



**TRIGEMINAL NEURALGIA ASSOCIATION  
TEXAS SUPPORT GROUPS NEWSLETTER  
NOVEMBER 2005**

**TNA REGIONAL CONFERENCE – DALLAS, TX**

Save the date! TNA will hold a one-day regional conference at UT Southwestern Medical Center in Dallas on Saturday, February 18, 2006 for patients, supporters, and health care providers to attend. Registration brochures with all of the details will be mailed out later this month.

**LYRICA**

Mike's neurologist gave him some free samples of Lyrica to try in place of Gabapentin, the generic for Neurontin. Mike experienced his emotions bouncing all over the place so he switched back to Gabapentin.

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, 604 Aberdeen Way, Southlake, TX 76092 and we'll include it in an upcoming newsletter.

**CALL FOR VOLUNTEERS**

We need a new East Texas Support Group Leader. Ramona Smith started this group a couple of years ago in Tyler and now needs to step aside at the end of this year. Please don't let this support group die. If you are interested in taking over this role or are willing to become a co-support group leader for East Texas, please let Shelly know either by e-mail at [swilson@tna-support.org](mailto:swilson@tna-support.org) or by calling 817-416-7202.

Rhonda Ashby, the Houston Support Group Leader, is moving to Central Texas at the end of this month. So, we need a new Houston Support Group Leader. If you are interested in taking on this role or are willing to become a co-support group leader for East Texas, please let Shelly know.

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We have a support group website but need a webmaster to take it over. The key tasks include keeping the meeting schedule up to date and to upload our monthly newsletter. Currently, the website uses Net Objects Fusion 8 software, ftp host, and the newsletters are put into Adobe reader format. If you can manage this, please e-mail Shelly.

### **DO YOU HAVE QUESTIONS?**

Do you have questions about your trigeminal neuralgia or related facial pain and wish they could be answered in this newsletter? If so, submit your questions to [swilson@tna-support.org](mailto:swilson@tna-support.org) or mail them to Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092. We will try to get as many of these questions answered as possible by asking doctors and dentists in our community for answers.

### **MYSTERY DIAGNOSIS**

Emily, a four-year-old TN patient in Tucson, was featured on the Discovery Health Channel Network Show called “Mystery Diagnosis”. TNA worked closely with Emily’s mother and the producers of the show.

Mystery Diagnosis is a cable TV show telling incredible stories of how real people take “I don’t know” for an answer – and find a way to crack the toughest medical cases. What would you do if you were sick – or dying – and no one could figure out why? Would you turn to another doctor? Search for the cure on your own?

Pat, one of our support group members, saw this show and said “it was fabulous.” TNA Support Group Leaders will be getting a copy of this show to share with their support groups. As soon as our copies arrive in Texas, we’ll let you know when we plan to show it at our support group meetings.

### **TNA AT THE ADA**

Our Texas support groups helped TNA (the Trigeminal Neuralgia Association) with expenses for exhibiting at the American Dental Association’s national conference in Philadelphia last month. Over the course of four days, only 1 dentist knew not to use epinephrine in the block for TN patients.

Hopefully by educating the dentists about epinephrine and by advising them to use short acting anesthetics like xylocaine or carbocaine without vasoconstrictors, TN patients around the nation will have an easier time with dental work.

If you would like a dental brochure titled “What every dentist should know” to give your dentist, please send a self-addressed, stamped envelope to: Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092.

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## **HOUSTON TN PATIENT**

Denise is a 37 year old TN patient, married, mother of 2, in the North Houston area. She is interested in linking up with someone her age in the Houston area via e-mail for support. If you would like to correspond with Denise, please send an e-mail to her at [denisedivjak@entouch.net](mailto:denisedivjak@entouch.net)

If there are others of you who have similar requests, please e-mail them to Shelly Wilson at [swilson@tna-support.org](mailto:swilson@tna-support.org) and we'll post these in future TN newsletters.

## **WEBSITE OF INTEREST**

<http://news.softpedia.com/news/Botulinum-Toxin-Helps-Trigeminal-Neuralgia-Patients-11049.shtml> - Botox helps TN patients

## **PAIN MAY BE IN THE BRAIN, BUT IT'S STILL REAL**

If your doctor tells you that your chronic pain is in your head, don't be offended. You may be getting the latest medical advice.

For too long, some doctors and psychiatrists say, the link between emotions and pain has been ignored or pooh-poohed by the medical profession. It has left some people with chronic pain to suffer, they claim, because the symptoms of their problems are being treated without the causes being addressed.

"Pain actually is an emotion, so clearly there is a connection," said Alex Zautra, a professor of psychology at Arizona State University, where he leads a research team whose work is centered on chronically ill patients with muscular-skeletal illness such as rheumatoid arthritis and fibromyalgia.

"Pain is the way the mind responds to trouble inside the body," he said. "Emotion is the same way. Whether you feel love or sadness is also a response to something you feel outside the body. With pain it is a closer-in response, to something inside the body, but it is a response in an attempt to learn about and motivate recovery."

A recent study in Europe found that more than 40% of people who suffer from depression also suffer from chronic pain, and a study conducted by the Stanford University School of Medicine in the United States, which has not yet been published, found similar results, said Dr. Alan Schatzberg.

Other studies have found even higher rates of co-morbidity between depression and chronic pain – as high as 60% to 70%, depending on how chronic pain was defined, Schatzberg said.

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“It is not a chance finding,” he said. “I think it is a real finding.”

The reason for the connection may be that the neurochemical problems responsible for the depression may also be responsible for the patient’s chronic pain.

Some doctors now prescribe certain antidepressants for people who suffer from chronic pain but apparently have no physical cause for the pain, even in people who do not suffer from depression. Duloxetine, for example, which is marketed as Cymbalta by Eli Lilly and Company, is the first drug to be approved by the FDA for treatment of diabetic peripheral neuropathic pain.

When discussing these findings, doctors and psychiatrists alike say it is important to understand that it is in no way a dismissal of the suffering endured by people who might not seem to have a physiological cause for the pain. Even when there is a clear physical cause, pain itself only occurs in the brain, they say.

“Pain is in fact all in our heads, but we have to be sure when we say that, we say it without the usual pejorative context, implying that pain is made up,” said Dr. Sean Mackey, the co-director of the Stanford University Pain and Clinical Research Center.” An injury out in our arm is not pain, that is ‘nociception.’ The perception of pain occurs in the head.”

Source: <http://abcnews.go.com/Health/print?id=720963>, May 12, 2005

### **BONNIE’S TN EXPERIENCE**

After 3 years and 10 months of TN, Bonnie was on 2400 mg of Neurontin and 1200 mg of Tegretol and had worked all but the last 3 months of the 3 years and 10 months. Needless to say, it was a difficult time in her life.

With people in over 8 states and the prayer warriors at FBC Grapevine praying for her, on 1/19/5 she went to Dallas Presbyterian Hospital for the Gamma Knife Radiosurgery performed by neurosurgeon, Dr. Huggins. There was no incision. Cobalt rays radiated through her brain to the trigeminal nerve. Since that time, over nine months ago, she has had NO PAIN. She can hardly believe what a blessing it was.

Her neurologist, Dr. Mohammed Khalid, took over after the Gamma Knife Radiosurgery and slowly but surely helped her eliminate the Neurontin and Tegretol. She took her last Tegretol on 9/12/5 and is amazed at how her memory works now. She feels great (at 64) and sometimes she thinks she could “bound over small buildings – sort of like Superwoman.”

Bonnie tells us there is “no guarantee” with Gamma Knife Radiosurgery but Dr. Huggins has the ability to perform this procedure. Gamma Knife Radiosurgery began as treatment

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for individuals with brain tumors. But, Praise the Lord, some wonderful doctor started using the same procedure on TN patients and found it to be successful.

Bonnie remembers the pain and prays for those who are less fortunate than her since she knows what pain means and how it impacts one's life. (Keep praying for us Bonnie!)

### **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). This helps us save on our mailing and copying costs.

Also, if you change your e-mail address, make sure to advise Shelly as well. Thanks!

### **UPDATES FROM OUR MEMBERS**

Bill had his second microvascular decompression surgery (MVD) by Dr. Peter Jannetta at Allegheny General Hospital in Pittsburgh last month. So far, he has been able to reduce his Tegretol medication by 300 mg.

Sybil has been pain-free for 5 months while taking 2400 mg of Gabapentin, the generic for Neurontin. Hurray!

Miguelita had a successful MVD by Dr. Zimmerman at Mayo Clinic in Scottsdale, AZ in mid-October and is now pain-free. She said it was a great place to be if you had to be in a hospital. We are so happy for you!

Martha applied on-line for Social Security disability for her TN on 7-5-05 and was approved in September. She got 10 months back pay. It was EASY! Congratulations!

Carroll, an 87 year old TN patient, reports that he is still in remission and takes only an insurance dosage of 150 mg of Trileptal a day.

Please pray for:

- Martha's husband who has been very sick, lost 40 pounds, and does not have a diagnosis yet.
- ImaJoy, a TNA co-support group leader in Waco, who was just diagnosed with Lymphoma and will have to undergo chemotherapy.

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.

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## FUTURE TEXAS MEETING DATES

Austin at St. David's Gamma Knife Center – T.B.A.  
Dallas at UT Southwestern Medical Center – **Regional Conference** – 2/18  
Fort Worth at Baylor All Saints – 11/1  
Hill Country – T.B.A.  
Houston – T.B.A.  
San Antonio – 11/8, 12/13  
Tyler at East Texas Medical Center – 11/2  
Waco at Hillcrest Baptist Medical Center – 11/14, 1/9, 3/13, 5/8, 7/10, 9/11, 11/13

## TREASURER'S REPORT – NORTH CENTRAL EAST TEXAS

<b>Beginning Balance 9/29/05</b>		<b>\$3697.79</b>
<b>Donations Received</b>	<b>\$61.58</b>	
ADA Exhibit Cost	607.37	
Supplies	18.42	
Long Distance	30.00	
Postage	<u>11.41</u>	
<b>Total Expenses</b>	<b><u>\$667.20</u></b>	
<b>Ending Balance 11/2/05</b>		<b>\$3092.17</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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