



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

Special thanks to Joan, Roger, Shannon, Tracey C., Linda, and Tracy K. who worked the TNA booth at the Southwest Dental Conference. We collected the names of 49 dentists in our support group territory who wanted more information from our organization. In addition to these dentists receiving this information from our national office, they were also sent a separate letter about our local support group, our newsletter, our meeting schedule, and a chance to be added to our support group mailing list. Immediately, we heard back from a couple of dentists who want to continue to receive our local information. Hurray!

Don Williams, another member in our support group, has decided to help raise awareness about trigeminal neuralgia. He was the guest speaker at a Kiwanis Club of Greater Lewisville meeting and raised \$100 for our support group. He's lined up to speak to three more Kiwanis clubs about TN too. Way to go!

Later this month, Joan Foster, the Austin support group leader, and I will be working the TNA booth at the Texas Neurology Conference in Austin. This will be our first time to display at this state-wide conference and we hope to reach a lot of neurologists.

Shelly Wilson
Support Group Leader

HOW CAN YOU HELP?

We have opportunities available for TN support group members. Below are just a few of them. If you have other ideas, please submit them to Shelly Wilson by calling 817-416-7202.

- Become the Fort Worth support group leader. We already have a meeting place and a great sponsor who provides dinner for our group. We just need someone to manage the needs of our growing Fort Worth facial pain community.
- Drive someone to a support group meeting

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- Make reminder phone calls to TNA members about upcoming meetings
- Make a financial contribution
- Refer TN patients to our support group

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

REGIONAL PATIENT WORKSHOP

If you missed the TNA Regional Conference in November and still haven't ordered the 6 hours of video tape along with meeting handouts for \$30, you can still do so. A limited quantity remains. To place your order, send a check payable to TNA with the memo field notated "video tapes" to Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092.

WEBSITES OF INTEREST

www.tna-support.org – Information about TNA's 5th national conference that is going to be held at the Hilton in the Walt Disney World Resort in Orlando, November 10-14, 2004 is continually being added to this website.

www.iacprx.org – International Academy of Compounding Pharmacies website

FUN IN THE SUN

Getting outside on your lunch hour could help keep winter blues away. Whether you walk to the store, eat lunch outside, or go for a walk, spending your lunchtime outdoors could help boost your mood. Research suggests that blood levels of mood-boosting serotonin may increase with increased exposure to sunlight.

Source: RealAge Tip of the Day, January 23, 2004

UPDATES FROM OUR MEMBERS

Within the last month, Jim, Catherine, Randy, and William have each had a MVD by Dr. White at UT Southwestern Medical Center in Dallas. We wish them each a speedy recovery!

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As this newsletter is getting ready to go out, Linda is having a MVD by Dr. Whitworth at UT Southwestern Medical Center in Dallas. You may remember Linda since she was the one featured in the Fort Worth Star Telegram's article on TN a couple of years ago.

Patti tried DL-phenylalanine (DLPA) that was mentioned in our December 2003 newsletter and got some TN pain relief.

Melvin made the switch! Overnight, he changed from Tegretol to Trileptal (a newer formulation of Tegretol). Just one week later, he was able to drive without problems. He reports the difference is like night & day. Hurray!

Brenda, Lizzie, and Loren have been having a lot of TN pain lately.

Please keep Jill in your prayers as she is having a difficult time with a non-TN related health issue.

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

MEETING NOTES

Dallas Meeting – January 7, 2004

Henry Gremillion, D.D.S. and a Trigeminal Neuralgia Association Medical Advisory Board member, was in town to speak at the Southwest Dental conference and agreed to come in a night early to address our group.

Dr. Gremillion mentioned TN tends to occur after 45-50 years of age. It may mimic dental pain. Dental treatment may cause nerve irritation/damage. Dental care may aggravate pre-existing TN.

In 1990, there was a study done of 1,052 TN patients. The study explained the differences between "classic TN" and "atypical TN". Classic TN was described as attacks not lasting more than two minutes and pain-free intervals. On the other hand, atypical TN was noted as having brief pain episodes with interval pain or attacks of several minutes in duration.

Did you know? According to Dr. Gremillion, 95% of TN patients experience their pain in either the V2 or V3, the maxillary or mandibular division. These are the bottom two branches of the trigeminal nerve. The V2 runs along the cheek bone and down to the corner of the nose. The V3 runs along the jaw.

More time was spent giving characteristics of atypical TN. It is often described as:

- Dull, aching pain (toothache/sinus-like)
- Spontaneous onset
- No specific trigger zone

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- Duration of pain – minutes to hours
- Pain may spread
- Sporadic, sharp, lancinating pain
- Can be triggered by chewing, drinking, brushing teeth, talking
- Pain decreases with somatic blocks
- May precede TN

Dr. Gremillion said “don’t ignore dental hygiene, consider the impact of neglect”. He stated timing is important, to perform oral hygiene when your TN medication is at its peak.

He explained that routine dental home care should consist of brushing, flossing, and the use of fluoride gels or rinses such as Peridex (prescription, can stain your teeth) or Biotene (non-prescription). You can purchase Biotene from most grocery stores or drug stores.

The following supplements can help with pain.

- Vitamin C – time release, 1500 mg/day
- Vitamin E – 400-1200 IU/day
- Beta Carotene – 25,000 IU/day

The following vitamins can help calm nerves and muscle tissue.

- Calcium – 1,000-1,200 mg/day
- Magnesium – 500-600 mg/day

Vitamin B6 can also be helpful. Dr. Gremillion recommended taking 100-200 mg/day for 3 weeks then 25-200 mg/day.

Dr. Gremillion concluded with “*the importance of a team approach to diagnosis and care can not be overstated*”.

Waco Meeting – January 12, 2004

Howard Biel, R. Ph., a compounding pharmacist, presented “Transdermal Prescription Effectiveness – How Topicals Can Help”.

He mentioned several syndromes are closely related to TN but have specific unique features as well. These include post-herpetic neuralgia (PHN), atypical facial pain (ATFP), and TN resulting from multiple sclerosis (MS).

Shingles is a painful disease caused by the herpes zoster virus which also causes chicken pox. It can affect the torso or the limbs (spinal ganglia shingles) or the face (trigeminal ganglia shingles). For most, shingles is an acute condition with the pain typically lasting one month.

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However, in older patients, or those whose immune systems have been compromised, post-herpetic neuralgia, a very painful chronic condition can develop. The incidence of post-herpetic neuralgia is almost negligible before age 50 but at least 50% of patients older than 60 years and almost 75% beyond age 70 become affected following an attack of shingles. Luckily, there is also a marked natural tendency for post-herpetic neuralgia to improve over time without treatment. Some estimates suggest that only 2%-3% of patients have pain that lasts for more than one year.

Atypical facial pain is a syndrome encompassing a wide group of facial pain problems. This category very likely has many sub-classes but research is needed to clarify this further.

Trigeminal neuralgia can be an early warning sign of Multiple Sclerosis (MS) as facial pain occurs in 1% to 2% of MS patients. Currently there is no cure for MS.

The major cause of typical (“classic”) TN is irritation of the trigeminal nerve root by neurovascular compression. This can lead to a state of hyperactivity within the trigeminal nerve nucleus.

How does the transdermal gel work? The pain message travels from Neuron 1 to Neuron 2 by releasing chemical substances at the synapse. These chemicals can be blocked, neutralized, and enhanced by various medications, applied in a transdermal gel, thereby eliminating the pain message from arriving at the brain.

Some of the advantages of topical gels include a reduction of dose of oral medications, a reduction of side effects, and local as well as some systemic effect.

A transdermal gel (PLO) is a local gel that can be applied to and absorbed directly through the skin. Drugs incorporated in PLO are absorbed directly into the blood stream, thus avoiding both hepatic first-pass effect and degradation by the stomach.

Before each application, the patient or caregiver should thoroughly clean the application site. A small amount (about the size of a dime) of prescribed gel should be applied topically, with a brisk rubbing action for about a minute, to the Trigeminal Nerve Nucleus Junction (just above and in front of the ear). Howard suggested avoid applying it to sensitive trigger points, generally around the mouth, lips, cheeks, and nose.

After application, do not wash or cleanse the area for at least 30 minutes. Patients may experience a warm or cooling sensation, which is normal and does not indicate an allergic reaction.

The gel should be applied regularly 2-4 times daily or as directed by a physician as a preventative medicine. The effectiveness of the medicine should be evaluated after 2-4 weeks. Howard suggested the patient should keep a pain chart and a diary of the therapy and report progress with the therapy.

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How do you get a prescription? Your physician must write a prescription for the transdermal gel. (Howard can provide information to your physician for reference.) The prescription then must be prepared by a compounding pharmacist.

For more information, e-mail Howard at hbiel@earthlink.net or call 254-741-0237 or go by see and see him at Eckerd's – 601 N. Valley Mills Drive in Waco.

FUTURE MEETING DATES

Dallas at Zale Lipshy Hospital – 4/7, 6/2, 8/4, 10/6, 12/1
Fort Worth at Baylor All Saints – 3/23, 5/18, 7/20, 9/21, 11/16
Tyler at East Texas Medical Center – 4/23
Waco at Hillcrest Hospital – 3/8, 5/3, 7/12, 9/14, 11/1

TREASURER'S REPORT

Beginning Balance 1/01/04		\$2918.64
Donations Received		\$2230.26
Postage	511.12	
Copies	256.90	
Striking Back books	254.25	
Printer	161.93	
Supplies	134.75	
Convention Candy	45.10	
Long Distance	<u>28.73</u>	
Total Expenses		\$1392.78
Ending Balance 2/21/04		\$3756.12

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.

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