



TRIGEMINAL NEURALGIA ASSOCIATION TEXAS SUPPORT GROUPS NEWSLETTER WINTER 2007-2008

Happy New Year! Our group continued to grow in 2007. We went from 1,262 to 1,329 people working together to try to end the pain.

2010 PLANNING MEETING

UT Southwestern is hosting TNA's 2010 National Conference. To ensure this is TNA's *best* national conference, we need ideas from patients, supporters, researchers, and health care providers.

You are invited to join us on Saturday, February 9 at the Southlake Town Square Hilton, 1400 Plaza Place, Southlake, TX 76092. At 8:30 a.m., we will have a hot breakfast followed by the brainstorming session from 9:00-11:00 a.m. There is no cost to attend.

Please RSVP to Shelly Wilson at swilson@tna-support.org or call 817-416-7202 to reserve your seat by February 5.

EAST TEXAS SUPPORT GROUP LEADER NEEDED

Due to work and family needs, Pam Rowlett has stepped 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.

COMMUNITY AWARENESS PROGRAM

A way we can increase community awareness about TN is to display our TNA brochures in health care provider offices around Texas. If you are willing to take a supply of TNA brochures in a brochure stand to their health care provider's office and ask that they be displayed, please let Shelly know either via email at swilson@tna-support.org or call 817-416-7202 and a set of brochures and a brochure stand will be mailed to you. Please make sure to tell Shelly who you plan to give the brochures to so we make sure we only give one set to each health care provider.

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Do you have more than one health care provider that you are willing to give brochures to? No problem. Just let Shelly know the number of sets of information you need along with the names of the health care providers you will visit.

Be sure to ask your health care provider to display the brochures in their office. By doing so, we will have a better opportunity to have our information displayed rather than us mailing the brochures out.

\$4 PRESCRIPTIONS

Thank you to Cal for letting us know that Wal-mart has just added Carbamazepine, the generic for Tegretol, to their \$4 monthly prescription list. This applies up to a 30 day supply of sixty 200 mg pills.

The list of covered drugs is subject to change. Not all prescription drugs are covered by this program.

For more details, go to <http://www.walmart.com/catalog/catalog.gsp?cat=546834>.

NEW! A GENERIC FOR TRILEPTAL

In December, Bertha learned the generic called Oxcarbazepine is now available for brand name Trileptal. She was told by her pharmacist that the generic became available only about a month ago.

HOUSTON SUPPORT GROUP LEADER NEEDED

Carol Preston, the Houston Support Group Leader, is moving in March. So we are in need of someone to keep this group going. 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.

ALAN'S TESTIMONY

I had my first episode in June 2001 and went to my dentist thinking it had to be tooth related. After two root canals and no relief, the dentist recommended I see a neurologist who immediately diagnosed me with TN. He briefly described the disorder and put me on Trileptol. He made some mention about maybe having surgery later on to place a "pillow" on nerve behind the ear if the medication did not work. I didn't like the sound of that and assumed the medication would work, which it did for awhile. I continued to have episodes (on average, about one to two a year lasting about one to two months at a time) but each time the pain got a little worse until late last year when it reached the point that I couldn't eat, talk or brush my teeth without pain. Increased medication only made me drowsy and disoriented. I finally decided to seriously research possible surgical alternatives. I joined TNA, read "Striking Back" from cover-to-cover, and decided the MVD procedure was how I wanted to go. I also talked to several people who were on TNA's referral list who had had the MVD surgery, all with good success. I travelled to Dallas to meet with Dr. Jonathan White at UT Southwestern Medical School. Dr. White has performed

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numerous MVD surgeries and is very active in TNA. While very impressed I wanted to consider another surgeon in Houston since that is my home. At least two of the people I had talked to recommended Dr. Rob Parrish, a neurosurgeon at Houston's Methodist Hospital Med Center (713-441-3849). I met with Dr. Parrish in February 2007 and decided that he would be my surgeon.

Then a funny thing happened. The pain went back into remission and since the "roof was no longer leaking", I decided to postpone "repairing the roof". Bad mistake! It returned in October 2007 and by mid November the pain was the worst I had ever suffered with no sign of letting up. It was almost constant. I called Dr. Parrish's office for an appointment with the intent to going straight to surgery if he could get me in. We met on November 29. Dr. Parrish initially told me that his schedule was completely booked until December 20 when he was scheduled to leave for the holidays. I guess the look on my face convinced him that I really couldn't wait that long. He rearranged his schedule to get me in on December 5, only 6 days later. His staff worked diligently to get me through all the pre-op screenings (I already had the MRI's and CAT scan from the initial examination) and took care of the insurance approvals in time for the surgery.

I was in surgery at 9:30 am on the 5th and in recovery by 12 pm. By the time I got to ICU and had regained consciousness, the pain was completely gone! I spent that night in ICU but by morning was feeling quite good. Dr. Parrish visited that morning and after checking my chart decided to release me to go home. I was back in my own bed by 1 pm that afternoon – slightly more than a day after I went in! Over the next few days I experienced some nausea and the normal discomfort and listlessness associated with head trauma but my strength steadily improved and my appetite was back to normal within a few days. I returned to Dr. Parrish's office on Dec. 17 for a checkup and to have the staples removed. All is well so far and I am scheduled back in a month for a final check. I returned to work (part time) the next morning but I don't expect to be back to full strength for another several weeks.

My special thanks to TNA (both national and state) for its help and support and to Dr. Parrish and his staff for making this a very Merry Christmas for me and my family.

Alan Stumbaugh
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WEBSITES OF INTEREST

www.texastna.org – PowerPoint presentations from prior Texas TNA support group meetings are available for you to view on our Texas TNA website. Special thanks to the health care providers who allowed us to post their presentations!

www.alpha-stim.com – Tracy Carmack, ND, CCN, MifHI has had success treating TN patients with this microcurrent electrical therapy which has also helped others suffering from acute, chronic, or postoperative pain.

<http://brain.hastypastry.net/forums/forumdisplay.php?f=271> – Brain Talk Communities trigeminal neuralgia forum

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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.

TRACY'S EXPERIENCE

Tracy Knight, a TNA Telephone Support Contact, had a microvascular decompression (MVD) in December 2003 for atypical TN which was mixed with some classic TN features. (Her pain started as a result of being hit in the face and her ear drum burst and bled.) Now that it has been a few years since her MVD and some of her pain has returned, I asked her what her thoughts were on MVD's for atypical TN patients. Below is her response. Shelly Wilson, TNA Support Group Leader

I still think I did the right thing with MVD. I would do it again and again for the years it gave back to me. Although I kept the atypical pain and had the burning, the absence of the excruciating pain left me the ability to enjoy life again. My husband could touch me on the head and face without fear of me going to my knees. No one but a TN patient knows what its like to not to be able to enjoy the touch of your spouse on your face, head, fingers through your hair.

I could run and play outside again with my children. Camp, Fish and Swim normally again, sit in the stands to watch my sons play football even in the fall with wind and rain. Sure I still protected because I didn't get a fix to the left side, so the protection was there to a point. But, I would not give back those years EVER! I had about 3 years of no pain in the right side.

The left side flared to a point, but, it was never as bad as the right, and hasn't gotten to bad until the last 6 months. MVD along with the hands of Dr. White and Dr. Kopitnik (at UT Southwestern in Dallas) gave me the freedom to enjoy life again, to smile again, to relax in a movie theater without fear of the loud noise, to go to the beach and enjoy the waves.

My personal thoughts on MVD for Atypical patients - Go for it - because even just a year, or 5 years without pain is something you won't have without it. You can make it through the atypical part of the pain, because by now, you have gained a high tolerance to pain and can walk with your head high again, uncovered and be normal, even if only for a few years.

I wouldn't give back those years for anything. I will tell you - that even though I have attacks that will put me in a dark room and in a bed for a little while, I still have not had the extreme pain that I tolerated before MVD that left me wishing for death. Although the pain has returned, it has not yet gotten to the extent it was before MVD. Tracy

UPDATES FROM OUR MEMBERS

Sam's been pain-free since a radiofrequency rhizotomy in December 1989. Thank you for continuing to supporting those with facial pain.

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Wanda's MVD in January 2000 provided her with many years of pain relief. However, the nerve has just started to kick up again...not bad but she is aware of it so she is limiting her bending over and does not go out in the cold, windy weather.

Beth had a MVD in April 2000 by Dr. Harold Smith in Lubbock. So far, the TN has not returned although she still takes Neurontin. She thanks God for Dr. Smith and for Dr. P. Carter Snodgrass who sent her to Dr. Smith.

In January 2005, Maureen had a gamma knife at Baylor All Saints in Fort Worth. She has been totally pain free since then. She would like to share her experience with others who had the procedure especially those who have had it recently. She felt it would have helped her in some areas if she had someone to contact at the time she had it done. Since November 2006 she has had some partial numbness on the left side of her face which doesn't seem to improve but she is thankful that is all she has to deal with as it is just an irritation more than anything else and she welcomes that over TN pain. If you would like to email Maureen, her email address is jckndmoe@peoplepc.com.

Ken ended eight years of TN pain with a gamma knife at Baylor All Saints by Dr. Donahue on October 18th. Since that time, he's been pain-free. So far, he's reduced his Trileptal from 600 mg/4 times a day to 600 mg/3 times a day and plans to continue to reduce the medication. His wife said "she feels like she has her old husband back". Many thanks to Cora and her staff at Baylor All Saints for taking such great care of Ken!

Also in October, Tommie had a successful micro-vascular decompression (MVD) by Dr. Weiner at Dallas Presbyterian Hospital. She is now back to normal with no pain at all.

Carol, the Houston Support Group Leader, reports GREAT news in that Dr. Thomoseck, a Conroe area neurosurgeon, injected her C4-C7 bilateral under anesthesia and fluoroscopy, and reduced her shoulder pain and pain in both arms 100%. Her headaches are reduced by 80% and the ear pain 50% after almost two months since the injections. She can have three of these a year, and as long as they are effective she will not need surgery. She feels better than she has in 7 years and on top of that, she now weighs in at what she was in 2001 so now she only has 15-20 pounds left to lose. HURRAY!

Four years after having TN pain, Judy was referred to Dr. Wayne Hurt, a Houston neurosurgeon. In November, Judy had a radiofrequency rhizotomy and is now dealing with the numbness in her face from the procedure. Judy says "the numbness is definitely better than the excruciating pain that she had for so long but is definitely taking time to get used to along with the soreness under tongue".

Geraldine had a gamma knife at UT Southwestern by Dr. Whitworth on December 6th. Just three weeks later she wrote "she never expected this much relief so soon. This is the most wonderful Christmas I have had in years."

Amy is seeing Dr. Day at Texas Tech for her neuropathic facial pain. She was recently prescribed Opana, a medication for the relief of moderate to severe pain. This has done her more good than anything else she has tried. For more information on Opana, go to www.opana.com.

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Please pray for:

- Carol who is on high doses of Trileptal and Lyrica which she takes every six hours to help manage her TN pain.
- Brian who has stage 4 cancer.
- Billy who is going through rehabilitation from AVM surgery.

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 – 1/19
Dallas/Fort Worth – 1/16 (Allen), 2/9 (Southlake)
Houston – 2/4
San Antonio – 2/12, 4/8, 6/10, 8/12, 10/14, 12/9
Waco – 1/14, 3/10, 5/12, 7/14, 9/8, 11/10

ADDRESS CORRECTION

Neurologist Joseph K. Vaughan, Jr., MD offices at 925 Shiloh Road, Suite C200, Tyler, TX 75703. His office number is 903-534-4700.

TREASURER'S REPORT

Beginning Balance – 12/6/7		\$4,661.26
Donations Received		\$80.00
Postage	48.88	
Supplies	<u>48.92</u>	
Expenses		<u>\$97.80</u>
Ending Balance 12/31/7		\$4643.46

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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