

Nerve Center

May/June
2006

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

6th National TNA Conference in Portland

The National TNA Conference will be held **September 14-16th** at the **Doubletree Lloyd Center Hotel**. There are many new and exciting things happening this year that we haven't had before! This patient driven conference is one-of-a-kind in the way that the sessions are being held and what topics are being covered. It is very unusual at any medical conference to find patients and their families sitting side by side with the medical professionals at the sessions, meal breaks, receptions, etc. The fact that we are attending the same teaching sessions gives us an additional opportunity to ask pertinent questions of the experts who are there along side of us. According to one attendee from the last conference; *"It feels as if you have the entire Striking Back book interactive and live right here with you! I've met and talked with the doctors who are quoted in the book, I've seen the slides of their statistics and research, and I finally understand all the surgeries and other things that are discussed in the book and on the TNA website. It's so much more than I thought I could ever learn!"*

At the previous conferences each participant was given a suggestion form and questionnaire so their likes and dislikes along with new ideas can be collected and implemented by TNA at future conferences. As a result, we now have 3 days with 3 concurrent sessions going on, with topics and speakers that cover every possible aspect of TN and facial pain. There are around 75 speakers invited to attend, and they consist of the very best experts on TN and Facial Pain in the country and abroad! Because it's impossible to attend all 3 sessions at once, it will be very helpful if members communicate with each other before the conference. By doing so, they can make plans to attend the different concurrent sessions that interest them most and compare notes with each other afterwards. *(Continued on page 2)*



New Ways to Help TNA When You Shop

There is a new way for you to give to TNA when you shop online! We have joined **BuyForCharity.com** where over 350 stores are participating to help benefit the charities they support. Up to 35% of your purchases will be donated to TNA when you buy *(cont. on page 3)*

Caregivers Learn to Deal with TN

Our April 1st meeting had lively conversations going on in the room as members were excited to relay the current changes in their lives. Our focus of the meeting was to discuss the effects of TN on our personal, family, and social life under the topic, ***TN is Not for Fools – Deal with It!*** After some announcements and talk from members about their recent conditions, the group divided into separate sides for the patients and caregivers. This allowed us to talk about issues that were affecting TN'ers personally, and from the family members' perspective. While the family/caregivers gathered and discussed several things on the agenda, the patient's group got caught up in some (very worthwhile) conversations and weren't able to get to the program as planned. We had several helpful guides ready that are geared for chronic pain patients, and we'll work through those at the next meeting. We will continue the group agenda on May 20th, where we will go into depth on the issues that dealing with TN and chronic pain brings to our lives. *(Continued on page 3)*



Talking About Chronic Pain in May

The next support group meeting will be held on May 20th, 1:00pm at Legacy Meridian Park Hospital in Tualatin, OR. We will continue on the subject of dealing with Chronic Pain in our lives and how to overcome the negative affect it can have on us. **Concrete Ways to Beat Chronic Pain** will be the topic of the meeting. There will be worksheets to go through that have an excellent step by step approach to making our lives more productive and enjoyable. When we just let the TN pain get by us and don't attack it with deliberate insight, our thoughts and actions can become automatic and counter-intuitive. This meeting will give patients and caregivers alike some distinct ideas and actions they can take to make their lives flow easier despite the pain.

We will continue to discuss and make plans for the upcoming **6th National TNA Conference** that will be hosted in Portland. Help us to make this the best conference yet by becoming involved. Join us at the meeting on May 20th where we will work on making our TNA motto come true ***...together we will end the pain.***

Conference in Portland (cont. from p.1)

Registration

The registration fee for patients, family members or supporters before 6/1/06 is \$250; \$275 until 8/1/06 and \$300 after 8/1/06. The Conference Brochure and Registration form can be found on our website at www.endthepain.org or by contacting the national office at 1-800-923-3608. They are also available at the Pacific NW Group office or by writing or calling the Conference Chairperson, Shelly Wilson at swilson@tna-support.org or fax 1-817-416-9871, ph. 817-416-7202 or write to: TNA Registration, PO BOX 92604, Southlake, TX 76092.

Your Healthcare Providers

We need our members to forward the names and addresses of all of their healthcare providers so that we can send them the CME and Conference Registration information. It is in your best interest to get as many of your doctors and dentists to attend as possible – it can only help your treatment in the long run. Remember that our nurses, physicians' assistants, oral surgeons, chiropractors, and other healthcare providers can all benefit. We encourage all medical professionals who are interested in treating facial pain patients to attend the conference, and have sent out many brochures to invite them. There are no required invitations for attending the conference and we want to include all of the healthcare providers that our members can make available to us

TNA and OHSU are offering **Continuing Medical Education Credits (CME)** for medical and dental professionals during Saturday morning of the conference. ***Understanding Trigeminal Neuralgia and Other Facial Pain*** will feature speakers from TNA's Medical Advisory Board along with other invited specialists. Please send your referrals to us right away. (see contact info. box on pg. 5), or for CME info your healthcare providers can directly contact OHSU's Joanie Mastrandrea at mastrand@ohsu.edu or, phone 503-494-6207.

Express Yourself!

There will be a display for poetic expression of your experiences in a non-juried exhibit, and participation in the conference is not required for submission. Submissions must be received by TNA no later than August 1, 2006. Please mail your submission along with your name (unless anonymous) and city and state to TNA, c/o Poetic Expression, PO Box 92604 Southlake, TX 76092

There will be a new opportunity this year for patients to share their experiences and be recorded for a compilation CD that will be available for those who want to know that they are not alone. There will be a sign up sheet at the

Registration Desk at the conference hotel for those who wish to participate.

Fun Events

We will have the **Welcome Reception** on *The Portland Spirit*, a 150' yacht while it cruises at sunset on Thursday, September 14th, 2006. The conference registration fee includes the Welcome Reception, and guest tickets will be available for \$55. The Cruise includes complimentary hors d'oeuvres and a cash bar. Transportation is provided from the hotel to begin loading at 5:30 pm. Due to security matters, photo identification is required by the US Coast Guard to board, bags may be inspected and passengers may be photographed upon boarding.

The **Gala Dinner** at the hotel on Friday, September 15th, is also included in the conference registration fee and additional tickets are available for guests. The Gala Dinner is always entertaining with guest performers and excellent food that is provided. The cocktail reception begins at 6:30 and the dinner begins at 7pm.

To purchase guest tickets include them on your registration form to assure a space, or they can be bought at the conference check-in desk at the hotel.

Volunteer Opportunities

The Pacific NW Support Group along with **Seattle** and many others will be helping the conference in many ways and we still need volunteers to sign up. We are committed to helping make this the best conference that TNA has ever had - with your help!

Donations for the **Silent Auction** are greatly needed! We know that our members and their families are very resourceful and we are calling on all of you to help in this very important part of the conference. Each year, TNA must raise \$50,000 to help keep the conference costs low enough for all of us to participate! (Similar conferences usually cost \$500 or more and with higher hotel rates.)

Items for the auction need to be a new item that most people in the U.S. could use and that can be shipped easily. Examples of what will work are a gift card to a national chain restaurant or store, a long-distance calling card, or a new strand of pearls. What will not work is a gift card to a local car wash or restaurant, or anything used like clothing, (contact us about antiques of value). We'll accept a big new Plasma TV since the value will support the shipping costs, where an inexpensive coffee maker's value would be canceled by the shipping costs.

We know that our members and their families are business owners, artists, manufacturers, and big-hearted resourceful people! We appreciate those of you who will donate or collect donations for the auction, and we thank

you in advance! Remember to be ready to bid on some great things when you attend the conference also!

Volunteers are needed during the conference to man tables, greet people, help with seating, etc... With enough of us helping out no one will have to spend too much time working instead of attending the sessions. *This is yet another way that you can give back to the TNA association who has given you so much!*

We are gathering the names of local members who are willing to **share their homes** overnight with patients who otherwise could not afford to attend the conference. We are asking any local members who have extra bed space in their homes or RV's, travel trailers, etc. to contact us right away so we can proceed with helping others in need!

We are also putting together members who want to share a room – so they can **save costs at the hotel**. The rooms are \$115.00 single or double occupancy and only \$155.00 for up to 4 people. If you are planning on attending the conference and want to share a room with other group members, contact Ruth with your preferences, ie: male/female, smoking or not, local or not.

If you can volunteer to help in any of the areas listed above, or if you have additional ideas, please send an email to Ruth Purchase at pacificnwtna@hotmail.com or phone 503-886-9606 or 503-842-4938 and leave a message with your name, phone number or email address.



Help When You Shop (cont. from p.1)

in places like Barnes & Noble, GAP, Office Depot, 1-800 flowers.com, Wal-Mart, Expedia and more! There is NO cost to you and you can even save money on purchases by using coupons and specials. A new shopper needs to sign up only once and you don't have to give personal information. Go to www.BuyForCharity.com, sign up, and go to "select a cause" click on "general disabilities and diseases", then scroll down and select the Trigeminal Neuralgia Association. That's it! Take a look at the great stores you can buy from while they donate to TNA. Help make a difference today, if you're going to buy online.... Buy to help us end the pain!

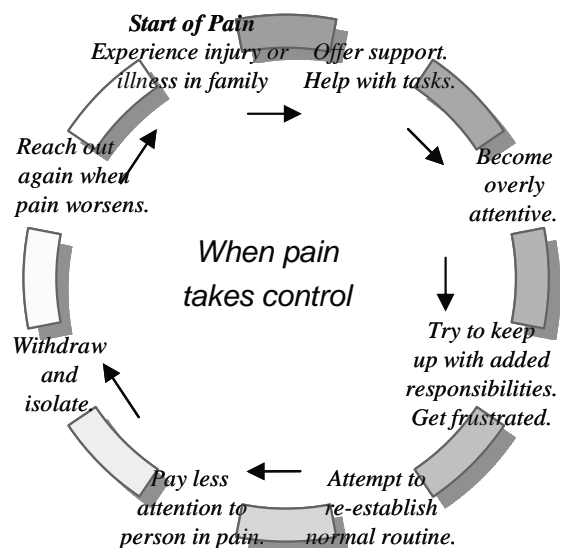
TNA's new logo is available on many new items to share our message with others! Your purchase will support TNA and help to spread the word of our message to *end the pain*. There are Shirts, Mugs, Caps, Tote Bags, Journal, even an "end the pain" Teddy Bear! Go to the website <http://www.cafepress.com/endthepain> and see what we have to offer. Shop today and *together we will end the pain!*

Caregivers Learn (cont. from p.1)

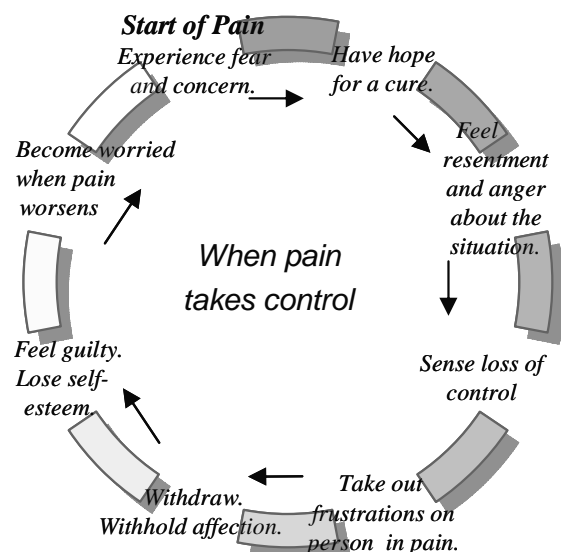
Some caregivers actually had fun with one of the questionnaires handed out; a few of the couples were overheard teasing each other and reading at it in a light-hearted manner... a sure sign that they are dealing pretty well with the depth of disruption that TN has in their life. A few others there had more serious looks on their faces as they read it and they will surely take their time to ponder the questions posed and how they can make changes for the better. (See p.2 for questionnaire)

There are two basic patterns that begin to emerge when we take a look at the effects of chronic pain on the patient's family members or caregivers. They come in the form of behaviors, (things that are done) and as emotions, (things that are felt). These charts give us a look at how chronic pain can affect caregivers and how it can become a vicious cycle. When they recognize the steps they are at in these circles, they can work on making changes in actions or feelings. (cont. on p.4)

Behavioral Cycle



Emotional Cycle



This questionnaire that we handed out at the meeting is called the *Zarit Burden Interview*. It was developed to measure how caregivers are coping with an illness or disability in the family, so that healthcare providers could find tools to help caregivers cope better.

Indicate how often you (the caregiver) experience the feelings listed by writing the number that best corresponds to the frequency of these feelings.

0 = Never; 1 = Rarely; 2 = Sometimes;
3 = Quite Frequently; 4 = Nearly Always

- 1) Do you feel that your relative asks for more help than he/she needs?
- 2) Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?
- 3) Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
- 4) Do you feel embarrassed over your relative's behavior?
- 5) Do you feel angry when you are around your relative?
- 6) Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?
- 7) Are you afraid of what the future holds for your relative?
- 8) Do you feel your relative is dependent upon you?
- 9) Do you feel strained when you are around your relative?
- 10) Do you feel your health has suffered because of your involvement with your relative?
- 11) Do you feel that you don't have as much privacy as you would like, because of your relative?
- 12) Do you feel that your social life has suffered because you are caring for your relative?
- 13) Do you feel uncomfortable about having friends over, because of your relative?
- 14) Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?
- 15) Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?
- 16) Do you feel that you will be unable to take care of your relative much longer?
- 17) Do you feel you have lost control of your life since your relative's illness?
- 18) Do you wish you could just leave the care of your relative to someone else?
- 19) Do you feel uncertain about what to do about your relative?
- 20) Do you feel you should be doing more for your relative?

- 21) Do you feel you could do a better job in caring for your relative?
- 22) Overall, how burdened do you feel in caring for your relative?

Now add up the scores you gave to each question. Like so many other situations in life, when we understand what is affecting us we can make changes for the positive. Recent literature suggest that if the Burden Interview score is high enough, there is a good chance that the caregiver may be experiencing depression and/or the need for further help with the patient. If your score is troubling to you, be sure to seek out help from a professional (or other person you hold in high regard) who is truthful and trustworthy to you. Get help evaluating your situation so you can get an honest opinion about what might not be working for you or the family, and what you can do to change it.

There are several ways for caregivers to get help, and the TNA support group is one way that they can begin. By learning from and listening to others in the same situation, caregivers and family members will find out that there are many ways to handle the stress and responsibility involved. Many local hospitals and clinics have classes and respite care for caregivers of people in all types of medical situations. Several members have talked about their Churches and Temples that have people who volunteer to help out families in all types of need, especially those who are undergoing medical problems. Yet as caregivers and patients, we must reach out for the help that is out there for us... before we let the situation get to the point that resentment or depression sets in.

There is a wonderful booklet that we hand out to families at the meetings. It is called, *But You Look Good! A guide to understanding and encouraging people living with chronic illness and pain*. Many members have commented that this booklet says exactly what they wish they could tell their families and friends. It gives caregivers and families the words to say, (and not to say), along with very good ways help a person in chronic pain without making them feel helpless. This handy booklet is available through **IDA, the Invisible Disabilities Advocate**, and can be found online at www.myIDA.org - or it can be ordered at PO Box 4067, Parker, Colorado, 80134.

Internal and External Environments

Learning to control our internal environment and functioning within a controlled external environment can be accomplished with help and diligence.

If you could be in a controlled environment external to yourself most of the time, you could decide what

activities to be involved in that would be less likely to trigger your pain. For TN patients, this would be the ideal situation! However, like most people, the more probable situation is to find yourself in an environment that you have little control over. When this happens the best thing to do is to have control over your *internal* environment. This means using proper medications or pain reducing behaviors such as relaxation techniques. It also means having the internal fortitude to let others know you have a problem at hand so they can support your needs. When the pain is roaring, you may need to leave the area (or request solitude) to get the pain to lighten up and to apply your strategy for reducing the pain.

One of the best methods of learning to control your internal environment is by using Cognitive Therapy. It can be fairly quick to implement, is practical and goal orientated. It involves three primary activities that are taught to the patient: Education; Skill Building; and Problem Solving. During treatment, the patient actively applies strategies learned to help solve the problems which brought them to seek therapy. If indicated, Cognitive Therapy might include the use of any number of pain reducing behaviors, medical treatments, or medications.

As pain catches us with us, there is anxiety and a diminished sense of expectation of healing and pain-free times. As it becomes more constant there can be a setting in of hopelessness and depression. It is up to the patient to seek out help to overcome this cycle and begin learning how to control their internal environment. When the medications or other pain reducing behaviors do have good results for the patient, they report overcoming the negative effects of the environment at hand and participating in more activities they want to do - with fewer pain episodes!



TN in the News

We are pleased to find that TN has been reported on lately by the national media! The **CBS News program, Medical Watch** had an excellent segment on in early April about a TN patient. The video and transcript of the news segment could still be seen on some of the CBS affiliates websites as of this printing. TN patient Jim Kirkpatrick was featured, along with Dr. Kim Burchiel of OHSU. The articles often referred to TN as the “suicide disease”. There was a good amount of background information about the disorder along with clips of Dr. Burchiel talking about the Microvascular Decompression Surgery, (MVD). In one article, the patient was quoted as saying that he was still looking into alternative treatments should the pain return. It was a short segment, but it was well written and got the audience’s attention!

The local newspaper **The Oregonian** had an article written by the popular journalist, *Margie Boule* in her column on Sunday April 16th. The article was titled, *After Terrible Pain, Terrific Relief*. In this article, the story line featured TN patient Melissa Hill’s problems about losing a career and having to re-make a life for herself after the pain struck. She was an attorney and had an active social life before she felt the first shock of the pain. Due to her pain and the disability from it, she sold her home in California and moved to Wilsonville. Boule’s article captured the appreciation that Melissa has for her new pain-free life here in Oregon since her MVD surgery.

This article also quoted Dr. Burchiel and gave information about the online diagnostic questionnaire that OHSU developed. In this article TN is also referred to as the “suicide disease.” Dr. Burchiel described the MVD in brief terms but it was very clear about what the operation consisted of. The article was very interesting, and we heard from several new people who hadn’t understood how painful TN was until they read the article for themselves. We are pleased to have the recognition of TN in the media. The more people hear about it the more likely patients are to be treated seriously and get a proper diagnosis early on.



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