



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

SUPPORT GROUP LEADERS - E-MAIL ADDRESS CHANGES

ImaJoy Jansky, a co-support group leader in Waco, has changed her e-mail address. Please note, it is now imageojansky@sbcglobal.net

Ramona Smith, the East Texas support group leader, has also changed her e-mail address. You can now e-mail her at RPS30@earthlink.net

TNA SEPTEMBER SUPPORT GROUP MEETINGS

Tuesday, 9/13, 5:30-7:00 pm – Methodist Healthcare Systems Office in San Antonio

Tuesday, 9/13, 6:00-8:30 pm- Hillcrest Baptist Medical Center in Waco

Thursday, 9/15, **12:00-1:00 pm** – East Texas Medical Center in Tyler
Note: meeting time changed!

Tuesday, 9/27, 6:00-8:30 pm – Baylor All Saints Medical Center in Fort Worth

See the meeting schedule for details.

MEDICATION MELTDOWN

Summer alert! Mail-order drugs should not sit in your mailbox. Gelatin capsules can warp, the powder inside may clump and-most alarming-the medicine may deliver less than expected dose. That's what researchers at the Carl T. Hayden VA Medical Center in Phoenix found when they exposed a common asthma medication to four hours of heat at a temperature comparable to that inside an Arizona mailbox. In fact, the capsules delivered only half the original dose. You don't live in the desert? Leaving store-bought drugs in your car on a hot day could be just as risky, say the researchers.

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Source: Good Housekeeping, August 2005

SOMETIMES, VACCINATIONS HELP CURTAIL SHINGLES

The following article appeared in the Tyler Morning Telegraph on July 27, 2005.

DEAR DR. DONOHUE: My sister has shingles really bad. She is in great pain. They say if the shingles connect, you will die. Is that so? She is so afraid of dying from them.
– J.M.

ANSWER: Shingles is the resurrected chickenpox virus. It lies low in nerve cells after a person comes down with chickenpox in childhood (or later in life). The immune system keeps it pent up. From time to time, especially at older ages, the immune system has a temporary lapse, and the chickenpox virus escapes from the nerve cells and travels down to the skin. When it reaches the skin, it causes the typical shingles rash. The rash is in a band that encircles half the body. If your sister is worried that the rash will wrap entirely around the body, it won't. It never does. I have never heard any authority say that if the shingles rash connects, a person dies. I'm not sure what that means. At any rate, death from shingles is almost unheard of. Your sister can scratch that thought off her list of worries.

The worst complication of shingles is pain that can linger long after the skin rash has disappeared. That condition is called postherpetic neuralgia. It is a difficult condition to have and a difficult condition to treat.

Recently, an investigational vaccine that contains the shingles virus was given to healthy adults over age 60. Those vaccinated had far fewer outbreaks of shingles than did the unvaccinated, and those who did have outbreaks had fewer instances of postherpetic neuralgia. This news is not going to help your sister or anyone who happens to have shingles right now. It might be a boon to people when further trials have been made.

WEBSITES OF INTEREST

<http://www.canadadrugsonline.com//DrugMoreInfo2725.aspx> – Lyrica, the improved formulation of Neurontin, manufactured by Pfizer is available in Europe, Mexico, and Canada. FDA approval has been granted in the U.S. but Lyrica is not available yet. As soon as it becomes available, it will be noted in our newsletter. For more details about Lyrica, check out this website.

<http://www.aans.org/education/journal/neurosurgical/may05/18-5-3.pdf> - Definition and Classification system for trigeminal neuralgia developed by Oregon Health & Science University who is sponsoring the TNA 2006 National Conference, September 14-16, 2006 in Portland, OR.

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www.aarpmagazine.org/health/prisoners_pain.html - Why are millions of suffering Americans being denied the prescription drug relief they need?

www.aarpmagazine.org/health/pain_pitfalls.html - ABC's of OTC's: How to avoid common pain-relief pitfalls

WHAT MUSIC CAN DO FOR YOU

Clinical studies and anecdotal evidence from music therapists suggest that the sound of music...

- Manages pain
- Relives anxiety
- Lowers blood pressure
- Eases depression
- Enhances concentration and creativity

The best part is to take advantage of music's healing power; you don't need to take a prescription to your local music store. You don't even have to do to the music store at all. The home remedies you need are probably already in your music collection.

Source: Prevention.com/article/0,5778,s1-1-52-160-2196-1-P,00.html

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. This helps us save on our mailing and copying costs.

CUTTING EDGE: FILLINGS, NO DRILLING

Your dentist visits will soon get better: Researchers are developing two new tools that repair cavities without drilling. Dentists currently drill out decayed enamel and fill the hole. But Japanese scientists have invented a crystalline white paste that integrates into the tooth. When researchers applied the substance on small surface cavities, the crystals bonded to tooth's natural enamel in 15 minutes, neutralizing the decay. Clinical trials are examining the paste's long-term effects.

Already on the market are lasers that can burn away tooth decay—no Novocain required. The gap is then filled with resin. Only a handful of dentists are trained in laser dentistry; find one at www.laserdentistry.org

Source: Prevention, August 2005

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CELLUTOX

Frances had shingles a year ago. The post-herpetic neuralgia is getting better; however, the healing is slow. She's had some good days, thinks it is clearing up and then wham! there it goes again.

For pain, Frances uses a spray called Cellutox made for skin irritation. Her daughter who is a massage therapist in San Diego got it from a homeopathic physician for her.

Apex Energetics makes Cellutox. Products are available via the Internet and do not require a prescription.

Thanks Frances for sharing a tip with the group!

UPDATES FROM OUR MEMBERS

Lois has been trying to get Neurontin at a reduced cost. Her physician referred her to the manufacturer's website – www.pfizer.com where she could apply on-line for medication assistance. He also gave her Pfizer's toll free number to call where she could talk to a live person at 866-706-2400. She did and found the Pfizer representative to be very helpful.

Helen was taking Lorazepam which wasn't doing anything for her TN so her doctor prescribed 30 mg of Cymbalta a day which helped with the pain. Later her doctor increased her to 60 mg of Cymbalta a day and since that time she has only had one very minor TN episode.

Carolyn had a MVD by Dr. Whitworth at UTSW last month. She is getting back on her feet and feeling tremendously better. Hurray!

Charles reports he has a cyclic recurrence of steady TN pain on the right side of his face in the cheek and lower jaw every one to three months. Neurontin and other medications have not been effective. He finds that chewing a piece of sugarless gum all day relieves the pain. In approximately five days, the pain eases off. Thanks Charles for sharing your tip!

Jennifer had a MVD by Dr. Weiner at Dallas Presbyterian Hospital in December 1999 and has been 100% pain-free ever since. No signs of TN whatsoever. She counts it as a blessing every day.

Please pray for:

- Leslie as she tries to control her face pain.

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- Joanna's gamma knife to provide her with pain relief. Dr. Weiner at Dallas Presbyterian Hospital just did a gamma knife treatment on her at the beginning of this month.

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 or a written note to 604 Aberdeen Way, Southlake, TX 76092.

MEETING NOTES

Fort Worth Meeting - June 6, 2005:

Thank you to Robin Earp, Regional Director for the American Chronic Pain Association, for sharing pain management techniques with us. Lots of great handouts were available for meeting participants.

Dallas Meeting – July 13, 2005:

Jerald Tennant, M.D. spoke about integrative medicine. He also demonstrated how SCENAR Cybernetic Biofeedback, a medical technology developed and patented by the Russian government, works. A CD-rom of his presentation was going to be sent out by Barbara Forsberg with Senergy Medical Group to all meeting participants.

The *initial fee* to see Dr. Tennant is on average \$200. Fees thereafter are based upon therapy and will vary. His office does not file insurance but will provide you with a statement with necessary codes and diagnosis for your own filing purposes. To make an appointment, call 972-580-0545.

Southlake BBQ Dinner – July 24, 2005:

56 people attended our social event. Thank you to Michael Pasternak, the Trigeminal Neuralgia Association (TNA) President, for sharing his TN experience.

Tyler Meeting – July 25, 2005:

Michael Pasternak, the TNA President, shared a videotaped TV interview done by a Gainesville, FL television station and then provided us with an update on how TNA can help.

Waco Meeting – July 25, 2005:

Michael Pasternak, the TNA President, shared a videotaped TV interview done by a Gainesville, FL television station and then provided us with an update on how TNA is making a difference. There's a huge research project in the works!

Houston Meeting – July 30, 2005:

This meeting was cancelled since we did not have a volunteer offer to run it. We hope someone will volunteer to take over the Houston Support Group soon! If you are interested, please contact Jane Boles at TNA's national office: jboles@tna-support.org or call 800-923-3608.

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FUTURE TEXAS MEETING DATES

Austin at St. David's Gamma Knife Center – 10/12
Dallas at Zale Lipshy Hospital –10/26
Fort Worth at Baylor All Saints – 9/27, 11/1
Hill Country – T.B.A.
Houston – T.B.A.
San Antonio – 9/13, 10/11, 11/8, 12/13
Tyler at East Texas Medical Center – 9/15
Waco at Hillcrest Baptist Medical Center – 9/13, 11/14

TREASURER'S REPORT – NORTH CENTRAL EAST TEXAS

Beginning Balance 7/31/05		\$3356.53
Donations Received	\$155.00	
Postage	42.00	
Supplies	<u>8.97</u>	
Total Expenses	<u>\$50.97</u>	
Ending Balance 8/31/05		\$3460.56

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

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