.

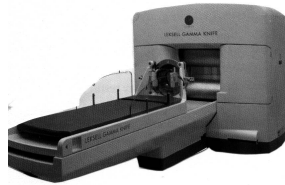
UPDATES ON THE MEMBER'S TN STATUS:

Al Hummel told us about his Gamma Knife treatment that he had at the Baptist Cancer Center last month. It is fortunate that we have already had one of our members take advantage of the availability of the Gamma Knife so he could give us his evaluation of it.

Al told us he was surprised that he was in and out on the same day. He described the procedure which involves putting a stereotactic head frame on your head which lets them take measurements of your head to plan the dose of your treatment, and help guide the treatment itself. It is attached to your head with four pins after you've been given a small amount of local anesthetic to help keep you comfortable. Al said that for him that was the only painful part of the procedure. Imaging tests were done with the head frame in place and an MRI and CT scan were done. After resting you are moved to the Gamma Knife treatment room, where you are placed on a comfortable motorized table. The frame on your head is attached to a large steel helmet that has many holes that allow the team to focus the radiation on the precise area of treatment. The table slides into the GK unit and your procedure begins. (I apologize that I don't remember how many minutes that Al told us he was having the radiation, but I believe it was about an hour. I will have to confirm that with him). Al said that there is no pain and you are

awake unless you want a sedative. After the procedure the head frame is removed and then they observe you before you are released.

Picture of Gamma Knife



Al was told it could take some months before the effects of his treatment will occur. However, Al told us his pain has already lessened, but he is continuing his medication and will go off of it slowly when his doctor advises him that he can. Extended observation, including periodic diagnostic imaging tests, will be required. Al has previously had a number of procedures done and that always lowers the chances of the GK working as well as it would if he hadn't, but the signs look encouraging for Al and we wish him the best. We are grateful to have his first hand account.

New member, Dorothy Lederman, told us about her Trigeminal Neuralgia Dorothy first experienced her TN pain about 4 years ago after a dental procedure (sound familiar?) She is now on four Tegretol tablets taken through the day, and takes three Neurontin tablets at night. She often feels unsteady, nervous and drowsy and these are the side effects that most TN patients experience from the anticonvulsant medicines that we take for TN. We are happy that Dorothy has joined our support group and hope we can help her through the experiences of our members, and our support. We are looking forward to seeing you at the next meeting, Dorothy!



REFRESHMENT TIME

Ruth Eisen brought the goodies. Home made chocolate chip cookies, and a white cake decorated with Halloween characters. A cheese ball and crackers were also furnished. We all pigged out as usual! Drinks were available also brought by Ruth. It would be nice if we had coffee available. Has anyone any ideas?



TIME FOR A LITTLE HUMOR

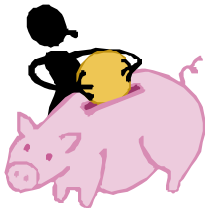
GREAT TRUTHS ABOUT GROWING OLD

- 1) Growing old is mandatory, growing up is optional
- 2) When you fall down, you wonder what else you can do while you're down there.
- 3) Wrinkles don't hurt.
- 4) It's frustrating when you know all the answers, but nobody bothers to ask you the questions.
- 5) Laughing is a good exercise. It's like jogging on the inside.



THE FOUR STAGES OF LIFE

- 1) You believe in Santa Claus.
- 2) You don't believe in Santa Claus.
- 3) You are Santa Claus.
- 4) You look like Santa Clause.



TREASURY REPORT

Hello! Pinky is back! Had a nice vacation but it's great to be called back to duty for this issue. We had a good collection once again, as usual. You guys are still the greatest. Thanks also to member Katherine Mosby who sent us a very generous check even though she can't come to our meetings as she lives in Lake City and doesn't drive. We appreciate loyal members like you Katherine!

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.

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.**

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

Contacts for information about group: Local Calls: Patty Hill – 904/285-5307
For calls to St. Augustine, Florida area: Charlie Doolittle – 904/797-2382



NOVEMBER 1, 2003 IS OUR NEXT MEETING
DATE --- MARK YOUR CALENDAR NOW
PLEASE COME ! WE NEED YOU!



Northeast Florida TNA Support Group
106 Overlook Drive,
Ponte Vedra, Florida 32082



**WATCH OUT FOR THE LITTLE TRICKSTERS
HAPPY HALLOWEEN!**

