



**TRIGEMINAL NEURALGIA ASSOCIATION
TEXAS SUPPORT GROUPS NEWSLETTER
DECEMBER 2005**

TNA REGIONAL CONFERENCE – DALLAS, TX

A TNA regional conference will be held at UT Southwestern Medical Center in Dallas on Saturday, February 18, 2006. If you have not received a conference registration brochure in the mail yet, please let Shelly Wilson know via e-mail at swilson@tna-support.org or call 817-416-7202 and provide your mailing address so a brochure can be mailed to you.

Seating is limited so be sure to register early!

HOUSTON SUPPORT GROUP MEETING – DIFFERENT LOCATION

A Houston Support Group meeting and tour of the West Houston Gamma Knife Center will be held on Saturday, January 7, at 10:00 a.m. at the West Houston Doctors' Center (adjacent to West Houston Medical Center), 12121 Richmond Avenue, Suite 305, Houston, TX 77082. Doctors' Center is west on Richmond from Beltway 8 between Kirkwood Drive and Dairy Ashford.

LYRICA UPDATE

Dr. Steven Bender, an orofacial pain specialist in Plano, Texas reports he has had very good success using Lyrica at a dose of 150 mg per day on his patients who have post traumatic TN. He defines post traumatic TN as caused by factors such as facial trauma, dental procedures and the like.

Shirley, a 70 year old TN patient who also has anesthesia dolorosa, made the switch from Neurontin to Lyrica and felt immediately better. She highly recommends it!

CALL FOR VOLUNTEERS

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We need a new East Texas Support Group Leader. Ramona Smith started this group a couple of years ago in Tyler and now needs to step aside at the end of this year. Please don't let this support group die. If you are interested in taking over this role or are willing to become a co-support group leader for East Texas, please let Shelly know either by e-mail at swilson@tna-support.org or by calling 817-416-7202.

Rhonda Ashby, the Houston Support Group Leader, has moved to Central Texas. So, we need a new Houston Support Group Leader. If you are interested in taking on this role or are willing to become a co-support group leader for East Texas, please let Shelly know.

We have a support group website but need a webmaster to take it over. The key tasks include keeping the meeting schedule up to date and to upload our monthly newsletter. Currently, the website uses Net Objects Fusion 8 software, ftp host, and the newsletters are put into Adobe reader format. If you can manage this, please e-mail Shelly.

TN QUESTIONS AND ANSWERS

Question: Kay in Abilene has had TN since 1997. She takes Carbamazepine (Tegretol), 100 mg chewable tablets. Usually one tablet a day controls her pain but sometimes the pain is worse so she may take 2-3 tablets on those days. Her doctor assures her that the small amount of medicine is not enough to cause any side effects from using this medicine for a long time and that the small amount of medicine would not harm her.

Answer: In *Striking Back! The Trigeminal Neuralgia and Face Pain Handbook*, it says the following:

Over time, the side effects (of Carbamazepine) become intolerable, and over more time, the pain can begin to break through even at higher and higher doses. In the long run, one study found that after 10 years, only about 40-56% of all patients are still getting adequate relief from Carbamazepine.

Carbamazepine is metabolized by the liver. (Metabolism refers to how the body processes a drug in order to eliminate it from the body. This is done in either the liver or kidneys. Problems with these organs can impair the body's ability to get rid of drugs, allowing toxicity to occur.)

Precautions. Besides that potentially life-threatening allergic reaction (signaled by the skin rash, fever and mouth sores), Carbamazepine can cause a few serious blood disorders.

The most serious is aplastic anemia, a rare but potentially fatal disorder caused by damage to the bone marrow. Four other conditions also can occur: 1.) leucopenia, a deficiency in white blood cells, which protect the body against disease-causing microorganisms; 2.) neutropenia, a diminished number of neutrophils, which is a type of white blood cell; 3.) thrombocytopenia, a decrease in the platelets, which is the

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component of blood needed for clotting, and 4.) hyponatremia, abnormally low levels of blood sodium.

All of these disorders can be headed off by keeping tabs on the patient's blood, which is one reason why doctors routinely order periodic blood tests for those on Carbamazepine therapy. Blood tests will show if any of these side effects is developing so the medicine can be decreased or stopped before problems develop.

Blood tests also can tell doctors how much Carbamazepine is being absorbed and carried in the blood.

Long-term use may cause a folate vitamin deficiency, so some doctors advise patients to take a daily supplement of folic acid.

Carbamazepine does have an effect on several other medications that patients may be taking for other conditions. For example, it decreases the effectiveness of some oral contraceptives. It also can lessen the effectiveness of blood-thinners, such as warfarin (Coumadin) and aspirin. And it can lead to sudden rises in body temperatures, dangerously high blood pressure and even convulsions when taken with MAO-inhibiting antidepressants.

Carbamazepine should be used with caution by pregnant women, people who are allergic to Tricyclic antidepressants, people who have glaucoma, and people with a history of liver, kidney, heart or bone-marrow problems.

If you would like to purchase Striking Back!, make a \$30 check payable to the Trigeminal Neuralgia Association and mail it to Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092.

Question: Kay says that her pain hops around her face. It is never in the same place when it is hurting. Is this normal or the way TN works?

Answer: Dr. John Claude Krusz, Ph.D., M.D., a North Dallas neurologist, responded "Most of the time, TN sufferers can identify one or more places where their severe pain begins. The trigeminal nerve has such a wide distribution on the face that TN pain can have many sources in some people. You didn't spell out what "hops around" means to you so I can't comment directly on the specifics on your multiple pain sources. I hope this helps a little. Obviously, this is something you would want to discuss with your pain physician.

If you would like to make an appointment to see Dr. Krusz, call 214-750-6664.

If you have facial pain questions, submit them for future newsletter consideration to Shelly either via e-mail at swilson@tna-support.org or mail them to Shelly Wilson at 604 Aberdeen Way, Southlake, TX 76092.

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REQUEST FOR E-MAIL ADDRESSES

If you have an e-mail address where we can send you this newsletter and our meeting schedule via blind copy, please e-mail Shelly Wilson at swilson@tna-support.org. This helps us save on our mailing and copying costs since we have over 1,200 active members on our roster.

Also, if you change your e-mail address, make sure to advise Shelly as well. Thanks!

E-mail addresses are not shared or sold by TNA to protect your privacy.

CAREGIVERS NEED CARE, TOO

For family members caring for a loved one suffering from dementia or a debilitating illness, stress is a fact of life. It can also be a treat to their health. Caregivers often neglect their own health as they tend to their loved ones.

The Leeza Gibbons Memory Foundation and Home Instead Senior Care have created a website called www.caregiverstress.com which offers a 20-question survey to help caregivers gauge their level of stress, tips on how to reduce that stress and a list of links to resources that can provide help.

Among the tips for avoiding and managing caregiver stress: exercise, practice meditation, seek outside help, take time out for yourself, follow nutritious eating guidelines, take care of your own health, pamper yourself, and join a support group.

Source: Fort Worth Star-Telegram, November 26, 2005

UPDATES FROM OUR MEMBERS

Valerie was diagnosed with TN a few months ago. For the past three months, she's been taking 200 mg of Carbamazepine, the generic for Tegretol. For the past week and a half, she has had NO pain. What a relief!!!! She plans to keep taking the Carbamazepine for another month and then will try to back off of the dosage slowly.

Mike had a microvascular decompression surgery (MVD) by Dr. Jonathan White with UT Southwestern Medical Center in Dallas in March. He thanks God every day that he is still pain free and has been since he awoke from surgery. He's not taking any medicine and hasn't since April. He can't recommend Dr. White enough.

Maureen was diagnosed with TN in October 2004. In January, her neurologist referred her to Baylor All Saints Hospital in Fort Worth for the gamma knife procedure, a one-time radiation treatment done on outpatient basis. She had it done and within 4-5

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months, she was free of TN pain and off of Tegretol. She is so thankful that her neurologist recommended early on that she have the gamma knife so she didn't have to live with the pain for an extended period of time. If you are interested in having the gamma knife and want to contact Maureen about her experience, please e-mail her at jckndmoe@aol.com or call her at 817-677-3999.

Janie is completely off of her medication for the first time. Hurray!

John is now on ½ the amount of medication since he has received upper cervical chiropractic treatment from Dr. Dixon in Tyler. We're glad he's feeling better.

Ken is still off of medication since having chiropractic treatment from Dr. Dixon in Tyler. If anyone is interested in setting up an appointment with Dr. Dixon, call 903-531-2243.

Ethel heard from a friend of a friend who had a more constant severe TN pain who had almost complete pain relief from an allergist and hormone specialist named Dr. Russell R. Roby, J.D.M.D.P.A. with Roby Institute with offices in Austin, San Antonio, and Marble Falls. Ethel went to his San Antonio office and started treatment in August. She puts 3 hormone drops under her tongue daily and has been almost completely free of pain since with no side effects. She said it is a wonderful feeling and glorious relief.

Bill who had a MVD by Dr. Jannetta with Allegheny General Hospital in Pittsburgh a couple of months ago is now off Tegretol and completely free from TN pain. He was concerned at first when the pain flared up and it took 700 mg of Tegretol to block the pain but he guesses it just took a while for things to settle down after the surgery. Dr. Jannetta told him he protected the nerve with four Teflon pads so he is hopeful.

Please pray for:

- George Weigel who wrote the book called Striking Back! The Trigeminal Neuralgia and Face Pain Handbook. He previously had a successful MVD. However, a few years later, his TN returned with a vengeance. He just had another MVD by the same neurosurgeon who did not find anything compressing the trigeminal nerve so there was nothing he could do for him. Right now, George is considering his options since he doesn't want to have to live on a high dosage of anti-seizure medication. He is looking at the Omura Protocol practiced by Dr. Allen Sprinkle, DDS in Arlington, acupuncture, and upper cervical care.
- Cal who just had a MVD by Dr. Rob Parrish at Methodist Hospital in Houston.
- Joy who is having a MVD by Dr. Jonathan White with UT Southwestern Medical Center in Dallas this month.

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.

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FUTURE TEXAS MEETING DATES

Austin at St. David's Gamma Knife Center – T.B.A.
Dallas at UT Southwestern Medical Center – **Regional Conference** – 2/18
Fort Worth at Baylor All Saints – T.B.A.
Houston – 1/7
San Antonio – 12/13
Tyler – T.B.A.
Waco at Hillcrest Baptist Medical Center – 1/9, 3/13, 5/8, 7/10, 9/11, 11/13

TREASURER'S REPORT – NORTH, CENTRAL, & EAST TEXAS

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|----------------------------------|--------------|------------------------|
| Beginning Balance 11/2/05 | | \$3092.17 |
| Donations Received | | \$61.58* |
| Supplies | 154.26 | |
| Website renewal fee | 88.00 | |
| Postage | <u>53.77</u> | |
| Total Expenses | | <u>\$296.03</u> |
| Ending Balance 11/28/05 | | \$2857.72 |

*Awaiting reimbursement from TNA national office for taxable donations made to support group.

TREASURER'S REPORT – HOUSTON, TEXAS

| | |
|---------------------------------|-----------------|
| Account Balance 11/28/05 | \$823.38 |
|---------------------------------|-----------------|

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.endthepain.org

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