



TRIGEMINAL NEURALGIA ASSOCIATION TEXAS SUPPORT GROUPS NEWSLETTER SPRING 2007

Once the “what” is decided, the “how” always follows. We must not make the “how” an excuse for not facing and accepting the “what”.

Pearl S. Buck (1892-1973, American novelist)

TEXAS TNA SURVEY

Thank you to everyone who took time to complete and submit the Texas TNA Survey. Results are being compiled and will be shared in upcoming newsletters.

VOLUNTEERS NEEDED

Joan Foster, the Austin Support Group Leader, has gotten TNA discounted exhibit booth space for the Texas Dental Association meeting in San Antonio. We need a couple of people to help Joan work the exhibit on Friday, May 11. If you can help, please call Joan at 512-892-2273. *Thanks to Jeanne who has already volunteered to help on Thursday.*

JANNETTA DINNER

The Trigeminal Neuralgia Association invites you to a Lifetime Achievement Dinner honoring Peter J. Jannetta, MD, a pioneer in neurosurgery, as he retires from leadership of TNA’s Medical Advisory Board. The dinner will be held on Saturday, April 28, 2007 at the DoubleTree City Center Hotel in Pittsburgh, PA at 6:00 p.m. Tickets are \$125 per person and seats can be reserved via TNA’s website at www.endthepain.org.

Dr. Jannetta performed the first microvascular decompression surgery for relief of TN. Since that time, thousands of people have benefited from the surgical techniques Dr. Jannetta has refined, perfected, and taught around the world.

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Dr. Jannetta “challenged” one of his TN patients, Claire Patterson, TNA Founder and President Emeritus, to do something about the great void of knowledge about TN. Today, TNA serves as a world-wide advocate for facial pain patients providing information, encouraging research and offering support.

The **Peter Jannetta Initiative** will develop *medical educational materials* and strengthen *outreach programs*. Help fund Dr. Jannetta’s initiative by sending a tax-free donation to TNA Events, PO Box 92604, Southlake, TX 76092.

At the dinner, Dr. Jannetta will be given a book of letters/cards of gratitude from patients, health care professionals, friends, and family. If you would like to have your letter or card included, please mail it to TNA Events, PO Box 92604, Southlake, TX 76092 by April 20.

SUPPORT GROUP MEETING UPDATES

Please note, the East Texas Support Group meeting in Tyler scheduled for April 27 has been changed to April 20.

Carol Ann Preston has volunteered to be the new Houston Support Group Leader. She has scheduled a meeting for Monday, May 7th. Check your meeting calendar or the Texas TNA website at www.texastna.org for details.

IMPLANTS

At TNA’s 6th National Conference, a panel of dentists answered questions submitted by conference attendees. The most frequently asked question was “Should I get dental implants if I have TN?”

The panelists agreed that if you have TN on the same side of the face where the dental implant is needed, you should not have an implant. Instead, they recommended a “Maryland bridge” since it is lighter in weight than most bridges. However, if an implant is being considered for the opposite side of the face from where you have TN, an implant should work fine.

TNA REGIONAL CONFERENCES

TNA holds one-day regional conferences around the US to educate patients, supporters, and health care professionals about trigeminal neuralgia and chronic facial pain. Registration is available now for conferences in Nashville on May 19th and Richmond on July 14th. TNA has also scheduled a regional conference for San Diego on October 27th and registration will be available later this summer.

For more conference details and online registration, go to TNA’s website at www.endthepain.org or call Shelly Wilson at 817-416-7202.

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WEBSITES OF INTEREST

www.tna-support.org/newlook/Youth/face_pain_and_tn_in_young_people.htm - New information we have available for patients who are children or youth with trigeminal neuralgia or related facial pain.

www.texasrna.org – Texas TNA website includes our newsletters, a *2006 national conference review*, a video of a TN patient's surgical experience and much more!

LECTURE BY DR. ZUNIGA

In January, John R. Zuniga, DMD, PhD, Chair of Oral and Maxillofacial Surgery at UT Southwestern in Dallas, gave a management of TN and post-traumatic TN continuing education lecture to 65 dentists during the Southwest Dental Conference in Dallas. Based on the Dallas/Fort Worth metroplex population of three million people, Dr. Zuniga estimated there are 150 new cases of trigeminal neuralgia in the Dallas/Fort Worth metroplex each year. This equates to 15,000 new cases in the US each year.

Other interesting facts presented by Dr. Zuniga included:

- The mean age for a TN patient is 64
- 50% of TN patients will only need one medication to control their TN
- Botox works 50% of the time (for approximately 3-4 months)
- 8,000 TN patients will undergo surgery each year

Dr. Zuniga sees approximately 25 new TN patients each year. To book an appointment, call 214-648-5700.

DRUGS TO WARN OF SLEEP DANGERS

The following article written by Rita Rubin appeared in USA Today on Thursday, March 15, 2007.

Ambien and other popular sleep aids will now carry warnings about risks of “complex behaviors” such as driving or preparing food when not fully awake and potentially lethal allergic reactions, the Food and Drug Administration said Wednesday.

Makers of the 13 affected drugs will begin sending letters to doctors this week to alert them to these risks, and the companies have until May to submit consumer-friendly “Medication Guides” to the FDA, Russell Katz, director of the FDA division that reviews neurology drugs, said at a news conference. After the FDA approves the leaflets, they are to be distributed with every filled prescription.

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“We do believe that all of the drugs in the class are capable of producing these adverse events,” Katz said.

Ambien is one of the most widely prescribed and heavily advertised prescription drugs of any type. In 2006, pharmacists filled about 30 million prescriptions for Ambien, far ahead of the rest of the class, according to IMS Health, a health care information company.

The risk of sleep-driving after taking a sleep medicine made headlines last May when Rep. Patrick Kennedy, D-R.I., crashed his car near the Capitol at about 3 a.m. Kennedy said he had taken Ambien and Phenergan, a prescription anti-nausea drug. He said he did not remember the incident.

The FDA has received reports of other complex behaviors that sleeping people have engaged in while using the drugs, including talking on the telephone, having sex and eating, Katz said. He called such behaviors “rare,” although he noted that makers have not yet done studies to show how rare.

The FDA began looking into these because of reports at medical meetings, Katz said. “I don’t think we are reconsidering whether the drugs ought to be available. The drugs are useful for an important medical problem some people have.”

Melissa Feltmann, a spokeswoman for Ambien maker Sanofi-Aventis, said drug labeling has always mentioned the risk of somnambulism, which refers to walking or engaging in other unusual behaviors while asleep.

Katz said patients can reduce their risk of such behaviors by taking no more than the prescribed amount and not mixing it with alcohol. The FDA has recommended that makers conduct studies to help determine the risk of sleep-driving and other complex behaviors for individual sleep medications, but the agency cannot force them to comply. “Whether or not we will get any of these trials, I just don’t know,” Katz said.

Severe, potentially deadly allergic reactions that can hinder patients’ abilities to breathe appear to be more common than the complex behaviors, Katz said.

The 13 Drugs by JB Reed, Bloomberg News

The FDA has asked makers of the following sleep aids to add warnings to their labels about risks of a severe allergic reaction and of behaviors such as “sleep-driving”:

Ambien	Ambien CR
Butisol Sodium	Carbrital
Dalmane	Doral
Halcion	Lunesta
Placidyl	Prosom
Restoril	Rozerem
Seconal	Sonata

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UPDATES FROM OUR MEMBERS

Bobby Jo flew in from Mississippi and had successful neuro stimulation for occipital and trigeminal neuralgia implanted by Dr. Tony Whitworth at UT Southwestern in Dallas. His equipment was manufactured by Medtronic and was rechargeable.

Philip has been in remission for almost one year. Hurray!!!

Ellen went to Austin and had a success with stimulation implanted by Dr. Craig Dubois. Her stimulator is an EON rechargeable that is manufactured by ANS (Advanced Neuromodulation Systems).

Cal has been pain-free (knock on wood) since Mother's Day last year. He had a gamma knife in April 2006.

Please pray for:

- Eva who is recovering from a MVD.
- Randy who is contemplating gamma knife treatment.
- Amy who is battling face pain on both sides of her face.

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 PO Box 92604, 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 REPORT

Baylor All Saints Hospital, Fort Worth – January 30, 2007:

Thank you to Husam Alkhersam, MD with Neurology Specialists of North Texas. Dr. Alkhersam, a Bedford, TX neurologist gave a TN overview and then spent over one hour answering questions from our support group members. Everyone in the room with a question or questions got to ask them and Dr. Alkhersam answered them. If you would like to make an appointment to see Dr. Alkhersam, call 817-685-4485.

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FUTURE MEETING DATES

Austin – T.B.A.

Dallas/Fort Worth - T.B.A.

Houston – 5/7

Plano – 4/4

San Antonio – 4/10, 6/12, 8/14, 10/9, 12/11

Tyler – 4/20*, 6/29, 8/31, 10/26, 12/14 *Note the April meeting date changed to 4/20.

Waco - 5/14, 7/9, 9/10, 11/12

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

Beginning Balance – 1/1/7		\$3,709.32
Donations Received		\$4,204.00
Checks	\$ 12.99	
Copies	215.87	
Postage	651.68	
Renew Bulk Mail Permit	160.00	
SW Dental Conference exhibiting	247.48	
Striking Back & Insight books	719.00	
Supplies	<u>287.86</u>	
Expenses		\$2,294.88
Ending Balance 3/31/7		\$5,618.44

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.

TNA
925 NW 56th Terrace, Suite C, Gainesville, FL 32605
Phone: 800-923-3608, Fax: 352-331-7078
www.endthepain.org

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