



TRIGEMINAL NEURALGIA ASSOCIATION
TEXAS SUPPORT GROUPS NEWSLETTER
May 2005

NEW! SAN ANTONIO SUPPORT GROUP

Thank you to Guillermo Wolff and JoDee Kerestes for starting a TNA (Trigeminal Neuralgia Association) support group in San Antonio, TX. Their first meeting is May 10th. They will continue to meet the 2nd Tuesday of every month. For meeting specifics, please check the TNA Support Group meeting schedule.

TNA PRESIDENT IS COMING TO TEXAS!

Michael Pasternak, Ph.D., TNA's President (*a volunteer role*), will be coming to Texas to visit with the following support groups: Dallas, Fort Worth, East Texas, and Waco.

On Sunday, July 24, everyone is invited to the home of Shelly and Scott Wilson for a BBQ potluck dinner. The Wilsons will provide the BBQ and beverages. Please bring a side dish or dessert and remember to RSVP by July 20.

On Monday, July 25, Michael will meet with the East Texas support group in Tyler at East Texas Medical Center in the Pavilion Building's room 1 from 1:00 – 2:00 p.m.

On the evening of July 25, Michael will meet with the Waco support group members. As a result, the Waco support group meeting that had been previously scheduled for July 11 has been changed to July 25, same time, same place.

Please check the TNA Meeting schedule for more details.

OUR TEXAS SUPPORT GROUPS WEBSITE

Special thanks to Scott for relocating our website and paying for the first year of the website costs. He's donated this in memory of his favorite Aunt Lil who had facial pain for many years and did not get it diagnosed or treated.

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To view the website which includes our support group newsletters for the last 1-1/2 years, go to www.texasrna.org.

If you have suggestions for the website, please e-mail them to Shelly at swilson@tna-support.org.

NEW E-MAIL ADDRESS FOR AUSTIN SUPPORT GROUP LEADER

Joan Foster, the TNA Austin Support Group Leader, has a new e-mail address that is up and running now. Please send all e-mails for Joan to jef@fosterfamilydentistry.com
Thanks!

STRIKING BACK! THE TRIGEMINAL NEURALGIA AND FACE PAIN HANDBOOK

Last November, the new Striking Back handbook was published and made available for purchase through the TNA national website at www.tna-support.org. It has over 500 pages full of information for facial pain patients. This is twice the size of the first book called Striking Back! that was published in 2000.

If you haven't already ordered a copy of the new Striking Back, you now have a great incentive to consider. The new Striking Back sells for \$24.95 plus shipping. For Texas support group members, you have the opportunity to purchase this book for \$20.00, a 20% discount, by sending a check for \$20 made payable to TNA (Trigeminal Neuralgia Association) to Shelly Wilson, 604 Aberdeen Way, Southlake, TX and in the memo field write name of the support group location from where you'll pick-up your copy to save on postage.

If you would like to order the book but can't make it to a support group meeting to pick it up, Shelly will mail it to you. For these orders, please make your check for \$25 made payable to TNA and mail it to Shelly.

ZALE LIPSHY RENAMED

Zale Lipshy University Hospital in Dallas has been renamed University of Texas Southwestern University Hospital, Zale Lipshy Building.

SPECIAL PRAYER REQUEST

Brian, a Houston support group member, has suffered with TN since May 2004. Last July, he had a MRI which didn't show anything. Last August, he had a MRI and MRA

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that were also fine with the exception of a pinched nerve resting on the spinal column. An EMG was done determined the problem was of minor concern for a nerve in the leg.

At the end of last year, Brian's symptoms started changing and his pain increased. When he urged his doctor to order more imaging, the CT-scan with contrast showed a tumor in his cheek. Unfortunately, additional imaging showed the tumor in his cheek was cancerous and he also had one in his neck.

Brian was told by a M.D. Anderson physician in Houston that his care is very rare. There may only be 25 cases occurring at any one time in the U.S.

A procedure to remove the bulk of the cancer will be tough and challenging. With chemotherapy and radiation, there may be some lessening of the pain but not a lot as radiation will add a bit to the burden.

He's got some tough treatment options to consider and not an easy road ahead. Please keep Brian in your thoughts and prayers.

If you would like to follow Brian through his treatment, you can view his website at www.briannelsonconsulting.com/trigeminal-neuralgia-tn/faq-info.html

If anyone would like to send him a card, please mail it to Brian Nelson, 31 Gessner Road, Houston, TX 77024.

MUSCLE UP

Does stress make your blood pressure spike? If so, then build up your biceps.

Lean body mass helps your blood pressure return to normal after a stressful event, a recent study revealed. Muscle tissue improves your body's ability to regulate sodium, a key for blood pressure control. Tone your muscles by lifting weights a minimum of 10 minutes, 3 times per week.

Source: RealAge Tip of the Day – January 26, 2005

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

Just a reminder, if you change your e-mail address, please let Shelly know.

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CYMBALTA

In last month's newsletter, we asked if anyone had tried Cymbalta to help relieve their facial pain. 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. Below is feedback from our support group members.

Ann and Mary have tried it but didn't get any pain relief.

After Lynn's first episode with TN, her general practice doctor prescribed her 40 mg and it has helped.

Angela was diagnosed in March 2003 with TN and is now 50 years old. She started taking Cymbalta on Thursday, April 28, 2005. Her psychiatrist prescribed it since he had read some articles on how it helped with neuropathic pain. She's taking 30 mg a day now and will have a follow-up visit in about three weeks. If at that time, she is not having any side effects, the psychiatrist plans to up her dosage to 60 mg.

DID YOU KNOW...

In the new Striking Back! The Trigeminal Neuralgia and Face Pain Handbook, it mentions:

It's difficult to get an accurate handle on exactly how widespread TN is because patients may be seeing so many different types of practitioners for treatment of TN and other face pain, including family doctors, oral surgeons, neurologists, neurosurgeons and chiropractors.

TN also happens to be a disorder that's not required to be reported to government agencies, so there's no national data base kept by agencies that track specific health problems.

UPDATES FROM OUR MEMBERS

Mary had glossopharyngeal and trigeminal neuralgia. Last month, she had a MVD by Dr. Jonathan White with UT Southwestern in Dallas. She's at home recuperating now.

Ronnie had a MVD for trigeminal neuralgia and hemifacial spasm by Dr. White last month. Since the surgery, he hasn't experienced a hemifacial spasm and a lot of his TN pain is gone. We wish him a speedy recovery!

Linda had a MVD by Dr. White in December 2003. As of this month, she is still completely pain free and back on her normal routine after having been totally incapacitated for almost four years.

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Jerry's still doing great and hasn't had to increase his TN medication since the Botox injection he got last fall from Dr. John Claude Krusz, a North Dallas neurologist.

George is receiving relief from 1200 mg of Neurontin after having pain for many years. He just went to a new doctor who ran all of the tests again and discovered he did not have TN but atypical sinus trauma from an old operation that mimicked TN. Live and learn!!!

Bonnie had the gamma knife by Dr. Hudgins at Dallas Presbyterian Hospital's Gamma Knife Center in mid January. Since that time, she has strung together 66 consecutive pain-free days and has reduced her Neurontin from 2700 mg a day down to 1800 mg. Working with her neurologist, Dr. Khalid, she thinks she'll be off of Neurontin in 12 more weeks and then will work on getting off of 1000 mg of Tegretol which she has been taking for three years.

Jean tried acupuncture twice. The second treatment took away all of her pain. Unfortunately, the pain did return later so she continues to take 2700 mg per day of Neurontin.

Heather found out she has a B-12 deficiency so she began taking B-12 sublingually (under the tongue) and as long as she is taking it and cuts back on her caffeine and chocolate, she doesn't have any TN pain. However, when she is not taking it, her TN pain comes back.

Please pray for:

- Carolyn because she's in a terrible TN pain cycle right now.
- Pat because in addition to TN, she was just diagnosed with Fibromyalgia.
- Lisa since she is going to have a block done this month to see if it will help relieve the burning pain she experiences from anesthesia dolorosa.
- Leslie as she tries to lose weight from the TN medication and inactivity due to atypical facial pain.
- Melvin as he recovers from a TIA stroke.
- Juna since she is having severe pain attacks.

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

The June 2005 newsletter will include meeting notes for several 2005 support group meetings.

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FUTURE MEETING DATES

Austin – T.B.A.

Dallas at Zale Lipshy Hospital – 7/13, 10/26

Fort Worth at Baylor All Saints – 6/7, 9/27, 11/1

Houston at Christus St. Joseph Hospital – 7/30

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

Southlake (NW of DFW airport) – 7/24 BBQ potluck dinner

Tyler at East Texas Medical Center – 7/25

Waco at Hillcrest Baptist Medical Center – 5/2, 7/25, 9/13, 11/14

TREASURER'S REPORT – NORTH CENTRAL EAST TEXAS

Beginning Balance 3/31/05 **\$4320.26**

Donations Received **\$267.50**

Long Distance 17.31

Postage 111.65

Supplies 6.45

Total Expenses **\$135.41**

Ending Balance 4/30/05 **\$4452.35**

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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