



**TRIGEMINAL NEURALGIA ASSOCIATION (TNA)
TEXAS SUPPORT GROUPS NEWSLETTER
September 2004**

Please note, the TNA Waco support group meeting in September will be held on *Tuesday*, September 14th not Monday, September 14th as previously noted in a prior meeting flyer. Sorry for any confusion this has caused.

If there is something you want to learn more about, feel free to write, phone, fax, or e-mail Shelly Wilson at: 604 Aberdeen Way, Southlake, TX 76092, phone (817) 416-7202, fax (817) 416-9871, kayser-wilson@charter.net.

2002 TNA SURVEY

In a 2002 survey conducted by the Trigeminal Neuralgia Association, of 1,458 patients with Trigeminal Neuralgia, *only 5% of the TN patients got a correct immediate diagnosis*. 41% got diagnosed properly within six months. It took 13% of TN patients 6-12 months to get the right diagnosis of their facial pain. However, 41% of the patient respondents indicated that more than one year was required for diagnosis.

What does this tell us? We need to continue to educate the health care community about our disorder so the first diagnosis is the correct one.

WEBSITES OF INTEREST

<https://neurosurgery.ohsu.edu/tgndiagnosis/TGNPublic.asp> - TN Diagnostic Questionnaire (18 questions) helps with the diagnosis and treatment of patients suffering from various types of TN

www.forteso.com/tna.htm - our TNA support group website that lists all of our 2004 newsletters

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WHAT WORKS FOR WELLNESS?

Russ, one of our East Texas support group members, has received an incredible amount of pain relief from classic TN for several months now by receiving SCENAR treatments from Dr. Jerry Tennant in Irving, TX. To learn more about these treatments, go to www.senergymedicalgroup.com/profile.htm.

Since our 2004 meeting calendar is full, we have invited Dr. Tennant to come speak in 2005 to some of our support groups. In the interim, if you would like to learn more about what helped Russ, TNA members are invited to attend a free SCENAR meeting. Reservations are required since space is limited. Below are meeting specifics and RSVP numbers.

Thursday, September 9th, 7:00 p.m. – 10:00 p.m.
NeuroSCENAR Biofeedback Therapy Seminar

AmeriSuites – Walnut Hill
5455 Green Park Drive, Irving, TX 75038

Directions from Hwy. 114: Exit MacArthur Blvd. Travel East on 114 side of road toward Walnut Hill Lane (.03 mile). Bear right on Green Park Drive towards Walnut Hill Lane (.01 mile). The AmeriSuites Hotel is directly in front of you.

For more information & reservations contact:
Senergy Medical Center
972-580-0545, 866-514-8221 toll free
info@SenergyMedicalGroup.com

Saturday, September 18th, 2:00 p.m. – 5:00 p.m.
An Intro to Energetic – Integrative Medicine Seminar

Body Mind Spirit Center
5521 Bellaire Drive South, Suite 114
Fort Worth, TX 76109

For more information & reservations contact:
Body Mind Spirit Center
817-738-7284

Topics of discussion at both of these seminars will include: Cellular Physiology, Biologically Closed Electric Circuits, Magnetic Fields, Electronics for Energetic Medicine, Healing of Injured Tissue and Bones, Integrating Energetic Medicine with Traditional Medicine, and the NeuroSCENAR 97.4+ Biofeedback unit.

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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.

GET A GOOD MIX

Are you playing favorites with your vitamins? If so, research suggests that you may need to get a better mix.

Vitamins A, C, and E are some of the most popular nutrients taken in supplement form by older adults. However, many people don't get enough of several other essential nutrients, such as vitamins B9 (folate), B6, B12, and D, as well as calcium. Be sure your supplement routine contains a balanced mix of nutrients.

Source: RealAge Tip of the Day, February 10, 2003

NEWSLETTER IDEAS

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UPDATES FROM OUR MEMBERS

Jesse had a successful MVD by Dr. White with UT Southwestern Medical Center in August. When he was released pain-free from the hospital, his TN medication was reduced by 50% and has since been decreased further.

Jo Ann also had a MVD by Dr. White at the end of August. We wish her a speedy recovery!

Lynn called to report that he had a successful MVD by Dr. Sam Finn with Baylor in Dallas. After two nights in the hospital, he was able to go home pain-free.

Pat, one of our long-distance support group members from up north, had a MVD by Dr. Pollock at Mayo Clinic in Rochester, MN. After surgery, she still had a little face pain but her doctor thinks it might go away with time and healing. Keep your fingers crossed that it will!

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Ruth's taking her TN medication as prescribed and Vitamin B-50 every other day and hasn't had any pain flare-ups. Hurray!

Larry's TN has come out of remission with a real vengeance. It's actually woken him up three times in the night which he had never experienced until now. Please pray that his pain cycle will end soon.

Nancy had non-TN related surgery at the end of August. Please pray 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 – July 12, 2004:

Program was a sharing of TN experiences, treatments, surgeries, medications, and suggestions for pain relief that was moderated by Joe, a TN support group member. TN patients' spouses told of pain endured by TN sufferers.

The following feedback was provided by TN patients who attended the meeting.

What suggestions would you give a new TN patient regarding treatments, medications, surgery, vitamins, hints for pain relief, etc.?

- Find out all you can about treatments, be sure and take your B Vitamins – they do help!
- Try medications before surgery.
- Evaluate success ratio of neurosurgeon. Have a positive attitude. Stay busy. Exercise. Walk. Investigate all types of treatment – vitamins, herbs, chiropractic, acupuncture, rub-on medication, etc.
- Vitamin E, Cilantro, Sudafed, B-12 shots
- Vitamin B seems to help control the pain.

Additional comments:

- Finding out about the Trigeminal Neuralgia Association has helped me so much, knowing there are so many out there helping all of us know about this pain. We have so many wonderful people helping to get help for all of us.
- This support group is wonderful. It has helped me so much.
- Thanks so much for this support group. I have learned a lot by attending the meetings.

Fort Worth Meeting – July 20, 2004:

Patients and supporters took turns sharing their experiences, frustrations, and success with TN and related facial pain.

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Loren shared that he had four root canals on one tooth before a dentist properly diagnosed his TN pain. Loren's been able to reduce his Dilantin dosage from 360 mgs down to 200 mgs because of successful acupuncture treatments by Dr. Kopazna who has offices in Arlington and Grand Prairie.

Linda had a radiofrequency rhizotomy, 2 glycerol injections, and a balloon compression before finally getting TN pain relief from a successful MVD by Dr. Whitworth at UT Southwestern in Dallas. She mentioned the MRI imaging technique used by Dr. Whitworth clearly showed a compression of the trigeminal nerve which convinced her to have the MVD. Today she is pain and medication free!

Margie got immediate pain relief from a gamma knife performed a couple of years ago. She was able to completely get off all of her TN medication. However, now the pain is coming back but is able to be controlled by Neurontin. She is now contemplating another gamma knife.

It is hard for friends and family to *really* understand what TN is. Support group members are frustrated when they tell their friends and family they have to cancel plans with them because of TN pain. People don't know what TN is and often just brush it off like it was a headache which is a pain that most people can relate to. The group thought if there was public awareness about our rare disorder, it would help.

However, friends mean well. They all seem to want to help once but not all of the time.

The meeting attendees put together a list of suggestions for new TN patients based on their experiences.

- Be willing to experiment with things that don't do any harm to the trigeminal nerve.
- Taking Vitamin B-50, getting acupuncture and Upper Cervical Care chiropractic treatments helped a classic TN patient.
- Make sure you talk and talk to a neurosurgeon to make sure you understand what surgical procedure they are recommending and why.
- Soaking in a hot tub of water has helped a classic TN patient take her mind off of her TN pain.
- Acupuncture has helped an atypical TN patient.
- A classic TN patient suggested try a little of everything you read. A hot shower helped her.
- Usually, going to the Emergency Room is not helpful.
- If your teeth hurt, go see a dentist to rule out other possible problems.
- Compounded medications and gargling with Lidocaine help.

A couple of tips for supporters of TN patients were also provided.

- Be prepared to be available on demand, 24 hours a day, 7 days a week.
- Get soft food a TN patient can eat when in pain (i.e. foods that can be mashed up).

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FUTURE MEETING DATES

Dallas at Zale Lipshy Hospital – 10/6, 12/1
Fort Worth at Baylor All Saints – 9/21, 11/16
Houston at Christus St. Joseph Hospital – 9/18
Tyler at East Texas Medical Center – 10/12
Waco at Hillcrest Baptist Medical Center – 9/14, 11/1

TREASURER'S REPORT NORTH CENTRAL TX SUPPORT GROUP

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|----------------------------------|------------------------|------------------|
| Beginning Balance 7/31/04 | | \$3533.01 |
| Donations Received | \$80.00 | |
| Copies | 7.79 | |
| Long Distance | 24.16 | |
| Postage | <u>81.80</u> | |
| Total Expenses | <u>\$113.75</u> | |
| Ending Balance 8/27/04 | | \$3499.26 |

Note: The Houston support group will keep their finances separate. A Houston financial update will be provided in an upcoming newsletter.

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

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