



**TRIGEMINAL NEURALGIA ASSOCIATION  
TEXAS SUPPORT GROUPS NEWSLETTER  
WINTER 2006-2007**

*Happy New Year! Our group continued to grow in 2006. We went from 1,169 to 1,262 people working together to try to end the pain.*

*2007 will be what we make it. Our support groups will meet, we will educate the health care providers about our disorder, we will send out a survey to identify ways we can improve, we will continue our Texas quarterly newsletter, and will help to promote research.*

**VOLUNTEERS NEEDED**

TNA will be exhibiting at the Southwest Dental Conference at the Dallas Convention Center on January 18, 19, and 20. Last year's attendance was 9,872 so this is a big show! If you would like to volunteer your time to help staff the exhibit booth, please call Shelly at 817-416-7202 and let her know what time you can work. Exhibit times are Thursday and Friday from 10a-6p and Saturday from 10a-3p. TNA will reimburse you for your parking expense.

*Special thanks to Dr. Phil Williams, Jr. for lecturing at this year's Southwest Dental Conference regarding trigeminal neuralgia!*

Due to 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](mailto:hlippe7133@aol.com).

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 any or all of these tasks, please contact Shelly at 817-416-7202 or via email at [swilson@tna-support.org](mailto:swilson@tna-support.org).

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## DID YOU KNOW?

The TNA national office has compiled lists of people who are willing to network about the following topics. To receive one of these lists, please email the TNA national office at [tnanational@tna-support.org](mailto:tnanational@tna-support.org) or call the TNA national office at 1-800-923-3608.

Acupuncture	Lyme Disease
Alcohol Injection	Microvascular Decompression Surgery
Amitriptyline	Motor Cortex Stimulation
Anesthesia Dolorosa	Multiple Sclerosis & TN
Atypical Facial Pain	Nerve Sectioning
Balloon Compression	Novalis Shapped Beam
Bilateral Face Pain	Occipital Neuralgia
Botox	Pain Free
Chiari	Percutaneous Procedures
Children with TN	Post Herpetic Neuralgia
Cluster Migraines	Pregnancy
CyberKnife	Radiation Surgery
DREZ Procedure	Radiofrequency Rhizotomy
Fibromyalgia	Glycerol Rhizotomy
Gamma Knife	Sjoren's Syndrome
Geniculate Neuralgia	Trauma
Glossopharyngeal Neuralgia	Tumors
Glycerol Injection	Upper Cervical Chiropractic
Linac Accelerator	Young People 20-30 years old

## WEBSITES OF INTEREST

[www.texastna.org](http://www.texastna.org) – Texas Support Group website that includes previous newsletters, *2006 national conference review*, and much more!

<https://neurosurgery.ohsu.edu/tgn.php> - OHSU neuralgia diagnostic questionnaire

[www.caregiver.com](http://www.caregiver.com) - Sponsored by *Caregiver* magazine, a discussion forum, articles from *Caregiver*, chat room, and other resources are available. Information for rural caregivers is also offered.

## UPDATES FROM OUR MEMBERS

Eva is scheduled for microvascular decompression surgery at UT Southwestern's Zale Hospital in January with Dr. Tony Whitworth. Please keep her in your thoughts and prayers.

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Evelyn is currently taking Lyrica. She has TN and TMJ. Both are behaving right now. Hurray!

James had a radiofrequency rhizotomy also known as a PCGG by Dr. Phil Williams, Jr. in Dallas. So far, he has been able to greatly reduce his medication.

Guillermo, the San Antonio support group leader, heard from one his members that her TN pain had gone away by taking B12. Guillermo decided to try taking a Vitamin B12 tablet daily and has been pain free since early August. At that time he had been taking 600 – 800 mg of Tegretol a day and now just takes 200mg of Tegretol a day as insurance.

Virginia is doing really well. She takes 300 mg of Neurontin as necessary. Dr. Rebecca Shank in Fort Worth is her neurologist. She's thankful since there is no neurologist in her area.

Jean has been feeling quite well. Neurontin seems to keep her TN quiet.

Please pray for:

- Kory who is working toward the right cocktail of medications to control his TN pain.
- Melvin who struggled with TN over Thanksgiving.
- Christina who has a lot of pain right now.
- Bill whose pain has returned after two successful MVD's.
- Belinda who is trying to stop her pain.
- Brian in Houston who is battling cancer.
- Mary Ann, a Waco support group co-leader, who is undergoing treatment for cancer.

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](mailto:swilson@tna-support.org) or a written note to PO 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](mailto: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 – 1/20, 3/17

Dallas at Zale Lipshy University Hospital – T.B.A.

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Fort Worth at Baylor All Saints – 1/30  
Houston – T.B.A.  
San Antonio – T.B.A.  
Tyler – 2/23, 4/27, 6/29, 8/31, 10/26, 12/14  
Waco at Hillcrest Baptist Medical Center – 1/8, 3/12, 5/14, 7/9, 9/10, 11/12

### **TREASURER’S REPORT – NORTH, CENTRAL, & EAST TEXAS**

<b>Beginning Balance – 7/31/6</b>		<b>\$3,541.97</b>
<b>Donations Received</b>		<b>\$1,550.75</b>
Copies	\$54.90	
Long Distance	32.48	
Natl Chronic Pain Society	500.00	(2 TN Internet programs on Voice America)
Postage	245.60	
SW Dental Conference exhibit fee	125.00	
Striking Back & Insight books	175.70	
Supplies	171.84	
Website fee & file usage cost	<u>77.88</u>	
<b>Expenses</b>		<b><u>\$1,383.40</u></b>
<b>Ending Balance 12/31/6</b>		<b>\$3,709.32</b>

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. TNA, 925 NW 56<sup>th</sup> Terrace, Suite C, Gainesville, FL 32605, Phone: 800-923-3608, Fax: 352-331-7078, [www.endthepain.org](http://www.endthepain.org)

### **IS THERE A ROLE FOR VITAMIN B12 IN TN MANAGEMENT?**

Hypothesis presented by Irene Wood, the Australia TNA President, December 2006 – January 2007 newsletter.

*It is possible that a low B12 would fail to sustain the demand of repair to the myelin from a nerve that is continuously being traumatized.*

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*Absorption of B12 depends on the stomach to produce high concentration of hydrochloric acid and to produce enough intrinsic factor.*

*Causes of Low B12*

1. **Malabsorption**

a) low hydrochloric acid in the stomach

Low B12 or B12 deficiency most often results from food – cobalamin malabsorption due to gastric dysfunction and may be exacerbated by the use of acid- lowering agents.

H2 blockers / antacid such as cimetidine (Tagamet, Tagamet HB); famotidine (Pepcid, Pepcid AC, Pepcid RPD); nizatidine (Axid, Axid AR); ranitidine hydrochloride (Zantac, Zantac EFFERdose, Zantac GELDose, Zantac 75) sharply decreases acid production in the stomach.

Naturally found B12 is dissociated from proteins in the stomach via the action of acid and the enzyme pepsin. The forms of B12 released by this process are methylcobalamin and adenosylcobalamin. All forms of B12 bind to proteins called haptocorrins or R proteins, which are secreted by the salivary glands and the gastric mucosa. This binding occurs in the stomach.

Pancreatic proteases partially degrade the B12-haptocorrin complexes in the small intestine where the B12 that is released then binds to intrinsic factor (IF). Intrinsic factor is a glycoprotein which is secreted by gastric parietal cells.

The B12-intrinsic factor complex is absorbed from the terminal ileum into the ileal enterocytes via a process that first requires the complex to bind to a receptor called cubilin. Within the enterocytes, B12 is released from the B12-IF complex and then binds to another protein called transcobalamin II which delivers it to the portal circulation. The portal circulation transports B12 to the liver which takes up about 50% of the vitamin; the remainder is transported to the other tissues of the body via the systemic circulation. Vitamin B12 in the circulation is bound to the plasma proteins transcobalamin I (TCI), transcobalamin II (TCII) and transcobalamin III (TCIII). Approximately 80% of plasma B12 is bound to TCI. TCII is the principal B12 binding protein for the delivery of B12 to cells, via specific receptors for TCII. This B12 binding protein (TCII) is identical to the one that delivers B12 from the enterocytes to the portal circulation.

b) Immune System - Intrinsic factor in the stomach.

The most common cause of B12 deficiency is the stomach being unable to produce enough intrinsic factor. This is frequently caused by an immune system problem where antibodies attack the stomach lining and damage the cells that produce intrinsic factor.

c) Bacterial overgrowth and infestation with tapeworms or other intestinal parasites that can compete for dietary vitamin B12 in the small bowel.

d) Antibiotics: The use of antibiotics may alter the intestinal microflora and may decrease the possible contribution of B12 by certain inhabitants of the microflora (e.g., Lactobacillus species) to the body's requirement for the vitamin

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- e) Lack of calcium in the food can also reduce the uptake and so can heavy metals.
- f) Megadoses of vitamin C and/or copper can cause B12 deficiency

## 2) **TRANSPORT**

a) Once absorbed, vitamin B12 binds to transcobalamin II and is transported throughout the body. Congenital transport-protein deficiencies, including transcobalamin II deficiency, are another rare cause of vitamin B12 deficiency.

b) It has been suggested that in the presence of heavy metals, the cobalt atom is oxidized from  $CO_2^+$  to  $CO_3^+$  (denaturation) at the same time as the heavy metal is reduced. The properties of the cobalamin are hypothetically changed and B12 has lost its biological properties.

### Commercial forms of B12:

cyanocobalamin – tablets @ 1000mcg per day

hydroxocobalamin – injections 1mg. (?)

Methylcobalamin – compounded sublingual @ 4 mg per day.

## **PROBIOTICS** – ( Lactobacillus acidophilus and Lactobacillus bifidus.)

What are Probiotics? Probiotics are live micro-organisms administered in adequate amounts which confer a beneficial health effect on the host. It has to be LIVE and at a minimum of 1 billion microbes per day.

Probiotics can provide some answers to the malabsorption problem of B12. A healthy gastro intestinal track may mean being able to be rid of H2 Blockers, improving the immune system via elimination of antibodies, rebalancing the ecosystem of the intestine, and your body getting the nutrients instead of the parasites.

Certain intestinal microbes are known to produce vitamins. Acidophilus and bifidobacteria may manufacture B vitamins, including niacin, folic acid, biotin, and vitamin B6.

Additional benefits: If you are taking warafin or other blood thinners – do NOT use the probiotics program because of the vitamin K benefits. If in doubt, please seek the advice of your doctor.

Daily intake of B12 at minimum = 1000 microgram (mcg)

Probiotics = minimum 1 billion microbes per day.

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