



**TRIGEMINAL NEURALGIA ASSOCIATION
TEXAS SUPPORT GROUPS NEWSLETTER
July 2005**

DR. TENNANT – DALLAS SUPPORT GROUP SPEAKER

Dr. Jerry Tennant, who used to suffer from chronic pain, will be our guest speaker this month at the Dallas Support Group meeting on Wednesday, July 13, at UT Southwestern University Hospital (formerly known as Zale Lipshy University Hospital) from 7:00 – 8:30 p.m. In addition to Dr. Tennant's lecture on energetic medicine, he has agreed to also talk about the work he is doing on macular degeneration. Don't miss it!

Dinner is provided by UT Southwestern from 6:00 – 7:00 p.m. so please remember to RSVP to Shelly Wilson at 817-416-7202 by July 10.

TNA PRESIDENT IS COMING TO TEXAS

Michael Pasternak, Ph.D., TNA's President (*a volunteer role*), is coming to Texas this month to visit with the following support groups: Dallas, Fort Worth, East Texas, and Waco. Please check the TNA Meeting schedule for more details.

KEEP THE HOUSTON SUPPORT GROUP ALIVE

Rhonda Ashby, the Houston support group leader, is unable to continue running the Houston support group. She has multiple health issues that need immediate attention and she's a new grandmother of twins which she has committed to help take care of.

Please don't let this support group fall apart. We've got support group money in the bank and supplies on hand. We need one or two volunteers to keep the support group going. We already have two others who are helping with the group.

If you can help keep your support group alive, please call Jane Boles, the Executive Director for TNA, at 800-923-3608. Many thanks to Rhonda who started the Houston support group all by herself!

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WE NEED YOUR INPUT!

Throughout the month of July, we will be enhancing our TNA Texas website, www.texastna.org. Please e-mail your suggestions to Shelly Wilson at swilson@tna-support.org to let us know what features you would like to see incorporated.

AFTER ATTENDING A SUPPORT GROUP MEETING...

After attending the April support group meeting in Dallas, Steve from Oklahoma decided to contact the guest speaker, Dr. Jonathan White with UT Southwestern, for an appointment and scheduled a microvascular decompression surgery (MVD). He had his surgery at the end of May and was released from the hospital 3 days later.

He's had almost no pain except for a tiny shock when touching his cheek that lasted a couple of weeks after surgery which has now gone away completely. He is now off of all of his TN and pain medication.

Steve reports the care he got at UT Southwestern University Hospital (formerly called Zale-Lipsky Hospital) was the best he had ever seen. The nursing staff was right on top of everything.

According to Steve, attending the TNA support group meeting helped immensely, mostly because he got to hear Dr. White speak and received data on how many MVD's Dr. White had done, etc. He plans on staying in touch with our association and has offered to attend more TNA support group meetings to help others.

WEBSITES OF INTEREST

<http://www.aans.org/education/journal/neurosurgical/may05/18-5-nsf-toc.asp> - Published online by the Journal of Neurosurgery and the American Association of Neurological Surgeons, the May 2005, Volume 18, Issue 5 topic is TN. Peter J. Jannetta, M.D. and Chair of the TNA Medical Advisory Board served as editor of this issue which includes articles written by other TNA Medical Advisory Board members: Kenneth F. Casey, Jeffrey Cohen, Kim J. Burchiel, Bruce E. Pollock, and Jeffrey A. Brown.

<http://abcnews.go.com/Health/Healthology/story?id=627533> – Two-Drug Combo Lessens Chronic Nerve Pain (treatment involves lower doses, which decrease side effects, too, Canadian research finds)

<http://www.msnbc.msn.com/id/8294219/> - Extra Folic Acid (a B vitamin) may help memory loss

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DEAR DR. DONOHUE

Dear Dr. Donohue: You wrote about trigeminal neuralgia some time ago. I have it very bad and need to know what you have to say about it. Will you repeat the information? - M.N.

Answer: The trigeminal (try-JIM-in-ul) nerve transmits sensations from the face to the brain. Trigeminal neuralgia is a malfunction of that nerve that causes repetitive, brief but intense paroxysms of intolerable pain on one side of the face. The attacks can come out of the blue, or such innocent acts as shaving, chewing or talking or even a light breeze touching the cheek can spark an attack. Even though attacks are brief, they are so violent that a person spends every waking minute living in fear of the next wave of pain.

Usually the cause is a wearing away of the insulation that surrounds the nerve. Often that occurs at the spot where the nerve leaves the brain, where a blood vessel wraps around it. The pulsation of the blood vessel can fray the nerve insulation.

Medicines used to control seizures can often control trigeminal neuralgia pain. Tegretol, Dilantin and Neurontin are examples of such medicines.

Another treatment is destruction of the pain-carrying fibers of the nerve. That can be achieved with radio-frequency waves, with injections of substances like glycerol, or by balloon compression of the nerve.

A surgical technique (the microvascular decompression – MVD) has brought many patients relief. It entails placing a spongelike material between the nerve and the encircling blood vessel. The sponge absorbs the pulsations of the vessel on the nerve.

Source: Tyler Morning Telegraph, May 24, 2005

E-MAIL ADDRESSES

Thanks to everyone who's 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 swilson@tna-support.org

SENIORS AND DEPRESSION

Because of its prevalence in seniors, many people mistakenly believe that experiencing depression is a natural part of aging. The link is due instead to the fact that the elderly are more likely to experience loss, pain and social isolation, all of which can lead to feelings of depression.

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This treatable medical problem can be caused by chemical imbalances in the body, alcohol or substance abuse, loss of a spouse or loved one, chronic pain or medication interactions. Talk with your physician if you feel depressed.

To find out more about the symptoms of depression, go to www.BaylorHealth.com and search for “depression.”

Source: BaylorHealth, March 2005

BIOGEN LOCATES KEY NEUROLOGY MOLECULE

In a news release, Biogen said that its researchers discovered how to make the molecule LINGO-1 produce large amounts of myelin, a substance essential to the proper functioning of human nerve cells. This molecule may be the key to central nervous system repair and regeneration in multiple sclerosis (MS) and other demyelinating diseases.

Source: Biogen, Cambridge, MA, May 17, 2005

UPDATES FROM OUR MEMBERS

Does anyone from the Dallas support group remember Amy who had TN and wanted to have a baby a couple of years ago? Well, Amy’s in remission thanks to Dr. D’Amanda, an upper cervical chiropractor in Aubrey, TX. Her daughter, Savannah Michelle is now 15 months old. What a blessing!

Ronnie had his MVD for TN and facial hemispasm by Dr. Jonathan White at UT Southwestern in April. Since early June, he has been off of all of his medication and is pain-free. If anyone wants to talk to Ronnie about his experience, you are welcome to call him at 817-875-9584.

Pat wants to thank everyone for praying for her. She’s got her facial pain somewhat under control and her flare up of the fibromyalgia is finally starting to end.

Marion reports her neuralgia is much improved by TMJ treatment.

Leslee has had facial pain since 1981. At the end of last month, she had a successful radiofrequency rhizotomy by Dr. Phil Williams in Dallas. We wish her many pain-free years to come!

Jesse had his MVD by Dr. White last August. Today he is still pain-free and off of all TN medication. He continues to help educate others with TN in the Corpus Christi community. Thank you and hurray!

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Please pray for:

- Martha as she determines the best treatment plan to control her pain.
- Juna as she's been in a pain cycle since March.

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 604 Aberdeen Way, Southlake, TX 76092.

MEETING NOTES

New York City Regional Conference – April 30, 2005:

Dr. Jeffrey Cohen, a neurologist at Beth Israel Medical Center in New York City, stated for classic TN patients, it is time to consider a TN surgical procedure when you have done at least two adequate medication trials, pain fails to resolve, the amount of medication to stop the pain leads to intolerable side effects, unable to tolerate even low doses of medication or quality of life is significantly compromised.

Dr. Peter Jannetta from Allegheny General Hospital in Pittsburgh, PA who developed the MVD surgical procedure tells his MVD patients that the MVD will be harder on the family than on the patient except for when the patient has some pain and possibly nausea.

Dr. Jannetta's MVD patients no longer go to the ICU after surgery, they go to the recovery room and then to a regular room where they rest better. Dr. Jannetta's MVD hospital stay is 1.7-2.4 days. Although Dr. Jannetta can't guarantee his MVD results, he is currently running a 92% initial success rate on classic TN patients.

Dr. Jeffrey Brown with Winthrop University Hospital on Long Island, NY stated 19% of balloon compression patients experience jaw weakness as a result of having the procedure.

Dr. John Golfinos from NYU School of Medicine stated that 5 years after Cobalt is installed in a gamma knife machine, it only has half the effectiveness so it takes longer to treat patients. For new Cobalt, the gamma knife treatment only takes 20 minutes.

NYU treated 24 TN patients with the gamma knife. 5 weeks after the procedure, 92% had initial pain relief. However, 2 years after the procedure, 33% were pain-free and medication free.

Dr. Golfinos pointed out that if a classic TN patient had a gamma knife that failed, it is still OK to have a MVD.

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FUTURE TEXAS MEETING DATES

Austin – T.B.A.
Dallas at Zale Lipshy Hospital – 7/13, 10/26
Fort Worth at Baylor All Saints – 9/27, 11/1
Hill Country – T.B.A.
Houston at Christus St. Joseph Hospital – 7/30
San Antonio – 7/12, 8/9, 9/13, 10/11, 11/8, 12/13
Southlake (NW of DFW airport) – 7/24 BBQ potluck dinner
Tyler at East Texas Medical Center – 7/25
Waco at Hillcrest Baptist Medical Center – 7/25, 9/13, 11/14

TREASURER'S REPORT – NORTH CENTRAL EAST TEXAS

Beginning Balance 5/22/05	\$3510.78
Donations Received	\$402.78
Airline Ticket-TNA President	390.80
Postage	229.05
Striking Back Books	200.00
Center for Non-profit Dues	65.00
Supplies	63.97
Long Distance Call	<u>.96</u>
Total Expenses	<u>\$949.78</u>
Ending Balance 6/30/05	\$2963.78

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.

Trigeminal Neuralgia Association
2801 SW Archer Rd., Gainesville, FL 32608
Phone: 800-923-3608, Fax: 352-376-8688

www.endthepain.org

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