



**TRIGEMINAL NEURALGIA ASSOCIATION
TEXAS SUPPORT GROUPS NEWSLETTER
April 2005**

WELCOME AUSTIN!

The TNA Austin Support Group has joined our newsletter distribution. This brings the number of people receiving our Texas newsletter to 1,128.

If you have an e-mail address, please help us by e-mailing it to Shelly Wilson at swilson@tna-support.org. By doing so, we will be able to save on postage and the number of copies we have to make of the newsletter and meeting schedule.

HOUSTON SUPPORT GROUP LEADERS – DID WHAT???

Rhonda and Jim Ashby, the Houston support group leaders, have moved to live closer to Rhonda's son and daughter-in-law who are expecting twins. Their new address is 5525 Reading Road, #605, Rosenberg, TX 77471. Their phone number and e-mail address remain 281-534-3076 and rhonda@idesolutions.us.

HOWARD BIEL, R.PH. IS WHERE?

On March 21, 2005, ReCept Pharmacy opened in Waco with Howard Biel, a compounding pharmacist, running it. ReCept is based in Fort Worth and has 15 other pharmacies scattered around the state. Their goal is to buck the trend of super-sized, impersonal chain pharmacies by offering individualized service to customers. It also dictates the services ReCept pharmacies offer, such as home delivery and custom medications.

According to a Waco Tribune-Herald article "from the minute customers walk in, they will likely sense a difference in the way ReCept looks and feels. The walls are painted in bright colors, and the area where medications are made or dispensed is behind large glass windows so customers can see."

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ReCept Pharmacy in Waco is located at 577 N. Valley Mills Drive, next to Cavender's Boot City. Their phone number is 254-399-8718.

CYMBALTA?

Has anyone tried taking the prescription medication called Cymbalta for TN or related facial pain? If so, please let Shelly know about your experience. Send an e-mail to Shelly at swilson@tna-support.org or write a note to Shelly Wilson at 604 Aberdeen Way, Southlake, TX 76092.

Cymbalta works to treat more than one condition. Not only has Cymbalta been proven effective in treating depression, including both its emotional symptoms (such as sadness and irritability) and its physical symptoms (such as fatigue or vague aches and pains), it has also been proven effective managing the pain of diabetic peripheral neuropathy pain (DPNP).

It is believed that Cymbalta acts as an antidepressant and pain reducer due to its effect on two naturally occurring chemicals in the brain and body, serotonin and norepinephrine.

Cymbalta comes in a capsule and can be taken once a day. The recommended daily dose for Cymbalta is 60 mg. However, your doctor may prescribe a different dose based on his or her medical judgment. Cymbalta is available in 20 mg, 30 mg, and 60 mg capsules. Cymbalta is not recommended for those under 18. Cymbalta is not a narcotic.

Source: www.cymbalta.com/

COMPUTER CHAT ROOM

Tracy Knight, a Trigeminal Neuralgia Association Telephone Support Contact, voluntarily takes phone calls from TN patients and their supporters at 972-617-7809. She also donates her time to run a Yahoo! Group called TexasTNsupport. This group is made for those who suffer from TN or have a loved one that suffers from TN and lives in the Texas area.

To visit this chat room, go to: <http://health.groups.yahoo.com/group/TexasTNsupport/>

Thanks to Tracy for the time she gives our association!

DO YOU HAVE ANESTHESIA DOLOROSA?

We are compiling a list of facial pain patients that have anesthesia dolorosa so they can network with each other to learn what has helped relieve the pain.

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As defined in the book “Striking Back! The Trigeminal Neuralgia and Face Pain Handbook”, *anesthesia dolorosa is a troubling and hard-to-treat combination of pain and numbness.*

If you have anesthesia dolorosa and want to share your experience with other Texans suffering from with the same problem, please send an e-mail to Shelly Wilson at swilson@tna-support.org or send a written note to Shelly Wilson at 604 Aberdeen Way, Southlake, TX 76092. Please state that it is OK for TNA to share your name, phone number, and e-mail address (if you have one) with other anesthesia dolorosa patients.

WEBSITES OF INTEREST

www.pfizerhelpfulanswers.com – If you’re one of the millions of Americans without insurance coverage for prescription medicines, Pfizer has a comprehensive savings program that may be able to help you. (*Pfizer manufactures Neurontin.*)

www.iom.edu/report.asp?id=24487 – Use of Complementary and Alternative Medicine (CAM) by the American Public

www.nap.edu/catalog/11182.html - Read “Complementary and Alternative Medicine in the United States” online for free.

UPDATES FROM OUR MEMBERS

Rick reported he’s still pain-free, 1-1/2 years after his MVD by Dr. Weiner at Dallas Presbyterian Hospital. Outstanding!

Tammy’s been pain-free since February. Every day counts!

Mike feels great! His MVD by Dr. White with UT Southwestern in Dallas last February was a success. He’s totally off of the Tegretol and down from 7000 mgs to 900 mg of Neurontin each day. He should be completely off of the Neurontin in about three weeks. He feels like a new man with a lot more energy than he has felt in years. He suggests anyone with TN contemplating a MVD should not hesitate to see a well-regarded neurosurgeon to find out if they are a candidate.

Glen had a MVD by Dr. Kopitnik at UT Southwestern 1-1/2 years ago. He’s been pain-free and medication free for the last year.

Jeanne in Austin who has occipital neuralgia just got tremendous pain relief from Dr. Mike with 1st Chiropractic North Research at Anderson Mill. His office phone number is 512-250-2225.

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Please pray for:

- Ronnie who is having a MVD by Dr. White this month.
- Carolyn's pain free period of 16 months and 1 week has come to an end. She's increasing her Tegretol in hopes of controlling the shocks.
- Barbara's had pain everyday for the last three weeks. Please keep her in your prayers while she searches for pain relief.
- Unfortunately, Martha's MVD has not relieved her TN pain. Please keep her in your prayers as she continues to work with her neurosurgeon to find relief.
- Lily's MVD did not help her at all. She is considering a radiofrequency rhizotomy.
- Juleena, a 26 year old who has had TN for less than a year. She's already struggling to control her pain with a cocktail of medications and is exploring the possibility of surgery.
- Brian who had been told he had atypical facial pain and just recently found out why! He has a tumor in his cheek. He's having a pet scan soon to determine if it is benign or malignant.
- Michael's Mom is searching for her next TN surgical procedure in hopes of relieving her TN pain.
- Yolanda is having sinus surgery on April 13.

Another former member of our support group, who has asked to remain anonymous, suffered with TN for 30 years. Many years ago, she had a destructive procedure called the glycerol rhizotomy and it only made her pain worse. A few months ago, she had a MVD and it didn't work. Needless to say, she's frustrated, no longer wants information from the Trigeminal Neuralgia Association and wants others to know that the MVD doesn't always work. She, like everyone else in our support group, is welcome to request to be taken off our support group list and the TNA National Office list at any time for any reason and will always be welcomed back into our organization at a later date if she would like to participate again.

In "Striking Back! The Trigeminal Neuralgia and Face Pain Handbook", it mentions *several recent studies have found that MVD (microvascular decompression) success rates seem to start dropping off after people have had their pain for more than seven or eight years.*

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.

MEETING NOTES

Fort Worth – November 16, 2004:

Tracy Carmack, a Certified Clinical Nutritionist, presented "Integrative Alternative Nutritional Strategies for Pain Management".

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1 out of 8 people are deficient in Magnesium which interferes with the transmission of nerve and muscle impulses, causing irritability, nervousness, depression, muscle weakness, PMS, constipation, insomnia, cramps, and high cholesterol. Magnesium aids the absorption of calcium. When Magnesium is taken with B6, it helps prevent kidney stones.

Potassium is important for a healthy nervous system and regular heart rhythm, proper muscle contraction, and water balance. Potassium deficiency results in cognitive impairment, constipation, diminished reflex, edema, thirst, low blood pressure, muscle fatigue and weakness, headaches, high cholesterol, glucose intolerance.

The enzyme Bromelain is a nerve anti-inflammatory agent. It works by increasing the breakdown of fibrin which forms around inflamed areas, blocking the blood and lymphatic vessels and leads to swelling. Bromelain should be taken on an empty stomach.

Tracy recommended the following nutritional strategy:

- Use targeted supplements indicated for nerve protection and repair
- Use complimentary pain supplements
- Replace nutrients depleted by pharmaceutical drugs and poor diet
- Treat the whole person

For more information, call Tracy Carmack at 817-456-5962, e-mail her at Tracy.Carmack@juno.com or to view her speaking schedule go to www.looklocally.com/10316. Tracy offers nutritional consultations in the DFW area.

Waco Meeting – January 10, 2005:

Michael Carruth with Fit For Health in Waco spoke about the benefits of weight persistence training and Valerie Bailes discussed nutrition and health.

A handout titled “12 Reasons Every Adult Should Strength Train” by Wayne L. Westcott, Ph.D. included: avoid muscle loss, avoid metabolic rate reduction, increase muscle mass, increase metabolic rate, reduce body fat, increase bone mineral density, improve glucose metabolism, increase gastrointestinal transit time, reduce resting blood pressure, improve blood lipid levels, reduce low back pain, and reduce arthritic pain.

The SuperSlow strength training was explained. A typical SuperSlow workout involves four to six weight machines, each targeting a specific muscle group. Weights are slowly raised in 10 seconds and lowered in 10 seconds non-stop until the targeted muscles reach total momentary fatigue – about 1-1/2 to 3 minutes per machine. The turning point comes when you try to push beyond total fatigue for an extra 10 seconds. That’s what triggers fast, noticeable improvement.

For more information, call Mike or Joy Carruth at 254-235-4279 or visit their website at www.superslowzone.com/usa1003.

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FUTURE MEETING DATES

Austin – T.B.A.
Dallas at Zale Lipshy Hospital – 4/13, 7/13, 10/26
Fort Worth at Baylor All Saints – 6/7, 9/27, 11/1
Hill Country – T.B.A.
Houston at Christus St. Joseph Hospital – 4/30, 7/30
San Antonio – starting soon!
Tyler at East Texas Medical Center – T.B.A.
Waco at Hillcrest Baptist Medical Center – 5/2, 7/11, 9/13, 11/14

TREASURER'S REPORT DALLAS, FORT WORTH, TYLER, AND WACO (*combined*)

Beginning Balance 2/28/05		\$5218.10
Donations Received		\$235.00
Center for Nonprofit Mgt.-training	100.00	
Copies	73.85	
Copy Machine w/supplies	605.90	
Postage	150.57	
Striking Back books	153.70	
Supplies	<u>48.82</u>	
Total Expenses		<u>\$1132.84</u>
Ending Balance 3/31/05		\$4320.26

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: 800-923-3608, Fax: 352-376-8688
www.tna-support.org

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