



Nerve Center

May/June
2004

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

Members Share Their Triumph Over TN

Many new people were at the **March Group Meeting** and had the opportunity to learn from our more seasoned members how they have triumphed over TN throughout the years. Several folks came with their family members and others had close friends who accompanied them from afar. It was an excellent chance for the supporting people to learn how TN patients must deal with stressful details everyday and still keep the big picture in mind when making decisions regarding their care.

Members talked about areas where they had the upper hand when dealing with TN, such as how to get the proper diagnosis, what criteria to use when deciding on surgery, how to keep up with medications and side effects, and techniques they've learned to cope with pain. Due to space limitations in this issue of *Nerve Center*, we can't fit all their great ideas into this article. We thought better to include a copy of the TN Patient Survey so that *all of our members* can participate in creating an information base for doctors, scientists, researchers and patients, in the hopes that we can all learn how to Triumph Over TN.

Your Medical History Can Influence TN

The next meeting of our support group will be held on **Saturday, May 22nd**, where we will learn more about how our medical history can influence the face pain that we deal with everyday. If you suffer from other medical conditions, or if you have wondered about prior invasive procedures, hormonal influences, dental work or cold sores, this will be a good chance to learn more about their affects on face pain. We will also discuss why and how to maintain good medical records and how to relate your history to healthcare providers or others in an efficient manner. Bring your supportive spouse, friend or family members along too - all can learn something of value at this meeting! (*See directions to meeting on back page.*)

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 over the other. Please discuss any information in these pages with your own physician.

Importance of the TNA Patient Registry

TNA has been moving forward rapidly since the new President, Michael Pasternak, Ph.D. took over the helm and we moved to Florida where more teaching and medical and dental facilities can become involved with research and treatments. Due to our growth we have added more personnel and opened up many opportunities for development, funding and research for TN and related face pain. The TN Patient Registry is a valuable tool to help us continue this growth, and it is of utmost importance to have as many patients as possible fill one out so researchers know how many more people are affected than previously thought. The survey has been available on-line at our website, www.tna-support.org for several years now, but we wanted to reach out to those who haven't accessed it yet. (*If you have completed a survey before, you should go to the website to update it.*) Please take a few minutes to complete the confidential survey included in this newsletter! *With your help - together we will end the pain.*

March/April 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 03/01/04 -- \$344.89
Donations and Book Sales --\$191.45
Expenses:
Postage and Supplies -- \$170.40
Ending Balance 04/30/04 -- \$365.94

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<http://homepage.mac.com/pacnwtna>

Sponsored by the National Trigeminal Neuralgia Association,
a 501 (c)(3) non-profit organization based at: 2801 SW Archer
Rd, Gainseville, FL 32608 -www.tna-support.org ph. 352-376-
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Please Fill Out This TNA Survey for The Patient Registry

Now, more than ever, your participation in the TNA Patient Registry is an opportunity for you to contribute to scientific research and expand what we know about TN and related facial pain. It can yield significant benefits, and influence treatments in the future. Please join us in this effort, and build hope for the future by filling out a confidential survey today. *Your history* adds to the importance of our new TNA motto: *Together we will end the pain.*

Mail Completed Survey to: TNA 2801 SW Archer Rd. #C Gainseville, FL 32608

Section 1 Contact Information:

**Please Note* All personally identifying information is held in complete confidence.* Today's Date: _____

First Name _____ MI _____ Last Name _____

Gender: M: ____ F: ____

Password: _____ This is used for reviewing and editing your information later.
Please write down your password and store it in a safe place.

Address: _____

City: _____ State: _____ ZIP _____

Country _____

Daytime Phone: _____ Evening Phone: _____

FAX Number: _____ E-Mail Address: _____

Date of Birth: Month/day/year ____/____/____

Section II: Present Diagnosis

Some people have more than one disorder. Check any that you've had and indicate if you are pain free now.

Trigeminal Neuralgia: ____ Multiple Sclerosis: ____ Other: ____ Atypical Trigeminal Neuralgia: ____
Glossopharyngeal Neuralgia: ____ Occipital Pain or Neuralgia: ____ Temporomandibular Joint Disorder: ____
Atypical Face Pain: ____ I am pain free at present: ____

Section III: Family And Personal History

Has anyone in your family had any of the following conditions? (Check for Yes, If No please, skip to your medical history)

Facial Spasms: ____ Seizure: ____ Neurofibromatosis: ____ Trigeminal Neuralgia: ____
Migraine: ____ Aneurysm: ____ Multiple Sclerosis: ____ Brain Tumor: ____

Which Relatives?

Father: ____ Mother: ____ Siblings: ____ Cousins: ____ Grandfather: ____ Grandmother: ____ Other: ____

Section IV: Your Medical History

Have you Ever been told by a doctor that you have any of the following conditions? (Check all that apply)

Migraine: ____ Multiple Sclerosis: ____ High Blood Pressure: ____
Fibromyalgia/Myofascial pain: ____ Other Headache Syndrome: ____ Seizure / Epilepsy: ____
Stroke: ____ Chicken Pox: ____ Cold Sores / Herpes: ____ Sinus Problems: ____
Lupus: ____ Arthritis: ____ Benign Brain Tumor: ____

Before your face pain developed, did you have a root canal or dental therapy? Yes ____ No ____

If "Yes", how many days/weeks/months before your face pain developed did you have this dental therapy?

Days: ____ Weeks: ____ Months: ____

When did pain first develop in your face?

Year: ____ Your age then: ____

Please describe your pain when it first started: (check all that apply)

Type of Pain:

Aching: _____ Throbbing: _____ Prolonged, Burning Pain: _____ Repeated, Electric Shock Jabs: _____

How Often:

Constant: _____ Several times per day: _____ Several times per week: _____ Several times per month: _____

Less frequent: _____

Which Sides Were Affected: Left Side: _____ Right Side: _____ Both Sides: _____

Did Pain Awaken You From Sleep? Yes: _____ No: _____

Please select the Intensity for each area affected: (on a 1 = slight discomfort, to 10 = very intense, overwhelming pain)

Forehead or Temple: _____ Cheek: _____ In or "Behind" the Eye: _____ In the Ear: _____
Upper Jaw: _____ Lower Jaw: _____ Joint of Jaw: _____ Specific Tooth: _____
Tongue or Roof of Mouth: _____ Throat: _____ Neck: _____ Back of Head: _____

Have you had any Pain in the Last Year? Yes: _____ No: _____

If "yes", please describe your pain: (check all that apply)

Type of Pain:

Aching: _____ Throbbing: _____ Prolonged, Burning Pain: _____ Repeated, Electric Shock Jabs: _____

How Often:

Constant: _____ Several times per day: _____ Several times per week: _____ Several times per month: _____

Less frequent: _____

Which Sides are Affected: Left Side: _____ Right Side: _____ Both Sides: _____

Does Pain Awaken You From Sleep? Yes: _____ No: _____

Please select the Intensity for each area affected: (on a 1 = slight discomfort, to 10 = very intense, overwhelming pain)

Forehead or Temple: _____ Cheek: _____ In or "Behind" the Eye: _____ In the Ear: _____
Upper Jaw: _____ Lower Jaw: _____ Joint of Jaw: _____ Specific Tooth: _____
Tongue or Roof of Mouth: _____ Throat: _____ Neck: _____ Back of Head: _____

Section V: Finding Help For Your Disorder

How long did it take to get a diagnosis? # of Months: _____ # of Years: _____

What type of caregivers did you see before you were diagnosed with TN, ATN, GN, or ATFP?

Dentist: _____ Neurologist: _____ Psychiatrist/Psychologist: _____ Oral Surgeon: _____
Ophthalmologist: _____ Chiropractor: _____ Neurosurgeon: _____ Ear - Nose - Throat Specialist: _____
Doctor (General Practitioner): _____ Endodontist: _____ Pain Specialist: _____

Were you ever incorrectly diagnosed? Yes: _____ No: _____

What incorrect diagnoses did you receive? (Please check all that apply - SKIP if you had no problems getting a diagnoses.)

Abscessed Tooth (root canal or extraction): _____ Tooth Problem (other than abscess): _____ Bite/Occlusion problem: _____
Headache/Migraine: _____ Psychological Problem: _____ Addiction Problem: _____ Gum Problem: _____
TMJ or TMD Problem: _____ Allergy Problem: _____ Sinus Problem: _____ Chiropractic Dislocation: _____

How many times were you misdiagnosed, and for what reasons other than those checked above?

What kind of caregiver first told you that your symptoms might be caused by TN, ATN, GN, or ATFP?

Dentist: _____ Neurologist: _____ Psychiatrist/Psychologist: _____ Oral Surgeon: _____
Ophthalmologist: _____ Chiropractor: _____ Neurosurgeon: _____ Ear - Nose - Throat Specialist: _____
Doctor (General Practitioner): _____ Endodontist: _____ Pain Specialist: _____

Section VI: Drug Treatments You Received

Choose how much of your pain was relieved by each drug you have used. Enter the dates most frequently used.

Circle one type of Relief	Drug Treatment	mg. used/day	(Month / Year) - Start	(Month / Year) - End
None- partial -complete	Carbamazepine (Tegretol)	_____ mg/day	_____/____	_____/____
None- partial -complete	Gabapentin (Neurontin)	_____ mg/day	_____/____	_____/____
None- partial -complete	Ibuprofin, Advil (NSAIDS)	_____ mg/day	_____/____	_____/____
None- partial -complete	Morphine Sulfate (MS Contin)	_____ mg/day	_____/____	_____/____
None- partial -complete	Misoprostol (Cytotec)	_____ mg/day	_____/____	_____/____
None- partial -complete	Baclofen (Lioresal)	_____ mg/day	_____/____	_____/____
None- partial -complete	Phenytoin (Dilantin)	_____ mg/day	_____/____	_____/____
None- partial -complete	Fluoxetine (Prozac, Seronil)	_____ mg/day	_____/____	_____/____
None- partial -complete	Oxycodone (Percodan, Percocet)	_____ mg/day	_____/____	_____/____
None- partial -complete	Sumatriptan	_____ mg/day	_____/____	_____/____
None- partial -complete	Clonazepam (Rivotril, Klonopin	_____ mg/day	_____/____	_____/____
None- partial -complete	Oxycarbamazepine (Trileptal)	_____ mg/day	_____/____	_____/____
None- partial -complete	Amitryptline (Triptyl, Elavil)	_____ mg/day	_____/____	_____/____
None- partial -complete	Codine	_____ mg/day	_____/____	_____/____
None- partial -complete	Pimozide (Orap)	_____ mg/day	_____/____	_____/____
None- partial -complete	Other: _____	_____ mg/day	_____/____	_____/____

List of current or most recent medications and their side effects:

Check here if you experienced no side effects: _____

Select the severity of each side effect on a scale of: 1= mild, 2= moderate, 3 = severe, 4= very severe

Rash: _____ Poor Attention Span: _____ Liver Toxicity: _____ Nausea: _____ Memory Loss: _____
 Dizzy: _____ Felt like a Zombie: _____ Tired: _____ Low Blood Count: _____

Have you discontinued use of medications because of side effects? Yes: _____ No: _____

If "Yes" which drugs and which side effects?

Satisfaction with most recent drug treatment: Very satisfied: _____ Somewhat satisfied: _____ Outcome Acceptable: _____
 Somewhat Dissatisfied: _____ Very Dissatisfied: _____

Section VII: Surgical Treatments

If you had surgery more than once please indicate *how many times*. Give the most recent date you had that kind of surgery. Please select how severe your side effects were. Please indicate how long the relief lasted.

Number of Surgeries	Type of Surgery	Year	Pain Worse	No Change	Partial Relief	Pain Free	Side Effects (please check)				How Long Did Relief Last?	
							Mild	Moderate	Severe	Very Severe	# Months / #Years	
	Microvascular Decompression											/
	Partial Surgical Sensory Rhizotomy											/
	Surgical Cutting of Nerve											/
	Radiofrequency Rhizotomy											/
	Glycerol Rhizotomy											/
	Balloon Compression											/
	Gamma Knife											/
	Linear Accelerator											/
	Nerve Block (Injections)											/
	Neurectomy											/
	Other											/

Why did you select your most recent surgery? I was desperate: _____ My doctor does only this procedure: _____
 Doctor recommended as best alternative for pain relief: _____ Doctor recommended as safest: _____
 I got a second doctor's opinion: _____ I heard of another patient's successful outcome: _____ Based on my own research: _____

Did you feel pressured by your doctor to have the recommended surgery? Yes: _____ No: _____

For your most recent surgery, if you had side effects please describe them:

Check here if you had no side effects: _____

Select the severity of each effect you experienced after surgery on a scale of 1= mild, 2= moderate, 3 = severe, 4= very severe. Leave blank if you did not have that effect.

Pain: _____ Dizzy: _____ Painful Scar: _____ Paralysis: _____ Face Stiff: _____ Hearing Loss: _____
 Hearing Damage/Loss: _____ Stroke: _____ Face Numb: _____ Cloudy or Double Vision: _____ CSF Leak: _____
 Anesthesia Dolorosa: _____ Headache: _____ Uneven Gait: _____

Satisfaction with Surgeon Follow Up Care: Very satisfied: _____ Somewhat satisfied: _____ Outcome Acceptable: _____
 Somewhat Dissatisfied: _____ Very Dissatisfied: _____

Section VIII: Recommendations

Would you recommend a physician who treated you to other face pain patients? Yes: _____ No: _____

Please provide the name, city and state of the physician you would recommend:

Please enter any comments about TNA or our survey.