



**TRIGEMINAL NEURALGIA ASSOCIATION
NORTH CENTRAL TEXAS SUPPORT GROUP
April 2004**

Have you seen TNA's newly revised website, www.tna-support.org? It was launched on April 7th and will continually be updated through June so be sure to check it frequently.

Have you had a chance to review the Spring TNAAlert newsletter? It includes the brochure for TNA's 5th National Conference at the Hilton in the Walt Disney World Resort, Orlando, Florida, November 11-14, 2004. Attendance is open to TN and related facial pain patients, their supporters, health care and dental professionals, and medical industry representatives from around the world.

I encourage you to try to attend the National Conference. They are only held every other year. I attended the last conference in 2002 and was absolutely amazed by the amount of knowledge gained. Don't miss out on this opportunity!

If you did not receive a Spring TNAAlert, please let me know either via e-mail at kayser-wilson@charter.net or call me at 817-416-7202 and I'll make sure one is mailed to you.

Shelly Wilson
Support Group Leader & National Conference Chairperson

URGENT: EXPANDED PRODUCT RECALL

**JANSSEN PHARMACEUTICA EXPANDS
NATIONWIDE RECALL OF 75 MCG/HOUR DURAGESIC
(FENTANYL TRANSDERMAL SYSTEM) CII PATCHES**

TITUSVILLE, NJ, April 5, 2004 – Janssen Pharmaceutica Products, L.P., is expanding its U.S. recall of DURAGESIC (Fentanyl transdermal system) CII 75 mcg/hour patches to include five manufacturing lots (**control numbers 0327192, 0327193, 0327294, 0327295, and 0330362**). No other dosage strengths or control numbers are affected. Available by prescription only, DURAGESIC patches contain a potent opiate medication.

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Anyone who has 75mcg/hour DURAGESIC patches should examine the control number that appears on the bottom flap of the outer carton or back of the foil pouch. Those who have patches from the lots with **control numbers 0327192, 0327193, 0327294, 0327295, and 0330362** must contact their physician or pharmacist immediately for specific instructions on returning patches from recalled lots and obtaining a new supply. Patients wearing other dosage strengths of DURAGESIC patches that are not from the recalled lots can continue to wear them. Sudden discontinuation of DURAGESIC can cause serious health problems.

For more detailed information, see www.Duragesic.com .

Source: Carol Goodrich, Media Contact for Janssen Pharmaceutica Products, L.P.

SUGGESTED READING

One of our member's psychologist suggested getting a book called "Managing Pain Before It Manages You" by Margaret A. Caudill. Our member highly recommends this workbook for anyone who has chronic pain because it tells you how to think and live differently with your pain. There are work sheets in the back to fill-in (i.e. pain diaries, relaxation diaries, food diaries).

The first edition of this book came out in December 1994. The revised edition was made available in November 2001 which is available at most major bookstores and on-line.

FLEXIRIL USERS BEWARE!

Anna, one of our support group members, experienced severe hair loss while taking Flexiril, a non-addictive muscle relaxer to help her sleep. She suggests people who have a lot of drug reactions like she does, should take note.

HEALTH INSURANCE HELP

Getting health insurance coverage can be a real struggle if you have been diagnosed with trigeminal neuralgia or related facial pain. However, Dale's willing to help.

Dale Mason, an independent insurance agent, represents several health care plans. Whether you are self-employed, just need to re-evaluate your current health care coverage, or are looking for a Medicare supplement, Dale can help. If you live in the Dallas/Fort Worth area, you can reach him at 817-770-8804. Outside of the DFW area, *including Oklahoma*, call him toll-free at 800-687-1818. He can also be reached via e-mail at dmasonins@msn.com.

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SHORT CIRCUIT YOUR BLUES

Don't let a mild case of the blues put your heart health at risk. More and more research is suggesting that depression can impact heart health. When you feel a blue mood coming on, cut it short by spending time with good friends or going for a walk.

Source: RealAge Tip of the Day, April 9, 2004

WEBSITES OF INTEREST

www.WholeHealthMD.com – dedicated to providing the best in complementary and alternative medicine. All of their information is developed by a team of board-certified doctors and specialists.

www.benderdds.com/inthenews.html - news clip of Dr. Bender and his work with TN patients

FLOWER POWER

Flowers are the loveliest tension tamers. One of nature's oldest soothers for women, much more than décor, blossoms have these newly discovered, scientifically proven powers:

- Pretty blooms boost pain tolerance. Women who eyed flowering plants in a lab designed to look like a hospital room kept their hands in ice water, a typical pain test, nearly a minute longer than those whose view was flowerless.
- Flowery fragrances ease sadness and anger.

Source: Jennifer Matlack, Prevention Magazine

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

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

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REGIONAL PATIENT WORKSHOP

If you missed the TNA Regional Conference in November and haven't ordered the six hours of video tape along with meeting handouts for \$30, you can still do so while supplies last. *Only 2 video tapes and meeting handouts are available.* To place your order, send a check payable to TNA with the memo field notated "video tapes" to Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092.

UPDATES FROM OUR MEMBERS

Karin had a MVD by Dr. White at Parkland Hospital on April Fool's Day. She's eager to get her stitches out and to start decreasing her TN medication.

Lizzie had a MVD by Dr. Weiner at Dallas Presbyterian Hospital this month. Dr. Weiner found two compressions on her trigeminal nerve that he was able to decompress. Since surgery, Lizzie hasn't had any TN pain!

Please continue to keep Jill in your prayers as she continues to struggle with a life-threatening, non-TN related health issue. Lee also has a non-related TN health issue and could use your prayers at this time. Joan's husband, a TN supporter, is battling cancer and could benefit from your prayers as well.

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

MEETING NOTES

Waco Meeting – March 8, 2004

Tony Whitworth, M.D. from U.T. Southwestern Medical Center in Dallas covered classifications and help for facial pain patients. His presentation featured neuromodulation in which he explained the advantages (testable, reversible, safe, efficacy, and long term cost) whereas the disadvantages include a learning curve, follow-up, and acute cost.

The five neurostimulation procedures include:

1. Peripheral Nerve Stimulation - Good for patients who have pain in the V1 or V2 and requires at least some remaining sensation in the pain region.
2. Ganglion Stimulation - Can treat pain in any trigeminal distribution but has a high rate of dislodgement, 50% at one year.
3. Spinal Cord Stimulation - Uses a very stable electrode, is good for treating pain in the V3 and requires some preserved sensation.
4. Deep Brain Stimulation – Good for pain in any trigeminal distribution, does not require intact sensation, offers *at best* a 50% success rate, and is often used to

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treat anesthesia dolorosa, trigeminal neuropathic pain, and trigeminal deafferentation pain.

5. Motor Cortex Stimulation – Good for pain in any trigeminal distribution, doesn't require intact sensation, and its success rate runs 60-70%. It was developed 10-12 years ago in Japan and has only been used in the US for 5-6 years. Often used to treat anesthesia dolorosa, trigeminal neuropathic pain, and trigeminal deafferentation pain.

Dr. Whitworth told us if a stimulator helps: 1/3 of the patients come off all of their medications, 1/3 of the patients are able to reduce their medications, and 1/3 of the patients remain on their same dosage of medication prior to the stimulator procedure.

To make an appointment with Dr. Whitworth, call U.T. Southwestern's neurosurgery clinic at 214-648-8500.

Fort Worth Meeting – March 23, 2004

Psychologist Ramon Cuencas-Zamora, Ph.D., a licensed professional counselor whose practice focuses on chronic pain management, biofeedback, and psychotherapy gave us examples of acute pain (i.e. broken arm, medication for a cold) versus chronic pain (i.e. intense pain, varies, never goes away).

In 1965, the Gate Control Theory of Pain stated “emotions can increase or decrease pain”. Pain creates tension and tension creates pain – a cycle. Our support group attendees agreed!

In 2002, Corsini defined pain as “a common, unpleasant sensation evoked by a harmful stimulus. Pain is similar for everyone physiologically but widely varied in terms of behavioral response, interpretations, and presumably, subjective experience.

Dr. Cuencas-Zamora explained how Biofeedback works. It teaches physical awareness and voluntary control over the body's systems. It is the use of electronic equipment to reflect the physical state of the individual while the person learns techniques to regulate the body's systems and to reduce unwanted symptoms. Biofeedback is a painless and non-invasive therapy.

We learned that when you breathe deeply, 700 chemicals in the blood change. When you are under stress, 1400 chemicals in the blood change.

A chronic pain program will get a patient to exercise their right brain more. For example, if you can't sleep, start deep breathing, then think of something nice (i.e. art, music).

Dr. Cuencas-Zamora encourages his patients to do something to have fun *despite their pain!* Relaxation, a positive attitude, inner peace, exercise, good eating habits, and a healthy lifestyle can benefit chronic pain patients.

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To make an appointment to see Dr. Cuencas-Zamora with Prisma Behavioral Health Providers, Inc. in Coppell, just north of DFW airport, call 972-304-1252. *Note:* He does not accept insurance.

FUTURE MEETING DATES

Dallas at Zale Lipshy Hospital – 6/2, 8/4, 10/6, 12/1
Fort Worth at Baylor All Saints – 5/18, 7/20, 9/21, 11/16
Tyler at East Texas Medical Center – 4/23
Waco at Hillcrest Hospital – 5/3, 7/12, 9/14, 11/1

TREASURER'S REPORT

Beginning Balance 3/21/04		\$4704.61
Donations Received	\$358.00	
Copies	6.82	
Long Distance	22.99	
Postage	<u>156.14</u>	
Total Expenses	<u>\$185.95</u>	
Ending Balance 4/25/04		\$4876.66

FINANCIAL CONTRIBUTIONS

Local TNA chapters *do not receive* funding from the national office. If you would like your tax-deductible contribution to go toward our local chapter, please make your check payable to the order of Trigeminal Neuralgia Association and in the memo field put North Central Texas chapter, then mail it to Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092.

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: 352-376-9955, Fax: 352-376-8688
www.tna-support.org

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