# TNA Quarterly

The Journal of
The Facial Pain Association

Autumn 2011
Volume 1 Issue 3

## Communicating How You Hurt

## TNA Receives Major Gift to Fund Research

## Support Group News

## Patient/ Entrepreneur Joins TNA Board

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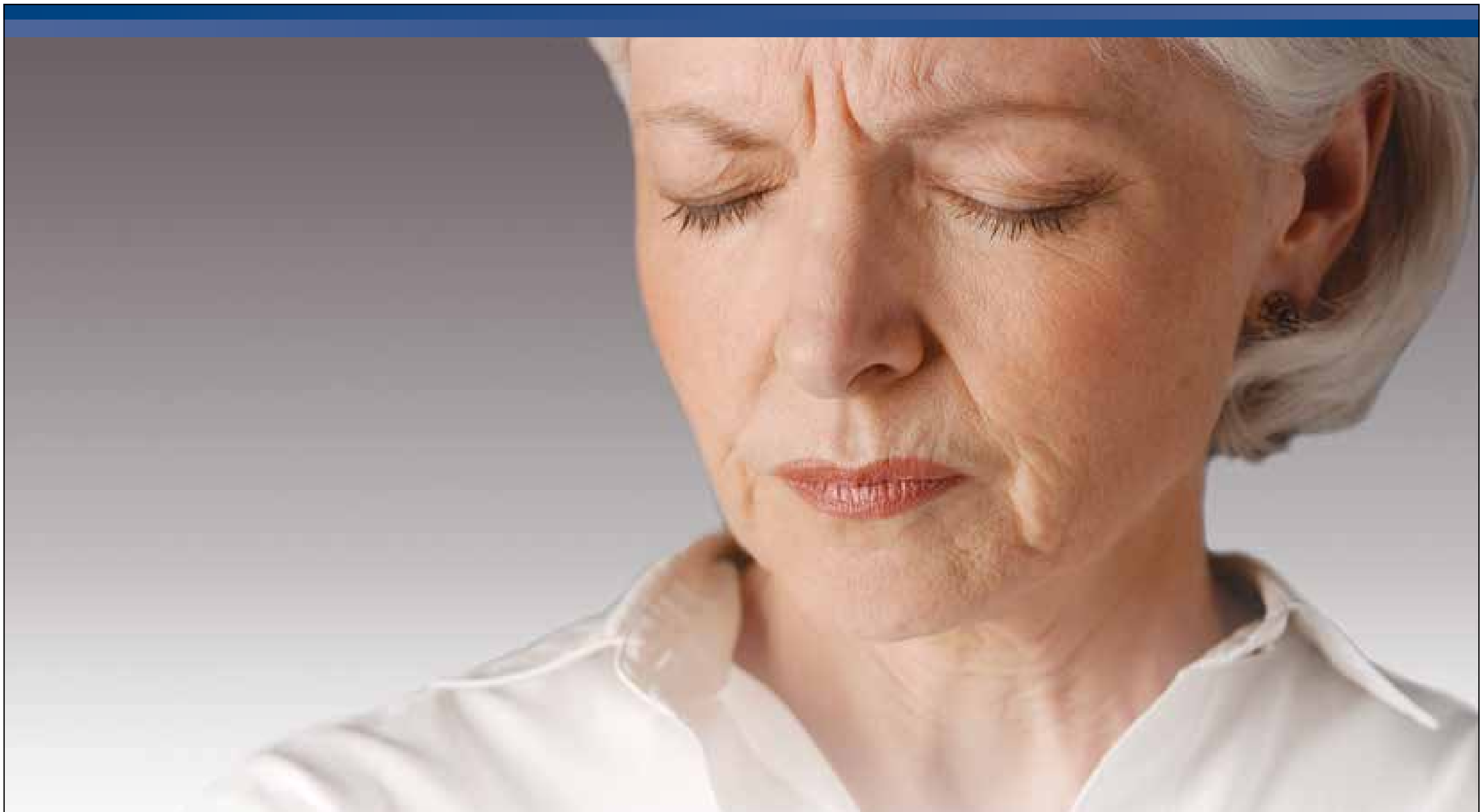

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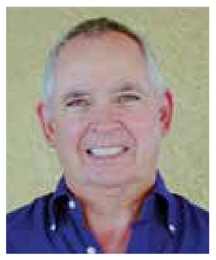

## From the Chairman of the Board

Continuing weakness in the economy, downgrades in bond ratings, and increased market volatility all combine to create a gloomy outlook. Not what the doctor ordered in terms of stress, as if facial pain was not enough to contend with!

Following on the heels of 2008, the markets' impact on nonprofits will likely be significant. Even the nation's largest charities have seen a decline in contributions in the last two years, an experience TNA has felt more acutely with a two year decline of more than 20%, and we will all brace for more.

To compensate for this decline, TNA has trimmed expenses and diversified its sources of income so that we can maintain and even expand our programs, such as we are doing with our regional conferences and online presence. This is due to the hard work of our staff and the support of our Board and volunteers, including the members of our Medical Advisory Board.

However, in common with many other nonprofits, particularly those regarded as single, rare disease organizations, we are primarily dependent for our income on charitable contributions from the families of those touched by the disease in question; in our case, trigeminal neuralgia and similar facial pain disorders. So, while we are doing our best to make do with less, I hope you will continue and, if you are able, consider increasing your financial support. Anyone whom the Association has helped knows what's at stake.

Another way you can help is by becoming a volunteer. TNA has a rich history of volunteerism as exemplified by our wonderful Support Group Leaders and Telephone Contacts around the country, but we need to expand and strengthen our network so that we can reach more patients on a local level and, of course, we need help with fundraising. So, as you read this edition of the TNA Quarterly, please consider whether you or someone you know would have the desire to make a difference in the lives of patients and would be willing to volunteer for our Association. Also, you may have some other idea for helping us which you would like to share. In either case, please contact me at rlevy@tna-support.org or our CEO, John Koff, at the national office. We would love to hear from you.

In the meantime, rest assured that our Board, CEO and staff are committed to the long term health of our Association and to being there when patients need us.

Roger Levy, Chairman of the Board
TNA – The Facial Pain Association

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# San Francisco executive in electric power industry brings energy of an entrepreneur to TNA Board

### By Arline Phillips-Han

**Jeff Bodington** of San Francisco, founder and president of an investment banking firm that serves the electric power industry, has joined the TNA-Facial Pain Association Board of Directors.

"I am enthusiastic about the Association, appreciate how helpful it is to facial pain patients, and look forward to making a contribution," he said. "I want to help the Association make sure that every patient with TN or other facial pain gets the education and assistance he or she needs, and that every healthcare professional receives the education needed to accurately diagnose and treat facial pain."

Bodington has spent nearly 35 years in the business and financial aspects of the electric power industry. In 1990 he founded Bodington & Company, which has advised more than 150 clients on power-related transactions with a combined value over $7 billion. He has authored more than 50 professional articles on finance and energy, and has served as guest speaker or chairman at more than 70 energy industry conferences.

In his personal life, Bodington has another story. Intense jabbing pain began in his left jaw one afternoon, and getting an accurate diagnosis became a difficult process. For six years he cycled through combinations of eight medications, and they gradually lost their effectiveness.

> "Balancing work, family, debilitating pain and the side effects of medications was a continuous contest," he recalls, "Pain began to win."

In 2003, he underwent microvascular decompression (MVD) performed by neurosurgeon Hyrar Shahinian, M.D., at Cedars Sinai Medical Center in Los Angeles. Bodington summarizes the outcome of the operation in five words: "Wonderful; no pain; no drugs." He remains pain-free after more than eight years. He expresses thanks to Dr. Shahinian and also to Stephen Graff-Radford, DDS, a member of the TNA-FPA Medical Advisory Board, who leads the Cedars Sinai Pain Center.

The opportunity to serve on the governing board of TNA-FPA came out of the blue through a phone call from an Association officer. "I had served on several non-profit boards before, but this was a special opportunity to be useful. I had to say yes." The call was a reminder of his long bout with TN, and of how much help he received through the Association. Hearing about the experiences of people he met through the local (San Francisco) TN Support Group, and the book, ***Striking Back: The Trigeminal Neuralgia and Face Pain Handbook***, were particularly useful to him in making treatment decisions.

> "I am happy to be invited to serve on the Board," Bodington said. "I look forward to working with the other Board members and organization staff to enhance programs and build on the great foundation they have established."

He earned degrees from the University of California Berkley and Cornell University. Outside his work life, he likes to hike, listen to classical music, and collect maps. He and his wife, Cecile, have two sons in college. ●

# Clinical Classification of Facial Pain: Communicating How You Hurt

**By Kim J. Burchiel, M.D., F.A.C.S**

Dr. Burchiel is the John Raaf Professor and Chairman of the Department of Neurological Surgery at Oregon Health and Science University and a member of TNA's Medical Advisory Board.

"The surgeon, however, is chiefly concerned with the question: 'What cases of neuralgia are suited for operative treatment, and what are the best methods to employ?' The answer, obviously, should depend upon a scientific classification, based solely upon the causes of neuralgia; at present such a classification is impossible"

J. Hutchinson, The Surgical Treatment of Facial Neuralgia, p. 1, 1905

Trigeminal neuralgia (TN) has been studied and written about since antiquity. Despite this, there has never been a "natural history study" (a scientific documentation of how the disorder behaves over time) done on the condition. Why is that, if TN has been known about for so long? The problem derives from the language used to describe the pain.

The classic history of TN is fairly easy to recognize: Unilateral severe episodic facial pain, often described as electrical or lightening-like (lancinating), that is often brought on by a triggering touch stimulus to the area around the mouth (talking, eating, brushing teeth, shaving, washing the face, wind on the face, etc), with pain episodes usually lasting seconds to minutes. The most common areas of the face to be affected are the jaw, lower teeth, and tongue (mandibular), or pains in this area combined with pains in the cheek, nose and upper teeth (maxillary). Isolated pains in the cheek are the next most common form, followed by pains in the cheek, eye and above the eye.

The least most common are pains isolated to the region of the eye and above (ophthalmic). The initial history of TN is characterized by one or more bouts of pain, followed by a completely pain-free interval lasting months or even years. This pattern of pain-free intervals is often repeated over the course of the condition. In the more modern era, a good response to a medication such as carbamazepine (Tegretol), or more recently gabapentin (Neurontin), is also considered to support the diagnosis of TN.

When I was training to be a neurosurgeon, I was taught that there were three types of facial pain: "Typical" TN (a classic case, such as above), "atypical" TN (recognizable as a variant of TN, but not a classic case), and "atypical facial pain" (everything else). Atypical cases had some typical episodic pains, combined with a substantial degree of constant, or background, pain. Atypical facial pain was effectively constant facial pain.

These definitions work reasonably well for physicians, but not very well for patients. The first problem is that defining pain as either "classical" or "non-classical" is imprecise, and the subjective nature of the terms leaves considerable room for differences of opinion. The second problem is that lumping all facial pain from traumatic causes (facial injury, shingles, prior sinus or oral surgery) into one big "wastebasket" (atypical facial pain) does little to illuminate and separate these conditions that might, in fact, respond to therapy. The imprecision of this terminology is more than just confusing; it effectively paralyzes progress towards unraveling the causes of facial pain, and

*continued on page 4*

# "Clinical Classification . . ." cont.

prevents any serious scientific study of the clinical nature of TN. The reason being, that if you can't describe and classify a pain, it is difficult to study and understand it.

To be fair, a "scientific classification, based solely upon the causes of neuralgia" along the lines of Hutchinson's comments above, was not possible in 1905, and remains an elusive goal today. Our understanding of TN has improved, as have both the medical and surgical options available to patients. Nonetheless, that increased knowledge and technology has not produced an improved means of thinking about, or studying, the nature of TN.

In order to try to improve on this situation, seven years ago we decided to take a different approach. Our rationale was that after many centuries of history, physicians and surgeons still had no systematic way to characterize facial pain. Perhaps it was time for patients to have a shot at this? Our plan was simple: To develop a facial pain classification system based solely on patient history and symptoms. That type system should allow facial pain patients to classify themselves, and would minimize the impact of physician bias in the diagnosis.

What we came up with is a classification scheme based on the most common facial pain diagnoses:

- TN (and its variants)
- TN secondary to multiple sclerosis (MS)
- Postherpetic neuralgia (pain after facial shingles around the eye)
- Trigeminal neuropathic pain (after trigeminal nerve injury)
- Facial pain resulting from intentional disruption of the trigeminal nerve intended to treat TN (anesthesia dolorosa)
- Atypical facial pain

According to this approach, patients with facial pain and no history of MS, shingles, facial injury, prior orofacial surgery, or prior destructive procedures intentionally directed at the trigeminal nerve, were considered to have TN, or at least some form of it. While most TN patients have episodic pain, patients with some degree of constant background facial pain, comingled with their episodic pain, are also commonly seen in clinical practice. Our impression was that, contrary to the old terminology, there was no reason to think that there were two distinct types of TN (typical and atypical), but rather that TN occurs along a spectrum from purely episodic to mostly constant pain. By this logic, patients suffering the spontaneous onset of facial pain, without any antecedent history, have one condition (TN), with variable symptomatology. However, this assumption created another dilemma; that being then how to separate the different varieties of TN. Our solution to this was to simply divide TN right down the middle: Patients in whom their pain was more than 50% episodic, were termed "Type 1", and those in whom pain was more than 50% constant were called "Type 2". The final list of available diagnoses then looked like this:

| **Pain Type** | **abbreviation** |
|---|---|
| • Trigeminal Neuralgia | |
| • Type 1 [mostly episodic pain] | TN1 |
| • Type 2 [mostly constant pain] | TN2 |
| • Symptomatic TN [from multiple sclerosis] | STN |
| • Postherpetic Neuralgia [after facial shingles] | PH |
| • Trigeminal Neuropathic Pain [unintentional nerve injury] | TNP |
| • Trigeminal Deafferentation Pain [intentional nerve injury] | TDP |
| • Atypical Facial Pain | AFP |

One of our goals was to implement this type of diagnostic scheme on the Web, to allow patients to confidentially diagnose themselves, thereby avoiding unnecessary or even dangerous therapies based on a wrong diagnosis. This required that we come up with a series of questions with "yes" and "no" answers, which would reliably sort facial pain patients into their proper diagnoses. The development of these questions took several years of analysis, but eventually we came up with a list of approximately 20 questions, that can accurately result in a correct diagnosis in most cases.

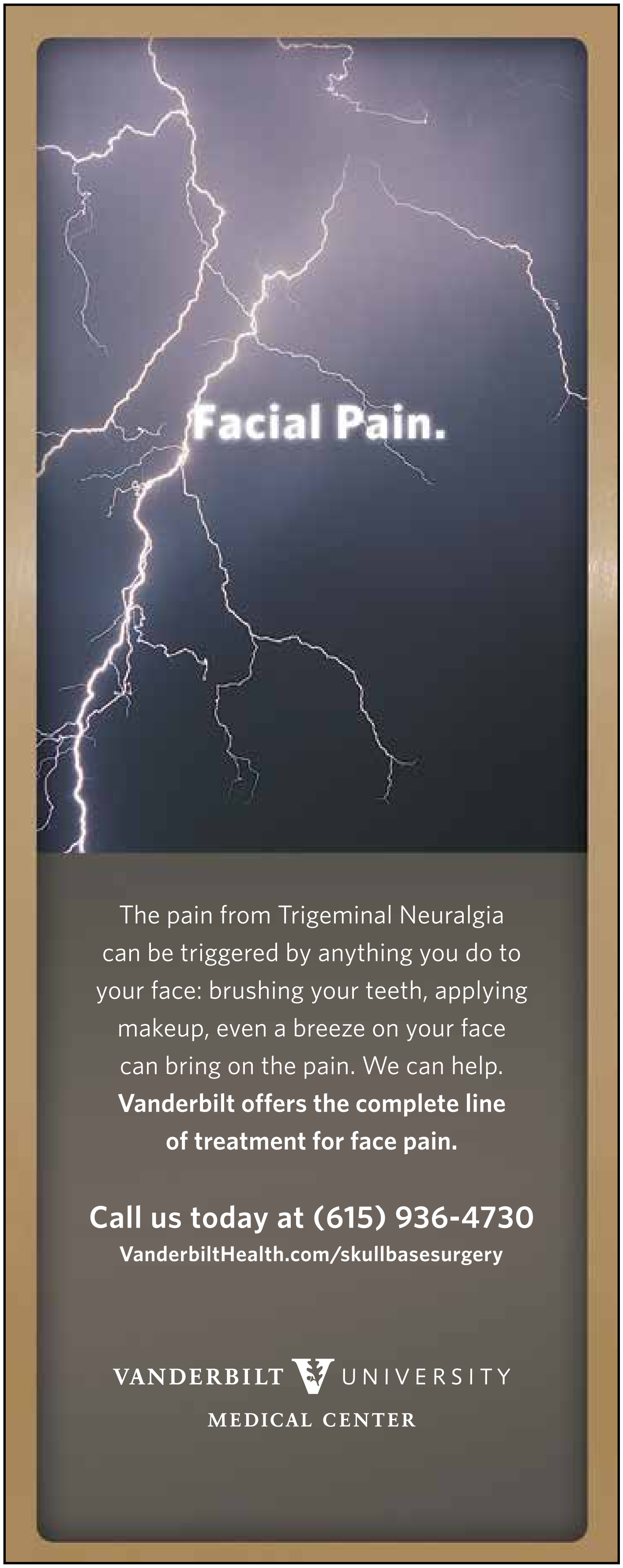
Our method for converting an individual patient's answers into a diagnosis, utilizes an "expert system" (computer software) that is trained to "think" like an experienced clinician (myself) and come up with the best diagnosis, based on the information available. Patients can easily access this diagnostic tool on the Web at https://neurosurgery.ohsu.edu/tgn.php

Once the patient has entered the answers to 22 questions, and submits the information, the computer server hosting the expert system will immediately return a diagnosis with links to information on that particular disorder. No information of any kind from this website is collected or stored, and patients can use this information to seek out appropriate information, and specialists. If you don't have this link handy, "Google" the key words "trigeminal neuralgia" and "questionnaire", and the questionnaire website will come up at the top of the first Google search page.

Using this new classification scheme for facial pain, we now have the ability to conduct scientific studies on the incidence of trigeminal neuralgia, and its medical and surgical treatment. For example, based on recent studies, we have now concluded that this new system for classification is a strong predictor of surgical outcome from microvascular decompression (MVD), and also is strongly correlated with what type of blood vessel is impacting the trigeminal nerve to produce the disorder in most cases. One of the most significant conclusions we have drawn harkens back to the days before MRI or even CT scans, in that the type of pain experienced by a person with TN is the strongest predictor of outcome from surgical therapy.

This new classification scheme for facial pain allows patients to take control over the establishment of their diagnosis. It also has allowed us to begin to look in depth at the nature of trigeminal neuralgia, and both its medical and surgical therapy. ●

*Editor's note: After this article was in print, The Facial Pain Association and its Medical Advisory Board, under the guidance of Dr. Peter J. Jannetta, concluded that the term atypical facial pain be replaced with the term facial pain of obscure etiology. The complete statement addressing this change can be read on our website www.tna-support.org*



# Managing Your Pain Through the Holidays

**ByCindy Ezell,** Cindy has been a TN patient for more than 25 years and currently is in charge of patient services for TNA.

The holiday season is fast upon us and with this joyful time come many occasions that can often exacerbate neuropathic facial pain. Having neuropathic facial pain myself I have learned over the years that I can predict and therefore prevent several triggers that make the pain worse. I am not saying they will prevent the pain from occurring, but I do follow these commandments and my TN stays under control:

- Being overtired - Get plenty of rest and ask for help from your doctor if you are not sleeping well. Remember, you might need more sleep than average.

- Cold wind - Wear a jacket with a hood or a scarf, even when making a quick trip to the mailbox. Do not let your body and face get cold. This only takes a minute to avoid, but once the pain is triggered it made take hours to become bearable again.

- Stress – Now this is a big trigger and difficult to manage, but it is very important for us to reduce stress. Much of the advice we receive on reducing stress is easier said than done. But, we must try. Say "No," Feel No Guilt, and Ask for Help! Take time out of your day for You. Read, listen to a book-on-tape, watch a movie, take a hot bath, light candles, play relaxing music. Most of all "Do Not Feel Guilty," ask your doctor about an antidepressant, it can make a big difference in how you cope.

- Changes in Barometric pressure - not much can be done about this, but it does help knowing that it is temporary and will stabilize.

- Take medications on time!

- Give back and help someone else! Even when you do not think you feel up to it, you will find that you are better off than someone else. Often you can't change the pain, but you can change your emotional response to the pain. Helping others can change your emotional response. Be proactive not reactive! Share the information you have gained.

Neuropathic facial pain is something that must be managed; there is no "Home Depot Quick fix." But, we have many opportunities to share the information we have gained with each other. Here at TNA we are always looking for information that we can share with you.

We found these tips from the American Pain Foundation to be very helpful in easing neuropathic pain during the holidays and we want to share them with you!

## Top Ten Tips:
## Easing Pain Around the Holidays

It's supposed to be the "most wonderful time of the year," but the rush of the holiday season can leave many people anxiety-ridden. Juggling competing demands, such as work, visiting relatives, parties, cooking and crowded stores and shopping, can be stressful. And stress aggravates many chronic pain conditions and can trigger pain flare ups. It's important to pace yourself and take plenty of deep breaths.

Here are some helpful tips to reduce stress and help ease pain around the holidays:

1. Get organized and plan ahead! Make to-do lists and delegate tasks to trusted family and friends, so you won't feel overwhelmed.

2. Don't feel pressured to entertain house guests. Tell them to make themselves at home and show them where to find the essentials (e.g., towels, newspapers, beverages and snacks). Surround yourself by people who are supportive of you and will pitch in and help.

3. Be true to yourself. As hard as it might be, put your own needs first. If you feel the need to withdraw to another room to rest, do so. Pass on activities that you're only doing out of obligation;

instead, concentrate on those that have meaning to you. You'll be able to enjoy the festivities much more as a result.

4. Prepare food well in advance or, consider hosting a pot-luck dinner. Order a pie instead of baking it yourself. If you decide you want to chop vegetables or peel potatoes, do it sitting down rather than crouched over the counter.

5. Stay on top of your treatment, plan ahead to avoid interruptions in routine care. Don't let your treatment slip over the holidays. Talk with your healthcare providers to find out who you should call over the holidays, so you get help when you need it. Be sure to have enough medications on hand. Many pharmacies are either closed or have limited hours.

6. Set expectations. It's difficult to enjoy time with family and friends when you have too many responsibilities and not enough time. Talk openly with loved ones about what activities you think you may or may not be able to handle.

7. Pay attention to your mood. The holidays have a way of reminding us of loss and how things could have been. If you have the holiday blues, talk about your feelings with friends and family.

8. Keep up with regular sleep schedules, eat healthful meals, exercise within your limits and stay hydrated. If you don't already, consider practicing relaxation techniques, including deep breathing and visualization, to help ease stress.

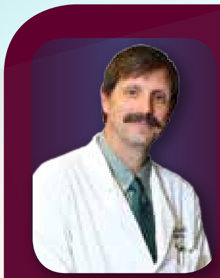
9. Avoid crowded stores. Standing in long lines and fighting against masses of people may worsen your pain. Think about ordering online or through catalogs instead.

10. Keep a healthy sense of humor. Not everything has to be perfect.

Don't let the holidays become something you dread because of neuropathic pain. Instead, take steps in prevention where you can. You know how your pain reacts and your limit! Stay within that limit and enjoy the holidays!

For further reading TNA suggests visiting the following sites to read their articles about stress during the holidays:

- www.nationalpainfoundation.org
- www.webmd.com
- www.mayoclinic.com
- www.medicinenet.com



# Support Group News

**By Ron Irons**

It has been almost 2 months since I have taken over the TNA Support Group Services. This has given me the opportunity to talk with most of the Support Group Leaders. What a positive and energetic group of leaders. They range from 1 year to over 10 years experience for some and quite a variety in between.

We have also sent out 6 new start packets to prospective Support Group Leaders interested in starting support groups in Central, North Carolina, Anaheim, CA, Jacksonville, FL, Amarillo, TX, Longbranch, NJ, and Omaha, NE.

If you are a TN or facial pain patient and have had a procedure or found another way to stop your pain we need you to come back to the support groups and share your experiences so that others may find relief also. Too often when patients get relief from their pain they quit coming to the meetings and do not share their success with others who are looking for answers. Another benefit of attending TNA Support Groups is that a lot of patients not only have TN or Facial Pain but other medical issues and they would love to talk with others who are dealing with the same issues. You could have the answer that could stop the pain for others.

TNA Phone Camp, a conference call, that lets 5 Support Group Leaders interact and ask questions in regards to, TN, Facial Pain and issues that support groups face. The first TNA Phone Camp was attended by Rohn Harmer in Florida, Bill Starr in Nevada, Jacque Roland in Illinois, Bennett Bloomfield in California, Stephen Goolsby in Virginia, along with Dr. Kenneth Casey, TNA Medical Advisory Board and Ron Irons, TNA Support Group Services. It was enjoyed by all attendees as being informative and educational.

Another TNA Phone Camp is scheduled for September 17, 2011 along with others during the year. Contact Ron Irons with TNA Support Group Services to attend. rirons@tna-support.org

# Ask the Doctor

**Featuring Cindy Ezell and Jeffrey Cohen, MD, PhD ,** Ms. Ezell is in charge of patient services for TNA and Dr. Cohen is Assistant Professor of Neurology, Albert Einstein College of Medicine, and a member of the TNA Medical Advisory Board. He is an international lecturer, author and researcher.

**Q.** When a patient comes to you with facial pain, what steps do you take to determine a diagnosis?

**A.** The most important aspect is the patient's medical history. It is essential to understand the following basic questions: When did the pain start? What did the pain feel like at the beginning? What part of the face is painful? Has the frequency and quality of pain changed over time? How would you describe the pain? Did it ever go into remission? Is there anything, or an activity that makes the pain worse? Is there any trick that you have figured out that makes the pain better, even if it is only for a short while? What therapies have you tried already for the pain? Have you been to the dentist? Did you have any dental work for the pain, and did it help? Has there been any injury to your face?

Other than history, depending upon how long the facial pain has been going on, it may be helpful to review what, if any tests were done, or treatments tried to diagnose the cause and eliminate the pain.

Physical examination will follow. In particular, the sensory examination is important. It may be normal, or it can demonstrate sensory loss, or excessive sensitivity to mild stimulation (hyperalgesia and allodynia).

After all of this, the information is synthesized and a diagnosis of neuropathic facial pain is considered. Neuropathic facial pain refers to pain that is initiated or caused by a primary lesion in the nervous system. (An alternate definition is "pain arising as a direct consequence of a lesion or disease affecting the somatosensory system.") If detailed information is available, it is possible that a more specific facial pain diagnosis can be made (e.g. Trigeminal Neuralgia, left side, second division, type I (see article by Dr. Burchiel in this issue), or Trigeminal neuropathic pain, etc.).

**Q.** Is there a treatment that will alleviate neuropathic facial pain that is not classic trigeminal neuralgia?

**A.** The short answer is yes. There are several medications that are marketed in the US, that have at least some research backing and even more clinical experience for the treatment of neuropathic facial pain. In general, the choice of a medication may depend upon the quality of the pain (is it sharp, dull, burning, constant). There is probably no one medication that is clearly superior to others, though. The choice is often individualistic, and has to take into account the quality of the facial pain, the patient's other medical conditions (and the medications they are taking for those conditions), and the patient's ability to tolerate a specific medication. There has to be a balance between a medication's ability to control pain (efficacy) and its potential negative impact (safety/tolerability). Some medications that are used include or fall into the categories of antidepressants, muscle relaxants, anti-anxiety medications, beta-blockers, and anticonvulsants. Some patients report that opioids may be helpful. For those in whom medications do not provide sufficient relief, procedures such as motor cortex stimulation are considered.

**Q**. Why is it difficult to treat neuropathic facial pain?

**A.** Although there are many treatments, none of them work all the time, and there are often differences in what works for any individual. Sometimes it is difficult to treat neuropathic facial pain, but other types of pain may be just as challenging. Some reasons for this include: the diagnosis is delayed, or not considered at the onset (therefore allowing the pain process to develop), non-"neuropathic pain medications" are chosen, the patient (and sometimes the physician) are reluctant to use adequate doses of medications, medications are not taken per directions, or the doses of medications needed cause too many side effects.

Another important factor, is that there is still much to be learned about the mechanisms that cause neuropathic pain. If these were better understood, there might be a way to intervene sooner and stop the process that leads to the chronicity of neuropathic facial pain.

**Q**. Are there any "tests" to diagnose neuropathic facial pain?

**A.** There are no specific tests for neuropathic facial pain; it is largely a diagnosis that is based on history and the patient's description of pain. However, depending upon the history, certain tests may be indicated. These may include MRI of the brain and neck, as well as a complete dental/orofacial evaluation. Most of these tests serve to exclude other diagnoses, rather than to "diagnose" neuropathic facial pain.

**Q.** Some doctors recommend I stop taking medication after I achieve pain relief, should I completely stop all medication.

**A.** This question is commonly asked. I usually ask if the pain is truly gone, or is it just better. For some, all of the pain is gone, they no longer think about the pain, and they can't notice a difference if the medication "wears off", or if they forget to take a dose. If all this were true, these patients can consider a slow taper of medication. I would not recommend this for at least a month after the pain is truly gone. Even then, medication should be cut back slowly, with the help of the treating physician.

For others, the experience is that the major pain (shocks, severe pain) is gone, but a low level pain persists. Sometimes there is no severe pain, but the patient is still very worried about the facial pain, is still unable to eat regular food on that side, or still has an "awareness" of facial pain. For these patients, it is probably a good idea to continue medication. If side effects are a concern, it may be possible to lower the dose, with the guidance of the treating physician.

**Q**. Why does TN stop hurting when you go to sleep?

**A.** This is commonly reported by many patients with TN. The perception that the pain stops during sleep is fortunate, as it would be devastating not to be able to experience the rest needed for normal daily function. It is possible that there may be a protective physiological mechanism during sleep which prevents the pain. However, a recent survey of bed partners of people with TN suggests that pain attacks do occur during sleep, that the sufferer looks as though they are in pain, but that they often do not completely arouse, and therefore do not remember the painful attacks. It is somewhat reassuring that that memory is blocked. ●

Let us hear from you; submit a question:

Ask the Doctor will be a regular feature of the TNA Quarterly Magazine. If you have a question you would like to see answered, please submit it to Cindy Ezell at: cezell@tna-support.org. We will try and select questions that address a range of concerns in the face pain community.


*Tom Wasdin at a UF alumnae event with Dr. Michael L. Good, dean of the UF College of Medicine, and his wife, Danette*


*Susie Wasdin with former Florida Governor Bob Graham and University of Florida President Bernie Machen*

# Tom and Susie Wasdin,

## tough fighters against trigeminal neuralgia, seek to help others through matching gifts for research

**By Arline Phillips-Han**

Business entrepreneur Tom Wasdin of Cocoa, FL. orchestrates a far-reaching real estate enterprise in Florida and Georgia, matching in its excellence his earlier championship performance in collegiate basketball and leadership in Florida sports. Yet the triumph he finds most rewarding today is pain-free life, after 30 years of on-and-off attacks of stabbing pain on both sides of his face.

Wasdin gained freedom from both facial pain and medications through a non-surgical treatment called balloon compression, and is back to enjoying a "wonderful life."

He and his wife, Susie, partners in marriage and in business, consider it a miracle that he gained freedom from pain immediately after the treatment—performed in 2007 on the left side of his face, and again in 2008 on the right side. Balloon compression was less invasive than other treatments he received to no avail over a stretch of many years. At times, he felt as if life, as he could enjoy it, was over.

Out of that long painful and often discouraging experience, Tom and Susie are resolved to do something to help others avoid a similar ordeal. They share a fierce drive to find a cure—not another temporary pain reliever—and have a plan for reaching that goal. They are establishing a $120,000 matching grant to support research aimed at repairing damage to the nerve coating called myelin, which often triggers facial pain. For every dollar donated, they will give a dollar, up to $120,000 during a one-year challenge.

Donations will be channeled through The Facial Pain Foundation, a division of the TNA-Facial Pain Association, to a team of neuroscientists at the University of Florida's McKnight Brain Institute. The grant will continue studies begun by the Association almost two years ago under the direction of Neuroscience Professor Lucia Notterpek, Ph.D., with Andrew Ahn, M.D., Ph.D., as co-investigator. The researchers seek to restore myelin that has been chipped or eroded away from the trigeminal nerve, setting the stage for piercing, shocking facial pain that progressively grows more severe.

Wasdin's empathy for patients with trigeminal neuralgia is born of tremendous suffering, starting with a five-year search for an accurate diagnosis! He first turned the corner in a positive direction when his family dentist, Dr. Wayne Robben of Cocoa Beach, read an article about TN and suggested this appeared to be his problem. The diagnosis was confirmed by Neurosurgery Professor Emeritus Albert Rhoton, Jr. (now semi-retired) at the University of Florida College of Medicine. Rhoton initially treated Wasdin with tegretol, the drug of choice for TN, which brought a few months of relief.

There followed a series of treatments that stopped the pain for short intervals before stunning recurrence. The treatments that failed to bring lasting results included the best available medications, acupuncture, microvascular decompression (MVD) surgery, and radiofrequency lesioning, in which the damaged trigeminal nerve is burned with a needle to purposefully numb the region. At various times, he took prescribed doses of tegretol, which impaired his balance and memory. He underwent a second, deeper radiofrequency procedure, and a second MVD operation that did not work.

The balloon compression treatments, which ultimately ended his pain, were performed by Neurosurgeon Jeffrey Brown of Great Neck, N.Y. Brown inserted a balloon-tipped catheter, and once in the desired position, he inflated the tiny balloon so that it squeezed the trigeminal nerve and damaged the pain fibers. Wasdin awoke from the anesthesia with no pain. His wife recalls that for the first time in four years, "his eyes sparkled and he had the biggest smile you have ever seen!"

Throughout the years of suffering and persistent search for relief, Wasdin managed to run his business enterprise with the continual support of Susie. There were days when following through at work required herculean motivation.

Tom and Susie have recently narrowed their business to the management of Wasdin family properties, along with philanthropy and volunteer services, but the results of their combined talents and hard work are visible in many places. Through Wasdin Associates, Inc., which they founded in 1993, they developed subdivisions, and Susie directed a custom home division that constructed more than 200 homes on the Space Coast and in the Orlando area. Tom also is president of Kennedy Point Marina Inc., which operates real estate holdings in Florida and Georgia, and participates in natural gas and oil leases in Texas and Alabama.

Wasdin served nearly 18 years on the Brevard County Tourist Development Council, and in 1999 won The Portrait of Excellence Award from the Space Coast Office of Tourism.

He remains widely known in sports, currently serving as chairman of the Florida Sports Foundation Board of Directors under appointments by former Governors Charlie Crist and Jeb Bush. He served as president of Florida AAU for two years and received the national "President's Award" for his contributions to AAU. He also was instrumental in forming the Space Coast Sports Commission. In 2010 he was elected to the Athletic Hall of Fame at Jacksonville University where he was head coach for the Dolphins and achieved a win-loss record that still ranks as one of the highest in the nation. While at JU, he recruited and coached Artis Gilmore, who recently was initiated into the Naismith Memorial Basketball Hall of Fame Class of 2011.

Wasdin is listed in the Brevard Community College Sports Hall of Fame and the Florida Community College Basketball Hall of Fame, and in the Alumnae Hall of Fame at UF's College of Health and Human Performance.

In both their professional and personal lives, Tom and Susie are a high-performing, winning team. Their growing family includes two sons, one daughter, six granddaughters, four grandsons, and another grandchild on the way. They enjoy travel, golf, sports and UF alumnae activities as graduates of the College of Health and Human Performance and the College of Education.

Success did not come readily or easily as Wasdin fought his battle with pain, and Susie shared his suffering. They reflect extraordinary ability to beat the "beast" of trigeminal neuralgia.

"I used to go to bed hoping I would not wake up in the morning," he recalls. "Today, I sit here happy, free of pain. The main message I want to give people in pain is, "Don't give up!"

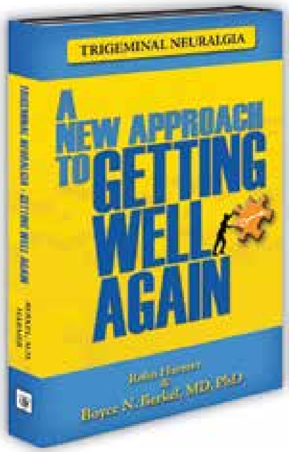
"We must, for many reasons, support research," said Wasdin, who champions all programs of The TNA-Facial Pain Association through his position on the Board of Directors. "Susie and I cannot do this alone, but we will prime the pump by matching gifts dollar for dollar."

To every person wanting to double the amount of their gift by donating to the Wasdin Matching Gift Grant, send contributions to:

The Facial Pain Research Foundation at 2653 SW 87th Dr., Suite 8, Gainesville, FL. 32608

# TNA Board Forming Young Patients Committee

The Young Patients Committee (YPC) will assist the Board of Directors in fulfilling the mission of the Association by representing the interests of neuropathic facial pain patients under the age of 40. The Young Patients Committee will advise the Board and make recommendations concerning issues that are of concern to young patients, as well as opportunities and initiatives that young patients would like to pursue to advance their interests. If you are under age 40 and interested in joining this committee please send a brief email about yourself and your diagnosis and treatment to info@tna-support.org ●



# Swedish Rice Pudding

## Easy to eat, not too sweet

½ C white rice
Rinse rice before cooking to remove excess starch
Cook rice:
Add ½ C rice to 1 C water
Bring to boil, put lid on pot and reduce heat, let simmer for 10 minutes.
After 10 minutes remove from heat, fluff rice, return lid and let sit
Rice should be dry and fluffy
Add to finished rice:
2 T. butter
2 – 8 oz. cans evaporated milk
½ C. sugar
¼ tsp. salt
¼ tsp. nutmeg
½ tsp. cinnamon
½ tsp. vanilla
Stir over low heat for sugar to dissolve

5 eggs separated
Whip whites until stiff peaks form
Whip yokes until creamy
Fold together

Fold whipped eggs into Rice mixture

Pour into 2qt. casserole or 8-6 oz. custard cups or ramekins
Place casserole or ramekins in warm water bath
Bake in 350° oven for 1 – 1 ½ hours until golden, yet slightly soft in the center
Note: Over cooking will diminish the creamy texture

Serve warm with fruit sauce or whipped cream
Or
Cover and chill to serve

## Coming in Spring 2012

## TNA Regional Conference
## New York City

Sponsored by:
NYU Pain Management Center
Winthrop Hospital

# The following individuals joined or renewed their TNA membership

## June

Fred Best
Christine Calabrese
Ann Clayton
Meredith Collins
Anne Creamer
Robert DiMattia
Trish Donnelly
Elizabeth Healy
Scott Holstad
William and Darlene Kasten
Patricia Kolditz
Lynn Kory
Joseph Martin
Sandy Martin
Susan Matte-Frina
Jim Mosenfelder
Barbara Omoth
Janet O'Neil
Nancy Oscarson
Andrew Petitjean
Lisa Ptak
Rose Rich
Susan Roth
Betty A. Smith
Jennifer Sweeney
Richard Vancil
Sue Vincent
Jenny Warburg
Beverly Williams

## July

Leonard Abrams
Lynne Armengol
Yoav Bar Israel
Sherry Birkby
Thomas Bowler
Eugene Bryan
John Clark
Nyda Concialdi
Kerrie Cross
Joyce Dadouche
Anna Ellsworth
Lisa Eschleman
Mike Fadel
Richard Fishman
John Galligan
Marian Gemmell
Sarah Goldberg
Donald Hansen
Merren Hao
Robert Heyman
Tracy Howard
Stephen Iacovino
Liz Johnson
Roslyn Apt Johnson
Ann Kinyon
Tina Krull
Kim Lumley
Jean Lumpkin
Karen Mahoney
Kari-Ann Matthews
Carol Murray
Joerdan Naraja
Thomas Pace
Joanne Palangi
Michael Pasternak
Diane Pendleton
Michael Phelan
Brian Power
George Rezner
Veronica Rone
Lynn Ruppe
Sylvia R. Schoenfeld
Philip Tereskiewicz
M.D. Weeks
Eloise Wickham

## August

John and Rosemary Ashby
Lynne Baron
John Bish
James Blodgett
Steph Burke
Sherry Burt
Douglas Carpenter
Carol Coudert
Emily Diaz
William Fenstermaker
Lauren Grasmick
Meagan Grasmick
William Grasmick
Rohn Harmer
Sharon Henley
Linda Hokit
Karen C. Hopwood
Kimberly Hutchins
Vicki Jankowski
Beth Lamb
Cheryl Lewark
Michelle Love
Charlcie Montgomery
Willa Jane Muterspaw
Maura Nolan
Kathy Norwood
Karrie Ann Ogilvie
Peggy Pflager
Daniel Ponce
Janice Przystal
Ray Rivera
Natalie Sachs-Ericsson, PhD
Candy Schoeneberg
Beverly Sherbondy
Laurie Simon
Marti Squyres
Craig Swanson
John Visneuski
Edward Welty
Rita Welz
Sue Wilson

## The following individuals are Lifetime members

Claude and Jean Aldridge
Linda Lee Alter
Gwen Asplundh
Millard Battles III
Jeffrey Bodington
John Boettner
Karen Burris
Nell Channell
Brent Clyde
Allan Cohen
Douglas Daugherty
Steven Giannotta
Mary Glynn
Denise Gorman
Ron Greiser
Suzanne Grenell
Betty Hare
Peter Jannetta
Nancy Montag
Franklin Naivar
Brenda Petruska
Patti Jo M. Phillips
Gayathri Rao
Aaron P. Running
K Singh Sahni
Philip Sine
Ronald Streich
Patty Sublett
Lori Sunderland-Klassen
Julie Thomas
Tom and Susie Wasdin
Christy West
Karen Wilson
Cheryl Wruk

# TNA's Memorial Tribute Fund

There are special people in our lives we treasure. Increasingly, TNA supporters are making gifts in honor or in memory of such people. These thoughtful gifts are acknowledged with a special letter of thanks, are tax-deductible, and support TNA's growing initiatives on behalf of TN patients and families. We are delighted to share recent Memorial Tribute gifts received as of August 2011:

## In Memory of :

**Leslie Bertrand**
Corinne Davison

**Mattie Brewer**
Jasper Brewer

**Cora Digby**
Jo Anne Beavers

**Kenneth Dixon**
Jamie Jodoin

**Shirley Glavich**
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Mr. & Mrs. Hickman
Louise Hyman
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**Margaret Ludwig**
Sandra Ludwig

**Ruth Ockert**
Frederick Ockert

**Margaret Owen**
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**Robyn Rubin**
Jonathan Bellingar

**Arlene Boumel**
Dorothy Crown
Alyson Dachelet
Lynn Eads

**Marcy Entin**
Alison Friedman
Paul Gettleman
Barbara Seidman
Raul Wong

**Connie Sfeir**
Joseph Sfeir

**Everett M. Story**
Phyllis Story

**Daisy Mae Young**
Robert Young

**Norma Zimmer**
Claire Patterson

**Howard Young**
Lynn Abravanel
Jayson & Sylvia Alberts
Nicholas & Paddi Arthur
Dave Brooks
Candance Carroll
Christine & Rick Filcoff
William & Ruth Healey

**Marilyn Rapoport**
Tanya Steinkamp
George & Toot Wergeles

## In Honor Of:

**All Who Suffer with TN:**
Michael Hanson, II
Bruce Pollock, MD

**Margaret Campbell Welz**
Salley Campbell

**Timothy Curtin**
Fayne Daniels

**Phylicia Fairbourn**
Jack Fairbourn

**Suzanne Grenell**
Naomi Grenell

**Peggy Luzzi**
Edward Luzzi

**Shelly Michell**
Lloyd Michell

**Josie Nunez**
Angela McMahon

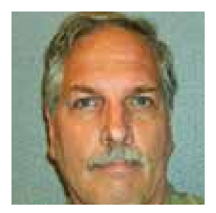
**Rob Parrish, MD, PhD**
Joe Christian

**K. Sing Sahni, MD, FACS**
Don Frank

**Xiunzhi Zhu**
Evelyn Jiang

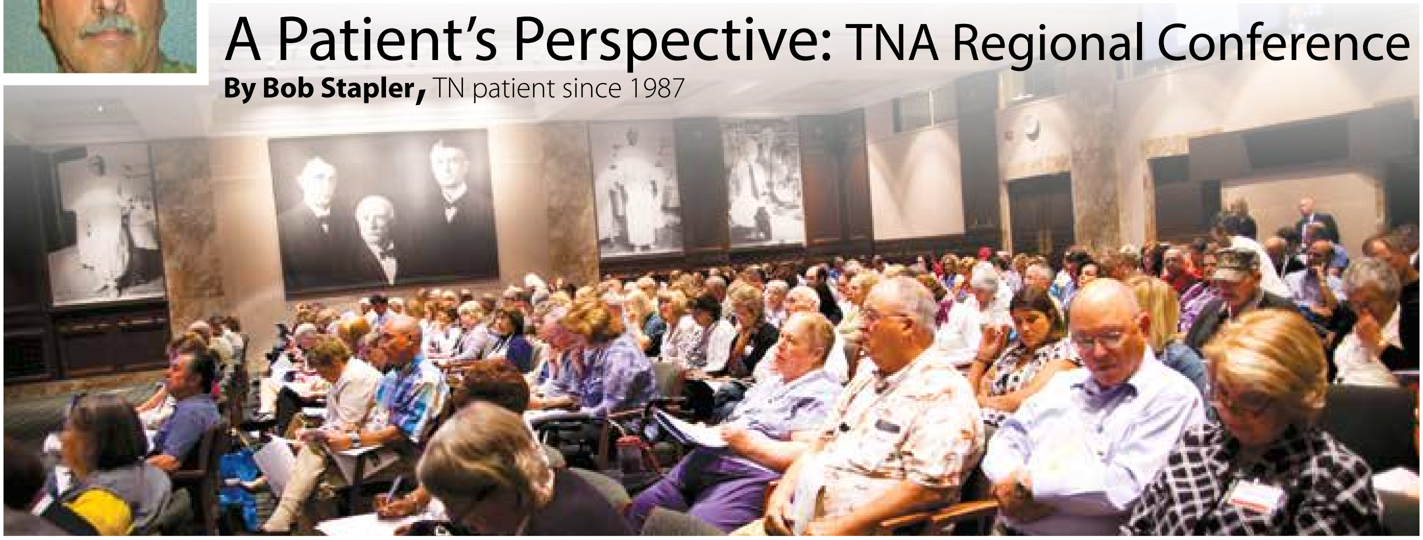
## AFFIRMATION

TURN YOUR FOCUS TOWARD YOUR POWER AND WHAT IS IN YOUR CONTROL



# A Patient's Perspective: TNA Regional Conference

**By Bob Stapler,** TN patient since 1987



In May I had the pleasure of attending the 2011 TNA Conference in Richmond, Virginia. Besides the presenters, I got to meet a fair number of fellow TN folk; including both the local and national TNA hosts. Cindy Ezell (TNA Coordinator of Patient Services) remembered me, and encouraged me to do a conference write up. Due to a space constraint I had to truncate my report, but you can read the extended version (including a great many background links) here: http://www.braintalkcommunities.org/.

The program consisted of nine presentations, plus a panel session in which audience questions were discussed among the doctors, providing insight into the collaborative approach doctors take to patients. Dr. Singh Sahni (Chief of Neurosurgery, Director CJW Neuroscience and Gamma-Knife Center) was the conference host and introduced the individual presenters.

Following the presentations and the Q&A session, the conference broke into groups; one to visit the GK facility, one to tour other neurology centers, and one that remained behind for one-on-one discussions with Drs. Sahni, Eichler and Brown. I took advantage of this last to push questions not answered in the general Q&A. *What are the long-term pharmacological side-effects on patient personality, emotional-state and behaviors (e.g., panic attacks, social withdrawal, confusion and suicide)? What recommendations do doctors make regarding medicinal use/over-use and over-reliance? Why isn't more done to alert and prepare patient's in dealing with psychological changes?* I recommended family be included in doctor/patient sessions as a backstop to patients struggling to memorize doctor instructions in a high state of pain/sedation; and coached on things to watch for.

Their consensus was that, other than confusion and memory loss, they were unaware of any pharmacologic emotional-state issues of this severity (assume they meant in significant numbers). At this point, I assured them I had personally experienced these side-effects; including (at one point) suicidal ideations alien to my nature, that the only time in my life I have ever experienced suicidal thoughts was at high doses of these particular medications for prolonged periods, that when I discontinued the medications the problem went away, and that I have lived several years in pain off meds with no such issues. I noticed a few heads nodding in agreement even as I recited this to the doctors. It is my feeling not enough has been done to alert and train prescribing physicians to this problem; and, if such problems do not show up in the first few weeks of taking meds, they assume all is well. It is my experience mental-state and behavioral shifts take time to develop and are potentially lethal. Others have related (here and elsewhere) they too experienced such changes, some over shorter time spans than mine. So, I was surprised the conference doctors were this unaware of the problem.

Nonetheless, I was greatly impressed by the doctors, their knowledge, integrity, dedication, skill, erudition, confidence, and humanity. Besides doctor-presenters, I'd like to thank the national and local chapter organizers for putting this conference together. If I have any complaint, it was the conference was too short and that I did not get to spend more time with my fellow TNers. I would estimate there were close to 200 attendees of various descriptions, though most were TNers and family. A few were medical professionals, staff and students, including a local dentist interested in learning about TN. TNers I met ranged in age from early twenties to late 80s, and travelled from as far as Nova

# Conference continued

Scotia. I even met a couple who live only three-miles from me in Maryland. There were TNers of all descriptions: classic, ATN, bilateral, AD, dental neuropathies, and surgically compromised.

No conference is complete without book offerings. I came intending to buy at least one, and have added Dr. Zak's 'Insights' to my bookshelf.

> I realize I don't have to describe all the support I witnessed, but I think it is important that I do. I will refrain from gushy superlatives like 'amazing', 'generous' and 'unconditional' as trite, overused and inadequate, however.

Perhaps a more useful way to relate this is to suppose instead of a TN conference this were a trade show. At trade shows, we expect to hear a lot of market hype, the objective being to persuede us to choose one virtually identical product over another. There is an undeniable element of this at medical conferences because doctor-presenters' promote surgical and therapeutic offerings. Unlike trade-shows, however, it is not the primary object; underlying which is every doctor's fundamental belief in his/her role as caregiver. These folks are wired this way both from training and inclination; and, what is (okay, I'm going to break my promise) 'amazing' is encountering so much of that in one room all focused on us. It feels extraordinary in this setting because all of that caring is brought to bear like a heat seeking missile seeking its natural prey – us. Doctors are, perhaps, no more evidently in their 'caring' persona than when preaching to the choir. Does that sound cynical? If so, it was not meant to be because I am trying to get at a very human truth; that we fundamentally are what we aspire to be and what we polish to near perfection. I am a better engineer partly because I have had some success, but also because it is what I love doing. I have a conceit some engineers 'choose' the profession; while others are 'chosen' by it; and exhibit greater enthusiasm for that. The doctors at this conference exhibit that kind of enthusiasm.

Then, of course, there was the mutual support of TNers meeting face-to-face for the first time. Is support spontaneous or is it a state into which we have worked ourselves? I did not meet a single person at the conference I knew from other settings. Outside of TN, I probably did not have much in common with many. Certainly, I had little I could chat about with the gals

***continued on page 20***

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# Conference continued

(about 2/3 of the crowd) outside our condition, and am at a loss discussing sports among guys. Yet, we introduced and spoke to one another as though longtime pals with so much to tell each other, so much to catch up, and too little time in which to tell it. There was no sense of strangers however well met, only of unmet brothers and sisters on holiday together. I'd already heard most of the storylines from other TNers. There was a gentle urgency to our mingling; that it was important we make contact with one another ("you got this crazy condition … what d'ya know, me too!"). That knowledge plus the physical presence of a real flesh-&-blood person means: you are not alone in this; others have it too, and they are not very different as matters. This may seem a triviality, but it is important knowledge when you are longtime hurting.

> The most common question among TNers? "How long?" Not, 'How long have you had TN?' or 'How long have you been in pain?' – Just 'How long?'

Often it is not what we say, but what we don't need to say as defines a bond. If any one thing defined the bond for us at this conference it was this simple, truncated question. There were other things that captured it as certainly. I caught myself more than once completing a thought for someone else, or they doing the same for me when stopped by pain. This is a behavior more common to spouses or siblings than strangers, and implies great familiarity.

I was a little unsure what to expect at the conclusion of my first TNA conference. Hollywood always depicts this as a tearful moment where people act like, well, a bunch of Hollywood actors. Watching these folks leave, I did feel some slight reluctance to let go of them or the moment. Was this just me? Many hurried to catch planes or beat rush-hour traffic, but I am sure others shared some of my reluctance to leave. It isn't enough just to learn. There is also that expectation of connecting with others not quite sated.

I lingered longer than most repeating my goodbyes if only to savor the good vibes and wishes for better days to come. There was no profound emotional outpouring; no group hug –just some handshakes and "Hope you feel better soon". It doesn't need to be better than that to know we've got your back … and you have ours. It was all good. So, bless you all and pain-free days … wherever you are now. ●

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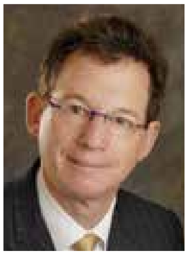
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Neurological Surgery, P.C., is a national leader in the treatment of trigeminal neuralgia and face pain. Trigeminal Neuralgia is a disease in which patients get sharp intermittent pains in their face. There are several different treatment options available for treating this disease including medication and five different surgical procedures: percutaneous rhizotomy (radiofrequency, glycerol and percutaneous balloon compression, a technique pioneered by Dr. Jeffrey A. Brown), stereotactic radiosurgery (Gamma Knife® and CyberKnife®), and craniotomy (microvascular decompression). Balloon compression, radiofrequency and glycerol rhizotomy, Gamma Knife and CyberKnife are all outpatient procedures. Any one of these procedures may be the best choice for a particular patient.

Dr. Michael Brisman, Dr. Jeffrey Brown and Dr. Alan Mechanic perform all of the different procedures for trigeminal neuralgia, and are leaders in the field of face pain surgery.

Dr. Brisman is Chairman of the Department of Neurosciences at Winthrop-University Hospital and Co-Medical Director of the Long Island Gamma Knife at South Nassau Communities Hospital.

Dr. Brown is Northeast Regional Director and immediate past Co-Chairman of the Medical Advisory Board of TNA-The Facial Pain Association.

Dr. Mechanic is the Chief of Neurosurgery at Huntington Hospital in Huntington, NY and the Chairman of the Nassau Surgical Society Section of Neurosurgery.

For more information about trigeminal neuralgia and face pain or to make an appointment, please call (516) 255-9031.

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