



Nerve Center

Sept/Oct
2004

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

Lessons Learned at August Meeting

Our August group meeting topic of **The Lessons Within the Journey** was an appropriate one, especially for the new members who were in attendance. They were interested in learning how long-time face pain sufferers have navigated their way through the many treatment options, different medical providers, and rollercoaster ride of emotions that are part of living with TN. During the meeting, the “old-timers” talked with the “newbies” answering their questions and giving advice on all manner of subjects. It was helpful for everyone involved as we went off-topic intermittently to focus on the new member’s need for information and emotional support.

Displayed at the meeting was a quote from the **International Association for the Study of Pain (IASP)**, (of which the TNA National Organization is a member). *The definition of pain is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.” According to the biopsychosocial model, pain begins with input from sensory structures, which cognitive processes interpret. Next, individuals respond at a feeling level, and then act on their feelings. The progression is sensory→ cognitive→ affective → illness behavior.* This quote opened the door to discussing where we are on our own journeys with facial pain, and how we can find the strength to continue on the path to wellness and contentment despite the pain. (continued. on p.4)



Aiding Diagnosis and Facial Pain Patients

Local Neurosurgeon and TNA Medical Advisory Board Member, **Dr. Kim Burchiel**, along with numerous Associates at **Oregon Health Sciences University**, (OHSU), have been making great strides in helping TN and face pain patients. Due to their extensive involvement in research and innovative treatments for TN patients, OHSU will be sponsoring the **6th National TNA Convention in Portland, Oregon to be held in 2006**. A visit to the OHSU Neurosurgery website brings up several areas where research and progress is being made, along with in-depth information about TN diagnosis, surgeries and treatments. It also has short intra-operative films of the MVD procedure showing the vascular compressions on the nerve. (continued on p. 3)

Trigeminal Neuralgia in the News

Another article about TN appears in **RVLife Magazine’s October Issue**. In the July/Aug issue of *Nerve Center* we told about an article in the magazine where Jim Tosetti, a TN patient and retired doctor, writes about his struggle with newly diagnosed facial pain. We are happy to report that Jim has become pain free recently with the help of a doctor referral from TNA’s Colorado Support Group Leader, Vince Nelson. He writes about the procedure and his related conditions in the magazine’s column, **RX for Healthy RVing**. The article, called **Persistence Pays**, is a very appropriate title for his story about TN! Congratulations to Jim and his supportive wife Cappy! The article can be found at www.rvlife.com, or through Business Day, Inc. at: 1-800-511-6918.

There is a new research project entitled **Relationship Between Trigeminal Neuralgia and Health Related Quality of Life**: Instrument Development and Testing, (TN-HRQOL). It is designed to analyze the quality of life of trigeminal neuralgia sufferers. While there will be no direct benefit to any individual who participates in this study, the TN-HRQOL Survey resulting from this effort should provide a means by which care providers can monitor the effects of Trigeminal Neuralgia on the health-related quality of life of the patients they care for over time. The project has several phases where TNA members can participate, and we will let you know when it has progressed to that point in future issues of the *Nerve Center*. The study has been approved (continued on p. 2)



2005 Pacific NW TNA Meeting Schedule

**February 12th - April 9th - June 18th
August 27th - October 22nd - December 10th**

*All meetings are held on Saturdays at 1:00 - 3:30
in the Community Health Education Center at
Legacy Meridian Park Hospital - Tualatin, OR.*



Cut out on the dotted lines and attach to your calendar.

TN in the News... *(from p. 1)*

by the **National TNA's Scientific Review Committee** and **Claire Patterson**, Founder and President Emeritus of TNA. It is being conducted as part of a master's degree requirement for student **Shaun Shore** from **Baylor College of Medicine** in Houston, Texas. Shaun had TN many years ago and was part of the Pacific NW Support Group prior to moving out of the area. We are happy to see that he is turning his experience with TN pain into a project that will benefit other TN sufferers for many years to come!

In the last issue of *Nerve Center*, we wrote about an **Independent Film** being made about TN by Seattle area **Filmmaker and Screenwriter Devin Maurer** of Forest Beach Productions. Many members have contacted him about being interviewed for the film's real-life patients that are being portrayed along side of the fictional characters and storyline. Mr. Maurer wasn't available to address the group at our last meeting and hasn't been able to interview more of the TN patients who contacted him, as he is out of town working on another film. He will resume work on the TN project when he is back in the area, so if you have not yet been interviewed please note that he will return your inquiries when his schedule allows. If you wish to be part of the project, he is now **looking for men with TN and/or Anesthesia Dolorosa patients** for interviews. Please leave your contact information at his email address: pappiriqqi@yahoo.com, or leave a message at: 206-524-8611.

Patients Need to Speak Up More

New research suggests that most patients who underuse medications because of costs do not discuss the matter with their physicians, according to a report in the *Archives of Internal Medicine* in September 2004. **Dr. John D. Piette** and colleagues from the **University of Michigan in Ann Arbor** surveyed 660 older adults who reported the underuse of medications in the previous year due to costs. In that survey they found that 2 out of 3 of patients didn't inform their physician of the plan to underuse medications in advance and about 1/3 didn't bring up the topic at all. Fully 66% said that no one ever asked about their ability to pay for prescriptions, while 58% percent of patients believed that their provider couldn't offer help anyway. When patients did discuss medication costs with their doctors, 72% found the conversations useful, but 31% said that they weren't offered anything to help with costs such as generic alternatives, comparable medications, or referral to a prescription assistance program, (PAP).

What can TN patients do? Contact their doctor or the physician's assistant, a nurse, the pharmacist, community

agencies, or TNA. Many members with income or medication cost limitations have already received help with their medications, but they had to ask about it first. We have information at our Pacific NW and National TNA offices about the prescription assistance programs for most all of the medications used to treat TN and related face pain. Help is available – don't underuse your prescribed medications. *Speak Up!*

October Meeting to Address Medications

Join us at 1:00pm on Saturday, **October 16th** for the Support Group meeting at Legacy Meridian Park Hospital in Tualatin, Oregon. We will focus on the subject of **Medications Used to Control TN and Related Facial Pain**. Whether you have been on a long-term medication regimen or are still trying to find the right ones to use, there is a call for up to date information. We will have handouts with facts about the common med's used to treat face pain, information about interactions with other drugs and reports about alternative and compounded topical applications of drugs. Bring a list of your current medications and bring your questions. The meeting on **December 12th** will feature **highlights from the 5th National TNA Conference** held in Orlando this November. The newest information about TN and related face pain from the world's best experts will be featured.

VOTE! VOTE! VOTE! November 2, 2004

Editorial comment by Ruth E. Purchase

I have been talking with my two sons' who are now 21 and 19 years old, trying to explain - once again - *why* they need to be registered to vote and take part in the elections process. I know that at their young age it doesn't always occur to them why their vote would make a difference, or what the political process, candidates or ballot measures would do that impacts their lives. But I am happy to say that they have become more interested in learning about the issues before the voters this November. You see, I have been telling them that no one person can possibly understand every nuance of every ballot measure – not even those who write the measures and advocate for them. We don't sit at dinner for months on end, talking with every candidate that is up for election, learning about their entire lives and knowing how they will run the office if elected. Yet we can read, we can talk to our friends and families, listen to the debates, and make use of our life experiences, our morals and our judgments. We can make a decision, make it with the most information we can gather, and then go to the polls. No matter what your beliefs, no matter who you want to be your next President, Governor, Congressperson, Representative, etc... you would not even have that choice if others before had not taken the time to fight for and then exercise their right to vote! *(continued...)*

The Trigeminal Neuralgia Association does not endorse any political party or candidate, whether at the national or local levels. TNA does, on occasion, advocate for funding and research along with other patient's issues before some government entities, and we do **highly encourage members to participate in voting and making their voices heard!** As I reside in the State of Oregon, I am familiar with the ballot measures that could have an impact on our TNA members specifically, and on my own life as a pain patient. We have Measure 33 which would change the Medical Marijuana laws, Measure 35 that changes some of the Medical Malpractice award limits, and Measure 38 which changes the State Accident Insurance Fund, (SAIF), (workers compensation laws). I know that in Washington State and in Idaho other measures could also have an impact on the lives of pain patients like you. Whomever you want to have in office, and whether you want the ballot measures to win or lose, please, do your part and **VOTE. Let your voice be heard!**



Aiding Diagnosis... *(from p.1)*

The OHSU website for facial pain can be found at: <http://www.ohsu.edu/facialpain/index.shtml> *(Follow the links to "progress in trigeminal neuralgia" for detailed treatment information.)*

The new OHSU interactive web page for diagnosing facial pain is now up and running! TN and related facial pain disorders have been diagnosed for a long time by using the patient's self-reported pain symptoms and medical history. Burchiel and associates have taken this idea much further by developing a series of questions designed to elicit responses that point to the proper diagnosis. Throughout several years of work, they have fine-tuned the questions by utilizing patients at OHSU, computer models, and TNA. Local group members have participated in several stages of the clinical study while under development both here in Portland and at the last TNA National Conference in San Diego. The web-based questions are geared for the patient to use, with descriptive terms in lay-person's words. After answering the questions, a web page gives the patient a diagnosis based on Burchiel's new classification scheme. *(See below.)* Although this certainly helps find a diagnosis for the patient who uses the website, it is not intended to replace clinical examination by a physician, which is necessary in the diagnosis and treatment of facial pain. *(Data entered on the web-based questionnaire is not collected, nor will it reveal the patient's identification.)*

In another of the clinical studies at OHSU, a specific **magnetic resonance imaging (MRI) protocol** is being used to determine the presence, source, location and severity of neurovascular compressions in patients with

trigeminal neuralgia. The MRI results are being confirmed during subsequent follow-up microvascular decompression, (MVD) surgery. Information for running the imaging protocol is available for Radiologists on the OHSU website and through direct contact with OHSU.

Dr. Burchiel is also the Editor and Contributor of a highly acclaimed medical textbook, ***Surgical Management of Pain*** published by Thieme Medical Publishers, 2002. *(This is one of his many writing contributions regarding neurosurgery and pain management.)* According to **The New England Journal of Medicine's** review: "The book is well organized, with broad coverage not only of surgical approaches to pain management but also of nonsurgical and pharmacologic methods of pain control. ... The list of well-known contributors to the book reads like a Who's Who in the field of pain management. ... This excellent book will interest anyone treating pain and pain syndromes, regardless of their specialty and regardless of whether they see patients whose primary symptom is pain or other patients. The material will be of value to those of all levels of expertise, from students to generalists, surgeons, and anesthesiologists and those who specialize in the day-to-day management of difficult, recurrent, and intractable pain."

Other notable research projects that are currently being done at OHSU include: **Neurophysiology of Trigeminal Neuralgia**, sponsored by The National Institute of Neurological Disorders and Stroke. The goal of this research is to apply a novel micro-neurographic recording technique to study directly the neurophysiological characteristics of trigeminal ganglion neurons in patients with trigeminal neuralgia. **Age-related change in trigeminal ganglion excitability** is a research project sponsored by the National Institute of Health / National Institute on Aging. The goal of this pilot research proposal is to determine if age is associated with a change in intrinsic electrical properties of trigeminal ganglion neurons. **Ion Channels in Spontaneously Active Dorsal root ganglion Neurons from Patients with Intractable Pain** is research funded by the Medical Research Foundation of Oregon. The results of this proposed study will ultimately lead to less invasive treatments for patients with neuropathic pain.

The OHSU website also has the new **Classification Scheme for TN & Related Face Pain** that Dr. Burchiel has developed, which incorporates descriptions for so-called "atypical" trigeminal neuralgias and facial pains. This classification scheme minimizes the negative connotations of "atypical", accepting that the physiology of neuropathic pains could reasonably encompass a variety of pain sensations, both episodic and constant. It is hoped that this classification scheme will be adopted by

the medical community world-wide, thereby allowing doctors to communicate effectively. It could also help to facilitate understanding between patients, clinicians, and insurance providers with globally accepted terms.

The TN and related facial pain diagnostic labels are:

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.



Lessons Learned in August... (from p. 1)

A **Chronic Pain Response Quiz** was handed out to the people in the group so that they could take a look at how they respond to pain in everyday life. More than half of the questions in this quiz relate to the psycho-social aspects of chronic pain. However, when it was initially given to pain patients during development and research the majority had noted using physical aids nearly twice as often as the mental/emotional aids. This underscores just how far we must come as patients in utilizing our mind and spirit to fight the impact of pain. By answering this quiz below you can see what your own pain response is, and where you might be able to improve upon it. *(There aren't any right or wrong answers, and only you can keep score on how it influences you!)*

Approximately how many times in the last week did your TN or facial pain, (and the treatments or medications used for it), cause the following to occur?

- 1) Encouraged self or changed thinking
- 2) Avoided painful activity
- 3) Physical exercise/stretching
- 4) Kept on doing an activity
- 5) Contacted friend/family for support

- 6) Asked for/accepted help with a task
- 7) Rested
- 8) Relaxed to reduce pain
- 9) Relaxed to function better
- 10) Paced activity
- 11) Realized that pain does not prevent activity
- 12) Used breakthrough pain medication
- 13) Sought health care/advice
- 14) Changed activity
- 15) Used ice, heat, massage, etc.
- 16) Accepted pain
- 17) Struggled to control pain
- 18) Tried not to think about pain

Listed below are ten cognitive exercises designed to help maintain a positive attitude. The group discussed many of them during the meeting and talked about their experiences using similar ideas to help with their outlook on life. Although the list came from a website for Fibromyalgia patients written by **Deborah A. Barrett**, it does relate all chronic pain patients.

Ten cognitive exercises to help maintain the most positive attitude we can:

1. **Expect bumps!** It is important to acknowledge that we will sometimes feel down. Who wouldn't in our condition? But by expecting rather than dreading down time, such periods become more tolerable. After accepting that we will sometimes feel sad, and even experience self pity, we can concentrate on ways to shorten these periods and make them fewer and farther between.
2. **Track the changes.** Living with chronic pain easily creates a Jekyll-and-Hyde persona, where your optimistic self and your flare-up self are not sufficiently acquainted. Counting and measuring the duration of the bad times - as well as the good ones - can put them into perspective. For example, it may be that over time our worst attacks occur about once a month, although it feels much more frequent. This knowledge is empowering because we can remind ourselves that a bad flare is, for example, our monthly temporary setback, and find ways to ride it out until our baseline returns.
3. **Stockpile fun distractions.** One of the cruelties of our condition is that when we need distractions most, we are least equipped to seek them out. For this reason it is important to compile a list of our favorite activities when we are feeling optimistic, to be used when we need them most. Our brains can only process so much input at once. When we are engrossed in a beautiful movie, talking to a good friend on the phone, or listening to our favorite music, we can trick our pain receptors into leaving us alone. Improvements in spirit have an added impact

on our entire well-being, while dwelling on our troubles tends to compound them.

4. **Shape your perspective.** Is the glass half empty or half full? Perspective determines, quite literally, how we view the world. Am I, for example, a successful pain patient or an unsuccessful professional? Having a chronic illness creates an ambiguous construction of reality for us. Our perspectives are shaped by the comparisons we make and the expectations they create. What keeps our spirits up and makes us thankful rather than bitter? Our perspective.
5. **Create a new self.** If we hang on tightly to the "old self" we were, finding the value of our "new self" becomes increasingly difficult. (We may even exaggerate how fit that person was: "I didn't need any sleep, I never felt bad and I could do anything!"). We should seek to find in our new bodies new ways to enjoy and experience the things we have done before. We need to recognize that our expectations of ourselves must shift so that we can once again meet them.
6. **Don't forget the good stuff.** While the physical symptoms of chronic pain can feel all-encompassing, there are other parts of our life - our social relationships, passions, family - that also exist. By focusing on the positive aspects of our life, we become more aware of how many there are. We should celebrate whatever we manage to accomplish, however small, as it eventually adds up to something we can be proud of.
7. **"Oy, it could be worse."** Try to think of it this way - many bad things happen in the world, and the odds are that some of it will happen to us. Not because of anything that we have done, but because, as the saying goes, "It" happens. So, this is what has happened to us. We too were caught. We are already experiencing the worst, and, to our credit we are getting through it. As we understand how our actions and emotions influence our general well-being, we can find ways to partake more in life.
8. **Keep the hope alive!** There is so much room for hope. It has only been since the last few decades that our condition has acquired real legitimacy from the medical community. We are in a far better position than the generations before us who suffered without ever receiving validation or proper treatments. Furthermore, as medical research increases, better treatments (and perhaps even a cure!) are being continually introduced.
9. **Lean on me.** A single most important predictor of how well we cope is the support network we create. Make sure that you continue to be a good friend to those you care about. We still have lots to give. Try to be open with family and friends while at the same time being supportive of their needs. Put yourself in

their shoes, it can be scary to have someone you love be in pain. Also make sure to seek help outside of your immediate circle so as not to drain your closest friends and family. By utilizing the TNA network, others who understand your pain can help you through the tough times.

10. **Indulge whenever you can.** When unable to function due to pain, we have time to focus on our thoughts. We really do have control over how we use this extra time in our minds. Instead of dwelling on what you are not doing, give your thoughts full liberty. We can use the time to think through problems we face and how we can spend our time when we are feeling better. We can turn these inactive periods of time around, and make the most of them as indulgent time in our mental playground!



July/Aug Treasury Report

Thanks to all the members who so generously contributed money to our Pacific NW TNA Support Group. We rely on our members for our mailing and meeting costs. Unfortunately we are not allowed to give a tax deduction for donations made directly to our local support group. However, donations sent to the national TNA are tax-deductible, and those earmarked for our Pacific NW group will be passed on to us. ***National TNA relies on members' gifts also. Donations for National TNA will be matched by donors until December 31, 2004 Thanks!***

Beginning Balance 07/01/04 -- \$397.94
Donations and Book Sales --\$241.17
Expenses:
Postage and Supplies -- \$202.70
Meeting refreshments --\$34.19
Ending Balance 8/31/04 -- \$402.22

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