



**TRIGEMINAL NEURALGIA ASSOCIATION
TEXAS SUPPORT GROUPS
March 2005**

ALERT: GABITRIL – 2/22/05

The FDA and Cephalon, Inc. notified healthcare professionals and the public that a Bolded Warning has been added to the labeling for Gabitril (tiagabine) to warn prescribers of the risk of seizures in patients without epilepsy being treated with Gabitril. The FDA has received reports of the occurrence of seizures in more than 30 patients prescribed Gabitril for conditions other than epilepsy. Most of these uses were in patients with psychiatric illnesses. Such off-label prescribing is a common practice among physicians. Because of the risk of seizures, however, in addition to adding the Bolded Warning to product labeling, the sponsor has agreed to undertake an educational campaign, targeted to healthcare professionals and patients, in which such off-label use will be discouraged.

Read the complete 2005 FDA MedWatch Safety Summary, including links to the Public Health Advisory, Drug Information Page, Dear Healthcare Professional letter and revised label, at: <http://www.fda.gov/medwatch/SAFETY/2005/safety05.htm#Gabitril>

BOTOX TRIAL

U.T. Southwestern Medical Center in Dallas is conducting a Botox trial on TN patients *who also have Multiple Sclerosis*. There is no cost to be included in this study and a few of our support group members are already enrolled.

If you are interested in learning more about this study, please call Jill Fowler at U.T. Southwestern's clinical trials office at 214-648-3613.

EAST TEXAS VOLUNTEER OPPORTUNITY

The East Texas Support Group needs volunteers to assist Ramona Smith, the Support Group Leader, with meeting preparation schedules. If you can assist her, either e-mail her at bowood@lci.net or call her at 903-569-6176.

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.

TNA NATIONAL CONFERENCE 2004 PATIENT SURVEY RESULTS

The top rated sessions were:

- Panels examining several approaches
- Management of facial pain
- Dental care
- 3D Neuroanatomy presentation
- Dr. Sprinkle's alternative therapy – The Omura Protocol

The best things about the conference were:

- Information and networking
- Well put together
- One on one time with the doctors
- The doctor's availability to answer questions

The one outstanding thing they learned was:

- They are not alone
- New research
- Microvascular Decompression (MVD)
- Alternative Treatments
- Motor Cortex Stimulation

Don't miss the 2006 TNA National Conference. Mark your calendars! TNA's 6th National Conference will be held at the Doubletree Hotel, Lloyd Center, September 14-16, 2006 in Portland, Oregon.

TEXAS NEUROLOGY CONFERENCE

Thank you to Joyce and Bill who donated their time last month to work the TNA exhibit booth at the Texas Neurology Conference in Austin.

DO YOU HAVE RELATIVES WITH TN?

Just before Nancy's 5th birthday, she started living in a foster home and for many years had almost no contact with her birth family. Her TN started at age 46 and she is now 67. It was very chronic for many years but stable and well controlled most of the time now.

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.

Nancy had TN for about 3 years before she found out that her birth mother also had TN. She was the last of 6 children and to date, none of her siblings has it and none of their children or Nancy's children have it.

Nancy's oldest daughter is 46. She has great concern at times that one of her daughters or grandchildren would have it later in life.

Nancy has made many changes in her life to cope with TN and feels they have all been worth it. She recently retired after 30 years in the medical field. She can remember only one day when she missed work but none due to TN. On the days when her TN was bad, she pointed to her face and all of her co-workers knew she did not talk to anyone on those days which helped. She was blessed with a job that made it possible for her to speak only when needed.

Nancy has an out-going, Type A personality. She's always busy and enjoys being a part of most everything around her so for her to tone that down was difficult. She just knew she did not want the TN pain. She now walks softly, speaks softly, and never uses the phone on the side she has TN, never chews gum and doesn't cry. If she gets upset or worried about something, she asks herself if it is worth it.

Nancy hopes that by sharing her story, she will help someone else in our support group as her heart goes out to you.

DID YOU KNOW...

According to data compiled by the Journal of Neurology, the Trigeminal Neuralgia Association, the University of Cincinnati Medical College, and the Mayo Clinic, Rochester, Minnesota...

- The percentage of TN patients with a family history of TN: 5%

Source: Striking Back! The Trigeminal Neuralgia and Face Pain Handbook, pg. 3.

BELL'S PALSY & TN ON THE SAME SIDE OF THE FACE... A COINCIDENCE?

Has anyone in our support group experienced Bell's Palsy on the same side of your face as where you experience your TN pain? Ronnie, one of our new support group members, would like to know.

Ronnie came down with TN on the left side of his face last October (right after turning 51). Coincidentally, he has had three episodes of Bell's Palsy on the same side, about 8 years apart (last one was 1992).

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.

Ronnie's doctor told him there are two separate nerves involved so they have nothing to do with each other. However, Ronnie noted that both problems have the same ultimate treatment, decompression surgery.

If you have an experience to share, please contact Shelly Wilson either via e-mail at swilson@tna-support.org or send a letter to 604 Aberdeen Way, Southlake, TX 76092.

UPDATES FROM OUR MEMBERS

Last month, Mike had a MVD by Dr. White with UT Southwestern in Dallas. He's doing great! 10 days after his MVD, he went back to his desk job part-time.

Sharon also had a MVD by Dr. White last month. She's at home on her way to recovery.

Please keep John in your prayers. He had a tough 6 weeks with TN pain and lost 12 pounds. However, he has switched his medication from Baclofen & Lamictal to Trileptal due to headaches and has since had three pain-free days.

Jesse had a MVD by Dr. White last summer. He reported he's got his life back. He's pain free and medication free, back to work, and feels like he is living again. Hurray!

After having shingles along the top center of her hairline, Sharon began having trigeminal neuralgia on the right side of her face which was further aggravated by TMJ. Her internist prescribed 300 mg of Neurontin at bedtime and it relieved the pain. However, after about a year, the pain and constant tightness in her jaw began to bother her again. Through a business opportunity, she met Dr. Brian T. Hickey, Chiropractor and Applied Kinesiologist. He began treating her for a number of symptoms, and after the first treatment, she could tell a tremendous difference. She is pleased to report that she has been completely off of the Neurontin medication, as well as some other medications, for about two months. Dr. Hickey has two office locations: Arlington Natural Wellness Center located at 1201 Road to Six Flags, Suite 103 in Arlington, and Advantage Health Care located in the Atrium at 1333 W. McDermott Dr., Suite 230 in Allen. His phone number for appointments and information is 817-461-2697.

Martha had a MVD in November. She was pain-free for six weeks and was able to decrease her Tegretol from 1200 mg/day down to 100 mg/day. Unfortunately, the pain gradually returned but never as bad as it was before the MVD. She's had to increase her Tegretol back up to 700 mg/day to control her pain which has been very discouraging. Please keep Martha in your prayers.

Pat had a lot of pain for about six weeks. A week ago, her doctor found a medication that has taken away her pain for the last few days. It is called Zonegran, an antiepileptic drug that only has to be taken once a day. Hurray!

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.

If you would like to share an update with our group, please let Shelly Wilson know. Send an e-mail to swilson@tna-support.org or a written note to 604 Aberdeen Way, Southlake, TX 76092.

MEETING NOTES

Dallas Meeting – December 1, 2004:

Tom Clark with Social Security was the guest speaker. Special thanks to a suggestion by Brian Bogard with Edward Jones who can be reached toll-free at 877-428-1577 for your financial management assistance.

In order to qualify for Social Security disability, you must have worked 5 out of the last 10 years before filing for disability and you expect to be disabled for 12 months or more.

Tom provided us with helpful hints when applying for Social Security disability.

1. Put down everything you think of on your application.
2. Put down other disorders you have as well (i.e. depression)
3. Make sure you give too much information on why you can't work – don't just list your diagnosis.
4. If your diagnosis isn't common (i.e. trigeminal neuralgia), provide lots of information about the disorder
5. Don't just go to the Social Security office when you have questions. Call 800-772-1213 to set-up an appointment. This will save you lots of time!
6. Tell the claims representative if you need help filling out the paperwork.
7. You have the opportunity to fill out your application on the Social Security website: www.socialsecurity.gov. You have 6 months to complete the application on-line. You can access your partially completed application on-line as many times as you need by using your re-entry number.

Tom told us that it usually takes Social Security 3-4 months to review your application before they make a decision. 70% of the people who apply for Social Security disability get their first application approved.

If your claim is denied, Tom shared with us that we then have 60 days to file an appeal for reconsideration. 30% of the people who don't get approved the first time, get approved on appeal – but if they had put more information on their first application then it probably would have been approved the first time.

If your claim is denied a second time, then you have 60 days to appeal again. At that time, you will get a hearing before an administrative law judge. Be ready to talk to the judge and give the judge all of the information needed to make a decision. You will need to attend this hearing and bring your attorney with you (if you have one).

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.

When Tom was asked “Do I need an attorney for appealing Social Security’s decision?” Tom responded “It depends”. You should be well organized before you go into court. If you are not, an attorney can help you with this.

If your claim is denied by the judge, then you have 60 days to go to an Appeals Counsel who will review the judge’s ruling.

If that ruling is denied, you can file a Civil Suit in Federal Court where you will need an attorney.

Tom also mentioned that after you have been receiving Social Security for two years, you qualify for Medicare. For more information on Medicare, go to www.medicare.gov

TREASURER’S REPORT – NORTH CENTRAL EAST TEXAS

Beginning Balance 1/30/05		\$5089.48
Donations Received	\$541.95	
Copies	4.40	
Long Distance	23.32	
Postage	31.34	
Striking Back books	338.30	
Supplies	<u>15.97</u>	
Total Expenses	<u>\$413.33</u>	
Ending Balance 2/28/05		\$5218.10

FINANCIAL CONTRIBUTIONS

Local TNA chapters *do not receive* funding from the national office. If you would like your tax-deductible contribution to go toward your local Texas chapter, please make your check payable to the order of Trigeminal Neuralgia Association and in the memo field put the name of your support group (i.e. North Central Texas chapter, Houston chapter) then mail it to Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092 for processing.

Please remember to also support the efforts of the Trigeminal Neuralgia Association’s national office. Typically, they are the first ones to make contact with new TN sufferers. They provide us with convention materials, run the national website, promote research, and a host of other activities.

Trigeminal Neuralgia Association
2801 SW Archer Rd., Gainesville, FL 32608
Phone: 800-923-3608, Fax: 352-376-8688

www.tna-support.org

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.

Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the service of your physician, but solely to give you information to help enable you to make informed decisions about your care.