



**TRIGEMINAL NEURALGIA ASSOCIATION
TEXAS SUPPORT GROUPS
November 2004**

TNA NATIONAL CONFERENCE

Make sure to check our local TNA website throughout the TNA National Conference, November 11-14, 2004. Your Texas Support Group Leaders will be providing you with updates throughout the conference. Our website address is www.forteso.com/tna.htm

After the conference, your Texas Support Group Leaders will be compiling a summary of what was presented at the National Conference. Due to a generous member of the Fort Worth support group, this summary will be mailed out to every one who receives this newsletter before the end of the year.

If you don't want to wait until the end of the year for your conference summary, come to the Dallas support group meeting at Zale Lipshy University Hospital's Main Dining Room on December 1 where we'll discuss all of the new information presented at the National Conference over our social hour from 6:00 – 7:00 p.m. Dinner will be provided by the hospital.

If you plan on attending the December 1 meeting, make sure to RSVP to Shelly Wilson either via e-mail at kayser-wilson@charter.net or by calling 817-416-7202 by Thanksgiving so we'll have enough food ordered to feed everyone. We expect a full house, so make your reservation today!

A GENERIC OF NEURONTIN IS NOW AVAILABLE!

There is now a generic of Neurontin available from your pharmacy. Several people in our support group will now be able to save money on the cost of their Neurontin if they elect to purchase the generic.

If you have tried the generic of Neurontin, how much did you save per pill? Did you notice any difference in side effects between the generic and the brand name? If so, how was it different?

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If you want to share your experience with our support group members in a future newsletter, either e-mail Shelly at kayser-wilson@charter.net or mail a written note to Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092.

DVD OF A MVD

In the last year, we have given out 100 copies of a DVD showing microvascular decompression (MVD) surgery to members of our support group. If you haven't seen this yet and have access to a DVD player and would like to see a DVD of a MVD for trigeminal neuralgia, e-mail Shelly Wilson at kayser-wilson@charter.net or call 817-416-7202 to request it. A DVD will be mailed out to you at no charge. Also, there is no need to return it.

TNA ELIGIBLE FOR COMBINED FEDERAL CAMPAIGN

TNA searches constantly for new ways to raise funds to support patient education and other programs.

It was through a tip last year from two Support Group Leaders in California that led to TNA applying for the opportunity to raise funds from federal employees through Payroll Deduction under the federal government's Combined Federal Campaign (CFC).

TNA has recently been approved by the U.S. Office of Personnel Management as an eligible nonprofit organization to participate in the 2004 CFC, a program which assists federal employees to make charitable contributions to the organizations they choose to support.

Now, TNA supporters who are federal employees have a simple, efficient way to make gifts to TNA and have the flexibility to make those gifts in any way they choose!

TNA is listed as a National/International Unaffiliated Organization and our number is CFC#2908 in the official CFC materials. If you want to designate TNA as a recipient of your 2004 pledge through a onetime donation or convenient payroll deduction, you must identify your choice by using this number.

Federal employees can refer to your local CFC brochure for more information about how to contribute to TNA through payroll deduction or can access the Campaign through the internet at www.opm.gov/cfc

The Campaign season usually takes place every fall in the federal workplace, during the months of October and November.

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Stuart Wegener, TNA's Director of Advancement, can assist you if you have any questions. He can be e-mailed at swegener@tna-support.org or by calling 352-376-9955 ext. 15.

E-MAIL ADDRESSES

Thanks to everyone who's provided us with their e-mail address. This saves on our mailing and copying costs. If you have an e-mail address where we can send this newsletter and any updates, please e-mail Shelly Wilson at kayser-wilson@charter.net

Just a reminder, if you change your e-mail address, please let Shelly know.

A NEW ATTITUDE

A sunny disposition may help protect you against age-related physical decline. Positive thinking may help older people remain physically active and strong, whereas a negative mental attitude may quickly lead to cognitive deterioration, a new study concluded. To see the glass as half full, spend time contemplating the good things in your life and try to avoid repeatedly mulling over negative experiences.

Source: RealAge Tip of the Day, November 5, 2004

WEBSITES OF INTEREST

www.aarpmagazine.org/health/Articles/a2004-09-09-mag-rooting.html - AARP Magazine article called "Rooting out Pain" (which includes trigeminal neuralgia).

"One third of Americans will have chronic discomfort. Finally – new discoveries – and new drugs – offer a hope of relief"

www.painfoundation.org/enews0904/fishmanneurontin.htm - Q&A: What is Neurontin?

UPDATES FROM OUR MEMBERS

Jerry got a Botox injection to help with his TN pain from a North Dallas neurologist, Dr. John Claude Krusz. On the sixth day after the injection, Jerry got pain relief and now feels numb on one side of his face. He reports the inside of one side of his mouth even feels numb. If you are interested in seeing Dr. Krusz, call 214-750-6664. (Please note: Botox injections usually wear off in approximately three months.)

Betty has TN on both sides of her face. In late July, she had the gamma knife procedure at Dallas Presbyterian Hospital where she received two gamma knife treatments at one time – one for the pain on each side of her face. We hope she gets pain relief soon!

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Henry is having great success with the Omura protocol, practiced by Dr. Allen Sprinkle, a dentist in Arlington whose special interests include chronic cranio-facial pain. Henry is TN medication free and following the protocol by taking Fish Oil and Cilantro that he purchases from Dr. Sprinkle along with Folic Acid that he buys on his own.

Vickie's doing great! She had a MVD by Dr. Kopitnik at UT Southwestern in Dallas in December 2003. Since the surgery, she hasn't had any TN pain. She no longer takes TN medication. Hurray!

Jeanene is scheduled for a MVD with Dr. White at UT Southwestern in Dallas. Please keep her in your prayers.

Cheryl's Mom, Evelyn, who has TN, has requested our prayers while she tries to find a medication to provide her with relief from atypical facial pain.

If you would like to share an update with our group, please let Shelly know about it.

MEETING NOTES

Waco Meeting – September 14, 2004:

Joel Gary Freitag, M.D., a neurologist with the Central Texas Neurological Association, gave a Power Point presentation which outlined some of the following points.

Nociceptive facial pain is inflammation or destruction of pain sensitive structures in the face causing chronic pain: neuropathic (sinusitis) and idiopathic (dental issues, mass lesions).

Neuropathic – Classic TN has:

- No objective sensory loss
- Motor function intact
- Focality of exam warrants MRI
- Most common age 60-70 years. Few under 40 years of age.

Causes of TN include a combination of nerve problems and brainstem problems, a loop of an artery or a vein in the wrong place near the origin of the nerve causing compression, and other things like shingles.

TN characteristics include very sharp jabbing or shocking pain, brief duration with variable frequency, and sometimes trigger points.

Dr. Freitag's medication management for TN starts with either Tegretol or Trileptal. Other things he prescribes include Dilantin/Baclofen, Clonazepam/Depakote/Orap, Antidepressants (Mexitil), and other anticonvulsants.

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Dr. Freitag suggested surgical treatment when medications fail. He reports the microvascular decompression has a 90% success rate with a low recurrence rate. The radiofrequency lesioning has an 80% success rate. However, be aware there are risks to surgery.

Other ways to manage TN include biofeedback, acupuncture, etc.

Fort Worth Meeting – September 21, 2004:

Martin Lazar, M.D. spoke about the most painful disorder – TN. In order for a doctor to properly diagnose TN, the doctor must listen to the patient according to Dr. Lazar.

He explained TN is usually caused by a blood vessel pressing on the trigeminal nerve. When the myelin sheath that insulates the nerve gets disrupted, the trigeminal nerve gets irritated and misfires. He also mentioned the rarest cause of TN is a stroke and that MS can cause it too. 10% of TN patients have a tumor or an aneurysm that can cause TN.

As we get older, Dr. Lazar told us our arteries start to harden which causes our blood vessels to get longer. High blood pressure can speed up the myelin disruption.

Dr. Lazar thinks all TN patients should have a MRI & a MRA which is a MR angiogram, a test of blood vessels going up to the brain. The MRI visualizes things within the head. When a MRI is done with contrast, it shows areas of increased blood supply (i.e. tumors have lots of blood supply). If a patient has not had a MRI with and without contrast & a MRA, Dr. Lazar would want a TN patient to have a CT with and without contrast as well as an angiogram.

When considering surgical treatments, Dr. Lazar suggests using statistics as a guideline but that they can't predict an individual response.

Dr. Lazar stated "if you cut the entire trigeminal nerve, the patient will be numb in their face".

A glycerol injection damages the trigeminal nerve to a small degree. 50% of TN patients who get a glycerol injection end up having pain again in 2-5 years when the nerve recovers from injury.

The radiofrequency rhizotomy procedure produces numbness and in 2-5 years after the procedure, 50% of TN patients have pain again.

Radiosurgery (i.e. the gamma knife) kills part of the nerve with radiation therapy. Patients may get some facial numbness. Dr. Lazar noted that this procedure does not treat the disease and pain often returns.

Dr. Lazar does not require TN patients to have a physician referral for him to see them. He will see all TN patients A.S.A.P. For an appointment, call 972-566-6444.

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FUTURE MEETING DATES

Dallas at Zale Lipshy Hospital – 12/1
Fort Worth at Baylor All Saints – 11/16
Houston at Christus St. Joseph Hospital – T.B.A.
Tyler at East Texas Medical Center – T.B.A.
Waco at Hillcrest Baptist Medical Center – 1/10, 3/7, 5/2, 7/11, 9/13, 11/14

TREASURER'S REPORT

Beginning Balance 10/1/04	\$3790.51
Donations Received	\$318.00
Copies	36.99
Postage	114.84
Supplies	<u>30.14</u>
Total Expenses	<u>\$181.97</u>
Ending Balance 11/5/04	\$3926.54

Note: The Houston support group will keep their finances separate. A Houston financial update will be provided in an upcoming newsletter.

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: 352-376-9955, Fax: 352-376-8688
www.tna-support.org

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