



Nerve Center

Nov/Dec
2005

Periodical Newsletter of the Pacific Northwest TNA Support Group
Serving the Pacific Northwest Region of Oregon, Washington and Idaho

December Group - Exploring CAM

The December meeting will include discussions and information on Complimentary and Alternative (CAM) treatments for TN and related facial pain. TNA has produced several new informational flyers for members to learn more about some of these treatment modalities and we will have them on hand at the meeting. Patients have reported on getting help with pain from treatments such as Upper Cervical Chiropractic, Acupuncture, Craniosacral Therapy, Homeopathic Medicine, Chinese Medicine, Dietary changes, Pain Safe Foods, and more.

Come and talk with other members who have tried CAM treatments, and see how they are faring with them. Families and friends are always welcome to join us at the free meetings. We'll see you on **Saturday, December 10th, 1:00pm** at Legacy Meridian Park Hospital Community Education Center in Tualatin, OR.



People Need People

By Heather Marcott

I am married to a TN patient and I am a 28 year old recovering from a drug habit. I've been clean since March 13, 1999, and I have been going to NA meetings since that day. I can't always go, but I try to make it to as many meetings as I can in moderation, to still put my family first and to maintain my recovery. Sometimes *I need to put myself first to put them first*. When I have my good days, I really feel that is when it's MOST important to go because I truly believe in the Law of Karma. I have learned that you reap what you sow.

We've all heard, "You can't keep what you have unless you give it away". But I know first hand that not only do you get to keep what you have but you get so much more than you could ever imagine by helping people. You help people by giving them hope. I help them by teaching others how I got clean and what tools helped me to stay clean. I know that we must learn to take care of ourselves, and become and remain a responsible productive member of society. In order for me to function I need to be abstinent from drugs, and in order for that to happen, I need my "medicine" - my *treatment*. Treatment to me is vital in order for (*Continued on p.2*)

Busting the Myths that Surround TN

Our meeting on October 15th was a fun one, with insight and laughter as we learned about the myths and facts that surround TN and facial pains. It's an odd combination for sure, but interaction between members always brings us smiles despite the pain we may endure and the sadness that learning about TN can bring us at times. Members were handed a list of comments about TN and then we talked about each point and whether or not it is a myth or a fact. (*See page 3 for the list and answers*) There were a few of the listed comments that brought about lively discussion as they were a little bit tricky, and some had information that the average patient wouldn't know. Everyone learned something new and had a great time joking around with others as we debated the comments and answers!

The group also focused on **updates from members** about their conditions, and many had questions about other members who weren't at the meeting this time. There is a real need for us to keep in touch and let others know if our treatments or surgeries are working, or if we have a cautionary tale to tell. It benefits us all, and it also can put our minds to ease to know how our friends in the group are doing. We welcomed another new member to the group, and she was immensely grateful to finally talk with others who have this condition. She's only in her early 20's and is very concerned about the effect of TN in her life. It was impressive to see the people in the group talking to her one at a time, surrounding her with care and concern, and helping to answer her questions. She is hoping to meet other members at the meetings who are near her age ... *we know you're out there - see you soon!*

We talked about a **new message posting website** that our Steering Committee Member **Ira Friedwald** has designed for us. Once signed up, members will be able to send messages and get information to each other efficiently. It includes a message board, archives of the Nerve Center newsletters, a calendar of events, and meeting notices. To join the free Pacnwtna message group you must send an email to airira@mac.com Our downloadable file website is still available to all at: <http://homepage.mac.com/airira> We are happy to have this new service and are looking forward to hearing from our members there. Great job Ira! (*Continued on p. 3*)

Disasters Lead to Declining Donations

Because of hurricanes Katrina and Rita, contributions to non-profit organizations are down with the exception of disaster relief agencies. TNA is one of those organizations who contributions are lower than expected for this time of year. Due to the sizeable disasters, federal tax laws have been changed to help facilitate more donations and are reported to be of benefit to many tax payers. Check with your tax consultant for information.

If you plan on making a tax-deductible donation to TNA this year and can afford to do it now rather than later, TNA could put your contribution to good use immediately. ***TNA could use your donations today!*** (See box on Page 3)

MARK YOUR CALENDARS!

2006 Meeting Dates:

1/28 - 4/01 - 5/20 - 8/19 - 10/07 - 12/09

All on Saturdays, 1:00 at Meridian Park Hospital

6th National Conference - Portland! Sept. 14-16

People (continued from p.1)

me to maintain recovery. I am not now and never will be cured fully. This is something I will have to work on for the rest of my life. Our Creator has taken away my urge, or obsession to use drugs for the majority of times. But I am not exempt. If I use drugs one time I probably won't stop until I end up in jail again, the psyche ward for the fourth time or even found dead in a ditch with a needle in my arm. Graphic, but a reality.

You're probably wondering, "***What in the Heaven does this have to do with anything?***" Here's my point. I believe you and I are very similar except; ***I go to NA and you go to TNA.*** And I know I can't possibly fathom your physical pain.

Here is a list of my treatments as they **relate to those who are in TNA** also:

- Attending meetings
- Building a strong support group by getting phone #'s of others in the group and *actually calling them*
- Learning about my steps towards recovery (similar to learning about TN treatments), by working them, practicing them, and living them
- Getting help when I need it and helping others when they need help

My husband who is 24 has been diagnosed with **Trigeminal Neuralgia and/or Focal Peripheral Neuropathy**. (Some doctors have told us it's the same thing). He has the MOST SEVERE CASE ANY OF HIS DOCTORS HAVE EVER SEEN. He has seen about 15

doctors. He has been to two or three TNA meetings and he's only made it through one whole one because he had severe attacks and had to go to the E.R. Luckily the meetings were at a hospital. I really encourage him to keep trying to go to as many as possible, not just *until* we find what treatment works for him, but even *after* so that he might give others hope.

The Doc told him *he had veins that were possibly intruding on his trigeminal nerve but in order to tell they would have to open him up and see*. I wouldn't recommend the MVD to anyone if you don't know *for certain* what is causing the pain. Unfortunately at that time we were desperate, and we were willing to do whatever it took. He was making at least one trip a day to the ER for four consecutive months, sometimes twice a day. In December of 2004 he had MVD surgery. On the day of surgery he woke up with an attack on the hour every hour for the next five days. Obviously it wasn't successful. He eventually had a period of remission once he was off all of the meds. But it came back. He has short severe attacks throughout the day and now about one huge one a week that will last up to four hours. Currently he is trying a new anti-seizure med that doesn't seem to be working.

We recently went to the Philadelphia Regional TNA Conference. We LEARNED new methods of treatment by talking with other patients and doctors who know about TN. He will be trying vitamin B12 shots starting tomorrow. We heard of one lady that uses B12 shots 3 times a week and is pain free. If that doesn't work then we are going to try acupuncture. What can it hurt? We heard of many people who do that once a week and are pain free. Also we have kept homeopathic treatment in mind. If we have to go that route and it works, or with whatever works, I will be sure to share the information with you.

My whole point is that everyone knows something that someone else doesn't. That is why it is so important for us all to meet together and discuss treatment options. ***We need to stick together!*** No one should ever have to live in that much pain. And no one should ever have to go through this alone. If you are in remission from TN or a related condition, then *please* if you have stopped coming to the meetings, ***please come back.*** For my husband's sake and for the sake of hundreds of other people who are suffering. And if you are suffering still, (even if groups aren't your thing), look at the meetings like a vital part of your recovery or treatment. It's your program. Your choice. You decide.

If anyone feels they would like to call me, feel free. Any day or any time of the night. I mean it. Thank you, and May God Bless you all, Heather Marcott 503-873-7255.

Busting Myths *(continued from p.1)*

These are the statements that the group went over during the meeting. Test your knowledge and check the box next to either Myth - M or Fact - F . *No peeking at the answers until you're done!*

- 1) Less than 1 million people in the US are afflicted by Trigeminal Nerve Pain. M F
- 2) 8,000 new cases of TN are diagnosed world-wide each year. M F
- 3) TN has been diagnosed in infants under 6 months old. M F
- 4) TN is more than one disorder resulting in the same kind of pain. M F
- 5) Typical TN patients experience electric shock-like pains more than any other pain. M F
- 6) Shock-like pains are always caused by an artery or vessel compressing the nerve. M F
- 7) The Trigeminal Nerve can cause pain on only one side of the face at a time. M F
- 8) Dr. Peter Jannetta developed the MVD surgery 25 years ago. M F
- 9) The MVD surgery won't help with "atypical" types of pains. M F
- 10) TN and Related Facial Pain can cause Temporal Mandibular Disorders, (TMD). M F
- 11) Dental anesthetic injections can be neuro-toxic, and shouldn't penetrate the nerve. M F
- 12) TN is a life-long disorder, even after surgery. M F
- 13) Opiates don't work on Trigeminal Nerve Pain. M F
- 14) Implanted electrical stimulators on individual branches of the nerve can stop the pain. M F
- 15) TN occurs most often in people aged 60 or older. M F
- 16) Tear production can be affected by the damaged trigeminal nerve. M F
- 17) The Trigeminal Nerve originates in the brain stem at the C1 – C3 level of the neck. M F
- 18) Gamma Knife surgery always takes at least a couple of weeks to work on the pain. M F
- 19) The Radiofrequency Rhizotomy procedure will cause numbness in the face. M F
- 20) Oral medications can be mixed into topical compounded formulas that work on pain. M F
- 21) It's better to avoid using a lot of breakthrough med's, and wait until the pain is full-blown. M F
- 22) TN was first described by a Physician in the 1700's. M F

Here are the answers, with some explanations as needed.

- 1) MYTH – 4,290,000 people in the US have some form of *Trigeminal Neuropathic Facial Pain**.
- 2) MYTH – 15,000 new cases of *Typical TN** are added each year. **Note the different terms used in 1 & 2.*

- 3) FACT – 3 month old children have been diagnosed.
- 4) FACT – TN can be caused by tumors, MS, aneurisms, and other disorders.
- 5) MYTH – They report having other pain symptoms more frequently.
- 6) MYTH.
- 7) FACT – The nerve on either side of the face acts independently.
- 8) MYTH – It was 39 years ago.
- 9) MYTH – MVD's can help atypical pain when typical TN symptoms remit also.
- 10) FACT – Strain from pain and favoring one side can cause stress on the jaw joint.
- 11) FACT.
- 12) FACT & MYTH – Experts agree that TN often returns, but it does not always come back, and people may die before the pain would have returned.
- 13) MYTH – They don't often help typical shocks, but do help other facial pain.
- 14) FACT.
- 15) MYTH – TN occurs most in folks 50 and older.
- 16) FACT – The tear glands are innervated by the nerve.
- 17) FACT.
- 18) MYTH – It can work right away.
- 19) MYTH – It can, but it doesn't always.
- 20) FACT.
- 21) MYTH – Always take med's at the first sign of an attack.
- 22) MYTH – TN was first described in the 11th century by an Arab Physician.

Now you know! If you didn't get too many answers right, then perhaps it's time to get to the meetings and read the best source of information out there - the book; ***"Striking Back! The Trigeminal Neuralgia Handbook"***.



Contact TNA National and Local Groups:

Ruth Purchase, Facilitator, Pacific NW TNA Support Group
1809 14th St., Oregon City, OR 97045.
Ph: (503) 650-1984 Email: pacificnwtna@hotmail.com.
Website: <http://homepage.mac.com/airira>

Please send donations for the Pacific NW Group to:
Jean Pierce, Pacific NW TNA Treasurer,
2309 S.W. First Avenue, #2141 Portland, OR. 97201.
Email: jeanglass@aol.com Phone: 503-220-0510.

Cathie Whitesides, Facilitator, Seattle Chapter of TNA
Ph: 206-525-6869 Email: cathiewhitesides@uswest.net

Sponsored by the National Trigeminal Neuralgia Association, a 501 (c) (3) non-profit organization based at
2801 SW Archer Rd, Gainseville, FL 32608
Ph. 1-800-923-3608 Fax 352-376-8688
Website: www.endthepain.org
Email: tnational@tna-support.org
Patient Representative, Alana Grecka, RN 1-800-929-3608



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