



TRIGEMINAL NEURALGIA ASSOCIATION TEXAS SUPPORT GROUPS NEWSLETTER FALL 2007

www.texasrna.org

REQUEST FOR E-MAIL ADDRESSES

We need your help in reducing our costs. Each month, approximately 20 email addresses in our confidential Texas database are no longer effective.

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 to help us save on mailing and copying costs.

Also, if you change your e-mail address, make sure to advise Shelly as well. This will make sure you don't miss out on receiving any information in our region or from the TNA national office. Thanks!

SAVE THE DATE!

Saturday, October 20, 2007 – Donald Nixdorf, the newest TNA Medical Advisory Board member from the University of Minnesota, will be speaking at two support group meetings. One meeting will take place in Dallas and one in Fort Worth. Check your meeting schedule for details!

EAST TEXAS SUPPORT GROUP LEADER NEEDED

Due to work and family needs, Pam Rowlett is stepping down as the East Texas Support Group Leader. We need someone to step up and take over this support group so it won't fall apart. If you are interested in becoming the new Support Group Leader or assisting with this support group, please e-mail Shelly Wilson at swilson@tna-support.org.

TEXAS TNA SURVEY RESULTS

A special edition of the Texas TNA newsletter will come out later this fall. It will include a list of health care providers recommended by our support group members. It will feature tips as to what has helped control or end the pain of our support group members. Thanks to the 100+ support group members who took the time to complete and submit the survey.

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SPECIAL THANKS

Thanks to Brian Nelson who jumped in and took over the management of the August Houston support group meeting on short notice since Carol Ann Preston, the Houston Support Group Leader, had to leave town to be with her daughter who was having medical tests done. At the meeting, Brian videotaped Dr. Robert Parrish's lecture on TN surgical treatment and posted it on www.youtube.com. As of early September, over 980 people had viewed Dr. Parrish's lecture.

To view Dr. Parrish's lecture go to www.youtube.com and in the search field type in Dr. Parrish. You can also view other trigeminal neuralgia clips by typing trigeminal neuralgia in the search field. We also have some videos on our Texas TNA website at www.texasrna.org.

JOE'S STORY

I want to share my story with you all, because after all I went through for 7 years of agonizing pain, literally tens of thousands of dollars and weeks absent from work, I really don't want anybody else to go through what I went through.

I had an atypical TN case, which was very hard to diagnose because it was complicated with a case of TMJ. Of course, when everything started, no doctor could figure out what was wrong with me. Because the pain was very bothersome, without the "electric shock" sensation, I was been treated for everything you could imagine: dental, sinus infection, ear infection, etc... As months and years went by, the pain escalated to sharp pains with long valleys of generalized dull pain all over the right side of my face.

During my third year with the condition, the clicking on the jaw started; clear indication of TMJ. I went to a few doctors until I zeroed-in onto a "neuromuscular dentist" that worked on non-invasive procedures to realign the bite and release pressure on the joint. That healing process for this was very slow, but effective. In about 2.5 years the pain produced by the joint diminished completely, including the clicking sound of the jaw.

On the other hand, the sharp "electric pain" attacks continue to increase in intensity and frequency. It was not until the TMJ pain started to subside that it was obvious that a case of TN was also in the midst. I visited a total of 3 neurologists. Medication after medication failed on me only after several months of usage. First was Neurontin and then Carbatrol (plus prednisone and vicodin).

Just this last November, 2006 after the TN attacks started occurring every other month and lasting for about a week, it was necessary to take another course of action. I felt that I was becoming incapacitated and not able to work any longer. After a successful career for 23 years, I was ready to call the quits, since absenteeism was already damaging my professional image.

After searching the web for a solution to my problem, I came across TNA's national website at www.endthepain.org. I learned a lot about the different surgical procedures available and I decided that MVD was the most appropriate for me. I selected a neurosurgeon in my area, based on his experience and the reputation of the hospital, and agreed to go under. When the surgeon opened me up, he was surprised to find that cranial nerve #5 (the one responsible for TN) was very afflicted: it looked very thin and surrounded by a "forest" of veins and arteries, according to him.

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It has been 7 month since the surgery, and I have been blessed because now I'm truly free of pain, of both TN and TMJ. And more important, I have been medication free for the first time in 7 years as well!

Dr. Ron Konig, DDS in Houston (713-668-2289) was my neuromuscular dentist that handled my TMJ and Dr. Rob Parrish, MD, PhD in Houston (713-441-3800) was my neurosurgeon who performed the MVD.

FIVE TIPS FOR A GOOD NIGHT'S SLEEP

- **Stay regular.** Get up about the same time every day, even on weekends.
- **Develop a pre-bed routine.** A warm bath or light reading might help.
- **Use common sense.** Avoid exercise, caffeine and alcohol four to six hours before bed.
- **Eat light.** A light snack before bed may promote sleep, but a heavy meal will keep you awake.
- **Avoid nicotine** at night or close to bedtime.

Source: American Academy of Sleep Medicine

INTERX UPDATE

Janice Walker, OTR, a clinical specialist with the Neuro Resource Group in Plano has been treating TN and atypical facial pain patients with an external hand-held stimulator device. She tracked nine patients. Five patients have had success using InterX and are now able to talk, chew, and brush their teeth without difficulty.

For more information on InterX, go to www.nrg-unlimited.com or call 972-665-1810. This product is covered under some insurance plans.

ERIKA'S EXPERIENCE

Erika has battled face pain for year. After being pain-free for a year while taking Cymbalta and Topomax, her pain returned so she contemplated having a surgical procedure.

Since she was on vacation in Northern California, she saw neurosurgeon Dr. Nicholas Barbaro at UCSF, a member of TNA's Medical Advisory Board. He didn't think she had TN so he referred her to Dr. Nagy, a UCSF headache specialist, who diagnosed her with "Episodic Paroxysmal Hemicrania" which is a headache disorder. He also changed her medication to the primary drug for this condition called Indomethacin. Please keep Erika in your prayers as she changes her medication regimen.

According to Answers.com, paroxysmal hemicrania (PH) is:

a rare form of headache. Paroxysmal hemicrania usually begins in adulthood, and affected persons experience severe throbbing, claw-like, or boring pain. The pain is usually on one side of the face, near or in the eye, temple, and occasionally reaching to the back of the neck. Red and tearing eyes, a drooping or swollen eyelid on the affected side of the face, and nasal congestion may accompany this pain. Persons experiencing

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the headache pain of paroxysmal hemicrania may also feel dull pain, soreness, or tenderness between attacks.

Paroxysmal hemicrania syndromes have two forms: chronic, in which persons experience attacks on a daily basis for a year or more, and episodic, in which the headaches do not occur for months or years. Episodic paroxysmal hemicrania is four times more common than the chronic form.

Source: www.answers.com/topic/paroxysmal-hemicrania?cat=health

UPDATES FROM OUR MEMBERS

Roy had a massive heart attack in May. Since his bypass heart surgery, his TN pain has let up. Some days, he just needs to take 100 mg of Neurontin. Hurray!

In mid-May, John had a gamma knife (one time radiation treatment) by Dr. Tony Whitworth at UT Southwestern in Dallas. At the beginning of July, John became pain-free and started backing off of his medication with approval from all three of his doctors. Now he's down to just taking 600 mg of Trileptal and is feeling good whereas before the gamma knife, he was taking 1800 mg of Trileptal.

Rosalinda's Mom had microvascular decompression (MVD) surgery done in early June by Dr. Jonathan White at UT Southwestern in Dallas and everything went wonderfully. She was so surprised to see her Mom recover so fast. In late June, her Mom was still at home doing light activity around the house, and so far has not had any complications or severe pain. Of course the neurosurgeons said that they won't know how successful the surgery was until two months after surgery but Rosalinda is confident her Mom will be okay. Her Mom is also being tapered off all of her anti-seizure medications so soon she will be medication-free. She is so happy that her Mom chose to have the MVD as she feels like she got her old Mom back. Praise God!

Dorothy reported she cured her TN by taking Lysine, an amino acid supplement that you can buy at the supermarket or in drug stores.

Marylyn had a MVD by Dr. Jonathan White at UT Southwestern in late June. Her electric shock-like pain is gone. When Marylyn asked if it was worth going through the MVD surgery, she responded "Absolutely". Her TN pain is slowly starting to get better.

James got anesthesia dolorosa (AD) from a gamma knife. To stop the AD pain, he had a motor cortex stimulator implanted 1-1/2 years ago. About 6 months ago when his pain returned, he doctor put him on Cymbalta which helped to reduce his pain. He's now taking 120 mg of Cymbalta a day and his pain is gone. He's back to living again and is even being productive!

Deanne was hit pretty hard with TN the last few months. Taking Trileptal and Lyrica seemed to work. She's figured out that when she starts getting even the slightest twinge, she has to take her TN medication immediately or she's in for it.

Jean usually has TN pain every spring and summer. It starts in March and continues through August. Last September she began to feel better and was able to decrease her medication. (She always dreads summer because it is a very painful time for her and she can't seem to find a neurologist who knows much about TN.) Jean's done a lot of reading on TN and has seen vitamin B12 mentioned several times which has been linked to the rebuilding of the myelin

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protective covering around the nerve. In January, Jean decided to try vitamin B12 tablets. She took 2000 mg in the morning and 2000 in the evening. She also started taking Omega 3 and folic acid, also linked with nerve health. She was a little afraid to say this but “she’s had no pain this summer!” She’s still taking some Trileptal but only as a precautionary measure. She’s said “she’s not naive enough to think that this will be a lifetime fix but is thankful for every painless moment that it affords her!”

In July, Heath came down with TN, went to a hospital emergency room and got diagnosed right the first time but was only given Loritab (a muscle relaxer) and was sent home with a prescription for more Loritab. Needless to say, three hours later Heath was back in the emergency room with uncontrollable electric shock like pain. After almost a two week hospital stay on narcotics and eventually a low dose of seizure medication, Heath requested to be transferred out of that hospital to UT Southwestern’s Zale Lipshy Hospital under the care of Dr. Whitworth. Two days later, Dr. Whitworth performed a MVD on Heath and just a couple of days after that Heath went home to recover from MVD surgery. He’ll be out of work for six weeks recovering but within 10 days of the surgery, he got his stitches out and is completely off of seizure medication. We wish Heath a speedy recovery!

In late August, Dorothy’s blood test indicated she was becoming toxic to Tegretol so her neurologist decreased her Tegretol dosage which made Dorothy’s TN go out of control despite also taking Neurontin. She went to her local emergency room (ER) and was able to get IV Dilantin which stopped her pain for six hours. Unfortunately, the pain then returned and the next ER visit where she got IV Dilantin did little to help her. She ended up going to see Dr. Jonathan White with UT Southwestern and had a MVD. Dr. White found the biggest vein he’s ever seen compressing her trigeminal nerve which he removed. Since surgery, Dorothy’s TN medication has been drastically reduced. We hope she’ll have an easy recovery.

Rhonda reported since she was on the Omura protocol for three months in 2005, she hasn’t had a migraine headache. She had suffered with migraines ever since she was a little girl. *(The Omura protocol involves taking 1000 mg of EPA Fish Oil, 4 times a day on an empty stomach along with putting 15 drops of Cilantro into one ounce of warm water and drinking it each time you take the Fish Oil. Also, it has been reported that taking ¼ tablet of Folic Acid each time you take a fish oil pill will boost the effectiveness of the fish oil. There are also dietary factors that go with this protocol including no sugar, garlic, onions, caffeine, Vitamin C, alcohol, and chocolate.)*

Eva had a MVD in January and then a Gamma Knife by Dr. Tony Whitworth at UT Southwestern in late April of this year. As of now, she is PAIN FREE!!!!!!!!!!!!!! She mentioned she was really discouraged after the MVD didn’t work and for the first couple of months after the gamma knife, she questioned whether the gamma knife had done any good since she was still having pain. Eventually, she was able to start reducing her medications and is now totally off of Neurontin and is only taking 150 mg of Trileptal. By the end of September she should be off all medications. Now she has days that she even forgets about TN and what a blessing that is.

Henry continues to be pain-free and TN medication-free since he had a radiofrequency rhizotomy by Dr. Phil Williams, Jr. in Dallas in May.

Please pray for:

- Ellen’s family as Ellen, a 30 year old Texas TN patient, passed away in her sleep in August. The family is awaiting autopsy results. Ellen is survived by her husband, parents, brother, and other extended family members.

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- Shirley who had a stimulator implanted to control her anesthesia dolorosa (AD) pain by Dr. Redco in Houston in mid August. Dr. Redco is a pain management doctor with offices in Houston and Beaumont.
- Lottie and her sons who are trying to get their Mom's TN pain under control.
- Robin who is recovering from a MVD and positional vertigo. The good news is she is out of pain, thank goodness for that!
- Brian who has stage 4 cancer.
- Billy who is going through rehabilitation from AVM surgery.
- Randy who has an acoustic neuroma pressing up against the trigeminal nerve.
- Jana who is going through a MS bout along with TN and Glossopharyngeal neuralgia.

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 PO Box 92604, Southlake, TX 76092.

FUTURE MEETING DATES

Austin – 9/8	San Antonio –10/9, 12/11
Dallas – 10/20, 11/7	Tyler – 10/26, 12/14
Fort Worth – 10/20, 12/6	Waco - 9/10, 11/12
Houston – 11/5	

TREASURER'S REPORT

Beginning Balance – 6/15/7		\$5,441.80
Donations Received		\$225.00
Airline ticket for Dr. Nixdorf	240.80	
Center for Nonprofit Management	155.00	
Clinical Manual of TN	94.95	
Copies	78.50	
Long Distance	32.48	
Postage	218.65	
Striking Back & Insight books	441.09	
Supplies	<u>126.79</u>	
Expenses		<u>\$1388.26</u>
Ending Balance 9/5/7		\$4278.54

Local TNA chapters *do not receive* funding from the national office. If you would like your tax-deductible contribution to go toward the Texas support groups, please make your check payable to the order of Trigeminal Neuralgia Association and in the memo field put 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. TNA, 925 NW 56th Terrace, Suite C, Gainesville, FL 32605, Phone: 800-923-3608, Fax: 352-331-7078, www.endthepain.org

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