



Nerve Center

May/June
2005

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

Group Family Reunion Coming in August

Join us for a fun-filled gathering in August where we will honor our families, friends, and caregivers who have stood beside us during our journey with face pain. We'll also be celebrating the Group's 4th Year Anniversary! We will meet on **Saturday, August 27th at 1:00pm**, at Legacy's Meridian Park Hospital Community Education Center in Tualatin, OR. (*see map on back*)

The Group Family Reunion will have a party atmosphere to show our friends and families how much we appreciate their care for us. We will have amusement and craft projects for the youngsters, door prizes will be given out, and families and members will have the opportunity for informal conversations and entertainment. There will be a special emphasis on the needs of our friends and families by having the opportunity for them to speak up on issues they want to discuss, and providing them with much needed information.

We hope to see those members who haven't attended in a while so you can update us on your condition, and bring your families along too. We hear time and time again that interaction with others in the group is the greatest learning tool and the greatest comfort for patients and caregivers alike. Come and see for yourself what a difference it can make. *We look forward to seeing all of our members, family, and close friends there to celebrate with us!*

The group will have a light luncheon included, and we are asking for volunteers to bring food dishes and help with set-up. Please contact Julie Hughson at 503-646-5499, or Ruth Purchase at 503-650-1984 to make arrangements.



TNA National is Growing and Changing

One of the constant things we can count on is change and growth with the National TNA Organization.

There are Regional TNA Conferences held throughout the year so that we can bring updated information to patients and medical professionals in various regions of the country. Although the National TNA Conferences are still the gold standard, they are held (*continued on p. 4*)

June 18th Meeting Cancelled

Our group meeting for June has been cancelled due to scheduling conflicts. The remaining meetings for 2005 will be: **August 27th, October 15th, and December 10th**. *Please note that the October date has been changed.* Check the dates on your calendars, and be sure to meet up with us at the end of summer!

Group Learns from Leading Scientist

The members who made the April 9th meeting were fortunate to learn about the influential research that is being done right here in the Portland area by the renowned Neuroscientist, **Dr. Thomas Baumann of Oregon Health Sciences University, (OHSU)**.

Dr. Baumann's extensive education began at Rensselaer Polytechnic Institute, in New York, where he earned his B.S. in 1974. He remained in N.Y. where he obtained the degree of M.S. at Cornell University in 1976. Baumann then went on to achieve his doctorate in 1983 at the prestigious University of Zurich in Switzerland. His research on TN related issues at OHSU has been so impressive throughout the years that he was one of a hand-full of people invited in 1999 to the only workshop the National Institutes of Health (NIH) has held on TN. The workshop, *Trigeminal Neuralgia, Opportunities for Research and Treatment*, was highly successful due to the hard work of those in attendance like Dr. Baumann. The NIH has since allocated \$1.2 million dollars for research on *The Neurobiology of Persistent Pain Mediated by the Trigeminal Nerve*.

Questions that Researchers Need to Answer

The Baumann Laboratory at OHSU has identified the need for studying TN due to several unique properties of the disorder that defy logic when compared to how other nerves function and how pain is normally transmitted. Although some sensory components of the other cranial nerves can miss-fire like the trigeminal nerve, the nerves that connect to the spinal cord react differently to damage. Several areas that kindle the interest of researchers are; why the pain of TN is so intense compared to the gentle touch required to trigger an attack, and why does the pain last beyond that contact? What explains the pain suddenly stopping and then not being able to trigger it again with the same stimuli for a period

of time, when normal neurons, (nerve cells), would respond immediately? What is stopping the nerve transmission at that time? Why does the pain radiate beyond the trigger zone, and how does it jump from one branch to the others within the trigeminal nerve? There is the question of why the intensity of pain doesn't match the minimal amount of damage caused by a compression on the trigeminal nerve as seen in subsequent Microvascular Decompression (MVD) surgeries. Other nerves would have to show very, very extensive damage for the intensity of pain experienced by TN patients. If damage to the nerve causes TN pain, then why does intentional damage such as the Radiofrequency Rhizotomy, (RF), or the Gamma Knife, (GK) cause the pain to remit? If the pain of TN is caused by a neuro-vascular compression as most doctors and researchers agree, why does it go into remission spontaneously when the compression still exists? There is also the question of why some anti-convulsive medications stop the pain while others do not.

Theories about TN

According to Baumann, the hypothetical mechanisms of TN fall into one of three types of theories; Changes within the Peripheral Nervous System, (PNS); changes within the Central Nervous System, (CNS); and hybrid theories that may include changes in the PNS, the CNS, and the brain. Under the theory of the PNS causing TN, there may be changes within the trigeminal nerve itself after damage. This could include changes where the nerve cells *make contact*, (the synapsis), along the nerve as it sends signals higher up towards the brain. It could also be due to changes in the *strength* of the synapses between cells and those changes could influence how well the signal is received on the post-synaptic side. Another one of the PNS theories is that of trigeminal ganglion ignition. This idea runs on the theory that a chain reaction happens within the ganglion due to a compression on the nerve root. The properties of nerve cells are changed by the damage, and when light stimulation activates some cells, those ignite others, cell to cell, causing an explosion within the ganglion which in turn causes pain.

To study changes in the PNS, neuroscientists will usually damage the peripheral nerves intentionally and then look for changes in those nerve cells. This is not an ethical option for researchers who are studying TN in actual patients, as there would be added damage by obtaining samples of the trigeminal nerve. However, recently published data has looked at the PNS for information about neuro-vascular compressions as the cause of TN by using cadavers in the study. The scientists collected cadaver samples from the demyelinated area of the trigeminal nerve, and laboratory tests showed that the cell bodies did change in response to the damaged nerve. The CNS theory of TN pain has scientists looking at the lack

of inhibition of nerve impulses as they are processed. Under normal circumstances the CNS has a means of blocking out information from the nerves that is not needed, so the brain deals with only necessary information. This prevents the brain from overloading on excessive neural input. Many scientists believe that the trigeminal nerve impulses are not as inhibited as they should be by the CNS, and the brain may be processing normal touch signals as pain signals. The hybrid theory of TN pain involves the CNS and the PNS. There are several ways this could happen, with the peripheral nerve signals being distorted, the CNS may not inhibit those abnormal signals, and the brain's functioning could be changing in response.

Intra-operative Studies

Dr. Baumann's laboratory is on the cutting edge of understanding what causes TN pain. They have developed a novel neurophysiological method that allows testing of the PNS hypotheses of TN. For the first time in medical history, research has indisputably shown a TN attack recorded due to this innovative intra-operative approach. Until now, only information from the patient's self-reporting and the physicians' observations could be used to document an attack, and clearly this was a subjective observation at best for scientists to build studies on.

Dr. Burchiel, Department Head of Neurosurgery at OHSU, has been working with Dr. Baumann to develop microneurographic recordings of the nerve miss-firing, by using TN patients who come to OHSU for the RF treatment. The RF procedure involves inserting a long needle through the cheek and a natural opening in the skull, and into the trigeminal ganglion. The hollow needle allows an electrode to be passed through, and the tip of the electrode is heated up to selectively damage the nerve, causing an interruption in the pain signals. The patient is anesthetized during most of the treatment, but is awakened briefly so that doctors can confirm they have the proper placement of the needle.

Dr. Baumann showed slides of the instruments used in a normal RF treatment and explained how they work with tools that he uses for the recordings. The hollow needle has a center open just enough to allow an electrode to pass through. Dr. Baumann uses an insulated electrode with a sharp tip that he passes through the needle and allows to just barely touch the nerve fibers. By attaching sensitive electronic wires to both the electrode and the outer needle which is a tiny distance away, they can measure the speed of the nerve signals based on that distance. This information is forwarded to the computer and electronic recording devices where it is plotted on a graph. The bursts of electrical activity from the neurons, is called action potentials and looks similar to what you

would see on a seismograph during an earthquake. The patient is awakened during the testing so the researcher can question them as to the intensity and location of the pain. This allows them to use a time line that compares the patient's sensations to the microneurographic recordings.

Dr. Baumann showed us slides of some of the recordings and explained their observations of the patient's experiences during the recorded attacks. The graph shows only "noise" at first, a thick base line indicating the background activity that is always there. He explained that it is like the static you get on a radio when there is no station tuned in. In one study, the recordings correlated to a spontaneous attack, where the patient had pain spike without stimulation. The lines jumped straight up and then quickly tapered off to the base line. These action potential bursts repeated 3 or more times within 1.5 seconds. In another study, the recordings showed a prolonged burst of action potentials caused by gentle stimulation of the patient's trigger zone. The researchers stopped the stimulation as soon as the bursts started, but the action potentials continued for another 1.5 – 2 seconds. The bursts stopped abruptly even though the researchers tried again to stimulate the trigger zone. They could not activate the nerve fibers again despite several tries.

Now, researchers need to find out if TN originates from changes within the trigeminal ganglion, or if the changes come from further up along the brainstem, the thalamus, or any other area in the brain. More recordings will help to verify the data that Baumann now has, and may help point to whether the trigeminal ganglion neurons are *actively* involved in the attacks.

Communication Between Nerve Cells

Potential chemical mediators of cross-excitation between the trigeminal neurons is another area that Dr. Baumann and Dr. Chaudhary have been looking into at OHSU. In this research they were looking for substances *on* the nerve cell bodies within the ganglion that are causing the actions. There are chemical compounds between the cells which are released to penetrate the insulation of other cell bodies and act on receptors that are in the cell membranes. Those receptors then activate the signaling pathways inside the cell. Substances are then released from the cell bodies and reach out activating their neighboring cells, causing action potentials.

Primary sensory neurons produce dozens of short proteins called peptides, a neurotransmitter that is used for communication at the contact point, (the synapsis), between cells. These neuro-peptides are released and attach to receptors at the other end of the synapse and will activate the next cell, and the action repeats, cell to cell.

Although there are no known synapses inside the trigeminal ganglion, Baumann's research questions whether or not these neuro-peptides could actually act as *chemical mediators* that cause cross-excitation between cells without the release of the classical synaptic mechanisms. If so, which ones are involved and how do they identify them?

When there is a nerve injury, some neuro-peptides are produced by the nerve cells in larger quantities; some are in smaller than normal quantities. The research then needs to answer the questions of whether any of these receptors are actually *made within* the trigeminal ganglion.

Laboratory Studies

Animal studies were done where the trigeminal nerve was damaged to cause TN pain. The trigeminal ganglion was then dissected and researchers looked for molecules that have the RNA, (similar to DNA), of the cell receptors to see which ones were active or missing due to the damage. This slide resembled the ones we see showing DNA in bars of varying intensity of light and dark. They also needed to find out if the receptors were in the cell's membrane where they would normally expect to find them. That test used immunofluorescence, a staining technique that allowed them to see individual cells under magnification, and showed them which receptors were active. They were then able to observe that some receptors were where they should be found, on the cell membrane, while others were missing altogether. Some receptors were actually found *inside* of the cell bodies, and that raises another question. Will those receptors within the cells move to the membrane where they can become active?

To discover which neuro-peptides are active in the damaged trigeminal nerve cells, the laboratory uses a technique called patch clamp recordings. Under magnification, they are able to apply a miniscule amount of electricity to excite individual nerve cells harvested from the trigeminal ganglion, and record any action potentials on a graph. With a single cell, they add the electrical current and record the action potentials caused by the stimulation. The same cell is then bathed in one of the neuro-peptides, and the same current is applied again, recording the results. When the peptide is active in the cell to cell communication, the action potential bursts are much longer and more intense than the base recording. The same cell is washed to remove the peptide and is stimulated again, and the action potentials returned to the original state. This proves that certain receptors are being produced within the ganglion. Now, the challenge is to find out what cells and cell sub-types are involved in producing the receptors that cause the nerve to become over-excited.

Future Outlook

While additional recordings will help to build the database of what the nerve is doing when attacks occur, Baumann said that it will also help to verify their findings for other researchers to build upon. But there is more that he wants to do with patients inside the laboratory. Right now, the microneurographic recording test is limited to 90 minutes in the operating room, and although it usually takes less time, there are other limitations to consider. They have applied for funding to bring patients to the laboratory where they can utilize a similar technique to record the firing within the ganglion. By using a thin and flexible electrode, they plan on taking semi-chronic recordings while the patients are awake, without any anesthetics or the insertion of a needle that could affect the readings. They will be capable of monitoring patients on reduced medications, and will be able to interact with them during TN attacks. Along side of that study, they also have a method of collecting fluid from within the ganglion which will allow them to measure the neurotransmitters and neuromodulator substances that are released into the cerebral spinal fluid before, during, and after attacks.

New medications can be developed when we learn what causes the neurons to change their properties and create TN pain. When we understand where along the trigeminal nerve, CNS, or brain those changes are occurring, we may be able to target those areas directly with surgeries or medications. With the advances in technology such as computers, magnification, laboratory and medical devices, the information researchers collect is being processed more and more efficiently. The future of TN treatments is also dependent upon patients who are willing to participate in the studies. Baumann and his associates are hoping to have more volunteers for the intra-operative studies during RF procedures along with the studies that will soon begin inside the laboratory. When asked whether these tests might cause additional pain, he said that it is possible, but patients who volunteer for any study have the right to stop at anytime. Members of the group spoke up and said that if they were going to have pain spikes anyway, why not have them in the laboratory where it will help others in the long run.

We learned so very much from Dr. Baumann's research and the presentation he gave to the group. It really helped to shed light on the advances in TN research, and most of all, it gives each and every one of us of hope for a pain free future. With the help of dedicated and curious scientists like Dr. Baumann and others around the world, we can truly say, *together we will end the pain.*

Dr. Baumann wishes to acknowledge that funding for his laboratory and studies comes from the National Institutes of Health, under the National Institute of Neurological

Disorders and Stroke. He also receives support from OHSU's Medical Research Foundation and Department of Neurological Surgery. For more on Dr. Baumann's work, link to facial pain at: www.ohsu.edu/neurosurgery



National TNA (cont. from p.1)

only every two years, and are more involved and costly than the regional ones.

The Regional Conferences are one more way that TNA has designed to bring patients and doctors together, in the communities where they live and practice. The one in New York this April was a great success, with TN patients and health care professionals sitting side by side and learning from each other. Our group is fortunate that we have the next two regional conferences relatively close to the Northwest, and the 6th National Conference will be here in Portland!

Casper, Wyoming, August 13th

This one-day regional conference is co-sponsored by Central Wyoming Neurosurgery and TNA Colorado Support Groups. Plan now, this date is approaching fast!

San Francisco, California, September 17th

TNA will co-host a one-day regional conference with the University of California - San Francisco on Saturday, September 17, at UCSF Mission Bay in Genentech Hall. Patients, supporters, and the medical community are invited to this conference as well. Seating is extremely limited so be sure to register early.

Register for the conferences online or by phone through the National TNA. (*See box on page 5 for contact info*)

We are preparing the very best speakers, agenda, topics, and entertainment for **TNA's 6th National Conference** to be held in **Portland, Oregon, September 13-16, 2006**. Even if you live in the area, do plan ahead and save your money to join us at the hotel overnights, as the best conversations are the ones where you'll catch the doctors and other patients before and after the meetings.

If you haven't visited the **TNA website** for a while, you really should! They have re-designed the site and it has more info than ever before. Be sure to click on "what's new" for the latest updates. You can send ***your personal TN story*** to be posted on the site now, and you can read up on what others are saying. We are also adding another name to the TNA website so others may understand what they are linking to. It is: www.endthepain.org

When you visit the website, you can also order several books, including the very best one on TN ever published;

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. For those of you who already have this book, please note that the 2004 edition is like having a brand new book, it has nearly doubled in size - just like the information in it! The book is available for sale or loan at our meetings.



Treasury Report: January – June 2005

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.

Beginning balance 12/31/05:.....	\$704.81
Donations and book sales:	899.15
Meeting expenses:	93.68
Books:	561.40
Postage & Office supplies:	537.72
Ending balance 6/6/05:.....	\$362.32



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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.

Did You Know?

You could be eligible for a **Disabled Parking Permit** issued through your State Motor Vehicle Division. Many people erroneously believe that you must have difficulty walking to have a parking permit. This is not true! Although each State has their own criteria for getting a permit, there are many similarities. Most require the doctor to fill out a simple form that states the patient has a medical need for parking close to the entry of buildings. This is clearly an option for many face pain patients. Your doctor should be well informed, (*we hope!*), about the triggers that set off attacks and the intensity of pain those attacks deliver. The triggers for many TN'ers are relevant, such as wind, rain, heat, and even the jarring from taking steps. In addition, they often need to make a quick get-a-way from the public when an attack does happen. If this is of interest to you, don't hesitate to get the help you need and ask your doctor about it. You deserve a break from the triggers and the pain no matter where or when it may happen – even in a parking lot!



The philosophy of Charles Schultz,

Creator of the "Peanuts" comic strip.

You don't have to actually answer these questions. Just read straight through and you'll get the point.

1. Name the five wealthiest people in the world.
2. Name the last five Heisman trophy winners.
3. Name the last five winners of the Miss America contest.
4. Name ten people who have won the Nobel or Pulitzer Prize.
5. Name the last six Academy Award winners for best actor / actress
6. Name the last decade's worth of World Series winners.

How did you do?

The point is; none of us remember the headliners of yesterday. These are no second-rate achievers. They are the best in their fields. But the applause dies. Awards tarnish. Achievements are forgotten. Accolades and certificates are buried with their owners.

Here's another quiz. See how you do on this one:

1. List a few teachers who aided your journey through school.
2. Name three friends who have helped you through a difficult time.
3. Name five people who have taught you something worthwhile.
4. Think of a few people who made you feel appreciated and special.
5. Think of five people you enjoy spending time with.
6. Name half a dozen heroes whose stories have inspired you.

Easier?

The lesson: The people who make a difference in your life are not the ones with the most credentials, the most money, or the most awards. *They are the ones that care.*

By Charles Schultz