



**TRIGEMINAL NEURALGIA ASSOCIATION  
TEXAS SUPPORT GROUPS NEWSLETTER  
FEBRUARY 2006**

*“Any day we wish; we can discipline ourselves to change it all. Any day we wish; we can open the book that will open our mind to new knowledge. Any day we wish; we can start a new activity. Any day we wish; we can start the process of life change. We can do it immediately, or next week, or next month, or next year... You have the ability to totally transform every area in your life – and it all begins with your very own power of choice.”*

Change Begins with Choice – Jim Rohn

**TNA REGIONAL CONFERENCE – DALLAS, TX**

Free parking for conference attendees! The University of Texas Southwestern Medical Center will provide all conference attendees with *free parking* at the parking garage located at 6001 Forest Park. To get to the parking garage, take Stemmons Freeway/I-35. Exit Inwood Road. Go north on Inwood. Turn left onto Forest Park Road. The parking garage will be on your left hand side of the road.

Patti Phillips is new to the DFW area and has just moved to Bedford. She is going to the conference but would like to carpool with someone if possible. If you are interested in carpooling with her to the conference, please call Patti at 817-581-1073.

If you plan on attending the TNA one-day Regional Conference at UT Southwestern Medical Center in Dallas on Saturday, February 18, 2006 and have not registered yet, please do so either on-line at TNA's website, [www.endthepain.org](http://www.endthepain.org), or by calling Shelly Wilson at 817-416-7202.

**Another TNA Regional Conference will not be held in this area for 3-5 years so don't miss your opportunity!**

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## **FEEDBACK ON LYRICA**

There is a new anti-seizure medication available to facial pain patients in the U.S. The prescription drug is called Lyrica and it is manufactured by Pfizer.

Amy tried Lyrica and experienced the extreme side effects of bleeding, bruising, and inability to urinate. Due to these side effects, Amy is no longer taking Lyrica.

Dorothy is currently taking Lyrica for facial pain. She was supposed to take one 50 mg capsule, 3 times a day but it made her so sleepy. She can only take 1 capsule at night when she goes to bed. Sometimes the pain doesn't go away, especially if she is overly tired or stressed. She also wears 5% Lidoderm patches on her face at night where she is having pain. The two combined help her a lot. She hopes this information will help someone else.

Michelle has been on it a few weeks and just increased her daily amount to 75 mg, three times a day. She was awake all night and couldn't sleep. She also felt very dizzy and confused. She is going to continue taking it to see if these side effects were due to the increase in medication dosage.

Rhonda is a new TN patient and is taking 500 mg of Lyrica a day to control her pain.

Charlie is a new TN patient who got headaches from Tegretol so he switched to 75 mg of Lyrica, 3 times a day and it controlled his pain. Since that time, he has been able to drop down to 50 mg of Lyrica, 2 times a day and it is controlling his pain. His next step is to see if 25 mg of Lyrica, 2 times a day will work.

If you have tried Lyrica, please e-mail your experience to [swilson@tna-support.org](mailto:swilson@tna-support.org) or mail a note to Shelly Wilson, P.O. Box 92604, Southlake, TX 76092 and we'll include it in an upcoming newsletter.

## **DO TN PATIENTS HAVE A B-12 DEFICIENCY?**

Irene Wood, President of TNA Australia, wondered if TN and other facial pain patients have a B-12 deficiency. So, she asked Australia TN and other facial pain patients to volunteer to have their serum B-12 and folic acid measured in a laboratory test. A summary of her results that appeared in the TNA Australia newsletter, February 2005, follow.

According to laboratory results, no one was classified as B-12 deficient. However, 31 out of 33 results showed that they have low B-12.

The main problem with B-12 is in its absorption. Various factors contribute to this but it can be addressed.

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The small number (33 patients) can not support a conclusion. However, if there were 100 serum B-12 results and >90% recorded low serum B-12, it would be more convincing.

### **CALL FOR VOLUNTEERS**

We need a new East Texas Support Group Leader. 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](mailto:swilson@tna-support.org) or by calling 817-416-7202.

### **IF YOU NEED A SLEEPING PILL**

The following chart appeared in Good Housekeeping, September 2005.

<u>NAME OF DRUG</u>	<u>ADVANTAGES</u>
AMBIEN (Zolpidem)	Fast-acting and works well for falling asleep; stays in the brain for four to five hours, so it doesn't leave you feeling "drugged" in the morning. But because of its short duration, you may sometimes wake up earlier than desired.
LUNESTA (Eszopiclone)	The newest sleep medication on the market and also the only one studied for long-term use (six months); works well for both falling asleep and staying asleep, and acts fast, so you won't feel groggy when you wake.
SONATA (Zaleplon)	A short-acting medication (3-4 hours), making it useful for those who wake in the night but then need to be alert in the morning.
XANAX (Alprazolam)	Best for sleep problems that are associated with anxiety; works fast.
TRAZODONE	An anti-depressant taken at a low dose for insomnia; a safer option for those who have a history of addiction.

### **ACUPUNCTURIST PROVIDES AN ALTERNATIVE**

The following article by Todd L. Davis appeared in the Fort Worth Star-Telegram on April 24, 2005.

Many people cringe when they see a doctor holding a needle, but Winnie Au's needles can actually prevent pain.

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Au is an acupuncturist and owner of the Winnie Au Acupuncture Center in Bedford. Clients come to her for acupuncture, acupressure and herbal supplements to treat conditions ranging from depression to the common cold...

Au is one of 627 licensed acupuncturists practicing in Texas, up from just 349 in 1998, according to the Texas State Board of Medical Examiners...

Au attended Guangzhou University in China, where she received a degree in traditional Chinese medicine. Then she earned the title of doctor of acupuncture from the University of Health Science in Hawaii...

A number of Americans are turning to acupuncture when traditional medicine cannot provide solutions. An estimated 10 percent of Americans have tried acupuncture, according to a survey by the National Certification Commission for Acupuncture and Oriental Medicine...

Acupuncture is now covered under many health care plans. Often, referrals are not required for coverage, according to Au.

### **UPDATES FROM OUR MEMBERS**

Soon it will be two years since Linda had her microvascular decompression surgery (MVD) by Dr. Tony Whitworth at UT Southwestern in Dallas. She has not had a single TN pain since the surgery. She is expecting her first grandchild this summer and prays the pain stays away long enough to enjoy the occasion. Hurray!

Charlotte's trick for staying pain-free from TN is taking 25 mg of Trileptal, three times a day. However, she does suffer from a side effect of the medication which is double vision. To combat the double vision, she just wears her glasses.

Evelyn had pain in the V-1 supra orbital branch of the trigeminal nerve (behind the eye and up into the scalp). Dr. Dubois in Austin, Texas performed pulse radio frequency lesioning (peripherally) at the end of the trigeminal nerve on her. The procedure took about 45 minutes in the hospital. She reports the results are excellent! She is now cutting back on her medications gradually (Keppra, Dilantin, Neurontin & Cymbalta). She also said that Cymbalta had helped her with her pain. *Dr. Dubois will be speaking at the TNA Regional Conference in Dallas on Saturday, February 18, 2006. For registration information, go to [www.endthepain.org](http://www.endthepain.org) and click on meetings and conferences.*

In 2003, Margie had a rhizotomy by Dr. Hurt in Houston and ever since she has been pain-free. Hurray!

Carlos has had two gamma knife surgeries by Dr. William Gormley, M.D. at Memorial Hermann Hospital in Houston. The first surgery was in October 2000 and it took about 4 months for Carlos to become pain-free. However, in March 2002, the TN pain returned.

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His second gamma knife was in April 200 and while it left him with some numbness in the mouth area, he has remained without TN pain.

Luella's TN started after she retired. She's had it for 23 years. She notices stress makes the pain worse. She's had just about every TN surgical procedure and some more than once. She's had a glycerol injection, three radiofrequency rhizotomies, a MVD, and a gamma knife. Right now, she is just taking Trileptal twice a day. At present, she is doing very well and thanks God every day.

Tom had Botox injections by Dr. Bill Davis, a New Braunfels neurologist, at Neurology Clinic of Central Texas, P.A. a few days ago and is now pain free. He has been able to cut his Tegretol in half. He was given 2 injections in the head, just above his forehead, 2 in his eyebrow, 2 in the crease of his nose, and 2 in his upper lip. The injections were not covered by insurance because Botox is considered an "off label" treatment for TN. (However, they might be covered if the Botox injections are coded for "muscle spasm".) Tom thinks Dr. Davis is a really nice guy as well as competent. To book an appointment with Dr. Davis, call 830-606-9142.

Please pray for:

- Cynthia who's TN pain has returned. She had a successful MVD (microvascular decompression surgery), 3-1/2 years ago, got completely off of TN medication but has since had to go back to taking Tegretol. She is contemplating another TN surgery so she can get completely off of medication again.
- Ralph who was scheduled for a MVD at the end of January but had to postpone his surgery for at least six months due to finding blood clots in his legs which is now requiring him to take blood thinners. He's in a lot of pain and is maxed out on his Neurontin dosage.
- Marie who's face pain isn't being controlled by taking 900 mg, 3 times a day, of Neurontin.
- Maggie who's still in pain since her MVD in December. She is now contemplating another surgery.
- Lori who is in a lot of pain.
- Bob's wife who doesn't have TN but is battling breast cancer.

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](mailto:swilson@tna-support.org) or a written note to P.O. 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](mailto: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!

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## FUTURE MEETING DATES

Austin – T.B.A.

Dallas at UT Southwestern Medical Center – **Regional Conference** – 2/18

Fort Worth at Baylor All Saints – T.B.A.

Houston – T.B.A.

San Antonio – 2/14, 3/14, 4/11, 5/9, 6/13, 7/11, 8/8, 9/12, 10/10, 11/14, 12/12

Tyler – T.B.A.

Waco at Hillcrest Baptist Medical Center – 3/13, 5/8, 7/10, 9/11, 11/13

## TREASURER'S REPORT – TEXAS

**Beginning Balance 1/1/06** **\$4422.33**

**Donations Received** **\$679.48**

Copies 50.10

Postage 466.07

TX Academy of Family Physicians Directory 50.00

Supplies 28.17

**Total Expenses** **\$594.34**

**Ending Balance 1/26/06** **\$4507.47**

## FINANCIAL CONTRIBUTIONS

Local TNA chapters *do not receive* funding from the national office. If you would like your tax-deductible contribution to go toward the Texas support groups, please make your check payable to the order of Trigeminal Neuralgia Association and in the memo field put Texas Support Groups 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  
2801 SW Archer Rd., Gainesville, FL 32608  
Phone: 800-923-3608, Fax: 352-376-8688  
[www.endthepain.org](http://www.endthepain.org)

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