



# Nerve Center

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2005

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

## February Discussion: Planning for Action

We welcomed several new people at the last support group meeting, held on February 12<sup>th</sup>. There were TN patient's family members, spouses and partners in attendance too, many of who were also at their first meeting. All of the folks who turned out were interested in learning about the topic of the group's discussion, ***Planning a Course of Action against Pain.***

We gathered in smaller groups to talk, by matching up the face pain patients that felt their pain was under control and who had extensive experience, with the ones who were newly diagnosed or needed guidance. Family and friends sat in the different groups and participated in the planning along with their counterparts. Several also met up with each other on the side, sharing their experiences as caregivers and learning about supporting the person in pain.

We heard from two members who had undergone a Microvascular Decompression, (MVD) surgery about 2 months earlier. One of the men had excellent results, and is now pain free and off of all medications! He came to tell the group about his surgery, and spoke about how and why he came to the decision to undergo the MVD. He planned well in advance, getting his insurance in line and making sure he could afford to be off work long enough to recuperate. He learned about his treatment options by calling other members and coming to group meetings, and he had second opinions and many consultations with the best TN experts he could find in the Northwest. It should be noted that typical trigeminal nerve compressions by the arterial/vascular system were found right where the MRI had shown, and they were relieved by the surgery.

We were saddened to know that the other man's MVD surgery had failed to relieve his face pain. He and his family had made the same moves in planning for his treatments. They educated themselves by coming to the group meetings, reading up on all the literature and the Striking Back book, by talking to several members via emails and phone, and they consulted with well known TN medical experts in the Portland Metro area. Everything seemed to be right for the selection of the surgery, as his pain was hitting several times a day and making life unbearable. Now, his family is helping him to plan a course of action for his ongoing face pain, using a multi-modality approach *(continued on p.2)*

## Neuroscientist to Address Group in April

**Thomas Baumann, Ph.D., Associate Professor of Neurological Surgery, Physiology, and Pharmacology at Oregon Health Sciences University (OHSU)** will be speaking to the support group at the **April 9<sup>th</sup> meeting**. His talk to the group, entitled *Trigeminal Neuralgia: Intra-operative and Laboratory Studies* was presented at the 2004 TNA Conference in Orlando, Florida last November. It was one of the most talked about sessions by TN patients and Medical professionals who were lucky enough to see his fascinating lecture.

The slides from his research showing the microelectronic recordings of the nerve discharging during an attack will be explained in detail by Dr. Baumann at the meeting. TN patients will have the opportunity to ask him questions and gain a deeper understanding of how the nerve works and how it transmits pain signals.

Some of Dr. Baumann's other research activities with TN related issues include; "Neurophysiology of trigeminal neuralgia", "Ion channels involved in transduction of thermal, mechanical and chemical stimuli by trigeminal and dorsal root ganglion (DRG) neurons and their modulation", and "Ion channels responsible for ectopic, neuropathy-related action potential discharge in DRG neurons"

We encourage you to invite your doctors and other healthcare providers, along with family or friends to this important talk. We will all gain a deeper understanding of how the nerve works; how it misfires and how it causes pain. Saturday, April 9<sup>th</sup>, 1:00 – 3:30 at Legacy Meridian Hospital Community Ed. Ctr, Tualatin. *(see map on back)*



## Meeting Dates & Changes

The Pacific NW TNA Support Group meets on Saturdays at 1:00 – 3:30 at Legacy Meridian Hospital's Community Education Center. The remaining 2005 dates are: April 9<sup>th</sup> – June 18<sup>th</sup> – August 27<sup>th</sup> – October 15<sup>th</sup> – December 10<sup>th</sup>. **Please note that the October date has changed.**

**The Seattle Chapter** of TNA meets Saturdays at U.W. Medical Ctr. in Room BB389, at 2:00 – 3:30 pm. March 26, April 23, May 14, June 11. *(see contact info on p 3)*

**Planning** (from p.1) with pain specialists as well as medical treatments. It should be noted also, that his MVD surgery revealed a cluster of small veins on the nerve which were removed, but the pain returned soon after he awakened. Now there is a question as to whether or not he has TN *or* one of the other types of facial pains. His diagnosis is still undecided on by medical experts.

There was discussion among the groups about how TN and related facial pain syndromes can be so unpredictable, as these two cases illustrate. Even with the best planning and the best advice possible, there is a variable that we still do not understand. The world's foremost TN experts; doctors, scientists, and researchers are stymied by the "unknown" about the functioning of the trigeminal nerve, why one patient responds to a treatment that won't work for another, and why the pain can return at anytime despite having been pain free from a prior treatment.

We asked members who were available via our email list to send in their experiences about planning for a course of action, and we were pleased with the responses received. A few folks sent in their story about treatments and how they have handled their pain, a great way for us to learn from each other's insight. We appreciate the effort of those members who took the time to write in!

**Gary - ATN.** I have Atypical TN, have had the MVD surgery years ago and more recently the Gamma Knife, (GK) procedure (about a year ago). My pain is still present, mostly as an ache in the lower branch and it hurts when I chew, or talk. I take 1500mg. each of Neurontin and Trileptal and have been on this regimen the last few years with good results.

How to plan for the future is now my dilemma, so to speak, as I plan to retire this year. Do I continue with my medications, and incur the costs? Or do I consider the other types of procedures that will undoubtedly produce some numbness, and the risk of getting the Anesthesia Dolorosa (AD) type of pain? AD is unlikely, but in some ways it could be as bad as or worse than TN. There are always tradeoffs; something we all face with this condition. The easier way for me is to just continue on with taking the Neurontin and Trileptal, and depending on medications as I have for the last 30 years. But, I still have the pain day in and day out, and I would like to know what it's like to not have to deal with it. So, that's what's going through my mind about my future. I just don't have an answer yet.

**Jacqueline – TN, PHN.** I was diagnosed with TN in the fall of 2002. The primary cause was the herpes virus which also caused severe vertigo, vision and balance problems. I struggled to find the right treatment & pain

relief. After being on 9 medications, I decided I had to become informed about this condition. I bought the book "Striking Back". I studied neurology, physiology and even wrote my term paper for school about TN.

Here is what helped me the most: biofeedback and supplements for cranial nerve repair. Acupuncture for pain relief. I have returned to a normal life working at the Naturopathic College, running my own business and finishing my degree. I would like to thank you and other members for sharing their stories, resources and support at the few meetings I did attend.

While my case of TN was mild compared to some of the other members, I am writing this story to let others know that TN may not be permanent. I have a few mild lingering side effects but nothing to complain about.

**Judy – TN.** I was fortunate to attend the February Pacific Northwest TNA support group meeting. I can not tell you what a godsend this meeting and group of people were to me! It's the first time I had ever talked to anyone who had TN, let alone anyone who had even heard of it. The previous six months when my electric shocks had gotten to the point of unmanageable and dropped me to the ground and even with great support of my family and friends I had felt like my life was over.

Chatting with people who knew what I was talking about and actually could relate to it was a very emotional experience! I gained so much from that meeting and am so relieved I finally found out about this group so we could attend. I'll notify my neurologist about the next meetings so any of her future patients can be notified and won't feel as alone and crazy as I did! I learned a wealth of information that has made my life much more manageable, and my boyfriend who had basically been a caregiver for the last six months learned some great ideas to help us on a day to day basis. Talking about the pain and breaking into small groups and actually receiving input on how other people handle their pain was not only beneficial but gave us a new insight into the whole disease. My family plans on attending the next one!

**Kathleen – TN.** My experience with TN has been odd, or maybe not. I first noticed symptoms when living in the Caribbean; the right side of my face would feel cold, but there was no pain. I was a diver and had an increasingly difficult time descending--I got severe pain into my teeth with the descent and had to go down much more slowly than the other people I would dive with. I now wonder if it was the pressure on my skull that caused the TN to start up.

After returning to the states I had no symptoms until six month later. I had some odd feelings in my head, just a

weird sensation in my brain. Then on the 4<sup>th</sup> of July I had an excruciating attack of lightning like, piercing pain into my right cheek near my nose. It got worse and worse until I was sobbing on the floor. I managed to call a girlfriend to take me to the ER and my other girlfriend rushed over and gave me some Neurontin which I chewed up along with some pain reliever I had.

In the ER the doctor kept asking me to describe my "migraine". I kept telling them it wasn't a migraine but trigeminal neuralgia. I knew what it was because I was in my neurologist's office being worked up for carpal tunnel syndrome the week before and had told him that I had funny feelings in my brain. He immediately stopped the work-up and sent me for an MRI of my brain, telling me that I might have TN or Multiple Sclerosis. The MRI was 'normal'. Since then I have learned that a special MRI is necessary to really see the trigeminal nerve and the adjacent blood vessels. The pain stopped suddenly and I felt fine. My neurologist placed me on 300mg of Neurontin twice a day which seemed to keep the nerve calm and stopped the pain. For awhile.

In December of that year I was diagnosed with endometrial and ovarian cancer. I had a hysterectomy and was told I needed both radiation and chemotherapy. My worst fear was that my TN would get worse and no one could tell me whether or not the chemo (which is neurotoxic) might exacerbate my condition. Sure enough, my TN symptoms worsened. I upped my Neurontin to 2400-3600mg/day and this kept the pain pretty much under control. My feet hurt a lot too. (*a Neurontin side effect.*)

Soon after, I started taking Welbutrin for depression. I had been seeing Paul Dart, MD and osteopath, for at least 6 months, for cranial work to try to cure the source of my TN. Dr. Dart's theory is that the bones of the skull are not moving correctly with normal rhythms of the cerebral spinal fluid. His treatment is a gentle mobilization and allowing of the rhythm to reestablish itself. His treatments helped but did not totally eliminate the pain and hence the need for Neurontin.

The day after a cranial treatment and starting the Welbutrin, I noticed that my pain was totally gone. I do not know for sure what stopped it but I had no symptoms until the nine months later. I even went off the Welbutrin in a few months before that without any reoccurrence of TN symptoms. In the fall I once again noticed that a cold breeze across my face was triggering the pain. I mostly managed it by staying out of the cold air, and I took Neurontin once in awhile. The pain was mild but a daily presence. Then a few months ago I had a major surgery on my left femur. After coming out of the anesthesia and making sure I was not given morphine for pain, (I think it was coming off morphine after my hysterectomy that triggered the second most agonizing attack of TN), I

again noticed that my symptoms had totally disappeared. They have not returned, thank God and knock on wood.

**Alice - ATN.** Even if I do not come to the meetings which are too much travel for me, I am always happy to support the group and hear about our activities. I have had two periods of severe pain recently where I have had help from a Healer - I know it may sound odd but that is what has helped ME.

**Resources for planning a course of action:**  
**Striking Back! The Trigeminal Neuralgia and Face Pain Handbook.** Published by TNA in 2004 and authored by George Weigel and Kenneth F. Casey, M.D. It is written in layman's terms, describes all aspects of TN and facial pain, and provides information and resources for patients, family, and medical professionals. \$24.95 plus shipping. Order from TNA National on the website, by phone or by mail. (*See Box insert below*)

**Port in the Storm; How to Make a Medical Decision & Live to Tell About It.** By Dr. Cole A. Giller. A step by step guide for patients and families to get the best of care, along with references for learning about the medical and ethical decisions patients go through. Available at Amazon.com and national book retailers for appx. \$12.00



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Everyday I beat my own previous record for the number of consecutive days I have stayed alive!



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