



**TRIGEMINAL NEURALGIA ASSOCIATION
TEXAS SUPPORT GROUPS NEWSLETTER
August 2004**

The North Central Texas support group which holds meetings in Dallas, Fort Worth, Tyler, and Waco is combining its newsletter and meeting flyer efforts with the Houston support group. As a result, we will all benefit from learning what is going on in other areas of our state.

If you are a member of either support group and do *not* want to receive this newsletter along with meeting flyer announcements, please notify Shelly Wilson either via e-mail at kayser-wilson@charter.net or by calling 817-416-7202.

TNA NATIONAL CONFERENCE

For any TN or related facial pain patient who has not been to a TNA National Conference, you might want to consider attending this year's conference that is being held November 11-14 at the Hilton in the Walt Disney World Resort, Orlando, FL. The conference is open to patients and their supporters, health care and dental professionals, as well as medical and dental industry representatives from around the world.

The national conferences are only held every other year. The next conference won't be held until September 2006 in Portland. So, don't delay and register today to attend TNA's 5th National Conference on-line via www.tna-support.org.

If you didn't receive a TNA National Conference brochure (which was sent out by the TNA national office inside of the Spring TNAAlert newsletter), please notify Shelly Wilson either via e-mail at kayser-wilson@charter.net or by calling 817-416-7202 and request one be sent to you.

TEXAS ACADEMY OF FAMILY PHYSICIANS

The North Central Texas support group and the Houston support group teamed up in July to work the TNA exhibit booth at the Texas Academy of Family Physicians meeting in Houston. Thanks to those who volunteered their time to work a shift in our booth.

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A LETTER RECEIVED FROM A DALLAS SUPPORT GROUP MEMBER

“I am a Survivor from Trigeminal Neuralgia”

I HAVE BEEN 100% PAIN FREE SINCE DECEMBER 26, 1989, THANKS TO MY NEUROSURGEON, RICHARD JACKSON, WHO PERFORMED THE RADIOFREQUENCY RHIZOTOMY PROCEDURE WHICH IS DONE UNDER LOCAL ANESTHESIA AND SEDATION. A NEEDLE IS PLACED THROUGH THE FACE THROUGH WHICH AN ELECTRODE IS INSERTED TO HEAT THE NERVE AND DESTROY THE PAIN FIBERS.

My experience with TN, also known as TIC, began on a Friday summer evening in 1989 when I felt my first “ice pick stab” on the lower right jaw line. My first thought was a dental pain, and no way to get medical or dental attention before the following Monday. During the days following my first attack, my dentist found no x-ray problems, and sent me to an orthodontist, who finally sent me to a neurologist. My first, and only, prescription was Tegretol, which, in my case, was only partially effective. The “ice pick” never let up, and eating and teeth brushing became an unpleasant ordeal.

My family traveled to New Mexico on Thanksgiving weekend, and I was not very good company to my wife and son. On the morning we were to return to Dallas, the temperature in Santa Fe was 24 degrees. Unfortunately, no one had advised me to avoid COLD weather, and by the time we were back in Dallas, the pain had become so intense, it was almost impossible to eat.

An opportunity came to go to California on business, and my thought was warm weather would alleviate my pain somewhat. My trip was to last 5 days, but I cut it short after 2 days of just nibbling at my food.

After returning home, I became a “basket case” until my immobility caused a blood clot to form in my right lung on December 15. Hospitalization was necessary for treatment of the clot, and the decision was made to have Dr. Jackson perform the radiofrequency rhizotomy. So, my Christmas present came a day late, but it was most welcome to finally be free of pain for the first time in 6 months.

The right side of my face is numb, but I would have the surgery anytime my “ice pick” stabbed me. The only side effect is a small slowness in chewing food. (I just enjoy my food longer.) Yes, there are risks in this surgical procedure, as outlined in a complete written description furnished to me by Dr. Jackson before surgery, so I did not go into the surgery without being fully informed.

After 10 years, I went back to Dr. Jackson for a check-up, and was advised with no pain after 10 years, the chance of reoccurrence was almost NIL. It was heartwarming to hear

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those words, and I am most thankful medical science had progressed enough to cause my successful surgery.

My only regret is the procedure came too late for my own mother, who began suffering the same pain in 1946, and the alcohol injection was tried without success. She suffered for over 28 years, and I could not fully appreciate her pain until it struck me. You can imagine how we anguished over her and how helpless we felt through all those years.

Should any of you now enduring this awful pain like to discuss your situation, please feel free to call me at (972) 470-9457. Needless to say, I have strong empathy for any of you who are living with “TIC”.

Sam W. Stone, Jr.

Richard Jackson, M.D. is with Dallas Neurosurgical Associates, P.A. His office number is 214-750-3646.

MIGRAINES – UPDATE

After reading the July newsletter article called “Migraines”, I felt it was important to share some information that would be helpful to support group members.

Larry mentioned Excedrine Migraine was a helpful medication for headache and atypical facial pain. Although Dexedrine is a very effective analgesic, it should be used only sparingly and with caution in headache sufferers.

The components of Excedrine (aspirin, acetaminophen, caffeine) are big contributors to rebound pain. It has been found that in prone individuals these types of analgesics can alter the physiology of the pain processing part of the central nervous system. It has been reported that even using the medication 2-3 times per week for several weeks can affect this change. When this happens, our ability to tolerate pain is decreased. Some suspect the changes are permanent.

On a personal note, this happened to me with Excedrine. What one would notice is that it takes more medication and increased frequency in dosing to alleviate the pain.

Please pass this information on as I see many patients who have developed this problem.

Thanks!

Steven D. Bender, D.D.S.
North Texas Center for Head, Face & TMJ Pain
Plano, TX

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E-MAIL ADDRESSES

Thanks to everyone who have 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.

WEBSITES OF INTEREST

www.roomforhealing.com – Carol Preston, a registered massage therapist and one of our Dallas support group members, has opened up a massage therapy office. She also does foot treatments and Spiritual Healing Touch.

www.tdi.state.tx.us – Texas Department of Insurance website where you can submit on-line health insurance complaints or you can call 800-252-3439 to request a form be mailed to you.

UPDATES FROM OUR MEMBERS

Jesse's scheduled for a MVD with Dr. White in Dallas this month. We hope it rids him of TN pain!

Pat, one of our long-distance support group members from up north in a state where we don't have a support group yet, is scheduled for a MVD with Dr. Pollock at Mayo Clinic this month. Please pray for her.

Lillian who had a MVD in June by Dr. White with UT Southwestern Medical Center in Dallas, feels great. Sometimes she even forgets she had surgery!

Carol's quality of life has improved greatly under the compassionate care and quality pain management of John W. East, D.O. and C. Brandon Knutson, D.C. with Metroplex Rehab & Pain Medicine of Carrollton. For more information about these health care providers, call 972-417-9999 or go to www.metroplexrehab.com

At age 24, Misty had a MVD by Dr. Kopitnik, formerly with UT Southwestern Medical Center in Dallas. She's been pain-free ever since. Hurray!

Bill's been pain-free for 3 years now. He takes Tegretol XR (extended release formulation) and Clonazepam.

Rick reported he had his one year anniversary in July from being pain-free. He had a MVD done by Dr. Weiner at Dallas Presbyterian Hospital on July 1, 2003 and his life is great now. He gets to do the things he loves like being a fire fighter and *kissing his wife*.

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Ann's also gotten some facial pain relief from taking over-the-counter migraine medication. Also, she finds that using a battery-operated toothbrush will trigger an episode or even make one worse.

Yolanda, Mary, and Don haven't been feeling too good lately. Please keep them in your prayers.

Pat's TN pain has returned on her left side where she had a successful gamma knife six years ago. So far, Neurontin has helped to control her pain. Please pray for her.

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

MEETING NOTES

Fort Worth Meeting – May 18, 2004:

John D'Amanda, D.C. who specializes in NUCCA, Grostic, and Acupuncture stated 62% of the U.S. population has been to a chiropractor. Of those, 90% say their experience was beneficial.

Today, there are over 100 different chiropractic techniques. About 95% of all chiropractors practice Diversified (manual adjusting). Grostic and Atlas Orthogonal chiropractic techniques are upper cervical techniques that deal with the position of the atlas which is the first bone in the spinal column and can be felt just under the earlobe.

Three x-rays are required to determine the position of the atlas (Lateral cervical neutral, Nasium and Vertex). One x-ray is a side view to determine the angle of the neck. The second view is to determine if the atlas has moved to the right side or the left side and is also used to determine if the C2 (axis) has followed the atlas and if the C2 is rotated. The third view is used to determine if and how much the atlas is rotated.

Formulas derived from Physics, Calculus and Vector Analysis are used to analyze the x-rays. Once the analysis is complete, a formula is determined and a precise adjustment is given to the atlas.

In addition to the atlas adjustments, Dr. D'Amanda also uses auricular therapy, an electric way to stimulate acupuncture points on the ears without using needles.

Dr. D'Amanda's goal for TN and related facial pain patients is to decrease the amount of medication a patient needs while keeping the patient pain-free.

To make an appointment with Dr. D'Amanda, call 940-365-5888. His office is located at 2404 Oak Grove Lane, Aubrey, TX 76227. www.countrychiropractic.com

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FUTURE MEETING DATES

Dallas at Zale Lipshy Hospital – 10/6, 12/1
Fort Worth at Baylor All Saints – 9/21, 11/16
Houston at Christus St. Joseph Hospital – 9/18
Tyler at East Texas Medical Center – 10/12
Waco at Hillcrest Hospital – 9/14, 11/1

TREASURER'S REPORT – NORTH CENTRAL TX SUPPORT GROUP

Beginning Balance 7/1/04		\$4282.06
Donations Received		\$351.00
Center for Nonprofit		
- membership fee	65.00	
Copies	31.12	
Postage	100.95	
Striking Back Books	271.20	
Supplies	56.78	
Tabletop Exhibit Booth	575.00	
Total Expenses		<u>\$1100.05</u>
Ending Balance 7/31/04		\$3533.01

Note: The Houston support group will keep their finances separate. A Houston financial update will be provided in an upcoming newsletter.

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.

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www.tna-support.org

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