



TRIGEMINAL NEURALGIA ASSOCIATION TEXAS SUPPORT GROUPS NEWSLETTER FALL 2006

EDUCATIONAL PROGRAM ON THE RADIO

Gordon Griffin, a radio news announcer, will air a taped educational program interviewing Shelly Wilson with TNA. You have two times to listen: Saturday, November 4 from 1:45 – 2:00 a.m. and on Sunday, November 5 from 6:30 – 6:45 a.m.

The program will run on two different radio stations. KWRD, 100.7 FM, covers the DFW area and goes all the way out to East Texas. KSKY, 660 AM, includes the DFW area and 250 miles all the way around.

An additional airing is planned for a third radio station. As soon as this is confirmed, the information will be posted on our Texas website at www.texastna.org

GALVESTON NEUROLOGIST NEEDED

Marie needs the name of a Galveston or Dickinson neurologist. If you can recommend one, please email it to Shelly Wilson at swilson@tna-support.org or write Shelly Wilson a note with the doctor's information and send to P.O. Box 92604, Southlake, TX 76092. Neurologist names will be included in a future newsletter.

DENTON AREA TN DOCTOR NEEDED

Have you found a family practice doctor, internal medicine doctor, or neurologist who is successfully treating TN pain in the Denton area? If you can recommend one, please email it to Shelly Wilson at swilson@tna-support.org or write Shelly Wilson a note with the doctor's information and send to P.O. Box 92604, Southlake, TX 76092.

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TNA NATIONAL CONFERENCE REVIEW

If you missed attending TNA's bi-annual national conference in Portland, OR, you have a chance to hear the highlights. Be sure to check the meeting schedule for a presentation near you. The current meeting schedule can be found at www.texastna.org.

WAL-MART OFFERS \$4 GENERIC PLAN IN TEXAS

The October 20, 2006 Fort Worth Star-Telegram noted Wal-Mart began offering \$4 generic drug prescriptions in Texas and 13 other states building on a pilot program in Florida that generated a strong response from customers. Medicines in the program include 30-day supplies of a variety of drugs – including Carbamazepine which some brand-name equivalents are called Carbatrol and Tegretol.

THREE FACIAL PAIN PATIENTS MISDIAGNOSED WITH TN

Last summer, a TN patient for six years could no longer tolerate the pain. His medication wasn't helping as it had previously and he was maxed out on his dosage. He had been to the emergency room three times which only helped to relieve his pain for a few hours at most. So, he decided he needed surgery.

When this patient went to see Dr. Phil Williams, Jr. in Dallas, Dr. Williams ordered a MRI (magnetic resonance imaging) since the patient had never had one. The MRI showed a BIG AVM (arteriovenous malformation) pressing up against the trigeminal nerve which was causing trigeminal nerve pain. The patient ended up having AVM brain surgery by Dr. Jonathan White and is recovering now.

Two other Texas TN patients had MRI's that detected cancer. One patient's TN diagnosis was changed from TN to stage four cancer with a slim chance to live but the patient is alive today and cancer free. Brian, an atypical TN patient who attended the 2004 TNA National Conference, had his physician order a second MRI for him which detected facial cancer which required aggressive chemotherapy and radiation. He received a clean bill of health but just recently learned he has stage 4 lung cancer.

If you would like to send Brian a card or email, please send it to Brian Nelson, 31 Gessner Rd., Houston, TX 77024 or brian@nelsonideas.com.

THE ROLE OF A MRI

An MRI is a device that creates computerized images of the head. But instead of using radiation as in X-rays, MRIs involve collecting a rapid series of data while the subject is inside a magnetized chamber. The computer gathers the data and compiles it in "slices" to give a finished picture.

MRIs give a fairly clear look at the trigeminal nerve, which is the biggest of the 12 cranial nerves. MRI pictures are clear enough to get a good look at tumors and abnormal

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blood vessels – two other problems that can cause face pain – as well as plaques on the nerve caused by MS. Sometimes some of the vessels that surround it can also be seen. The drawback is that standard MRIs aren't refined enough to reliably show if vessels are compressing the nerve. They also don't pick up small blood vessels that could be compressing the nerve.

A newer approach called a "thin-cut MRI" is a refined MRI that uses less than 1 mm slices of data instead of the standard 3 mm slices. When gadolinium dye is injected into the bloodstream before the test and other enhancements are done to make the finished view three-dimensional (a technique known as "3-D volume acquisition), the view of even small vessels is much better.

To see how accurately thin-cut MRIs could pick up artery and vein compressions of the trigeminal nerve, Dr. Burchiel and his team in Oregon looked at thin-cut MRIs of patients who then went on to have MVDs. The thin-cut MRIs picked up 100 percent of the artery compressions found during the ensuing surgery, 100 percent of the combined artery-and-vein compressions and 82 percent of the vein-only compressions.

Dr. Alksne, a California neurosurgeon, says that while the new technique may not be 100 percent across the board, it's good enough to serve as a valuable bit of pre-surgery information. "I use it in decision-making," he says. "If you can't see a vessel, there's less case to go with an MVD, and you may opt for another surgery."

Dr. Apfelbaum, a Utah neurosurgeon, cautions that just because a thin-cut MRI does *not* show a compressing blood vessel doesn't mean there isn't one. "Certainly, if a vessel is seen, it adds assurance," he says, "but if not, it would, in my opinion, be a mistake not to explore the nerve in cases with distinct classical TN."

Most standard MRI scanning devices can be used to do a thin-cut MRI, but it takes different software, different protocol, more time and, of course, a technician who knows how to do this enhanced procedure.

If a MRI is not possible or available, the next best test is a computed tomography (CT) scan. This imaging system can pick up larger tumors and some blood-vessel problems, but it's not sensitive enough to reliably detect small tumors, multiple sclerosis lesions or blood vessels compressing the nerve.

Source: Striking Back! The Trigeminal Neuralgia and Face Pain Handbook, pgs. 24, 192-193

HELP NEEDED

Due to critical health problems, ImaJoy and Mary Ann in Waco need help with managing the Waco support group. Please contact Mary Ann if you can assist with support group needs. Mary Ann can be reached at 254-857-9166 or via email at hlippe7133@aol.com.

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Shelly still needs someone to take over the Fort Worth Support Group. This entails setting up meetings with Baylor All Saints staff, lining up speakers, and running the meetings. If you are willing to do part or all of these tasks, please contact Shelly at 817-416-7202 or via email at swilson@tna-support.org.

DO YOU REMEMBER EMILY?

For those who watched the Mysterious Diagnosis cable television show on the Discovery Channel called “Why is Emily Screaming”, you saw the agony that the family of a 4 year old girl went through trying to figure out what was causing Emily’s pain – TN.

Today, Emily is 6 years old. Unfortunately, Tegretol is no longer controlling her pain.

Emily’s mom and grandmother attended the TNA national conference this year in Portland. As a result of talking to many neurosurgeons for advice, they elected to take Emily to Dr. Mark Linskey, a California neurosurgeon on the TNA Medical Advisory Board, for microvascular decompression surgery since they had family living nearby.

Emily’s family just reported the MVD surgery was over. Dr. Linskey said “on a scale of 1 to 10, Emily was an 8 or 9. She had three veins and two arteries wrapped around the trigeminal nerve.”

Since the surgery, Emily hasn’t experienced a single tic. We wish Emily a speedy recovery and hope this surgery has ended her TN pain!

SPEND MORE, GET LESS?

The United States spends more on health care than any other country but we don’t seem to be getting our money’s worth. Average costs and life expectancies:

| | Life Expectancy | Health Care Cost Per Person Per Year |
|----------------|-----------------|--------------------------------------|
| United States | 70 | \$4,887 |
| United Kingdom | 71 | \$1,992 |
| Germany | 72 | \$2,808 |
| Canada | 72 | \$2,792 |
| Spain | 73 | \$1,600 |
| Sweden | 74 | \$2,270 |
| Japan | 75 | \$2,131 |

Source: World Health Organization

UPDATES FROM OUR MEMBERS

Stephen Rodrigues, MD is a north Dallas physician successfully treating facial pain patients. He reports that two of our support group members are doing well after going to

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him for acupuncture treatments. He suggests Magnesium, Riboflavin, and acupuncture for those who have not tried them for 4-6 weeks. Also, 1000 IU/day of Vitamin D is helpful for people who do not get enough sun.

Paul, one of our long distance support group members, had a MVD at University of Alabama in Birmingham at the end of August. Please pray for him to have a speedy recovery.

Vijay has been rubbing Tamanu Oil into his face twice a day and doing breathing exercises which he thinks have helped relieve his classic TN pain. Vijay purchases Tamanu Oil from a health food store and pays about \$25 for one ounce which lasts him about a month. He also mentioned Tamanu Oil is available in a cream but he hasn't tried it yet.

Previously, Steve had a gamma knife that worked for four years. When the pain returned, Steve came to a TNA support group meeting to hear Dr. Jonathan White at UT Southwestern in Dallas talk about surgical treatment options. Dr. White performed a microvascular decompression brain surgery (MVD) on Steve's left side May 28, 2005. Since the MVD, he has been 100% pain-free. He would not hesitate to recommend Dr. White to anyone.

Kaylan's TN came back with a vengeance. Kaylan went to a neurologist for a work-up including a MRI. Kaylan was prescribed Tegretol, 300 mg, twice a day which slowed the episodes but not the intensity. A month later, Kaylan's neurologist added 25 mg of Elavil at bedtime which worked very well. Kaylan has not had an episode now in two weeks. Hurray! Congratulations on finding the right drug combination that works for you!

Marie has suffered with neuropathic facial pain for a couple of years with daily pain. She called to report that on a hot daily recently, she stopped to get a refreshing drink at a gas station on the way to the mall. She doesn't usually drink caffeine but decided to try a Dr. Pepper. Amazingly, after she drank it and her pain went away. Each day since then, she has had a Dr. Pepper throughout the course of the day and hasn't had pain. It's been two weeks and she has been pain-free.

Please pray for:

- Ellen who is having a difficult time controlling her facial pain.
- Gloria Jean who's TN pain returned 4 years after a successful MVD. She is also struggling with Parkinson's.
- Brian in Houston who is battling cancer.
- Karin, a TN patient, whose husband, Fritz, died unexpectedly. If you would like to send her a card, please mail one to Karin Woeste, 6110 Blackberry Lane, Dallas, TX 75248.
- ImaJoy and Mary Ann, the Waco support group leaders, who are both battling cancer.

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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 P.O. Box 92604, Southlake, TX 76092.

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!

FUTURE MEETING DATES

Austin – **2007** - 1/20, 3/17

Dallas at Zale Lipshy University Hospital – 11/15 (Main Dining Room)

Fort Worth at Baylor All Saints – 11/8 (Private Dining Room)

Houston – T.B.A.

San Antonio – 12/12

Tyler – 12/15, **2007** - 2/23, 4/27, 6/29, 8/31, 10/26, 12/14

Waco at Hillcrest Baptist Medical Center – 11/13

TEXAS TREASURER'S REPORT

A financial update will be listed in our next newsletter. ***We are running low on funds!*** Please remember TNA when you contribute financially this year.

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, 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.

Trigeminal Neuralgia Association
925 NW 56th Terrace, Suite C, Gainesville, FL 32605
Phone: 800-923-3608, Fax: 352-331-7078
www.endthepain.org

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