



Together we will end the pain.

Trigeminal Neuralgia Association-Twin Cities Support Group Meeting Notice

Saturday November 18th, 2006

10:30a - 12 Noon

North Memorial Hospital, Pine Crest Room,

3300 Oakdale Ave. N., Robbinsdale, MN. Tel: 763-520-5200

SPEAKER

Gary Carlson Pharmacist: Site Manager Fairview Compounding Pharmacy - Minneapolis.

Technology Pharmacist, University of Minnesota Hospital Pharmacy and Fairview University Hospital Pharmacy, October 1980 to February 2004.

Assistant Professor, University of Minnesota College of Pharmacy, Minneapolis, Minnesota, 1983 to present. Instructor, University of Minnesota College of Pharmacy, Minneapolis, Minnesota 1975 to 1981.

Awards: College of Pharmacy B.S. Program Teacher of the Year 1978, 1979, 1981, 1989, 1991, 1992 and 1993.

Publications: Holmes GB, Rosenfeld WE, Graves NM, Rempel RP, Carlson GH, Kriel R. "Absorption of Valproic Acid Suppositories in Human Volunteers" Archives of Neurology, 1989;46: 906-9.

Carlson, GH, Matzke, GR. "Particle Formation of Third-generation Cephalosporin Injections", American Journal of Hospital Pharmacy, 1985;42:1578-9.

Blumenthal MN, Roitman B, Carlson GH, Fish L. "Isotope Assay of Histamine Release" Biochemical Medicine, 1974;11:312-17.

Special note to those who can't get to meetings:

The leadership team is available by phone or email whenever you have questions or concerns. We have the March and May meetings available on loan.

In the future Mary Lou Peterson plans to videotape our meetings. If this is a service you are interested in please contact Mary Lou.

IMPORTANT DATES FOR YOUR CALENDAR! 2007 MEETINGS

Saturday, January 20th ---- Dr. Masood _ Neurologist

Saturday, March 17th

A Message from Mary Lou Peterson TNA Twin Cities Support Group Leader

First of all I want to apologize for the delay in getting this newsletter out to you. Laurie Redmann has been extremely patient with me as I have had a lot going on in my life since I returned from the conference.

The Trigeminal Neuralgia Association National Conference was held on September 14-16 in Portland, Oregon. The conference was designed for patients, their family members, caregivers and health care professionals who have an interest in the management of TN and other neuropathic pain conditions.

The conference offered presentations on medical treatment, surgery, complementary and alternative medicine and research as well as panel discussions with renowned experts offering tools to help us live our best life with Trigeminal Neuralgia.

On Wednesday, Sept. 13th I attended the Leadership program for support group leaders and telephone support contacts. I found the information very helpful especially for providing resources to empower our members to make informed decisions about their treatment for TN.

On Thursday evening, the welcome reception was a sunset cruise on the Portland Spirit. We went down the Willamette River and enjoyed a scenic view of the Portland area.

The conference began every morning at 8am sharp and some sessions went to as late as 7pm. My dilemma was making the choice of which session to attend as there were always 2 -3 concurrent sessions all with very exciting topics. All the presentations I attended were excellent and some had controversy which made it very interesting to hear the other sides. Most of the sessions were recorded and will be available to us on DVD for our libraries. I will let you know when they become available.

It was great to touch base with a few of my friends from the 2004 Orlando conference plus I had an opportunity to make many new friends from all over the world. Everyone was very friendly and kind especially the TNA staff. Jane Boles, Shelley Wilson, Dr. Burchiel along with their staff did a fantastic job organizing this event. I didn't think that this conference could surpass the last one in Orlando. IT DID!!! I hope we will have a good turnout from Minnesota at the 7th TNA Conference in Detroit in 2008.

Thanks to all of you who contributed to my expenses especially Dr. Nixdorf, Dr. Pollock and Dr. Johnson which made it possible for me to attend the conference. It was a privilege for me to represent our support groups in Minnesota and to be in such fine company as Dr. Nixdorf and Dr. Pollock. They both contributed to the conference with very informative presentations.

It was quite an intense four days. I came home with my head spinning from all the overwhelming information. It will take me months to get back to normal.

Here are just a few topics I want to share with you at this time. I will continue to cover other presentations in future newsletters.

A complete **MVD** was performed by Dr. Burchiel and shown live on a large screen at the conference. The surgery was a success and the last we heard the patient is doing well.

Adult Stem Cell Research - We may have a long way to go, there was an atmosphere of hope for a permanent cure for TN and other chronic neurological diseases such as Parkinson's, epilepsy, Alzheimer's in the not too distant future. Dr. Dennis Steindler, Ph.D. from the McKnight Brain Institute in Florida has been conducting extensive research into stem cells and regenerative medicine.

An excellent presentation by Dr. Joanna Zakrzewska author of "**Insight**" Facts and Stories behind Trigeminal Neuralgia

Dr. Zak is a Professor of pain in relation to oral medicine in London and has taken a special interest in the experiences of TN sufferers. Her emphasis in the book is on the impact of drugs and surgery on TN patients which she summarized at the meeting.

If you are an **Anesthesia Dolorosa** patient Dr. Zakrzewska's presentation on video is a must see!
Please contact Mary Lou Peterson if you want a copy of her presentation on loan.

Cherie Sato of San Diego gave a presentation on **Service Dogs** for people with TN. For the past six years Cherie and Jake her Service Dog has shared a life together. Cherie discussed how a service dog is an alternative means of assistance for invisible disabilities such as TN or other facial pain. Apart from unconditional love and always ready to please, they can save lives, help you out of depression among multiple other services.

TNA HEADLINE NEWS

ONDAMED® is a FDA registered Class II biofeedback device and currently an IRB approved status as a secondary therapeutic device for the treatment of various disorders which alleviates pain, discomfort, or general malaise. The device is now awaiting final designation as a pain-treatment device.

New Windsor, NY ([PRWeb](#)) October 30, 2006 -- After passing its preliminary registration phase with the FDA, Ondamed is now awaiting final approval to be officially listed with the government agency as an effective pain-treatment device.

The cutting-edge device is already receiving great feedback from both patients and doctors, says Silvia Locke (CEO and president of the company), who adds that it is increasingly being recognized in the health community as a viable alternative to painkillers. Practitioners are also finding that ONDAMED® is helpful in relieving the symptoms of Lyme disease and trigeminal neuralgia. Lyme, like trigeminal neuralgia, is a disease that is dreadfully debilitating and for which people have great difficulty in getting effective treatment.

"I am very impressed with ONDAMED®," says Burton Goldberg, Ph.D. Hr. "In my opinion the ONDAMED® is one of the most astounding devices I have ever seen. I have witnessed several sessions and I am amazed at the fast and lasting effects this system offers."

"Patients with neuropathy who use ONDAMED® have up to 90% of their pain relieved," adds Dr. Steven J Bock, M.D., ACCUP. And, according to Dr. Stephen T. Sinatra, M.D., C.N.S., "This is the future of medicine."

Doctors are not alone in this assessment. Patients have also come forward to laud the device, including Rita Losee who was in her late thirties when she experienced her first blast of trigeminal neuralgia pain. Years of unending pain followed. Then, in May of 2005, she learned of ONDAMED®. She purchased a machine in late August, was trained, and has been treating herself 2 - 3 times per week since. Today, she is pain-free, tapering off her medications, and has boundless energy.

"ONDAMED® makes so much sense," she says. "We know scientifically that the origin of everything in our physical world is electromagnetic energy. Our bodies are also sourced by electromagnetic energy; energy becomes disharmonious before physical symptoms manifest. We measure bodily energy fields with respect to EKGs and EEGs. ONDAMED® is a therapeutic Biofeedback device that works with more subtle energy in our bodies.

"Traditional medical treatments are generally focused on treating the physical result, the symptom, not the energy imbalances themselves. ONDAMED®, like acupuncture, realigns the electromagnetic energy but this System has the advantage of not requiring needle sticks. This is particularly important for a person with TN as the slightest stimulus can trigger excruciating pain for the individual."

About ONDAMED®: GmbH was founded in 1994 by Rolf Binder, who developed the ONDAMED® Biofeedback System after 25 years of research in biophysical medical testing and therapy. Binder is well known for developing Bioterrain and EAV measurement devices, and other Medical Electronics equipment.

In 2002, the company opened its U.S. subsidiary, Ondamed Inc. and currently has customers around the world. The therapeutic Biofeedback device was invented in Germany 10 years ago and has been available in the US for the past four.

For further information, please contact: Silvia Locke, CEO Ondamed, Inc at 845-496-6673 ext 111 or visit www.ondamed.net

Twin Cities TN Support Group Mission Statement

To support and encourage patients and families of those who suffer from trigeminal neuralgia and related facial conditions: to assist and educate the medical and dental community in understanding the effects of these conditions.

"Share your Success"

Share your success and concerns living with Trigeminal Neuralgia. We would really like people to share their stories in writing also, since some of our group is not able to attend the meetings or are too far away.

A Great resource website that was found that was created by a person with Trigeminal Neuralgia.

www.creps.org/tn "Trigeminal Neuralgia, You are not alone"

If there is information you would like to add or see in our newsletter, please call or email Laurie Redmann or Mary Lou Peterson. We are trying to get the information out that people in our group would like. More information and any information you would like to share with the group. Even if it is a repeat it is nice to bring it up again for any new members of our group.

Twin Cities Leadership Team

Support Group Leader: Mary Lou Peterson 612-727-1715 marylou@giftofheritage.com
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ATTENTION E-MAIL USERS

To get up-to-date Trigeminal Neuralgia information via e-mail contact Mary Lou Peterson at marylou@giftofheritage.com.

Don't forget to let us know if your e-mail address changes Please put TN in the title so it doesn't go into spam. To ensure that your TNA Twin Cities e-mail messages are not blocked by a filter, please add e-mail addresses marylou@giftofheritage.com and redmann@izoom.net to your address book or safe list.

Volunteers Wanted!

A Co-Leader - Be a part of the support group team and lead the meetings if Mary Lou Peterson is unable to attend. **Someone who has access to make copies of our newsletters, every 2 months.**

We MUST have volunteers to continue with our support group! Please consider volunteering your time!
Remember - it's your group!

PLEASE SIGNUP AT BuyForCharity.com and help support TNA.

Shop online from over 350 stores like Barnes & Noble, Gap, Office Depot, 800-Flowers, Wal-Mart, Expedia, and more at BuyForCharity.com! Up to 35% of each purchase will benefit us if you select the Trigeminal Neuralgia Association as your cause of choice.

So anytime you buy online, whether you are looking for Airline Tickets, Flowers, Clothes, Music, Office Supplies or anything else... Buy for Charity and help support TNA. There is NO cost to you and you can even save money on your purchases by using their great coupons and specials. As a new shopper on BuyForCharity.com, you just sign up once - and you don't have to give any personal information!

Get all the details about the Buy for Charity program at: www.endthepain.org

Help us with our TNA Twin Cities support group and National TNA

1. **Contribute to support group costs if you are able.** Our biggest expense is the postage for the six newsletter/meeting-notice mailings of 400+ copies (about \$400 per issue). Thanks to the 50+ members who receive the newsletter by email and the generous donation of copier services for those sent with postage, costs are kept that low. We also have about \$100 expenses for labels, speaker gifts, nametags, coffee etc.

How to Contribute:

- *If you want your contribution to be tax deductible:* Make your check payable to TNA -- writing "for Twin Cities TN Support Group" on the memo line -- and send with form below to **Mary Lou Peterson**. **Mary Lou Peterson** will forward the check to TNA national, a registered charity, for processing. TNA national will send a check to us for the same amount, to use for our support group expenses.
- *If you do not want your contribution to be tax deductible:* Give cash/checks at meetings or send checks payable to **Mary Lou Peterson** (writing "for Twin Cities TN Support Group" on the memo line). These contributions are **not** tax-deductible.

If you have not already sent a contribution for national's work - to benefit all identified TN persons in the world - you may enclose an additional check made out to TNA -- writing "for TNA national" on the memo line.

Mary Lou Peterson will forward to national for their use or send directly to national

TNA, 925 Northwest 56th Terrace, Suite C Gainesville, FL 32605 or you can contribute on TNA's website at

www.endthepain.org.

2. Tell us if you (1) want to be removed from the mailing list, (2) have a new address, or (3) are willing to receive the meeting notice/newsletter via e-mail.

Use the form below to do any of the above. (Or e-mail) Thanks!

REPLY FORM send contributions to National or locally. Also, if your email or address changed, please contact Mary Lou Peterson, 5429 45th Ave S, Minneapolis, MN 55417 - (612) 727-1715 Email:

marylou@giftofheritage.com

- _____ Enclosed is my check in the amount of \$ _____ for our support group expenses.
(See donation reminder above).
- _____ Enclosed is my check in the amount of \$ _____ to support TNA national.
- _____ I've moved; please change my address from old address: _____ to address below.
- _____ I no longer wish to receive meeting notices. Please remove my name from the Twin Cities Support Group mailing list.
- _____ Please send the meeting notice/newsletter via e-mail. (Give street address and email address below.)

Name _____

Address _____

City _____ State _____ Zip _____

Phone (day) _____ (evening) _____ E-mail _____

[Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the services of your health care providers. It provides information only.](#)

News from National

To request FREE information from TNA go to <http://www.tna-support.org/>

click on **Educational Materials** click on **Information Sheets**. Then Click on the desired information.

National TNA Office Contacts

925 Northwest 56th Terrace Suite C Gainesville FL 32605

Telephone numbers 352-331-7009 or 800-923-3608 Fax: 352-331-7078

Email: tnanational@tna-support.org Website: www.tna-support.org

Michael Pasternak President

Jane Boles Executive Director/CEO

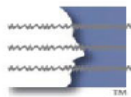
National's Patient Information Representative: Alana 352-331-7022 or 800-929-3608

Email: PatientRep@tna-support.org Website: www.endthepain.org

An easy way to remember the TNA website is www.endthepain.org which links to www.tna-support.org

Please send your tax-deductible contribution to TNA, 925 Northwest 56th Terrace Suite C Gainesville FL 32605 or you can contribute on TNA's website at www.endthepain.org. Thanks!

Shop online at over 350 major retailers and SAVE on your purchases while donating to TNA all at no cost to you. Get all the details about the Buy for Charity program at: www.endthepain.org



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1-800-923-3608