



**TRIGEMINAL NEURALGIA ASSOCIATION
NORTH CENTRAL TEXAS SUPPORT GROUP
June 2004**

Last month, Joan Foster, the Austin Support Group Leader, and I worked the TNA exhibit booth at the Texas Medical Association meeting in Austin. Over 2,000 physicians from Texas attended.

Thanks to a suggestion by Larry, one of our support group members, we'll have our TNA exhibit on display at the Senior Expo sponsored by the Mid-Cities Care Corps on Tuesday, June 8th.

Next month, TNA will have an exhibit booth at the Texas Academy of Family Physicians meeting in Houston. I'll be working the booth with members of Houston's TNA support group.

To draw people to our exhibit booth, we have a huge candy bowl. Typically, we go through 25 bags of candy at each conference. So, if you want to help spread the word about our organization, pick up a couple of bags and bring it to a TNA support group meeting. (*Snickers fun-size candy bars seem to go the quickest!*)

Feel free to write, phone, fax, or e-mail me at: 604 Aberdeen Way, Southlake, TX 76092, phone (817) 416-7202, fax (817) 416-9871, kayser-wilson@charter.net.

Shelly Wilson
Support Group Leader & National Conference Chairperson

CONSIDERING A DONATION TO TNA?

The next time you consider making a donation to the Trigeminal Neuralgia Association, either our local chapter or to the national organization, check to see if the corporation you work for matches your charitable, non-profit contributions. This might allow TNA to receive twice the amount in contributions.

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SUPPORT GROUP WEBSITE

Good news! We now have our own support group website. Scott C. volunteered his time and donated webspace for us so there was no charge to TNA to “get the word out”.

To view the website go to www.forteso.com/tna.htm The website includes our support group contacts, meeting schedule and our local 2004 monthly newsletters.

Scott reported that the first week our website was up and running, May 23-29th, 43 people viewed our website. They looked at an average of six web pages.

If there is something you would like to see added to this site, please e-mail Shelly at kayser-wilson@charter.net.

GETTING IN TO SEE A NEUROLOGIST

Several people in our support group have reported that when they called a neurologist office and requested a new patient appointment, they have often had to wait 3-6 weeks to be seen. Here's a tip that may help you get in faster:

Ask your family physician to call the neurologist and request a new patient appointment for you. This could greatly reduce your wait time!

DVD OF A MVD

In the last year, we have given out 100 copies of a DVD showing microvascular decompression (MVD) surgery to members of our support group. If you haven't seen this yet and have access to a DVD player and would like to see a DVD of a MVD for trigeminal neuralgia, e-mail Shelly Wilson at kayser-wilson@charter.net or call 817-416-7202 to request it. A DVD will be mailed out to you at no charge. Also, there is no need to return it.

WEBSITES OF INTEREST

www.trailblazerhealth.com – Medicare Home Page newsletters

www.aoa.dhhs.gov/naic - National Aging Information Center

www.tdoa.state.tx.us/ - Texas Department on Aging

www.nih.gov – National Institute of Health

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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 kayser-wilson@charter.net

Just a reminder, if you change your e-mail address, please let Shelly know.

DID YOU KNOW?

The Texas State Library and Archives Commission provides library services to Texans who cannot read standard print due to a visual, physical, or reading disability. To participate in this free service, call toll free 1-800-252-9605, M-F 8:00 – 5:00, and request a Talking Book Program application form.

Information required for borrowing of Library of Congress materials is kept confidential.

By law, preference in lending of books and equipment is given to veterans.

NOTE: The Disability Information and Referral Center (DIRC) features a wealth of fact sheets, books, organization contact information, and other materials related to disabilities and health conditions. You can reach the DIRC either by calling 1-800-252-9605 or by e-mailing tbp.info@tsl.state.tx.us

UPDATES FROM OUR MEMBERS

Don reports cranial adjustments from Dr. McAlister, D.C. in Lewisville have helped reduce his background atypical TN pain and that his pain episodes are getting further and further apart. (Cranial adjustments involve moving bones in the face.) If you are interested in seeing Dr. McAlister, call his office at 469-438-1369 or come to the August 2nd TNA Support Group meeting in Dallas to hear Dr. McAlister speak. Dr. McAlister does not file insurance but provides you with a form so you can do it yourself. He provides affordable care plans. *No one is turned away due to finances.*

Glen had a microvascular decompression (MVD) by Dr. Kopitnik, formerly with UT Southwestern, in July 2003. The MVD was successful and he was pain-free for 2-3 months. Then the pain returned but it was not severe. Dr. Kopitnik advised him to keep taking his TN medication to keep the nerve calm, as it would take the nerve a year to completely heal. In January, the pain left completely and he was able to slowly reduce the TN medication until he was off it completely. If he makes it through the hot summer, he will declare a complete victory. He had TN for 21 years and it had caused an indentation in the trigeminal nerve. (This is why he thinks Dr. Kopitnik said it would take a year to completely heal.) He is very pleased with the outcome and highly recommends a MVD for those in situations similar to his.

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Lillian is scheduled for a MVD with Dr. White later this month. We wish her a speedy recovery!

Please continue to keep Jill in your prayers as she continues to have a difficult time with a life-threatening, non-TN related health issue.

Tracy K. had non-TN related surgery and is at home recuperating. We hope she'll be back on her feet again soon!

If you would like to share an update with our group, please let Shelly know about it.

MEETING NOTES

Waco Meeting – May 3, 2004

Charles Holt, DDS, PC with Craniofacial Pain Associates in Bedford, Texas presented “Craniofacial Pain and Dentistry”. Below is the information he provided in a handout. If you would like to schedule a consultation with him, please call his office at 817-283-0025 or (metro) 817-267-8810.

Craniofacial pain as a specialty is the discipline of Dentistry that includes the assessment, diagnosis and treatment of patients with complex acute and chronic craniofacial pain and dysfunctions, temporomandibular disorders, orofacial pain, oromotor and jaw behavior disorders, and chronic head, neck and facial pain, as well as the pursuit of knowledge of underlying pathophysiology and mechanisms of these disorders.

The trigeminal nerve is the largest and most complex of the cranial nerves. It is the chief sensory nerve for the face, the anterior half of the scalp, the orbit and the eyeball, the nose and nasal cavity and sinuses, the lips, teeth, mouth and the anterior two-thirds of the tongue. The motor nerves of the third division of the trigeminal nerve supply the muscles of mastication (temporalis, Masseter, lateral pterygoid and medial pterygoid), the mylohyoid, anterior belly of the digastric, tensor palatine and tensor tympani muscles.

There are various facial pain disorders and temporomandibular problems that can cause significant facial pain and mimic some trigeminal disorders. Classic trigeminal neuralgia is usually easy to diagnose based on the type, location and severity of the pain.

In my practice, I see patients with conditions that may be confused with trigeminal neuralgia. These are:

- Atypical facial pain
- Deafferentation pain
- Sympathetically maintained pain
- Neuralgia-inducing cavitation osteonecrosis (NICO)

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- Temporomandibular disorders

Temporomandibular disorders are much more common than facial pain syndromes. Three percent of my patients have facial pain syndromes. The prevalence of temporomandibular disorders in the general population is:

- Twenty percent have one or more signs and symptoms of TMD.
- Ten percent of the population needs treatment.

Not all patients with TMD have the same symptoms. TMD symptoms can include ear pain, stuffiness in the ears, loss of auditory acuity, tinnitus, difficulty swallowing (tightness of the throat), tooth pain, facial pain, numbness or tingling of the face, neck and shoulder pain, chronic headaches, pain above and behind the eyes, TM joint pain, pain on mandibular function (eating and speaking), TM joint noises (crepitus, popping and clicking), locking episodes (closed and open) and a restriction in opening.

How do you know you may have a temporomandibular disorder?

- Does your jaw joint make noises when you open and close? Normal joints are silent during function.
- Is your opening restricted? Normal opening is three (3) fingers (45-50 mm).
- Does your jaw open properly? Your jaw should open straight without deviating to the right or left.
- Check for joint pain with two palpations. Press firmly against the jaw joint where it hinges in front of the ear. This should not cause discomfort. Place your little finger in your ear and press forward firmly as you open and close. This should not cause discomfort.
- Do your joints hurt when you open wide or when you clench your teeth firmly together? These movements should not cause discomfort.
- Are your muscles tender? Press firmly on your temples and cheek muscles. They should not be tender.
- Bruxism, grinding, or clenching your teeth may be a factor in TMD. Daytime clenching is stress and habit related. The rule during the daytime is “lips together, teeth apart”. Nighttime clenching or grinding has to do with brainwave activity during sleep. Abrasive tooth wear and awakening with headaches are classic signs of nocturnal (nighttime) bruxism.

A positive response to any of the above indicates the need for evaluation by a dentist who treats temporomandibular disorders.

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FUTURE MEETING DATES

Dallas at Zale Lipshy Hospital – 8/4, 10/6, 12/1
Fort Worth at Baylor All Saints – 7/20, 9/21, 11/16
Tyler at East Texas Medical Center – 7/21
Waco at Hillcrest Hospital – 7/12, 9/14, 11/1

TREASURER'S REPORT

Beginning Balance 5/11/04		\$4107.82
Donations Received		\$50.00
Door Prize for Sr. Expo	30.00	
Long Distance	1.32	
Parking at Texas Medical Conference in Austin	20.00	
Postage	87.60	
Supplies	<u>82.14</u>	
Total Expenses		\$221.06
Ending Balance 6/6/04		\$3936.76

FINANCIAL CONTRIBUTIONS

Local TNA chapters *do not receive* funding from the national office. If you would like your tax-deductible contribution to go toward our local chapter, please make your check payable to the order of Trigeminal Neuralgia Association and in the memo field put North Central Texas chapter, then mail it to Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092.

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: 352-376-9955, Fax: 352-376-8688
www.tna-support.org

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