



TRIGEMINAL NEURALGIA ASSOCIATION TEXAS SUPPORT GROUPS NEWSLETTER JUNE 2006

SOCIAL SCHEDULED IN ARLINGTON, TX

Come join us for coffee and soft pastries at the Shady Valley Golf Club in Arlington on Saturday, June 24, from 9:00 – 10:30 a.m. For more details, directions, and RSVP information, please refer to your TNA meeting schedule.

DONATIONS FOR TNA SILENT AUCTION

TNA will be holding a Silent Auction at the Gala Dinner during the TNA National Conference on September 15, 2006. If you would like to donate any *new* items or gift certificates for this function, please send them to Shelly Wilson, TNA, P.O. Box 92604, Southlake, TX 76092 by August 1. Thank you for your consideration!

FUNDING FOR PROFESSIONAL OUTREACH & EDUCATION PROGRAM

Roger Levy, Chairman of the Trigeminal Neuralgia Association, just returned from a presentation to the Asplundh Foundation Board where he asked for and received a \$50,000 to fund a professional Outreach and Education Program with a pilot program in Philadelphia, where the foundation's philanthropy is focused. He reported the 17 member Board voted unanimously to give TNA the full grant amount. *HURRAY!*

TNA'S 6th NATIONAL CONFERENCE

TNA holds a national conference, every other year, where approximately 75% of the attendees are patients/supporters. This year, TNA's 6th National Conference will be held in Portland, OR at the Double Tree Lloyd Center Hotel, September 14-16.

For conference details and online registration go to www.endthepain.org or call Shelly Wilson at 817-416-7202 and request a registration brochure be mailed to you.

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If you itemize your income tax return, this may be a deductible item for you. Please check with your tax advisor for more details.

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Shop online from over 350 stores like Barnes & Noble, Gap, Office Depot, 800-Flowers, Wal-Mart, Expedia, and more at BuyForCharity.com! **Up to 35% of each purchase will benefit us** if you select the Trigeminal Neuralgia Association as your cause of choice.

So anytime you buy online, whether you are looking for Airline Tickets, Flowers, Clothes, Music, Office Supplies or anything else... Buy For Charity and help support TNA. There is NO cost to you and you can even save money on your purchases by using their great coupons and specials. As a new shopper on **BuyForCharity.com**, you just sign up once - and you don't have to give any personal information!

LYRICA: SUMMARY OF PATIENT EXPERIENCES

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.

The feedback collected from our support group members who have tried Lyrica over the last 8 months are all over the page. About half of the patients who have tried it, liked it, and remain on it today. Some interesting findings include:

- Of the six people who switched from Neurontin (generic: Gabapentin), to Lyrica, five switched back to Neurontin (generic: Gabapentin).
- The two people who switched from Tegretol to Lyrica seemed to like Lyrica better.

The conclusion is Lyrica is another medication available in the facial pain arsenal. There is no way to determine how you will respond until you try it. For some, it has been a life saver and for others, it just didn't work as well as other things they had tried.

Thank you to everyone who provided input about their experience. For more information on Lyrica, go to www.lyrica.com.

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HOUSTON AREA NEUROLOGISTS

Sam very highly recommends Dr. Julia L. Jones, The Neurology Center, 7505 S. Main, Suite 290, Houston, TX 77030, 713-795-0074. He has been a patient of Dr. Jones since March/April 2000 when he was diagnosed with TN. After several years of various medications and success with my facial pain, the medicines stopped working. He elected to have the MVD surgery in March 2004, with much success. He's still on a very low dosage of medicine at the present time.

Linda recommends her neurologist, Dr. Brian Loftus. He has just moved his practice to Bellaire Neurology, 6565 West Loop South, Suite 401, Bellaire, TX 77401. (This is in Houston.) His office number is 713-715-6360. However, in March 2006, Dr. Bruce Pollock at Mayo Clinic in Rochester, MN (a TNA Medical Advisory Board member) performed a successful MVD on her so she's hopeful she will not require Dr. Loftus' excellent services again!

UPDATES FROM OUR MEMBERS

Great news! Cynthia's Mom who previously had a gamma knife in Mississippi that didn't work, got pain relief with the TN outpatient procedure called the Radiofrequency Rhizotomy or the PCCG by Dr. Phil Williams, Jr. in Dallas. After suffering with TN pain for seven years, she is now pain-free and talking non-stop. It is a bit strange but she is adapting to the feeling of numbness in a quadrant of her face which is a side effect of this surgical procedure.

Sylvia had the gamma knife done in April 2005 by Dr. Garza-Vale at Methodist Hospital in San Antonio, Texas. She didn't get relief until 4-5 months after the procedure. She is still taking two Tegretol pills a day because she gets threatening pains. Needless to say, she is still scared of TN pain. She prays the pain doesn't return.

When Tom's Botox injection wore off (in about 3 month's time), his TN pain returned. He had to go back on Tegretol and got up to 800 mg per day to control the pain. He had three Botox injections, 40 units each, around the eye and cheek and feels a lot better now.

Brian is one of our out-of-state members. He enjoys reading about the positive outcomes some folks are having after certain procedures. He also feels a level of unexplainable sympathy for those who are still struggling to find relief. With hopes of not jinxing his recent good fortune, he has recently found sizable relief from "the beast". This is the time of year when he braces himself for the worst. So, as spring started this year, so did the usual trickles of pain. However, to date, that is where it stopped and even recessed a bit. Late last winter, he began a series of Upper Cervical Chiropractic treatments. He thinks his posture may have played a role in his TN pain. Case in point, the one and only serious bout of pain he's had since Spring came after he lay on the sofa with his head moved way toward his chest – so he doesn't do that anymore. He's also sworn off his

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former favorite easy chair which was an invitation to pain (always after using it, not during).

Chestal got her TN pain "fixed" by Dr. David Baskin, a Houston neurosurgeon. His office is at 6560 Fannin, phone 713-441-3800. She suffered horribly and all it took was one procedure, one afternoon to get rid of her pain.

Cal had a gamma knife by Dr. Gary Kraus at the West Houston Medical Center on April 3. On Mother's Day, his TN pain disappeared and he is now off Tegretol. Hurray!

Roxanne belongs to the San Antonio TNA group. She has been to many doctors all over the Country and all have different ideas as to what she has ranging from TN, migraine and cluster headaches. She also has chronic idiopathic pancreatitis. Over the past six years, she has tried Tegretol, Dilantin, Topamax and many others. She cannot tolerate any of the drugs no matter the strength. Three months ago, Dr. Dar, her Pain Management doctor, put her on 75 mg of Lyrica at night. It helped with her head pain but left her disoriented and walking into walls. Dr. Dar lowered Lyrica to 50 mg at night then prescribed Provigil 200 mg in the morning. She also had Botox in the areas of the eye, temporal and forehead. Between the three, she felt great for a month then started with some break through pain. She went from a pain level of 3-7 on a 24/7 basis to maybe one bad day a week. Recently, Dr. Dar increased the Lyrica again to 75 mg but she started walking into walls and felt drunk. She called Dr. Dar's office and left a message that she was going back to 50 mg of Lyrica. She hopes 50 mg of Lyrica at night with Provigil and 25 mg of Lyrica in the morning will do the trick. Bottom line, she believes the Lyrica is of great help and is so thankful to be out of pain 24/7. She would like to add that Dr. Dar was a San Antonio Support Group guest speaker at the January 2006 TNA meeting. My thanks to TNA for inviting Dr. Dar!!!

Please pray for:

- Erika whose TN has returned after a year of being in remission.
- Martha who is taking *a lot* of TN medication and took care of her ill sister for eight months before she recently passed away.
- Julia who has TN. She was run over by a hit and run driver. Both of her legs were broken at the ankles.

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 P.O. Box 92604, Southlake, TX 76092.

A NATURAL ALTERNATIVE

Judy found that three drops of clove oil in a glass of water works great for constipation from medication. She just takes it as needed.

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WANT RELIABLE INFORMATION ON TN SURGICAL PROCEDURES AND MORE?

The book called Striking Back! The Trigeminal Neuralgia and Face Pain Handbook is a soft back book with over 500 pages written in laymen's terms. It includes information on medications, surgeries, alternative treatments, tips from facial pain patients, and how to cope with face pain.

The cost is \$24.95. It can be ordered through TNA's website at www.endthepain.org, www.barnesandnoble.com, www.amazon.com, or by calling TNA's national office at 800-923-3608 or you can order one from Shelly Wilson for \$24.95 plus \$5 for shipping. To order a book from Shelly, either send an email to swilson@tna-support.org or call 817-416-7202. Shelly will send you a book and you can send a check back to Shelly.

WEBSITES OF INTEREST

http://www.oregonlive.com/news/oregonian/margie_boule/index.ssf?/base/living/1144715151244840.xml&coll=7 – article about a TN patient who had a microvascular decompression brain surgery

<http://abcnews.go.com/Technology/Health/story?id=531217&page=1> – Studies: Chronic Pain Comes From the Brain

<http://www.webmd.com/content/Article/65/72758.htm?printing=true> – Do Your Aches, Pains Predict Rain? Though many people believe in the connection between weather and health, the medical evidence is unclear.

<http://www.weather.com/activities/health/achesandpains/achesandpains101/?fro> – Aches and Pains 101, be sure to look at *Barometric Pressure, humidity, precipitation, temperature & wind* information

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 SUMMARIES

May 8, Waco, TX: Thank you to Howard Biel, R.Ph., a compounding pharmacist with ReCept Pharmacy.

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May 15, Fort Worth, TX: Thank you to Wayne Martin, L.C.S.W., B.C.I.A.C. with Baylor All Saints Hospital who spoke about Mindfulness Meditation and also gave a review of 47 Hypnosis Cases over 160 years.

FUTURE MEETING DATES

Arlington – 6/24
Austin – T.B.A.
Dallas at Zale Lipshy University Hospital – 6/13
Fort Worth at Baylor All Saints – 8/9 (Faxel meeting room), 11/8 (Private Dining Room)
Houston – T.B.A.
San Antonio – 6/13, 8/8, 10/10, 12/12
Tyler – 6/30, 9/29, 12/15
Waco at Hillcrest Baptist Medical Center – 7/10, 9/11, 11/13

TREASURER'S REPORT – NORTH CENTRAL EAST TEXAS

Beginning Balance – 4/30/6	\$3,877.74
Donations Received	\$129.95
Copies	14.15
Long Distance Card	30.00
Postage	219.00
Supplies	<u>43.94</u>
Total Expenses	<u>\$307.09</u>
Ending Balance 5/31/06	\$3,700.60

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, 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.

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