



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

### **TNA REGIONAL CONFERENCE – DALLAS, TX**

Despite a predicted ice storm, we had over 150 people attend the TNA Regional Conference in Dallas on Saturday, February 18, 2006. Not only did people from our region of the U.S. attend but people traveled from as far away as Illinois and Florida to attend. To see pictures of the conference, go to [www.texastna.org](http://www.texastna.org).

### **DONATE \$50 TO TNA AND GET...**

For the first 6 people to contact Shelly Wilson via email at [swilson@tna-support.org](mailto:swilson@tna-support.org) or call 817-416-7202 and who donate \$50 to the Trigeminal Neuralgia Association will receive a TNA Dallas Regional Conference notebook filled with over 100 pages of handouts along with a TNA 2004 National Conference written report that has 135 pages.

### **TNA REGIONAL CONFERENCE ATTENDEES**

Did you purchase TN stat supplements from the American Wellness Alliance while at the TNA Regional Conference in Dallas? If so, please provide Shelly Wilson with your feedback via e-mail at [swilson@tna-support.org](mailto:swilson@tna-support.org) or by writing to P.O. Box 92604, Southlake, TX 76092.

### **THANK YOU TO OUR TNA REGIONAL CONFERENCE SPEAKERS**

The TNA Regional Conference Speakers were recommended by our Texas Support Group Leaders. Thank you to our speakers who did not get paid for speaking and who paid their own travel expenses.

Steven D. Bender, D.D.S. (orofacial pain specialist)  
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Howard Biel, R.Ph. (compounding pharmacist)  
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Carol Croft, M.D. (internal medicine)  
UT Southwestern Medical Center  
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214-645-8630

Miles Day, M.D. (pain anesthesiologist)  
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Kalyani M. Kumar, M.D. (supplements)  
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2103 E. Parham Road  
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214-645-9574

Joseph Vaughn, M.D. (neurologist)  
700 Olympic Plaza, Ste. 912  
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903-596-3830

Tony Whitworth, M.D. (neurosurgeon)  
UT Southwestern Medical Center  
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John D'Amanda, D.C. (chiropractor)  
Country Chiropractic  
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Craig R. DuBois, M.D. (pain neurologist)  
Neural Logics, P.A.  
7307 Creekbluff Drive  
Austin, TX 78750  
512-346-6969

John Claude Krusz, PhD, MD (pain neurologist)  
Anodyne Pain Care  
5446 Glen Lakes Drive  
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214-750-6664

Michael G. Pasternak, Ph.D. (TNA President)  
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2801 S.W. Archer Rd.  
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[www.endthepain.org](http://www.endthepain.org)

Richard Robinson, Ph.D. (psychologist)  
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214-820-7368

Jonathan White, M.D. (neurosurgeon)  
UT Southwestern Medical Center  
5323 Harry Hines Blvd.  
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Phillip E. Williams, Jr., M.D. (neurosurgeon)  
7515 Greenville Avenue, Suite 1000  
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214-369-3333

#### *OTHER INVITED SPEAKERS WHO HAD TO CANCEL*

Allen Sprinkle, D.D.S., P.A. (dentist)  
1106 W. Randol Mill Road, Suite 100  
Arlington, TX 76012  
817-461-9998  
[www.drsprinkle.com](http://www.drsprinkle.com)

John Wissinger, M.D. (neurosurgeon)  
Methodist Hospital  
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## **EAR PAIN**

In our March newsletter, George asked if anyone suffered with ear pain like he did. Below is a response from Tracy Knight, a TNA Telephone Support Contact in Dallas.

Tracy has ear pain too. Her pain has always been in her ear, then radiates to her lips, chin, nose, and forehead. She was misdiagnosed for years with ear infections, ear aches and even TMJ.

Tracy gets a pain that hits her ear, like an ear ache but 20 times worse and it shoots straight to her ear drum. It makes her want to run screaming!

Her ear pain is returning more and more now after microvascular decompression surgery (MVD) over 2 years ago. The wind is horrible lately, and at this point she is not even leaving her house unless she absolutely has to.

Rhonda, who used to be the Houston support group leader, remembers a man in Houston having ear pain like this. His physician diagnosed his pain and suggested he put ice on his ear to get relief.

## **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.

Linnie who has TN as well as facial pain from sinuses and fibromyalgia has been using Lyrica for about 3 months. It is doing wonders for her pain from fibromyalgia and TN. She is currently increasing her dosage from 150 mg to 225 mg per day and is discontinuing Trileptal. She's actually eating less since it settles her hunger pangs. For Linnie, Lyrica has made her virtually pain free after 18 years of seeking a "cure".

Gordon's family physician switched him from 900 mg of Carbamazepine (the generic for Tegretol) to 150 mg of Lyrica. At first, the Lyrica did not control the pain. The Lyrica dosage was increased quickly to 450 mg per day to get him out of pain. It just took him finding the right dosage to figure out if it would work for him.

Franklin has been taking 1800 mg of Gabapentin for right V1 temple area pain. Franklin's family physician gave him some 75 mg samples of Lyrica to try. He advised him to trade out 600 mg of Gabapentin for 75 of Lyrica each day for three days. Two nights later, Franklin had sleeplessness, was feverish, drowsy, dizzy, had some swelling of extremities, and had head pressure with numbness. The next morning, he had unclear vision. Since it was the weekend, Franklin called the pharmacist who advised him to discontinue the Lyrica, go back on his normal Gabapentin dosage and to notify his physician on Monday.

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

Cal had a gamma knife by Dr. Gary Kraus at the West Houston Medical Center on April 3. We hope he gets relief soon!

Marie put herself on the Omura protocol practiced by Dr. Allen Sprinkle, D.D.S. in Arlington, TX. Four days later, Marie's pain was almost gone. She's been on the protocol for 2 weeks now and reports she feels the best she has felt in 3 years. She has been able to discontinue the Duragesic patch and is only taking a low dose of Neurontin three times a day. She's also found that rubbing her trigger point inside of her mouth with Oragel has helped as well.

Jeanene reports she has been pain free and medication free for 15 months now thanks to Dr. Jonathan White at UT Southwestern in Dallas who performed her MVD (microvascular decompression).

Judy has found taking Gabapentin, the generic for Neurontin, several times a day works better than just three times a day since she used to experience pain between 4 – 7 a.m. She now takes Gabapentin at 7 a.m., noon, 5 p.m., 10 p.m., and 2 a.m. We wish you the best of health and hope you'll be happy in your new home.

Deanna had a gamma knife by Dr. Donohue at Baylor All Saints Hospital in Fort Worth in February. One month later, she went back to see Dr. Donohue and all is well. She was told it is going to take a few months before they can tell anything. She is still on Lyrica, Tegretol, and Baclofen. Switching from Neurontin to Lyrica before the gamma knife really helped her. She's now taking 600 mg of Lyrica a day. Deanna hopes to get off some or all of the TN medications she is on despite knowing she may have to keep taking some or all of the TN medications at lower doses.

In addition to taking Lyrica, Linnie uses a hand held Accu-pen on her nose and around her jaw and eyes for facial pain. She also meditates. She also has a wonderful biofeedback gaming program called "Journey to the Wild Devine". The game distracts her from her pain and teaches her breathing control. She purchased the game and equipment to attach to her computer through her medical flex plan with a note from her PhD psychologist.

Wayne's facial pain has never been classic in nature. However, after suffering with neuropathic facial pain for 6 months, his jaw bone had swelled some so he went to his dentist to make sure everything was OK. The dentist said he had a HUGE abscess but couldn't tell him how long it had been there. He was referred to an endodontist for a root canal. He declined anesthetic for the root canal and did fine. Since the root canal, he hasn't had any facial pain. Interesting...it's only been a few days. Wayne – please continue to let us know how you do, whether the pain returns or not.

Dee reported she had a gamma knife in Oklahoma. After the gamma knife, she was pain-free but later the pain returned so she went back on medication. She feels she will be free of pain soon.

Mildred is 77 years old and in remission now. She has suffered with TN four times. Each time there is more help but in the beginning there was nothing. She finds the newsletter supporting to know she is not alone.

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Manny has had TN for 1-1/2 years. He is taking 800 mg, 3 times a day of Gabapentin (the generic for Neurontin). He's also getting acupuncture treatments which help.

Tom is still out of pain and praises God for it. He cut his Tegretol from 1200 to 200 mg a day. He's back at work now and making money. Hurray!

Please pray for:

- Leslee as a CT-scan showed a mass around her auditory nerve.
- Jennifer as she looks at TN surgical options since the glycerol rhizotomy only gave her 5 months of pain relief.
- Amy has TN on both sides of her face. With only a 50% chance of getting pain relief from a MVD, she decided to have a MVD last month on one side. Unfortunately, it did not work. Amy plans to go back and continue to work with her pain management doctor.

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!

### **MEETING NOTES**

#### **Houston Support Group meeting – January 7, 2006:**

Neurosurgeon, Dr. Gary Kraus, Associate Medical Director of the Gamma Knife at West Houston Medical Center, spoke at the support group meeting. Dr. Kraus practiced in Ohio for several years before he was recruited to work at West Houston Medical Center, a year ago. He has treated 90-100 TN patients with the gamma knife. He has done over 300 gamma knife procedures. He became board certified in neurosurgery in 1995.

The gamma knife procedure at his facility takes 28 minutes since the machine is one year old and the cobalt is new. At other facilities, it can take up to 56 minutes, depending on the age of the Cobalt. The Cobalt lasts about 5 years.

Dr. Kraus has 2 websites – [neurosurgerypa.com](http://neurosurgerypa.com) and [cyberacuity.com](http://cyberacuity.com). Both websites include gamma knife information. (I looked at these sites earlier today and found them both informative.)

Dr. Kraus describes to TN patients that the day they have the gamma knife performed, it is just a long boring day since it includes frame placement, MRI, a physician planning process (on where they will target the trigeminal nerve), and the gamma knife procedure.

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If you are in a lot of pain and are considering the gamma knife, you can probably get in to be seen by Dr. Kraus for a consultation within 1-2 weeks and if you are a good candidate for the gamma knife and want to schedule the procedure, it can usually be done within a week. His office number is 281-870-9292.

### FUTURE MEETING DATES

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

### TEXAS TREASURER'S REPORT

<b>Beginning Balance 2/28/6</b>		<b>\$4,436.34</b>
<b>Donations Received</b>		<b>\$827.00</b>
Postage	75.81	
Supplies	64.98	
TNA Natl. Conference	<u>1000.00</u>	
<b>Total Expenses</b>		<b><u>\$1140.79</u></b>
<b>Ending Balance 3/31/06</b>		<b>\$4,122.55</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 write "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  
925 NW 56<sup>th</sup> Terrace, Gainesville, FL 32605  
Phone: 800-923-3608, Fax: 352-331-7078  
[www.endthepain.org](http://www.endthepain.org)

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