



**TRIGEMINAL NEURALGIA ASSOCIATION
NORTH CENTRAL TEXAS SUPPORT GROUP
March 2004**

While at TNA's national office last month, I noticed they had three new items available. If you would like a copy of any of the following items, let me know which ones either by e-mailing me at kayser-wilson@charter.net or send me a written note at 604 Aberdeen Way, Southlake, TX 76092.

- List of People 20-30 years old with TN who are Willing to Network
- Pain Management article called "Mastering Medications" which discusses adjuvants and their application in managing pain, Jan/Feb 2002
- American Chronic Pain Association's "Medication and Chronic Pain" supplement, 2002

At the end of last month, Joan Foster, the Austin support group leader, and I worked the TNA booth at the Texas Neurology Conference in Austin. This was our first time to display at this state-wide conference and it was time well-spent as we made a significant number of contacts.

While at the neurology conference, I learned from a Pfizer pharmaceutical representative for Neurontin that Neurontin is now available in 600 mgs and 800 mgs pills that can be easily scored (broken) in half. I was told this should save patients 5% over buying 300 mg or 400 mg capsules. Just ask your physician to write your prescription for the higher milligram dosage and then take them as directed by your physician.

I asked if someone was already receiving Neurontin in the 600 or 800 mgs pills, what would they have to do to get the scored tablets and was advised these scored tablets are already on the shelves in Texas pharmacies and are being dispensed in place of the capsules or tablets you had been receiving.

Shelly Wilson
Support Group Leader

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BOTOX TRIAL

U.T. Southwestern Medical Center in Dallas is conducting a Botox trial on TN patients *who also have Multiple Sclerosis*. There is no cost to be included in this study.

If you are interested in learning more about this study, please call Jill Fowler at U.T. Southwestern's clinical trials office at 214-648-3613.

TRILEPTAL REQUEST

Charlie, one of our support group members, is losing his \$25 prescription co-pay in 2-3 months. Right now, he is taking Trileptal to control his pain. He is price shopping the cost of this prescription and has found that he can get 100 Trileptal pills, 600 mg each, for \$320.69 from Costco?

Is anyone else getting a better deal on their Trileptal? If so, Charlie would sure like to hear from you. Feel free to e-mail him at CdubOK@aol.com or call him at 405-359-8866.

EAST TEXAS SUPPORT GROUP MEMBERS

Ramona Smith, the East Texas support group leader, received a request to hold a support group meeting on a weeknight in Tyler to let those who couldn't make it to a weekday meeting have the benefit of meeting others with TN or related facial pain and to hear a guest speaker.

East Texas Medical Center didn't have a room available for Ramona to reserve at night. So, she checked with Mother Frances Hospital and was told that they could not accommodate her request at this time because their policy requires an employee be present to facilitate the meeting for any outside group and there is no one currently available to commit to that responsibility.

Does anyone know someone who is presently employed by Mother Frances Hospital who could commit to helping us out, just one evening, one-time, so we can hold a meeting at this hospital? If so, it could help us better determine our East Texas needs.

If you know of someone who might be able to assist us, please call Ramona Smith at 903-569-6176.

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DID YOU KNOW...

At our regional patient workshop last November, Dr. Racke, a MS neurologist from UT Southwestern Medical Center, mentioned TN occurs in 2-4% of MS patients. The most common cause is vascular compression.

Dr. Racke also referred to a study of 250 microvascular decompression (MVD) cases. 10 patients had MS because of a nerve compression. 9 had an excellent response to the MVD.

HOW CAN YOU HELP?

We have opportunities available for TN support group members. Below are just a few of them. If you have other ideas, please submit them to Shelly Wilson by calling 817-416-7202.

- Become the Fort Worth support group leader. We already have a meeting place and a great sponsor who provides dinner for our group. We just need someone to manage the needs of our growing Fort Worth facial pain community.
- Drive someone to a support group meeting
- Make reminder phone calls to TNA members about upcoming meetings
- Make a financial contribution
- Refer TN patients to our support group

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

REGIONAL PATIENT WORKSHOP

If you missed the TNA Regional Conference in November and haven't ordered the six hours of video tape along with meeting handouts for \$30, you can still do so while supplies last. *Only 3 video tapes and meeting handouts are available.* To place your order, send a check payable to TNA with the memo field notated "video tapes" to Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092.

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UPDATES FROM OUR MEMBERS

Linda had a successful MVD by Dr. Whitworth at UT Southwestern Medical Center in Dallas. You may remember Linda since she was the one featured in the Fort Worth Star Telegram's article on TN a couple of years ago.

Lizzie is scheduled for a MVD by Dr. Weiner at Dallas Presbyterian Hospital in April. We hope Dr. Weiner will find a compression to relieve Lizzie of her pain!

William reports that he's still doing great since his MVD in January. Hurray! Thanks to Dr. White at UT Southwestern Medical Center in Dallas.

Anna's had a lot of drug reactions – including Tegretol. She experienced severe hair loss while taking Flexiril. Exercise, physical therapy, meditation, and acupuncture have really helped her relax.

Joan, Linda, Lillian, Loe Nell, & Leslee have been having a lot of TN pain lately. Please pray for pain relief for them.

Please continue to keep Jill in your prayers as she is having a difficult time with a non-TN related health issue. Lee also has a non-related TN health issue and could use your prayers at this time.

Joan's husband, a TN supporter, is battling cancer and could benefit from your prayers as well.

Joe's recovering from non-TN related surgery. We hope he bounces back soon!

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

TELL ME ABOUT IT

Be sure to seek your pharmacist's advice regarding your medications. It could be a life-saving health habit.

Drug complications can be life threatening. However, a recent study revealed that when people consulted their pharmacists about medications, their risk of hospitalization due to drug complications was greatly reduced. For people taking several medications, the risk of death due to drug complications also was reduced.

Source: RealAge Tip of the Day, March 10, 2003

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MEETING NOTES

East Texas Meeting – January 15, 2004

Jonathan White, M.D., a vascular neurosurgeon from UT Southwestern Medical Center, presented “Diagnosing Facial Pain Syndromes and Treatment Options”. He mentioned possible causes for trigeminal neuralgia and the importance of getting a MRI to rule out other diagnoses.

Dr. White explained the four treatment options for classic trigeminal neuralgia patients: observe, medication, destructive procedure (rhizotomy or radiation), and microvascular decompression (exploration).

Dr. White stated Tegretol was his medication of choice to alleviate the severe pain brought on by “classic” TN. However, there were other drugs that worked for patients and whatever was prescribed by their attending physician, being acceptable to the patient was fine.

We watched a brief video of the decompression surgery that showed Merocel (not Teflon) being used to keep the offending blood vessel off of the trigeminal nerve.

For a surgical consultation with Dr. White, please call 214-648-8500 and let them know you have trigeminal neuralgia. (Provided Dr. White is in town, most TN patients will be seen within 10 days. If you have to wait more than 10 days, please call Linda Mitchell, Dr. White’s nurse at 214-648-3229 and request to be worked into Dr. White’s schedule.) Also, make sure to bring your MRI with you to your appointment.

Dallas Meeting – February 4, 2004

Mike Vengrow, M.D. with Neurological Doctors of Dallas spoke to our group about “The Neurologist & the Facial Pain Patient”. He told us there are more neurologists in the Dallas/Fort Worth area than in Arizona.

Dr. Vengrow stressed there are differences between doctors! TN is not easy to treat or cure.

Dr. Vengrow stated don’t go to the Internet for a diagnosis. It is a good resource though to do research *after* you have a diagnosis. He suggested the following websites: American Academy of Neurology, Virtual Hospital, and WebMD.

He emphasized make sure to get a MRI. A CT isn’t good enough.

Dr. Vengrow explained the doctor-patient relationship is based on dialogue! Ask your doctor questions (i.e. Why do you like prescribing Tegretol?). If your doctor isn’t open to answering your questions, find another neurologist. You have many to choose from in the metroplex.

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When treating TN patients, Dr. Vengrow always wants his patient to have a drug trial before referring them to surgery. He noted that not all drugs work for everyone.

Drug treatment options that Dr. Vengrow considers for his TN patients include:

Tegretol	400-1200 mg
Dilantin	300-600 mg
Baclofen	40-80 mg
Valproic acid	500-2000 mg
Klonopin	2-8 mg
Orap	4-12 mg

Other – Trileptal, Keppra, Neurontin, Topomax, Lamictal, Zonegran

Dr. Vengrow doesn't like to prescribe narcotics. He refers his patients to a pain management clinic for narcotic management.

For those patients with acute herpes zoster, Dr. Vengrow thinks a nerve block is the most effective treatment.

FUTURE MEETING DATES

Dallas at Zale Lipshy Hospital – 4/7, 6/2, 8/4, 10/6, 12/1
Fort Worth at Baylor All Saints – 3/23, 5/18, 7/20, 9/21, 11/16
Tyler at East Texas Medical Center – 4/23
Waco at Hillcrest Hospital – 5/3, 7/12, 9/14, 11/1

TREASURER'S REPORT

Beginning Balance 2/21/04		\$3756.12
Donations Received	\$1056.00	
Supplies	46.37	
Copies	44.54	
Convention Parking	16.00	
Long Distance	<u>.60</u>	
Total Expenses	<u>\$107.51</u>	
Ending Balance 3/21/04		\$4704.61

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FINANCIAL CONTRIBUTIONS

Local TNA chapters *do not receive* funding from the national office. If you would like your tax-deductible contribution to go toward our local chapter, please make your check payable to the order of Trigeminal Neuralgia Association and in the memo field put North Central Texas chapter, then mail it to Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092.

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

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