



## **TRIGEMINAL NEURALGIA ASSOCIATION TEXAS SUPPORT GROUPS NEWSLETTER MARCH 2006**

*With money you can buy a doctor, but not good health.  
- Chinese proverb*

### **INSIDE EDITION**

For those of you who have given your e-mail address to TNA, I hope after getting the e-mail about the Inside Edition TV show airing the TN story of two patients, you got to watch it. The reviews have been overwhelmingly positive.

Two days after the story aired, Inside Edition called the TNA national office to report the unusually large number of inquiries they had gotten on the story. The Inside Edition website is directing TN inquiries to the Trigeminal Neuralgia Association.

This was TNA's first national TV exposure – and it was aired during sweeps week. TNA's awareness committee is targeting other national TV shows in hopes of getting more TN and neuropathic facial pain stories aired.

If you have an e-mail address where we can send you this newsletter and our meeting schedule along with any time sensitive information, please e-mail Shelly Wilson at [swilson@tna-support.org](mailto:swilson@tna-support.org) to help us save on mailing and copying costs.

### **TRILEPTAL: FREE 30-DAY TRIAL OFFER**

Go to [www.trileptal.com](http://www.trileptal.com) and click on “Free 30 Day Trial” of Trileptal. Then print off the voucher and take it to your physician to write you a prescription. Next, bring your voucher along with a valid, signed prescription for Trileptal to your pharmacy for a free 30-day trial (150, 300, or 600 mg tablets, or 300 mg/5ml oral suspension).

Note: Voucher for a free trial of Trileptal can be redeemed once. This offer is good through 12/31/06.

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Special thanks to Gladys for sharing this tip with us! She saved \$395 one month by using this free trial offer.

### **HYPNOSIS?**

Have you tried hypnosis for facial pain? If so, please share your experience with Wayne Martin, a TN patient, via e-mail at [WayneM@BaylorHealth.edu](mailto:WayneM@BaylorHealth.edu) or by calling him at 817-922-2060 or 817-922-7246. Thanks!

### **EAST TEXAS SUPPORT GROUP CONTINUES**

Pam Rowlett has volunteered to take over the East Texas Support Group Leader role. She has already scheduled the 2006 meeting dates at East Texas Medical Center for 3/24, 6/30, 9/29, and 12/15. Check the meeting schedule for more details.

### **EDUCATIONAL MATERIALS**

To request FREE information from TNA, go to [www.endthepain.org](http://www.endthepain.org) and click on “Educational Materials” and then click on “Information Sheets”. The following brochures are available.

- Anesthesia Dolorosa
- Choosing the Surgical Procedure that is best for you
- Emergency Room Management of Episodes of Severe TN
- A New Classification for Facial Pain
- TN and Future Dental Work
- TN and MS
- Complementary and Alternative Medicine (CAM) Overview
- Upper Cervical Chiropractic (UCC)
- Neuropathic Facial Pain and Vitamin B-12
- Pain-Triggering and Pain-Safe Foods

### **STRIKING BACK!**

#### ***THE TRIGEMINAL NEURALGIA AND FACE PAIN HANDBOOK***

Marita recently ordered Striking Back and reports she has read the first two chapters which has told her more about TN than her doctor has.

If you haven't purchased the new Striking Back book with over 500 pages, published in November 2004, it might just end up being the best \$24.95 you have ever spent on your facial pain condition.

Striking Back is available three ways.

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1. Contact Shelly Wilson via e-mail at [swilson@tna-support.org](mailto:swilson@tna-support.org) or call 817-416-7202 and request one be mailed to you and in return, mail Shelly Wilson a check for \$30 to cover the cost of the book and shipping.
2. Order the book by calling the TNA national office at 800-923-3608, place your order over the phone with a credit card and a book will be mailed to you.
3. Order the book on-line at either [www.endthepain.org](http://www.endthepain.org), [www.barnesandnoble.com](http://www.barnesandnoble.com), or [www.amazon.com](http://www.amazon.com).

### **BRIAN'S REVIEW OF STRIKING BACK ON AMAZON.COM**

Hi, I started with facial pain in May of 2004. Finally when I learned about Trigeminal Neuralgia I felt relieved because I was getting a real handle on what was causing my pain. I felt better because I was not alone. It ended up that my pain was caused by a malignant cancerous tumor resting on the trigeminal nerve in my lower jaw. Surgery would have totally disfigured me because the tumor was deep. After my first chemotherapy the electrical shocks went away because the tumor had shrunk at least a little bit. When the Doctors at Methodist Hospital in Houston found the tumor it was suggested that I get treatment across the street at the MD Anderson Cancer Center. You can read about my 33 radiations and 3 chemotherapies for my bout with cancer at [www.IamFightingCancer.com](http://www.IamFightingCancer.com).

The book "Striking Back" was most beneficial in learning about all the treatment options. It allowed me to keep the door open to getting PROPER treatment. I have also joined a Houston Support group which has been most helpful.

**I will personally guarantee this book. If you read this book and don't feel it did you any good I will buy it from you.** I just don't want anyone with facial pain to go it alone. It is dangerous.

Call me if you have any questions about the book. I am not selling mine to anyone. It is a great reference book. I have met both co-authors - great people. They are welcome to stay at my house anytime.

E-mail me through my web journal [www.IamFightingCancer.com](http://www.IamFightingCancer.com). It has a lot of links to 4 other pages about TN and Cancer.

Brian Nelson, Houston, TX, 713-467-3025

### **EAR PAIN**

George experiences ear pain about 2-3 times a month. When shocks go from his ear canal to his ear drum, his pain is "suicidal".

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Do you suffer with similar pain? If so, please send your experience to Shelly Wilson either via e-mail at [swilson@tna-support.org](mailto:swilson@tna-support.org) or U.S. mail to P.O. Box 92604, Southlake, TX 76092. Feedback will be put in a future newsletter.

## **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.

Frank has had atypical facial pain and headaches for 10 years. He just tried 25 mg of Lyrica, 3 times a day, and it is the first drug which has helped to alleviate his facial pain but it doesn't seem to help with the headaches. He sometimes gets drowsy during the day but has no other side effects.

Gwen's TN came out of remission and she is taking 100 mg of Lyrica, three times a day. Sometimes she takes an extra 50 mg of Lyrica if she needs it. Her balance is slightly off and her memory is awful. She's also experiencing constipation. However, taking Lyrica is worth it because her pain is gone.

Rhonda is taking 200 mg, 2 times a day, of Lyrica. She also takes Loritab to calm the pain.

George was prescribed 100 mg, 2 times a day of Lyrica for the pain he experiences from a pinched disc. He mentioned this also helps his facial pain and has kept him from having to go to the Emergency Room.

Sandy is taking Lyrica and remarks "it is good".

Tom tried taking Lyrica about 2 months ago. He had neither ill nor good effects from it so he is no longer taking it.

Deanna made the switch almost overnight from 3600 mg of Neurontin to 300 mg of Lyrica. Her neurologist weaned her off of Neurontin as she increased her Lyrica dosage. Within a week, Deanna has had no pain and loves Lyrica!

Bud mentioned his TN recently let up as soon as he quit taking Zocor, a prescription anti-cholesterol drug, because he was experiencing some severe shoulder aches (muscle aches are a side effect of Zocor). Bud had no idea until then that this might have also been triggering his TN.

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.

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## UPDATES FROM OUR MEMBERS

Last month, Deanna had a gamma knife done by Dr. Donohue at Baylor All Saints Hospital in Fort Worth. She hopes to be able to at least cut her TN medication in half since she is taking Tegretol, Lyrica, and Baclofen. *Please keep her in your prayers as she waits for the radiation to work.*

Tim reports taking 2 teaspoons of sugar free Metamucil and, at most, a cupful of MiraLax, a prescription drug used to treat constipation, has helped him tremendously since he is taking Methadone for his neuropathic facial pain. He also mentioned MiraLax's generic (called Polyethylene glycol 3350) works just as well.

Before Charlie experienced TN, he was drinking too much coffee while on the run and was stressed out due to his wife being in the hospital. Also, he had quit taking his B-12 shots even though part of his stomach had been removed and needed the B-12. Well, after Charlie's TN hit, he was put on anti-seizure medication which he didn't like the side effects. So, he in an effort to get off of the seizure medication, Charlie quit drinking coffee (eliminating the caffeine) and started taking B-12 shots again. He was happy to report he is now off of all of the seizure medication and is getting his mind back. Hurray!

Jean had a balloon compression in February by Dr. Desalomes at Dallas Presbyterian Hospital. She now has some facial numbness but is out of pain as long as she remembers to take her medication.

Elizabeth's father who lives in Puerto Rico suffered with TN for 2 years. Doctors in Puerto Rico told him there was nothing else they could do for him. After Elizabeth did some research and found the Gamma Knife Center at the Methodist Hospital in San Antonio, her Dad went to San Antonio in September 2005 and had the procedure done. Although sometimes her father feels like the pain is going to come back some day, he has not had moderate pain incident since a month after the gamma knife. Her father still takes his TN medication and the pain is expected to be completely gone soon.

Rick had a successful MVD by Dr. Weiner at Dallas Presbyterian Hospital almost three years ago and remains pain-free and medication-free today. Hurray!

Buoc had a successful MVD by Dr. Repogle with UT Southwestern in Dallas at Zale Lipshy Hospital. Within 10 days of the surgery, she was off of all of her Tegretol and Neurontin. We wish her a speedy recovery and hope she is able to start putting some weight back on soon!

Russ is using the Energy Patch and is getting a lot of pain relief now. He has seen numerous pains alleviated for people, including arthritis, sciatica, migraine headaches, and of course muscle pain. In a few months they plan to have a Patch that just addresses pain, but the Energy Patch can potentially help a lot of people right now as it has for the past 2 years. For more information, go to [www.lifewave.com/vonallmen](http://www.lifewave.com/vonallmen).

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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 604 Aberdeen Way, Southlake, TX 76092.

### FUTURE MEETING DATES

Austin – T.B.A.  
Dallas – T.B.A.  
Fort Worth at Baylor All Saints – T.B.A.  
Houston – T.B.A.  
San Antonio – 3/14, 4/11, 5/9, 6/13, 7/11, 8/8, 9/12, 10/10, 11/14, 12/12  
Tyler – 3/24, 6/30, 9/29, 12/15  
Waco at Hillcrest Baptist Medical Center – 3/13, 5/8, 7/10, 9/11, 11/13

### TREASURER'S REPORT – NORTH CENTRAL EAST TEXAS

<b>Beginning Balance 1/26/06</b>		<b>\$4507.47</b>
<b>Donations Received</b>	<b>\$657</b>	
Copies	109.71	
Postage	277.70	
Striking Back Books	243.02	
Supplies	<u>97.70</u>	
<b>Total Expenses</b>	<b><u>\$728.13</u></b>	
<b>Ending Balance 2/28/06</b>		<b>\$4436.34</b>

### 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.endthepain.org](http://www.endthepain.org)

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