



*Together we will end the pain.*

**Trigeminal Neuralgia Association-Twin Cities Support Group Meeting Notice**

**Saturday May 19, 2007**

**10:30a - 12 Noon**

**North Memorial Hospital, Pine Crest Room,**

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

**SPEAKER**

Dr. Alan Law is an Endodontist (Specialist in root canals) and trained as a pain neuroscientist.

*How dentists diagnosis tooth pain and why it feels the way it does.*

Dr. Alan Law received his Doctor of Dental Surgery, Certificate in Endodontics and completed his PhD "Mechanisms and Modulation of Orofacial Pain" from the University of Iowa, Iowa City, Iowa. He is an Associate Professor, Department of Endodontics, at the University of Minnesota, Past President of the Minnesota Association of Endodontists, and serves as a Director of the American Board of Endodontics.

**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 videotapes of the March and May 2006, January and March 2007 meetings available on loan. If this is a service you are interested in please contact Mary Lou Peterson.

**IMPORTANT DATES FOR YOUR CALENDAR! UPCOMING MEETINGS**

July 21, 2007: Annual Potluck Picnic at the Butcher's Cabin (Directions included in this newsletter)

September 15, 2007

November 17, 2007

January 19, 2008

March 15, 2008

**Trigeminal Neuralgia Association Twin Cities Support Group Revised Mission Statement**

- *To support the goals and mission of the Trigeminal Neuralgia Association*
- *To provide support and encouragement to patients and families of those who suffer from Trigeminal Neuralgia and other related facial pain conditions*
- *To educate and empower patients to learn about their condition and work with their physicians to achieve the best possible outcome for themselves.*
- *To assist the medical and dental community in understanding the effects of these conditions on patients and their families.*

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

## **Twin Cities Leadership Team**

**Support Group Leader:** Mary Lou Peterson 612-727-1715 [marylou@giftofheritage.com](mailto:marylou@giftofheritage.com)

5429 45<sup>th</sup> Avenue So Minneapolis, MN 55417

**Newsletter Editor:** Laurie Redmann 763-370-8135 [redmann@izoom.net](mailto:redmann@izoom.net)

**Phone Team:** Mary Lou Ackleson 651-451-6249

Mary Butcher 763-753-3018 [butcher70@earthlink.net](mailto:butcher70@earthlink.net)

### **ATTENTION EMAIL USERS**

Don't forget to let us know if you change your email address. Please put TNA in the title so it doesn't go into spam. To ensure that your TNA Twin Cities email messages are not blocked by a filter, please add email addresses [marylou@giftofheritage.com](mailto:marylou@giftofheritage.com) and [redmann@izoom.net](mailto:redmann@izoom.net) to your address book or safe list.

### **"Share your Success"**

Share your success and concerns living with Trigeminal Neuralgia. We would really like people to share their stories in writing so others who are who are unable to attend the meetings will be enlightened and inspired. If there is information you would like to add or see in our newsletter please contact Laurie Redmann or Mary Lou Peterson.

### **DO YOU KNOW WHAT I DID?**

Do you know what I did this morning? I took a shower. I not only took a shower, I took the showerhead, and put it on pulsating and let the water beat against my head...let it just vibrate...let it just massage me from the tip of my head to my whole body. And it felt so good. Have you ever been able to do that?

Do you know what I did today? I took a nice walk. It was a blustery day, the wind was blowing, and I didn't wear a hat. It felt great. I was really brave. I walked directly into the wind. I conquered the wind today.

Do you know what I did today? I rode in a car, on the passenger side. I rolled the window down and felt the wind come into the car and let it caress my head and it felt so good.

Can I tell you what I did today? I gave my wife a hug. I kissed my wife. She gently caressed my face with her hands. Let me tell you, it felt so great! Life doesn't get much better than that.

Do you know what I did today? I ate an apple. It was a tasty apple, a red delicious. I love red delicious apples. Don't you?

Do you know what I did today? I enjoyed a cook out. Corn on the cob tasted so delicious. I had a nice porterhouse steak on the grill. It was a little tough and chewy at one time, but that is what made it special. I devoured that steak even ate the meat close to the bone. What a great cook out!

Do you know what I did today? I gave a presentation that went really well. I mean I talked for over an hour. Everybody enjoyed it. I had practiced, drilled and rehearsed it. It went as I had planned. It was really great!

Hey! You know what I did today? I brushed my teeth. I not only brushed them, I took my time. I brushed up and down, in and out and across the front. What a joyful experience to just brush one's teeth.

Do you know what I did today? I was working in the yard, got all sweaty and took out my handkerchief and wiped my brow. I wiped my upper lip, I wiped my whole face. It felt so good, I did it again and thought to myself, life is good.

Do you know what I did today? I approached the day with child-like enthusiasm. A whole new world is there for me today. One that I can enjoy and really get into! Have I told you that I am excited about life? Excited about living!

Hey! Do you know what makes today so special? I don't have the pain of yesterday. Isn't that terrific? With such a great day going for me today, you would not believe my yesterday. Or maybe you would!

*Ron Irons Neuralgian*

### **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 and 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!**

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## Resources

**"Insight"** Facts and Stories behind Trigeminal Neuralgia Dr. Joanna Zakrzewska

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. If you are an Anesthesia Dolorosa patient Dr. Zakrzewska's presentation on video is a must see!

A Great resource is a website that was created by a person with Trigeminal Neuralgia.  
[www.creps.org/tn](http://www.creps.org/tn) "Trigeminal Neuralgia, You are not alone."

Dr. Kerry Johnson, a chiropractor in Rosemount who specializes in the NUCCA method of spinal correction, has written a book entitled *I'm Sick and Tired of Being Sick and Tired*. The book is loaded with practical advice to improve health in body, mind and spirit. Since the human body is holistic in nature, weaknesses in one or more body systems can affect others and actually contribute to the pain cycle of TN. Why does TN pain often ebbs and flows? Part of the answer can often be found in how well sufferers tend to all aspects of health. For more information go to [www.sixkeystohealth.com](http://www.sixkeystohealth.com).

### St. Cloud Support Group Change in leadership

We would like to welcome Mary Hall as the new TNA Support Group Leader for the St. Cloud group. A special thanks to Mary Kuhn who started and was the SGL for the St. Cloud group for many years. Their 2007 meetings will be held on May 5th, July 7th, Sept. 1<sup>st</sup> and Nov. 3<sup>rd</sup> at the CentraCare Health Plaza, 1900 CentraCare Circle in St. Cloud in the Kremer's Room from 10 am to 12 noon.

### Report on March 17, 2007 Meeting

General meeting notes: Apologies were given for Mary Lou Peterson's absence; her mother was rushed to the hospital. Everyone extended their sympathies and sent her their best wishes. Mary Butcher filled in for Mary Lou. Thanks were extended to Mary Lou Ackleson for the delicious cookies.

Presenter: Dr. Don Nixdorf, University of Minnesota

TNA Medical Advisory Board Member, University of Minnesota Assistant Professor Division of TMD and Orofacial Pain Department of Diagnostic and Biological Sciences Email: [nixdorf@umn.edu](mailto:nixdorf@umn.edu) 612-626-0140  
TMD and Orofacial Pain Clinic 6-320 Moos Tower 515 Delaware St. Minneapolis, MN 55455-0357

There was a good turnout for Dr. Nixdorf's return visit. This presentation was more of a diagnosis lecture than his previous one. Dr. Nixdorf presented slides, on the diagnostic criteria for trigeminal neuralgia and other facial pains. He stressed the importance of listening carefully to the patient, rather than rushing into an obvious diagnosis, the patient usually explains what he is feeling. "Listen to the patient, he is telling you the diagnosis" (Sir William Oslen). Some diagnostic criteria are: Expert of consensus opinion; anatomical or region based symptoms; presentation of recognized features or signs and symptoms; mechanism based classification. TN physicians want to move toward the latter, treating the cause rather than the symptom. He noted that TN appears in medical literature (not anecdotal letters/literature) as early as 1066! Dr. Nixdorf also presented several actual case studies of facial pain patients, how they presented themselves and his ultimate diagnosis. He commented that there appears to be a shift within the research community towards research on quality of life for pain sufferers. The presentation began at 10:30 a.m, and ended at 12noon. Dr. Nixdorf stayed on to answer patient questions individually.

"Mary Lou Peterson's mother passed away on March 23rd. A card was sent to her from her Trigeminal Neuralgia friends at the support group and we continue to extend out sympathy to her and her family as they grieve their loss". Mary Butcher

### Report on January 20<sup>th</sup>, 2007 Meeting

Presenter: Dr. Moeen Masood

Address: Minneapolis Clinic of Neurology, Mercy Health Care Center 3960 Coon Rapids Blvd., Suites 209 & LL.17, Coon Rapids, MN 55433. 763-427-8320 Fax: 763-427-1243. website: [www.minneapolisclinic.com](http://www.minneapolisclinic.com)

Dr. Masood introduced himself as originally from Pakistan, now resident in Minnesota and a Graduate of the University of Minnesota School of Medicine. During his presentation, he used several excellent views of the brain and showed how the Trigeminal Nerve originates and talked about why the condition is complicated - because the nerve itself is complicated. He explained how the ganglion (or relay station) works and how the nerve divides into V1,V2,V3. He spent time discussing the arteries, the various branches that are affected, the medications currently available and touched upon surgical options. He had indicated in his introduction that he preferred an interactive presentation, so during his discussion about TN and its complexity, he took many questions from the group, regarding NUCCA, cataracts, migraines, Gamma Knife. The group was very grateful for the time he spent with us, and congratulated him on his sympathetic approach to our condition, and the clarity of his presentation. We told him we will probably invite him again! Thank you Dr. Masood! Mary Butcher

### Report on November 18<sup>th</sup>, 2006 Meeting

Gary H. Carlson, R. Ph Compounding Pharmacist. He is Site Manager Fairview Compounding Pharmacy and Assistant Professor, University of Minnesota College of Pharmacy, Minneapolis, Minnesota, 1983 to present. Contact Information: 711 Kasota Avenue Minneapolis, MN 55414 612 672 5735 - Email: [gcarlso5@fairview.org](mailto:gcarlso5@fairview.org)

Gary gave a very informative presentation on a complex subject compounding medications. He covered many different drugs and how and why they work. The comments from attendees were very positive from great information to share with their doctors to his willingness to be available for their questions at anytime. He is a great resource for TN patients and their doctors. A videotape of his presentation will be available in the near future. Mary Lou Peterson

### Report on July 15<sup>th</sup>, 2006 Meeting - 7<sup>th</sup> Annual Twin Cities TNA Support Group Picnic

It was a blazing hot day at the lake! In spite of the heat, 18 hardy Minnesotans showed up at Butcher's cabin for a day of fellowship, good food, boat rides and mutual support. With the help of a couple of large fans, a gazebo awning, plenty of ice around the food and cold drinks, we all survived and enjoyed ourselves. Mary Butcher

### Mary Butcher's surgery in November 2006

Rare situation: Mary Butcher hit the jackpot again (she still wonders why it's never the Powerball!) with an unusual problem that occurred as a result of her last MVD. Over the years she began experiencing some hearing issues on her surgical site, pops, whistles, "hearing under water", etc. which progressively worsened. By last summer from 10 am every morning she was deaf on the one side until bed time. She could also bring on the deafness by pressing on the surgical site, combing her hair, washing her hair, etc. Dr. Stephen Haines said it was most unusual but he knew just the person to diagnose and fix it. So in October of 2006, she went to Dr. Samuel Levine at the University of Minnesota. The situation was not one that can be found in any text book, and involved a leak from the air cells. In November, Dr. Levine and Dr. Haines went in and removed a lot of scar tissue and build up, and then stuffed the air cells and the leakage with belly fat. Voila! Hearing normal and the giant divot in the head has also disappeared. Both Levine and Haines did say this is NOT something about which TN patients should worry. Mary's sisters are now having a field day: not only does she have two holes in her head, a teflon brain, but now they call her fat-head!

### A new classification for facial pain - Cause/symptoms

Neurosurgeon and member of the TNA Medical Advisory Board, Kim Burchiel, has proposed a classification system that divides neuropathic facial pain according to the cause of damage to the trigeminal nerve.

[http://www.ohsu.edu/facialpain/facial\\_pain-dx.shtml](http://www.ohsu.edu/facialpain/facial_pain-dx.shtml)

This classification system was used in the book, *Striking Back*, and will be used here to provide continuity in terminology. Please be aware that other medical providers may use different terms for the same problems. This discussion includes trigeminal neuropathic pain, trigeminal deafferentation pain and post herpetic neuralgia.

- **Trigeminal neuralgia, type 1, (TN1):** facial pain of spontaneous onset with greater than 50% limited to the duration of an episode of pain (temporary pain).
  - **Trigeminal neuralgia, type 2, (TN2):** facial pain of spontaneous onset with greater than 50% as a constant pain.
  - **Trigeminal neuropathic pain, (TNP):** facial pain resulting from unintentional injury to the trigeminal system from facial trauma, oral surgery, ear, nose and throat (ENT) surgery, root injury from posterior fossa or skull base surgery, stroke, etc.
  - **Trigeminal deafferentation pain, (TDP):** facial pain in a region of trigeminal numbness resulting from intentional injury to the trigeminal system from neurectomy, gangliolysis, rhizotomy, nucleotomy, tractotomy, or other denervating procedures.
  - **Symptomatic trigeminal neuralgia, (STN):** pain resulting from multiple sclerosis.
  - **Postherpetic neuralgia, (PHN):** pain resulting from trigeminal Herpes zoster outbreak.
  - **Atypical facial pain, (AFP):** pain predominantly having a psychological rather than a physiological origin.
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TNA publishes its newsletter, the **TNALERT** three times yearly. The newsletter is offered to members free of charge and contains the most up-to-date news and information on advancements in the care and management of TN and related facial pain conditions. Thank you for your continued interest in and support of TNA. Please let us know what you think of this newsletter and other TNA programs.

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#### **The Trigeminal Neuralgia Association honors Peter J. Jannetta, M.D. at a Lifetime Achievement Dinner on April 28<sup>th</sup>, 2007 in Pittsburgh, Pennsylvania.**

*Dr. Peter Jannetta*, a pioneer in neurosurgery retires from leadership of the Trigeminal Neuralgia Association's Medical Advisory Board. **Over Forty years ago**, Dr. Jannetta performed the first microvascular decompression surgery for relief of trigeminal neuralgia. Since that time, thousands of people have benefited from the surgical techniques Dr. Jannetta has refined, perfected and taught around the world. **In 1990**, Dr. Jannetta "challenged" one of his trigeminal neuralgia patients, Claire Patterson, TNA Founder and President Emeritus, to do something about the great void of knowledge about trigeminal neuralgia. Today, TNA serves as a world-wide advocate for facial pain patients providing information, encouraging research and offering support. The Peter Jannetta Initiative will develop *medical educational materials* and strengthen *outreach programs*. Help fund Dr. Jannetta's initiative by making a tax-free donation to TNA.

**Annual Potluck Picnic**  
**Saturday July 21<sup>st</sup>, 2007 - 11:00 until 3:00pm**  
**"North of the Cities" At Mary & Jim Butcher's cabin in Pine Lake (NW of Sandstone)**

Please come! This is a special invitation to all those on our mailing list, and particularly to those of you who live too far north of the Cities to come to North Memorial Hospital for the regular meetings. Family members and supportive friends welcome.

**Bring a dish to share, and enough chairs for everyone in your group.**

Weather permitting, we will be outdoors, otherwise we will squeeze inside the cabin! Come and enjoy good food, encouragement and learning from your fellow patients.

The fishing is usually good, Jim gives pontoon tours of the lake, and the company is outstanding. We have invited physicians to join us if their schedule permits. We will have handouts, and we welcome families. The purpose is an informal get-together to share information about TN. Claire Patterson, the founder of TNA, always says "TN always strikes the nicest people".

**Directions to Butcher cabin: Take I-35, heading north.**

Take the Banning Junction exit #195, north of Sandstone.

Turn west (left) over freeway onto 23.

At the T-junction, turn north on 18.

After about 1.5 miles you will come to a junction.

Turn left, following 18 west towards Finlayson.

Pass through Finlayson (about 2.5 miles west of that junction) and continue west.

About 5 miles west of Finlayson, pay close attention.

18 will take a bend to the right. Just before that bend, turn left onto 37.

Go west on 37 about 1 mile to the T-junction and turn left on 38.

The main road will turn left after about 0.5 miles.

At that point follow the blacktop to the left. Do not follow straight on.

You are now going south.

In a short distance, when the black top turns right onto 23, DO NOT TURN WITH IT but continue straight south on the dirt road, county 25.

After 1 mile, the dirt road will turn sharp right and go west. Follow 25 west for about 1 mile.

The road will turn left just after a junction on the right. The lake will be in front of you.

Take that left and you will see the cabin (brown in color, Fire #11627) ahead on your right.

We will have signage.

Pull off the road and park on the front lawn, or continue past the cabin and pull under the shade trees on the right.

**OR: Take Highway 65 North. Go through Mora. Continue on 65 North.**

After Knife Lake, turn Right on Hwy 3 (sign posted Hinckley). Drive approx. 9 miles.

Turn Left on County Road 20 to Kroschel.

**Note:** if you take this route, you may encounter significant road construction. It's been going on all winter we don't know when they will finish.

**Road work stops at Kroschel.** Follow 20 about 10 miles along black top. When black top ends at crossroads, continue straight on dirt road. After sharp S-bend, cabin is on left, beside the lake (11627 110<sup>th</sup> Ave.)

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

In case you haven't heard, after the recent controversy and lawsuits made over off-label use of drugs for arthritis, etc., TNA funding has suffered. There are no drugs designed specifically for our pain, all the drugs are off-label., so pharmaceutical companies have withheld much of their support. TNA needs our help more than ever.

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 56<sup>th</sup> Terrace, Suite C Gainesville, FL 32605 or you can contribute on TNA's website at [www.endthepain.org](http://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 email.**

**Use the form below to do any of the above. (Or email)**

**REPLY FORM** send contributions to National or locally. Also, if your email or address changed, please contact Mary Lou Peterson, 5429 45<sup>th</sup> Ave S, Minneapolis, MN 55417 - (612) 727-1715 Email: [marylou@gifttoheritage.com](mailto:marylou@gifttoheritage.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 email. (Give street address and email address below.)

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone (day) \_\_\_\_\_ (evening) \_\_\_\_\_ Email \_\_\_\_\_



*Together we will end the pain.*

Mary Lou Peterson  
5429 45<sup>th</sup> Avenue South  
Minneapolis, MN 55417  
TNATC Newsletter May 2007 Issue

#### 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 56<sup>th</sup> Terrace Suite C Gainesville FL 32605

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

Website: [www.tna-support.org](http://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](mailto:PatientRep@tna-support.org) Email: [tnanational@tna-support.org](mailto:tnanational@tna-support.org)

An easy way to remember the TNA website is [www.endthepain.org](http://www.endthepain.org) which links to [www.tna-support.org](http://www.tna-support.org)

#### PLEASE SIGNUP AT [BuyForCharity.com](http://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](http://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](http://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](http://www.endthepain.org)**