



**TRIGEMINAL NEURALGIA ASSOCIATION  
TEXAS SUPPORT GROUPS  
February 2005**

**THANK YOU TO OUR VOLUNTEERS!**

Thank you to Tracey and Yolanda who volunteered to help Joan Foster, the TNA Austin Support Group Leader, work the TNA exhibit booth at the Southwest Dental Conference in Dallas last month.

**HOW CAN WE IMPROVE OUR NEWSLETTER?**

This is your newsletter and we want to make sure we are targeting your expectations. Are there parts of our local support group newsletter you don't value and would rather see replaced by something? Is there something you would like to see addressed in an upcoming newsletter?

Please send your comments and suggestions to Shelly Wilson either via U.S. mail at 604 Aberdeen Way, Southlake, TX 76092 or via e-mail to [kayser-wilson@charter.net](mailto:kayser-wilson@charter.net).

**UPDATES FROM OUR MEMBERS ON NEURONTIN'S GENERIC**

Margie is on her second refill of Gabapentin, Neurontin's generic, and so far has not had any side effects. Her TN seems to be in remission. Keep your fingers crossed for her!

Cal takes 300 mgs/3 times a day of Gabapentin. He experienced no side effects when he switched from Neurontin to Gabapentin. Also, he pays just \$7 for a 30 day supply of Gabapentin (90 capsules) from the VA. So, if you are a veteran and aren't taking advantage of the VA prescription program, you might want to look into it.

Holly is taking 2400 mg/day of Gabapentin broken up into six doses of 400 mg each. So far it is doing little to help and her pain level is very high. However, she just increased her dosage from 1800 to 2400 mg last week.

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Vada reported she takes 900 mg of Gabapentin every day for TN. She doesn't think it helps much when the TN pain is bad. When she's in remission and tries to stop the Gabapentin for even a couple of days, it seems her pain starts coming back.

Martin was only taking Gabapentin every other dosage initially but when he ran out of Neurontin entirely and started only with Gabapentin, the pain became markedly worse and with other symptoms of nervousness and agitation. He suspected the new pills were a problem and was very glad to hear he was not the only one experiencing this. He is now only taking Neurontin. It is certainly helpful to be able to compare notes and share this information so quickly.

Joyce tried Gabapentin. It didn't help her and she experienced bad side effects. So, she switched back to Neurontin and is doing fine now.

### **DO YOU HAVE RELATIVES WITH TN?**

Vada wondered if anyone else has a family history of a sibling with TN? She compares notes with her sister who has had TN for 20 years that has had microvascular decompression surgery and 2 gamma knife procedures – nothing successful. Her doctor just keeps putting her back on Tegretol.

If you have a family history of TN, please share your comments with us. Send your input to Shelly Wilson either via e-mail at [kayser-wilson@charter.net](mailto:kayser-wilson@charter.net) or U.S. mail to 604 Aberdeen Way, Southlake, TX 76092.

### **SEEK PRESCRIPTION SAVINGS IN U.S. BEFORE MAKING ILLEGAL FOREIGN PURCHASES**

In an article written by Marc C. Duff with the Taxpayers Network he wrote:

*A new study released by The Taxpayers Network suggests some consumers may be better off purchasing prescription drugs in the U.S. than obtaining them from foreign sources.*

*Obtaining pharmaceutical products from foreign countries is currently illegal and only drug manufacturers can import their products from other countries for sale in the U.S. The Food and Drug Administration (FDA) warns pharmaceutical safety and quality from foreign sources cannot be assured.*

*The subsidies and discounts under the new Medicare prescription drug program should provide many seniors with significant savings. Medicare beneficiaries could save 10% to 25% off retail prices for most drugs and total prescription spending could be reduced by 20% by 2006 according to the Department of Health and Human Services, Public Affairs Office.*

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*Currently, many states and drug manufacturers have discount programs for individuals in need. If you know of someone struggling to pay for prescription drugs, please assist them by comparison shopping on the internet, neighborhood stores and other retailers. And, use extreme caution if you choose to order drugs from non-U.S. websites.*

Source: Network News, Edition II, 2004, pages 6-7.

## **VOLUNTEER OPPORTUNITIES**

The East Texas Support Group needs volunteers to assist Ramona Smith, the Support Group Leader, with meeting preparation schedules and preparing meeting minutes. If you can help her, either e-mail her at [bowood@lcii.net](mailto:bowood@lcii.net) or call her at 903-569-6176.

The Fort Worth Support Group needs someone willing to call support group members to remind them about meetings and someone willing to help with scheduling speakers. If you are interested, please e-mail Shelly Wilson at [swilson@tna-support.org](mailto:swilson@tna-support.org) or call 817-416-7202.

The Dallas Support Group needs people willing to call support group members to remind them about meetings. If you are interested, please e-mail Shelly Wilson at [swilson@tna-support.org](mailto:swilson@tna-support.org) or call 817-416-7202.

## **WORD OF MOUTH**

On average, during the day, your mouth swallows 2,000 times, which helps flush out bacteria. At night, it swallows only 20 times, allowing bacteria to build up. That's why it's so important to brush before sleeping...

Source: Foster Family Dentistry, Word of Mouth, Winter 2004/2005

## **DOES MEDICATION MAKE YOU WOBBLY?**

Making comfy sneakers a top footwear choice can help older people avoid potentially dangerous falls.

A new study revealed that, in a group of people aged 65 and older, the people in the group who wore mostly sneakers experienced fewer falls than the people who tended to wear lace-up oxfords, heels, or other kinds of footwear. Walking barefoot or in stocking feet was most likely to lead to a fall.

Source: RealAge Tip of the Day, December 13, 2004

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## **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](mailto:kayser-wilson@charter.net)

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

## **STRESS TEST**

Don't make any big decisions if you're feeling stressed! A little stress helps keep you on your toes for memory-recall tasks. However, research shows that it muddles your mind when you're trying to solve a problem. De-stress before tackling problems by practicing soothing activities, such as deep breathing or meditation exercises.

Source: RealAge Tip of the Day – December 29, 2004

## **WEBSITES OF INTEREST**

[www.helpingpatients.org](http://www.helpingpatients.org) – Offers a single point of access to more than 275 public and private patient assistance programs, including more than 150 programs offered by pharmaceutical companies.

[www.sciencedaily.com/releases/2004/01/040129072454.htm](http://www.sciencedaily.com/releases/2004/01/040129072454.htm) - Article on how pain may interfere with depression improvement. Treatment for depression may be stymied in people with moderate to severe body pain, according to a new study.

[www.painfoundation.org/eNews2004/1204/fishmanhypnosis.htm](http://www.painfoundation.org/eNews2004/1204/fishmanhypnosis.htm) - The Role of Hypnosis for Pain Management

## **DID YOU KNOW...**

From the new Striking Back! The Trigeminal Neuralgia and Face Pain Handbook written by George Weigel (a TN patient) and Kenneth F. Casey, MD:

Studies estimate there are somewhere between 15,000 and 50,000 new cases (of TN) each year in the U.S. At that rate, assuming an average 8-year bout with TN, that means somewhere between 120,000 and 400,000 Americans are coping with TN at any given time...

You can purchase this book via TNA's website at [www.tna-support.org](http://www.tna-support.org).

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## UPDATES FROM OUR MEMBERS

Mike is having a MVD by Dr. Jonathan White at UT Southwestern Medical Center in Dallas, the first week of February. Please keep him in your prayers this month.

As much as Carolyn hates taking Tegretol, it is holding her TN at bay for the time being. She's gone 15 months without a TN episode. HURRAY!!!

Robin's TN pain came out of remission in November and just won't go away. She's been having a really tough time with it. Please pray things get better for her.

Elizabeth had been taking Lamictal for 8 months which kept the pain at bay until October 28<sup>th</sup>. Her neurologist, Dr. Donald John, increased her dosage to 225 mg, 2 times a day, and she is now pain-free again. As we all know, she may have a different story for tomorrow. In the interim, enjoy the pain-free period!

Larry's been having a tough time with his TN due to all of the weather changes. Let's hope it warms up and stays warm for all of those who's TN flares up during big weather changes!

Georgia's been pain-free for over a year except for one period when her medicine was increased to control the pain by her Dallas neurologist, Dr. Jean Claude Krusz.

Four months after Joan's MVD by Dr. Jonathan White, she is now pain-free and has been completely off of Neurontin for a month now. Congrats!

Leslie had a MVD by Dr. Stovall at Medical Center of Plano in October. She said her neurosurgeon couldn't have been any nicer to her and he trained at UT Southwestern in Dallas.

Jennifer, a MS/TN patient, had a rhizotomy in May 2003 by Dr. Harold Smith, a pain management doctor, in Lubbock. She took a minimal amount of Neurontin a year after that. Last summer, she had an extreme flare up of TN pain when she was whitening her teeth. After that, she weaned off all her medications completely. Now, she only has an occasional flash of pain if she rubs her nose the wrong way. Otherwise, she feels she has a new life.

*In our TN brochure called "What Every Dentist Should Know", it mentions a few tips for facial pain patients:*

- *The importance of keeping up their dental care to prevent extensive dental treatment*
- *Perform oral hygiene when medication is at its peak level of effectiveness*
- *Use a soft toothbrush*
- *Stay away from tartar control and bleaching products*

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*If you would like a copy of this brochure, please send a self-addressed, stamped envelope to: Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092.*

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

### **FUTURE MEETING DATES**

Dallas at Zale Lipshy Hospital – 2/9, 4/13, 7/13, 10/26  
Fort Worth at Baylor All Saints – 3/9, 6/7, 9/27, 11/1 – **date changed from 3/1 to 3/9**  
Houston at Christus St. Joseph Hospital – T.B.A.  
Tyler at East Texas Medical Center – T.B.A.  
Waco at Hillcrest Baptist Medical Center – 3/7, 5/2, 7/11, 9/13, 11/14

### **TREASURER’S REPORT – NORTH CENTRAL EAST TEXAS**

<b>Beginning Balance 12/31/04</b>	<b>\$4102.14</b>
<b>Donations Received</b>	<b>\$1425.00</b>
Copies	92.13
Long Distance	1.20
Postage	201.99
Supplies	78.44
TN Books (2)	<u>63.90</u>
<b>Total Expenses</b>	<b><u>\$437.66</u></b>
<b>Ending Balance 1/30/05</b>	<b>\$5089.48</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  
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