



TRIGEMINAL NEURALGIA ASSOCIATION TEXAS SUPPORT GROUPS NEWSLETTER JULY 2006

SAN ANTONIO SUPPORT GROUP MEETING – DATE CHANGE

The San Antonio Support Group *will meet next on August 1* not August 8 as originally planned. Jonathan White, M.D. with UT Southwestern in Dallas will be the guest speaker. For more details, please check the meeting flyer.

FORT WORTH SUPPORT GROUP MEETING – CANCELLED

The August 9 Fort Worth Support Group meeting has been cancelled due to low turnout at the last support group meeting. We will hold our next Fort Worth support group meeting on November 8.

DONATIONS FOR TNA SILENT AUCTION

TNA will be holding a Silent Auction at the Gala Dinner during the TNA National Conference on September 15, 2006. If you would like to donate any new items or gift certificates for this function, please send them to Shelly Wilson, TNA, P.O. Box 92604, Southlake, TX 76092 by August 1. Thank you for your consideration!

A NEW TNA PUBLICATION – INSIGHTS

TNA has just published a new book by Joanna M. Zakrzewska, M.D called “Insights: Facts and Stories behind Trigeminal Neuralgia” about understanding and treating what is often called the world’s worst pain. This book is an enlightening collaboration between healthcare professionals supplying scientific facts, and patients sharing their perspective on the successes and shortcomings of various treatments.

The book provides an illustrated roadmap from diagnosis to the best available medical and surgical treatments, as well as a 10-step approach to “moving from patient to person” and practical tips on coping with recurrent pain.

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.

This book costs \$27.95 and is available on TNA's website at www.endthepain.org or by calling TNA's national office at 800-923-3608.

SPECIAL THANKS

Thank you to Vickie Anderson, RN of Killeen, TX who was a TN patient before she had a successful MVD a couple of years ago. Vickie volunteered by working 2 days at the TNA exhibit booth at the National Nurse Practitioners Conference at the Gaylord Hotel in Grapevine, TX. The conference had over 2,000 nurse practitioner attendees. Vickie, we appreciate your giving back to TNA!

Jana Wren of Arlington, TX suggested we see if there was enough interest in starting a TNA Mid-Cities support group. Jana helped set-up a Saturday morning coffee at Shady Valley Golf Club so support group members could meet to share their experiences. Thanks to Jana for taking time to make reminder phone calls to those in the area!

IMPLANTS & TN

Rita, a TN patient, wants to know if she should consider dental implants even though she has TN.

Below is a response from Steven Bender, DDS, an orofacial pain specialist in Plano, TX:

I have not seen any specific studies relating to implants and TN or any other facial neuropathic pains. It would stand to reason that any procedure which involves structures innervated by the trigeminal nerve would carry the potential for exacerbation of the pain paroxysms.

With that said, I do not feel that a TN patient would have a compromised level of success with dental implants. The patient should weigh the risk against the benefits and have a full understanding of the potential for increased pain. Increasing their normal meds along with other prophylactic measures would be beneficial in reducing the risk of increased TN pain.

I personally feel that dental implants are a great restorative option but it is an invasive procedure. That fact should weigh in on the decision of the patient as to what would be the best choice for them.

If you have TN and have recently had implants installed and are willing to share your experience with others via our newsletter, please submit your experience to Shelly Wilson via email at swilson@tna-support.org or via US mail to TNA, P.O. Box 92604, Southlake, TX 76092.

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ANOTHER NEW MEDICATION – NAMENDA

Dr. Joseph Vaughn, a neurologist in Tyler, Texas has started prescribing Namenda to some of his TN patients. So far, the drug is proving effective for TN patients.

Namenda is used in the treatment of moderate to severe dementia associated with Alzheimer's disease. Namenda may also be used for other purposes. *According to Dr. Vaughn, Namenda is proving to help pain patients.*

According to the FDA, patients should tell their health care provider if they:

- have kidney problems
- have a condition or take other medicines that make their urine alkaline
- are pregnant, are trying to become pregnant, or are breast-feeding

Also, tell your health care provider about all the medicines you take, including prescription and non-prescription medicines, vitamins, and herbal supplements. Namenda and other medicines may affect each other, causing serious side effects. Especially tell your health care provider if you take:

- medicines called NMDA antagonists such as amantadine (Symmetrel), Ketamine (Ketalar) and dextromethorphan
- other medicines that pass out of the body through kidneys such as hydrochlorothiazide (HCTZ), triamterene (TA), cimetidine (Tagamet), ranitidine (Zantac), quinidine and nicotine
- medicines that make your urine more alkaline such as carbonic anhydrase inhibitors and sodium bicarbonate

Some of the common side effects of Namenda include dizziness, headache, confusion, and constipation.

For more detailed information about Namenda, ask your health care provider or pharmacist.

WEBSITES OF INTEREST

<http://www.ohsu.edu/neurosurgery/what.shtml> - What is neurosurgery? Who is a neurosurgeon? What is the role of the neurosurgeon?

http://www.theeagle.com/stories/062406/health_20060624091.php - TN patient story from College Station, TX who had a balloon compression by Dr. El Nihum.

<http://www.detnews.com/apps/pbcs.dll/article?AID=/20060520/OPINION03/605200393/1279> - People who have TN know the depths of chronic pain article

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HEAD AND NECK CANCERS

Some 40,000 Americans annually are diagnosed with cancers of the head and neck- among them throat, tongue and tonsil tumors- and about 11,000 die each year. The vast majority of patients are smokers; drinking is also a risk factor. The key to survival: early detection. About 90 percent diagnosed with Stage 1 live five years or more, while those whose cancer is found at Stage 4 have a 30 to 40 percent survival rate. To learn more visit speakouthnc.com and oralcancerfoundation.org.

Source: People, May 1, 2006

UPDATES FROM OUR MEMBERS

Laurie had a microvascular decompression brain surgery (MVD) by Dr. Kim Burchiel with Oregon Health & Science University in March 2005. She was a little hesitant at first to say anything, because recovery from the surgery was long and she had a bit of residual pain from nerve damage. But, she truly considers the surgery a success. She thinks Dr. Burchiel is wonderful and the treatment she received while a patient at OHSU was excellent. She's glad to be off all that medication and to feel normal again. She highly recommends the procedure.

Mary Ann reports that Henry has been doing very well with his TN. He's had very few attacks since last November and they have been milder than those previously.

Wanda has been pain-free for two years and says "Thank the Lord".

Lelda has been pain-free since last August. Hurray!

Karin's MVD took about a year to work but since that time, she has been able to drop 2 of her 5 TN medications.

Stella reports after having gamma knife by Dr. Gary Krause in Houston on April 3, she has not had a single twinge of pain since April 23. She is now off all of her TN medication. Fantastic!

Please pray for:

- William whose nerve injury has continued to cause him to have facial pain which has progressed to both feet and hands.
- Joy whose pain has returned just 6 months after a successful MVD. She is now back on TN medication.
- Cynthia whose MVD and 2 radiofrequency rhizotomies have failed and she is also having to take TN medication again.
- Martha who is still struggling with her TN pain.
- Tom who has TN. He had a heart attack last month and is recovering.
- Jeryl who isn't feeling too well lately. She's having a MRI and a MRA this month.

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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.

REQUEST FOR E-MAIL ADDRESSES

If you have an e-mail address where we can send you this newsletter and our meeting schedule, please e-mail Shelly Wilson at swilson@tna-support.org to help us save on mailing and copying costs.

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

MEETING SUMMARIES

Dallas Dinner Meeting, June 13, 2006: Thank you to Carol Preston for presenting “Living with Facial Pain”. She shared her personal facial pain experience, gave attendees a handout full of suggestions for living with facial pain, and inspired the group to continue living despite our pain.

Some great points that Carol addressed were:

- Pain makes us feel self-centered
- Learn to live with pain, one day at a time
- Support from family and friends is vital
- Be a participant in your healthcare!
- Go to a doctor that wants you as a patient, find a doctor to partner with
- Have a plan if the pain returns and also a back-up “Plan B” to keep you out of the Emergency Room
- Remember supporters feel helpless at stopping a loved one’s pain
- Know the pain episode will pass.
- Despair, self-pity, hopelessness: Don’t go there – not even for 15 minutes!
- Be kind to yourself.
- Give your life structure.

Carol has written a workbook called “Remembering Who We Are: A Practical Guide to a Restored Life, Based on an Adaptation of AA’s 12 Steps. This book is for sale on amazon.com or from the publisher online at www.carolpreston.com or by calling 214-415-0302. The workbook costs \$28.30.

After the meeting, Dr. Stephen Rodrigues, a North Dallas family practice MD who does acupuncture on TN patients, offered to provide acupuncture on any attendee who wanted it that evening. Lots of people are still getting relief from this treatment!

Arlington Coffee, June 24, 2006: This gathering allowed a group of facial pain patients and their supporters to share their experiences and to learn from others. Dr. Rodrigues again offered acupuncture to attendees who were interested in trying it.

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FUTURE MEETING DATES

Arlington, Austin, Dallas, & Houston – T.B.A.
Dallas at Zale Lipshy University Hospital – T.B.A.
Fort Worth at Baylor All Saints – 11/8 (Private Dining Room)
San Antonio – 8/1, 10/10, 12/12
Tyler – 9/29, 12/15
Waco at Hillcrest Baptist Medical Center – 7/10, 9/11, 11/13

TREASURER'S REPORT – NORTH CENTRAL EAST TEXAS

Beginning Balance – 5/31/6	\$3,700.60
Donations Received	\$241.00
Center for Nonprofit	65.00
Copies	51.76
NP Natl Conference exhibit	67.66
Postage	198.61
TNA-Insights books	<u>264.00</u>
Total Expenses	<u>\$647.03</u>
Ending Balance 6/30/06	\$3,294.57

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, P.O. Box 92604, 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
925 NW 56th Terrace, Suite C, Gainesville, FL 32605
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www.endthepain.org

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