



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

### **SAN ANTONIO SUPPORT GROUP SCHEDULE**

The San Antonio support group meeting schedule has changed. They will now meet on a bimonthly basis, on even months. The 2006 remaining meeting dates are 6/13, 8/8, 10/10, and 12/12.

### **A QUESTION FROM 2 GAMMA KNIFE PATIENTS**

Stella and Cal each had a gamma knife for TN on the same day, at the same facility. They are both wondering if the new pain they are experiencing is something that other TN gamma knife patients have experienced.

If you have had a gamma knife and then got a whizzing, short pain that started after chewing food or clamping your teeth together, please let Shelly Wilson know at [swilson@tna-support.org](mailto:swilson@tna-support.org) or by calling Shelly at 817-416-7202. Please include whether or not this whizzing pain was just something you temporarily experienced or something you now live with.

### **TNA NATIONAL CONFERENCE – REGISTER NOW!**

The Trigeminal Neuralgia Association holds a National Conference, every other year. Approximately 75% of the conference attendees are patients/supporters who spend three days choosing between which sessions they want to attend. They have the opportunity to eat meals and mingle with the health care providers who are also there to learn from patients as well as provide information.

For those conference attendees who register by June 1, the cost is \$250 per person and includes conference handouts, all meals for Thursday and Friday and breakfast and lunch on Saturday. Although you can always buy a DVD of a session later, people indicate

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nothing replaces the face to face interaction you have with the health care providers and other patients/supporters who attend the conference. Everyone is searching for answers and most leave the conference with a list of options they did not previously know were available to them.

Please keep in mind, this conference is geared for trigeminal neuralgia patients as well as for neuropathic facial pain patients. So, the scope of the conference is not limited to classic trigeminal neuralgia.

For conference details and online registration, go to [www.endthepain.org](http://www.endthepain.org) or contact Shelly Wilson, TNA's Conference Chairperson, either via email at [swilson@tna-support.org](mailto:swilson@tna-support.org) or call 817-416-7202 and request a brochure be mailed to you.

### **HOUSTON SUPPORT GROUP MEMBERS**

What Houston area neurologists can you recommend to TN patients? Please e-mail the physician name, address, and phone number to [swilson@tna-support.org](mailto:swilson@tna-support.org) or mail the information to Shelly Wilson, P.O. Box 92604, Southlake, TX 76092. A list will be compiled and included in a future newsletter for patients to reference.

### **MEDINCE CABINET CHECKUP**

About 69% of Americans don't clean out their medicine cabinets every year. Nearly *half* have taken an out-of-date drug, which can be ineffective and even dangerous.

Source: Harris Interactive survey

### **DALLAS/FORT WORTH AREA VOLUNTEERS NEEDED**

TNA will be exhibiting at the American Academy of Nurse Practitioners conference on Thursday, June 22 and Friday, June 23 at the Gaylord Hotel in Grapevine from 11 a.m. – 5:30 p.m. If you are interested in volunteering to help work the TNA exhibit booth, please contact Shelly Wilson via e-mail at [swilson@tna-support.org](mailto:swilson@tna-support.org) or call 817-416-7202. TNA will reimburse you for your self-parking expense.

### **6 SMART WAYS TO DEAL WITH YOUR DOCTOR**

At the very least, these insider tips from the new book *You: The Smart Patient* by Michael Roizen, M.D., and Mehmet Oz, M.D. will save you time, money and aggravation at the doctor's office. They *could* even save your life. Your essential guide to getting more out of your next doctor's appointment:

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1. Start with a good doctor.  
When searching for an M.D., ask your friend, neighbors and coworkers for referrals, just as you would if you needed a good plumber or mechanic. If you're lucky enough to have friends or family who work in health care, make a beeline for them-nurses and EMTs see doctors at their *most* frazzled and can tell you which ones are really on top of their game.
2. Book the first appointment of the day.  
At that time, things haven't had a chance to become hopelessly backed up, as they typically have by the third appointment. Why? Most doctors schedule appointments in 15-minute blocks, but studies show that the average appointment lasts between 18 and 20 minutes. Mix in late patients, phone calls and a host of other little interruptions, and you'll see why you usually spend more time in the waiting room than actually talking to the doctor.
3. Getting a prescription? Ask the right questions.  
Take notes when your M.D. tells you how to take your medication, instead of just relying on that special shorthand that only the pharmacist-and maybe your doctor's head nurse-can read. Also ask your doctor if you really need the drug, why you need it and why she chose that one over another. Those questions may help keep you from becoming one of the 1.3 million people who are seriously hurt every year in the U.S. from accidental overdoses and dangerous drug interactions.
4. Befriend nurses and office administrators.  
They can make your dealings with your doctor very pleasant and convenient, so show them love at every visit. Learn their names and hometowns; have your niece draw a picture for them – it'll pay off when you need an emergency appointment or have trouble with your insurance company.
5. Bring notes.  
The surest sign of a smart patient? That telltale sheet of paper she pulls out of her purse with specifics about her medical history and symptoms, and a list of questions. It shows that you're a woman who means business and who will challenge us doctors to be our absolute best.
6. Never think twice about getting a second opinion.  
Don't feel awkward about telling your doctor you want one – it could save you lots of trouble. No smart detective would hang her entire investigation on the testimony of a single witness without making sure the story checked out, and no smart patient should accept a diagnosis that requires surgery or other serious treatment without doing the same. In fact, research has found that getting a second opinion results in a new diagnosis or treatment regimen in as many as 30 percent of all cases.

Source: Glamour, March 2006

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## **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.

Pat tried Lyrica but it didn't work and upset her stomach. She is now trying a high dose of Topamax, an anti-seizure medication, to control her pain.

Stella was taking 3 Lyrica pills a day in addition to Tegretol, Dilantin, and Keppra to try to control her pain. Nothing was working. She developed a blood condition from the Tegretol, so she decided to have a gamma knife. One week after the gamma knife, her pain went from a 25 (on a scale of 1 to 10) down to a 2 on the scale of 1 to 10 and she's only taking ½ of the medications she was taking before the gamma knife.

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.

## **UPDATES FROM OUR MEMBERS**

After battling TN for 3 years, Phillip had a MVD by Dr. Jonathan White last month at Zale Lipshy University Hospital. We wish him a speedy recovery!

Gloria had a balloon compression by Dr. Weiner at Dallas Presbyterian Hospital in October 2003 and is still pain-free today. Hurray!

Donna had a MVD by Dr. Jonathan Friedman of Bryan, TX in March. She thinks he is a wonderful neurosurgeon! Her TN pain is still the same, but she's hoping the nerve will regenerate in time. A vein was fused to the trigeminal nerve, causing the nerve to be discolored. She reports the surgery caused less pain than any surgery she has ever had.

After taking medication for years to control her TN pain, about seven months ago, Joanna had the Gamma Knife procedure done by Dr. Weiner at Dallas Presbyterian Hospital in Dallas. After a period of almost five months, the pain began to reduce until she was totally pain free. Now, two and a half months later, she is still pain free and off all TN medication. She is deeply indebted to the support group meetings that encouraged her to go ahead with the Gamma Knife surgery. Hurray!

Wanda is back at work and taking 600 mg of Trileptal and 20 mg of Baclofen. She still has pain but it is not that great. Hang in there!

Angela reports she also has ear pain, pain behind her eye, burning pain in her nose, and pain in her upper gums and cheek area. It is VERY painful. So she is able to empathize with George and the others with the same kind of pain.

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Marita also has ear pain. Her pain starts in her ear and then radiates to her jaw and then to both sides of her face. Her ear then becomes numb and she loses hearing from the pain.

Since Rich moved from Dallas to Colorado about 3 years ago, his atypical TN pain has subsided substantially. We hope it stays that way!

Lonny McKinzie, D.C. practices upper cervical care in East Texas and has good results in treating TN patients. His Tyler office number is 903-531-2243.

Renee has had TN since January 2004. She is currently in remission, taking only a low dose of Tegretol with very little pain.

Please pray for:

- Pat as she is contemplating a TN surgical procedure.
- Charlie's wife who isn't doing well. Charlie is doing his best to support her despite having TN.
- Tom, who's TN pain came back without warning, had three pain-free months from a Botox injection. He plans to get another Botox injection soon.

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

### **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](mailto: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!

### **CORRECTION TO MARCH NEWSLETTER**

The March newsletter said "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."

Please note the following correction. Tim has never taken Methadone. He has been taking MS Contin/morphine sulfate for over 11 years. Also, he suggests asking for a prescription of Glycolax, the generic name for Miralax.

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## FUTURE MEETING DATES

Austin – T.B.A.

Dallas at Zale Lipshy University Hospital – 6/13

Fort Worth at Baylor All Saints – 5/15 (private dining room), 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 – 5/8, 7/10, 9/11, 11/13

## TREASURER'S REPORT – NORTH CENTRAL EAST TEXAS

<b>Beginning Balance</b>		<b>\$4,122.55</b>
<b>Donations Received</b>	<b>\$135.00</b>	
Copies	15.00	
Postage	107.03	
Striking Back Books	224.50	
Supplies	<u>33.28</u>	
<b>Total Expenses</b>	<b><u>\$379.81</u></b>	
<b>Ending Balance 4/30/06</b>		<b>\$3,877.74</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 Texas support groups, please make your check payable to the order of Trigeminal Neuralgia Association and in the memo field put Texas support groups 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.

Trigeminal Neuralgia Association  
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