



**TRIGEMINAL NEURALGIA ASSOCIATION
TEXAS SUPPORT GROUPS NEWSLETTER
SUMMER 2007**

Once the "what" is decided, the "how" always follows. We must not make the "how" an excuse for not facing and accepting the "what".

Pearl S. Buck (1892-1973, American novelist)

TYLER SUPPORT GROUP MEETING – CANCELLED

The June 29th Tyler Support Group meeting has been cancelled. The next meeting is August 31st.

A SPECIAL INVITATION

Scott Sweeney, DC, a chiropractor who does Upper Cervical Chiropractic at Back 'N Balance in Austin, has invited our support group members to hear James Tomasi, a TN patient, tell how Upper Cervical Chiropractic changed his life. Appetizers and mingling begin at 6 p.m., James Tomasi will speak at 7 p.m. on Monday, June 25 at First United Methodist Church's Fellowship Hall, 1300 Lavaca Street, Austin, TX 78701. Gifts and door prizes will be awarded.

To get to the meeting from IH-35, take the 6th-12th Street exit. Turn onto 11th Street going west (left if coming from the south, right if coming from the north). Turn right on Lavaca, a one way street. The church is at 13th and Lavaca.

To confirm you attendance, call 512-479-7878.

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. Stay tuned for more details!

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NEW WEBSITE

TNA launched its new website on June 6, 2007. It can still be accessed at www.endthepain.org

The website is still under development and will continue to evolve. We will be adding numerous features in the coming months, including interactive capability. All the information featured on the old website is still available to everyone.

The site requires user registration once you start navigating off the home page. Registration is fast, easy and free. Check it out!

SMART PAIN-BLOCKERS

Thank you to Charlotte for submitting the following Readers Digest March 2007 article. It's an exciting new way to treat pain!

For over a century, doctors have treated seriously wounded soldiers with morphine, all the while knowing the narcotic's downsides. It impairs breathing, reduces decision-making abilities and, if taken over time, can be addictive. But three years ago, researchers funded by the Defense Advanced Research Projects Agency (DARPA) reported a remarkable alternative: a nonaddictive pain-blocker. While investigating the biochemical origins of pain, they developed an experimental drug--actually, a synthetic antibody known as RN624--that inhibits a molecular pain messenger called nerve growth factor. **The powerful antibody keeps the brain from receiving pain messages sent by nerve endings surrounding an injury.** And the drug is long-lasting; a single dose can block pain for several weeks. Best of all, it has no addictive side effects.

"A wounded soldier may get one dose on the battlefield that can take care of any pain until he's evacuated to a hospital days later," says Brett Giroir, MD, deputy director of DARPA's Defense Sciences Office in Arlington, Virginia. RN624 was developed at Palo Alto-based Rinat Neuroscience Corporation, which was bought by Pfizer last year. Pfizer is conducting clinical trials on the drug and hopes to market it. According to Dr. Giroir, "This could revolutionize the way we treat pain."

ROBIN'S STORY

I am 51 years old and at 19 I was struck severely with Trigeminal pain. I was on medication, Tegretal and Dilantin, until even this was not working after several years. In 1984, at the age of 28, I had an MVD at Methodist Hospital in Houston performed by Dr. James Rose. For 21 years I was completely pain free up until Dec 2004 when I was in a major car accident. I was going 50 MPH when a car pulled out in front of me at the last second. I hit the steering so hard with my chest it was crumpled up and totaled my husband's truck. Even though I did not hit my head on anything, my whole body was

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affected. I broke my right foot in 40 pieces due to bearing down on the brake. After about a month after the accident I started to have the trigeminal pain partially back. I was devastated fearing that the pain would keep getting stronger. I was inconsolable and knew if it started up again very strong I WOULD NOT be able to handle it. I stayed very upset and went to Dr. Hurt in Houston and he performed the needle procedure which DID NOT work.

He gave me the phone number of the Houston support group and I called Ann in League City. She told me she goes to Dr. Hickman (chiropractor) and has kept her out of pain. I have now been going to him for a year and ½ and now I have no pain. I go to him for maintenance every two months. He knew the minute he did my first examination that my whole body was out of whack so he said it will take 3 treatments to begin to feel better and he was right. I am now enjoying my life.

So, the bottom line is if you hear a story like mine with trauma to the body and the situation was fixed by MVD for many years and then flares up due to traumatic event, the body could just need adjusting by a chiropractor.

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 to help us save on mailing and copying costs.

Also, if you change your e-mail address, make sure to advise Shelly as well. Thanks!

BOBBY'S EXPERIENCE

A blessing. That is the best way to describe TNA for the Sorrell family. Bobby suffered for 10 years with an odd case of trigeminal AND occipital neuralgia. The past two years have been literally unbearable for our whole family. In June of 2006 Bobby finally gave up. After years of suffering he contemplated and then attempted the unthinkable. Luckily, we found him in time and by the Grace of God we began a journey through the darkest period in our lives.

With no other options left for us to explore, I, along with my 5 teenage children, started to rally around Bobby. At 42 years old, unable to work, unable to drive or be left alone, Bobby's depression accelerated. Friends didn't know what to say, extended family members were left with an awkward silence. If you are reading this then you know what it is like.

My phone rang one sunny and very humid Mississippi morning in the fall of 2006. To my pleasant surprise my cousin and her husband had taken it upon themselves to find us some help. They were determined and while browsing on the internet the previous evening they came across the TNA website.

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She gave me a number that she found through the website and as soon as we hung up I dialed Dallas, TX! That was the beginning of a very special friendship. Shelly Wilson, the Dallas area support group leader, UNDERSTOOD! Finally, after all of the tears I found someone who didn't just say "I'm sorry". She said "I will help you!"

Due to our relationship with Shelly and along with her contacts, we have been blessed beyond belief. In February 2007 Bobby underwent a neurostimulator implant. Dr. Tony Whitworth at UT Southwestern performed a cutting-edge procedure that produced instant relief in Bobby's case. We all reveled in the miracle that we experienced. Within 48 hours of final implantation, Bobby's bowel function was restored, he stopped throwing up after meals (he had done this for 10 years), his senses of taste, hearing and eyesight came back! Returning home our children, family and friends were all amazed to see the "new" Bobby!

In the past month our lives have drastically changed. We have gone from the absolute depths of despair to the joy of healing. In Bobby's case we realize just how fortunate we are. During our time in Dallas we were honored to meet members of the Fort Worth support group. We made some precious friends that we will never ever forget. Nor will we ever stop praying for their continued healing and health. We treasure these new friendships and what they mean to us.

The Fort Worth TNA meeting was the first time that we were able to meet other people that were going through the same struggles as our family. We met people who were in pain, people whose procedures had worked, people whose procedures had unfortunately failed, people in remission, loved ones who live with the patients. We all came together as a group, asking questions of the guest speaker, a neurologist, posing ideas, and sharing stories. We all had the same goal in mind - to "end the pain." And we all left with the same gift - HOPE.

For us, TNA has been the link to life, healing and love. For this, our family will always be thankful. As Bobby and I begin our time as the support group leaders for Mississippi, please be in prayer that we might be able to help others as we have been helped. There are many of us out there, but there are many more to reach. God Bless TNA and remember "Together, we WILL end the pain." *Amy*

WEBSITES OF INTEREST

www.texastna.org – Texas Support Group website, includes Bobby Sorrell's video experience

www.NeurosurgeryDallas.com – Dr. Martin Lazar's neurosurgical consultants website which reviews TN surgical options

www.nucca.org – information about Upper Cervical Chiropractic

UPDATES FROM OUR MEMBERS

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Stella has been pain-free for over a year. She had a gamma knife radiation treatment in April 2006.

On March 22, Charlotte had a successful MVD by Dr. Jonathan White with UT Southwestern. 48 hours later she was released from the hospital. She is now pain-free and medication-free.

At the end of March, Gloria had a gamma knife procedure done at St. David's Hospital in Austin by Dr. George Brown and Dr. Anant Patel. Before the procedure, she was taking 1500 mg a day of Carbatrol. At the end of May, she was only taking 800 mg of Carbatrol a day and experiencing no pain. Her doctors want her to taper off the Carbatrol slowly. Gloria mentioned the procedure was simple and the results are priceless. Hurray!

Eva had a MVD which relieved her lightening like strikes of pain 7 months ago. At the end of April, she had a gamma knife by Dr. Whitworth at UT Southwestern in Dallas to see if she could get the constant day to day hot burning type of pain to go away. Eva reports "So far so good." It took a few weeks for the gamma knife treatment to provide pain relief but now Eva has been able to reduce her Neurontin from 1600 mg to 400 mg a day and will be down to zero Neurontin next week and then she'll start reducing the Trileptal she has been taking. She believes because so many people are praying for her, that has helped as well.

Ten years ago, Valorie's TN pain started. She had a MVD five years ago but the pain has continued. In early May, Valorie was taking 1900 mg of Tegretol a day and still having pain, so she had a radiofrequency rhizotomy by Dr. Phil Williams, Jr. at Dallas Presbyterian Hospital. Valorie is doing well now and is completely off the Tegretol. She is adjusting to the numbness which is an OK trade-off for the pain.

Previously, Henry had 4 radiofrequency rhizotomies that each worked over a period of time and an unsuccessful MVD. On May 10th, Henry had his 5th radiofrequency rhizotomy by Dr. Phil Williams, Jr. (This was the first one he had performed by Dr. Williams.) It worked to relieve his pain. His wife reports he seems to be doing just great as she is having a hard time keeping him from working. He just wants to take care of his pecan trees, the garden, hay field, and all sorts of things.

In the middle of May, John had a gamma knife at UT Southwestern in Dallas by Dr. Tony Whitworth and Dr. Ramzi. Everything went well and John is just waiting for the radiation to start working. We'll update you on John's progress in our next newsletter.

Please pray for:

- Rosie's mother who is recovering from a MVD in early June.
- Randy who is still fighting TN pain.
- Amy who is battling face pain on both sides of her face.
- Kathy who has a complicated facial pain case. She is taking 75 mg of Lyrica, 3 times a day but is having trouble with the side effects.

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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 – T.B.A.
Dallas – 10/20
Fort Worth – 10/20
Houston – 8/6
San Antonio – 6/12, 8/14, 10/9, 12/11
Tyler – 8/31, 10/26, 12/14
Waco - 7/9, 9/10, 11/12

TREASURER'S REPORT – NORTH, CENTRAL, & EAST TEXAS

Beginning Balance – 3/31/7		\$5,618.44
Donations Received		\$1,123.80
Copies	176.44	
Long Distance	127.34	
Postage	496.38	
Striking Back & Insight books	297.47	
Supplies	124.90	
Texas TNA Website fee	<u>77.91</u>	
Expenses		<u>\$1,300.44</u>
Ending Balance 6/15/7		\$5,441.80

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, 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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