



# Nerve Center

July/August  
2004

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

## Your Medical History Can Influence TN

The support group meeting on May 22<sup>nd</sup>, 2004 was full of information geared to help our members learn about the importance of how our medical history can influence TN treatments. The discussions started when the group read a set of questions that addressed patient's confidence in communicating with their doctors. The questions helped to underscore the value of effective dialogue with our medical providers and how it can be reflected in our medical records, thereby influencing our treatment options.

**Why do we need to monitor and keep correct medical records?** As patients, we have to be responsible for the vast amount of information included in our many medical records. By the time our info is told to the doctor or others and is transcribed or recorded, it very well may have passed through several hands and can have omissions or errors. No one else can possibly know our history like we do, and it is our responsibility to take charge and be certain that it is complete and fairly portrayed.

The accuracy of our records can influence not only the particular issue at hand, but can be far reaching and sway future physicians' opinions about our case; even if it is a different problem we are seeing them for. Our records can influence insurance claims, disability claims and employment. The information recorded can alert doctors to changes in our symptoms, pain levels or medications, and help to forewarn them of any problems. We can utilize them for our own research, to coordinate our care, and to get second opinions. *(continued on p.2)*

## Conference Reaches All TNA Members

TNA Members who are unable to attend can still have a say at the National Conference in Florida this November 11<sup>th</sup> -14<sup>th</sup>. Your local support group leaders, Ruth Purchase and Cathie Whitesides will be attending this year, representing the Pacific Northwest and Seattle support groups. They want to get **answers for members' questions**, particular to each person's needs. They can talk with most of the Doctors and others within the TNA Organization, so let them know if you want a specific

person to answer. Please take a moment to write down your questions and give them to Ruth or Cathie at the next meeting, or send them an email online or a note in the mail. *(see info in box on p. 4)*

There will be another **Paint Your Pain** show this year, which has been a popular display at the conference. The invitation is open to all TNA members who wish to display their artwork. Entries can be anything that shows how the person feels about their face pain or their victory over pain - the written word, song, painting, multi-media, sculpture, etc... This is a non-juried exhibit with no prizes. Submissions must be received by October 8<sup>th</sup> at TNA, c/o Artistic Expression Contest, 2801 SW Archer Rd, Gainesville, Florida, 32608. Please include your name, (unless you wish to remain anonymous), your city, state, and phone number. Call the Conference Office at 615-255-6035 for questions.

## The Lessons Within The Journey

At the next meeting we will explore the lessons that have been learned by TN patients as they traversed the sometimes treacherous paths from illness and pain to wellness and contentment. The group will focus on issues that all pain patients experience no matter where they are along the journey. We will learn how to manage the changes in our lifestyle, relationships, and psychological well-being, and examine how TN has altered our view of the world around us. The support group meeting will be on Saturday, August 28<sup>th</sup>, at 1:00-3:30 at Legacy Meridian Park Hospital, Community Education Center in Tualatin. The Remaining 2004 meetings are: Oct. 16 & Dec. 11.

## Trigeminal Neuralgia in the News

An Independent Film Maker from Seattle is making a movie about TN patients. Several local TN'ers have already granted interviews to **Devin Maurer of Forest Beach Productions, the Screenwriter and Director of the film**. According to Mr. Maurer, "My hope is to paint an honest, realistic, and profound picture of a terrible and often misunderstood affliction. This is not a traditional documentary on TN (I'm using actors to tell the story of

two young people (mid to late 20's) afflicted with classical tic douloureux and "atypical" TN, respectively. And although their struggles are based on actual stories or accounts, they are still fiction). However, to ensure that I'm accurately portraying the complexity of TN, problems with misdiagnosis, and general lack of information, I'm using real people and doctors telling real stories about their experiences."

Mr. Maurer has been invited to give a short introduction about the film project at our next meeting at Legacy Meridian Park Hospital on Aug. 28<sup>th</sup>. (*appearance not confirmed as of printing date*) Members who wish to be involved or interviewed should contact him directly at: 206-524-8611, or email pappiriqqi@yahoo.com. *This is not a TNA sponsored film, and absolutely no information about, or images of any TNA member has or will be disclosed to the production company unless the member contacts them directly.* It will be up to TN patients individually to decide whether or not they want to talk Mr. Maurer or tell their story on film.

**A recent issue of Equine Magazine** featured an in-depth story about horses that have trigeminal neuralgia. It was brought to the May group meeting by long time member, Dot Schultz.

According to the article, the symptoms of TN are noticeable and treatable in horses. The affected horses have a tendency to throw back or shake their heads violently, they object to bits and bridles, and sometimes rub their faces on buildings and other sturdy objects incessantly. Most are known to have a vascular compression on the trigeminal nerve similar to humans, and they are using surgical techniques on the more valuable horses to relieve their pain.

The article went into great detail about TN both in humans and in horses, describing the similarity in our anatomy and in the treatments used. We are glad to hear when any awareness of trigeminal neuralgia reaches the public, even through the horses' mouth!

**The August issue of RV Life Magazine** has an article about TN written by a retired family doctor, Jim Tosetti, (with the assistance of his devoted wife Cappy). He writes a regular health column in the magazine called "RX for Healthy RVing." In the article he describes his TN symptoms and how he got a diagnosis. It is short and to the point, giving enough information for readers to understand what TN feels like and how to get help for it. The article listed information for contacting TNA.

The Pacific NW group has already taken a call from a reader of the magazine who was thrilled to find other

TN'ers. She was living in pain for over six years and was happy to hear that there is help for her pain other than medications alone, and that she can get updated information through TNA. We appreciate the insightful article and we are certain that it has helped many more people in the area. RV Life Magazine can be found at [www.rvlife.com](http://www.rvlife.com) or through Business Day Inc., at: 1-800-511-6918.



## **Your Medical History** *(continued from p.1)*

**Where do we find our medical records?** Most patients are aware of records that are with their regular Doctor or Hospital, but there are many other sources. We need to get copies of our records from all of our providers, such as: Dentists, Psychiatrists, Counselors, Laboratories, Physical Therapy, Pharmacy, Eye Care, Mental Health Clinics, Pain Management Clinics, Substance Abuse Clinics, Chiropractors and Acupuncturists. We can also get written reports from Radiology Departments or the Radiologist where images such as CT Scans, MRI's and X-rays, etc. are taken. Occasionally, we need to have the actual images to bring to a doctor, but they should be returned to the clinic for safekeeping

With the new Health Information Protection and Privacy Act, (HIPPA), we can now challenge errors or omissions in our records, and we have the right to keep a written statement in the record if the doctor or clinic chooses not to make our requested amendment. Copies of our records are easily gotten from clinics and offices by filling out a records request or release form. Occasionally there will be a charge for copying, but it can sometimes be avoided by asking for copies for "continuing care". Once we have copies of our existing records, we should fill out a request form at each visit, so we can easily maintain updated copies of our records.

**Communication is a 2-way issue.** Just as we expect our physicians to have accurate information in our records, they rely on us to provide them with accurate information about our health history and circumstances. There are several ways we can help to keep communications flowing. Keep your history written down in a concise manner and have it ready before your appointment. We've all filled out health inquiry forms at doctor's offices, so write down that information ahead of time when you can be more certain of accuracy. (*form on p.5*)

Make a short list of the issues you are seeing the doctor for and write down any questions you want to ask them. Tape record or write down what the doctor says, and make sure that you understand your treatments, medications or surgical options. Speak up and ask for

clarification or ask the doctor to speak in less technical words if you do not understand completely.

Ask the doctor what you should do if you miss a medication dose or if symptoms change. Find out what side effects or other results you should expect and what you should report to the doctor as unusual. Tell the doctor if you've had failures with similar treatments or medications, and tell them about other conditions you are being treated for. Let the doctor know if you can't afford medications, as most drug companies have assistance programs for low or no cost drugs. Don't be afraid to ask for a referral to a specialist if you think you need one. Call the doctor if you are expecting test results. Don't count on their office to contact you, they rarely will if the test outcome is considered "normal".

One of the handouts at the meeting showed a study where chronic pain patients were less likely than non-pain patients to have told their doctors about tinnitus, (ringing in the ears), even though it could be considered severely disabling in many of them. The researchers speculated that those patients are so involved in their pain issues that other medical conditions often become secondary, even though they can be amenable to treatments. Don't forget that TN patients can have other illnesses. Stay on top of your overall health and promptly report any problems to your doctor.

**The patient's right to know.** Be aware of your right to know everything relevant to your treatment and, based on that information, to accept or decline it. A report was done by the American Medical Association's,(AMA), Institute for Ethics, where 720 U.S. doctors were surveyed about the information they share with their patients. According to Matthew Wynia, MD, MPH, Director of the Institute, the survey found that one in three doctors don't tell patients about treatments their insurance doesn't cover. Wynia stated, "Our code of ethics is quite clear. A doctor *must* talk about all potentially useful services, regardless of whether they are covered by the patient's health plan." What the report uncovered is troubling: 31% of doctors sometimes don't offer useful care to a patient because of health plan rules. Nearly one in 10 doctors say they do this often or very often. 35% of the doctors who say they sometimes withhold information also say they do it more often than they did five years ago.

"Most information withheld doesn't threaten patient's health, but it's no excuse for violating their own ethical code. Doctors who withhold information are often just trying to help." Wynia says, "We are talking about a system that is broken, when doctors and patients feel

disempowered about coverage decisions. The most troubling thing is that if someone finds out their doctor did not tell them of something, that can erode trust in their relationship. And that is the last thing we need," he says. "We need doctors and patients to work together, not to be wary of each other." Some group members said that they avoid this situation by telling their doctors to give them all of their options regardless of their insurance coverage, and that they could come up with a way to pay for the treatments if needed.

**Informed consent is common sense.** It is your body, and you have to live with the consequences of treatment. The release forms we sign vary from one clinic to the others, but some general advice holds true for most cases. Read whatever you sign carefully. Ask questions if it doesn't clarify what you want to know about your treatment. Avoid signing any open releases forms – "Don't worry, it's routine," is not an answer. Insist on knowing the details.

The physician should provide the following information so the patient can make an informed decision: A description of the treatment or procedure; A description of the risks and benefits with emphasis on the risk of death or serious disability; A description of alternative treatments and procedures, with the risks and benefits; The likely results should you decide to refuse any treatment; The probability of success, and what the physician means by success; The major problems anticipated in recuperation and how long until you can resume normal activities; Any side effects that may be damaging to your personal lifestyle, work, or activities; Other information such as costs and how much your health plan will cover.

**Patients now have more rights than ever for proper pain control.** New pain management standards were implemented in 2001 by the Joint Commission of Accreditation of Healthcare Organizations, (JCAHO), and they were endorsed by the American Pain Society. The standards create new expectations for the assessment and management of pain in accredited hospitals and other health care settings such as: hospitals, home care agencies, nursing homes, behavioral health facilities, outpatient clinics and health plans. They have been called upon to: recognize the right of patients to appropriate assessment and management of pain; assess the existence and, if so, the nature and intensity of pain in all patients; record the results of the assessment in a way that facilitates regular reassessment and follow-up; determine and assure staff competency in pain assessment and management, and assure that all new staff are also knowledgeable; establish policies and procedures which

support the appropriate prescription or ordering of effective pain medications; educate patients and their families about effective pain management; and address patient needs for symptom management in the discharge planning process. The new standards unequivocally acknowledge that pain is a co-existing condition with a number of diseases and injuries, and requires explicit attention. In a similar move, and recognizing that undertreatment of pain is a public health priority, the Federation of State Medical Boards (FSMB) of the United States, Inc., is recommending a revision in 2004 of the Model Guidelines for the Use of Controlled Substances for the Treatment of Pain. The revisions state that undertreatment of pain, like overtreatment, is a practice violation.

**Our medical history often guides the direction of our TN treatments.** But we can also influence our treatments by being proactive. Foremost in advocating for the best therapy is to believe in ourselves. Because the symptoms of TN can change inexplicably, we will question our sanity, and friends and family may begin to wonder when the doctors can't find anything wrong. Listen to your inner voice when you know something isn't right, and don't give up until you get an answer. Keep track of your symptoms and pain patterns. Do your own research, and verify that it is from a reliable source. Seek out other opinions and insist on referrals to specialists. Talk to others who have TN and learn from their experiences. When you are proactive, you are less likely to become a victim.

Support group members discussed their own history and how co-morbid conditions affected their quest for proper diagnoses and treatments. Some of the problems developed because the medications prescribed often had side effects. Dry eyes and dry mouth were common; they can fire up the nerve and cause additional pain. Dry eyes can cause vision impairment, infections, and pain. Dry mouth can make the patient at risk for mouth sores, dental carries, and gum disease. Tinnitus, when severe, adds to sound sensitivity and stimulates the nerve. When the patient suffers from fluid retention there can be increased swelling and pressure in the sinus and facial tissues, also exciting the trigeminal nerve.

Conditions that can mimic or influence trigeminal nerve pain are widespread among our members. Some procedures like dental work and dental injections are known to cause face pain and can also change the nature of TN symptoms. Injuries or surgeries to the head and neck can damage the trigeminal nerve, adding to or causing pain. Patients can have organic causes for pain such as anatomical deformities of the bony structures; deformed arteries, vessels, or veins; and tumors or

growths which affect the face, head, or neck. Disorders and diseases that can cause face pain, or ones that can alter existing TN are numerous: Chronic Sinusitis; Multiple Sclerosis; Arthritis; Fibromyalgia; Lupus; Lyme Disease; Reflex Sympathetic Dystrophy (RSD); Complex Regional Pain Syndrome (CRPS); Herpes Virus; Temporal Mandibular Disorders (TMD); Hormonal Imbalances; Cervical Vertebrae Subluxation; Depression; and Psychological Disorders; along with many other conditions. Patients who might have any of these disorders are encouraged to discuss them with their doctors. The patient who is proactive will also research the condition themselves, talk to others who have it, and acquire the information in their medical records so they can make informed decisions regarding their care.



## **May/June 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 that are designated as being earmarked for our Pacific NW TNA Support Group are tax-deductible. (*contact info below*)

Beginning Balance 05/01/04 -- \$365.94

Donations and Book Sales --\$66.73

Expenses:

Postage and Supplies -- \$20.00

Meeting refreshments --\$14.73

Ending Balance 06/30/04 -- \$397.94



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*Disclaimer: This newsletter is not intended to diagnose, prescribe, or to replace the services of your health care provider. TNA does not endorse any one treatment or healthcare provider over the others. Please discuss any information in these pages with your own physician.*

# Personal Health History

Use this form to keep track of your health history. Make extra copies for future updates. Give completed form to your doctors.

Name: \_\_\_\_\_ Today's Date: \_\_\_\_\_

Address: \_\_\_\_\_ Home Phone: \_\_\_\_\_

City/State: \_\_\_\_\_ Work Phone: \_\_\_\_\_

Insurance: \_\_\_\_\_ Policy Number: \_\_\_\_\_ Phone: \_\_\_\_\_

1. I was in the hospital for: (list conditions and dates) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

2. I have had these surgeries: (list surgery and dates) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3. I have had these major injuries/conditions/illnesses: (list and date, indicate if any are on-going conditions)  
\_\_\_\_\_  
\_\_\_\_\_

4. I have these allergies (list type of allergy—food, medicine, etc.—and reaction): \_\_\_\_\_  
\_\_\_\_\_

5. I have had these immunizations (shots) / list dates:

Influenza: \_\_\_\_\_ Pneumococcal: \_\_\_\_\_ Tetanus (Td): \_\_\_\_\_

6. I take these prescription medicines - over the counter medications - other supplements: (list dosage & bring with you if possible)  
\_\_\_\_\_  
\_\_\_\_\_

7. My family members (parents, brothers, sisters, grandparents) have or had these major conditions: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

8. I see these other health care providers:

Name: \_\_\_\_\_ Why I see them: \_\_\_\_\_

Name: \_\_\_\_\_ Why I see them: \_\_\_\_\_

Name: \_\_\_\_\_ Why I see them: \_\_\_\_\_

List any other comments or concerns: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_