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From the Chairman of the Board

Welcome to New York and TNA’s 25th Anniversary National Conference. Dr. Jeffrey Brown and TNA’s CEO John Koff have organized two days of informative presentations and opportunities to meet with world experts in treating facial pain disease. Organizing this conference is a big project and we thank Dr. Brown, Mr. Koff, Dr. Sirois, NYU, TNA’s staff and the speakers who are making this conference possible. Reaching back 25 years, we also thank Ms. Claire Patterson, Dr. Peter Jannetta, and the many who have supported TNA with their ideas, time and funding.

TNA’s essence is providing proactive and personal assistance to people, and to caregivers of people, who have facial pain disease. That simple statement has huge strategic implications. The nature of social interaction is changing and that affects how TNA stays useful. Academics described a shift away from participation in organized groups by the early 2000s and Internet search tools such as Google and social media such as Facebook accelerate that change. TNA sees this change in its conferences, support groups, membership and the use of its Internet-based services. We are working to both preserve the essential benefits of personal assistance and to use the visibility and low cost of the internet to be as useful as possible.

Every time, attendees at TNA conferences and Support Groups say that one of the best aspects of the experience was the one-to-one interaction with each other and healthcare providers. However great the Internet may be, personal interaction remains extremely valuable. Attendees learn a lot about treatment options and managing drug side effects, relationships, work and other aspects of life outside of the doctor’s office. Here in New York, you can also lunch on Saturday or brunch on Sunday with a neurosurgeon or other expert in some aspect of facial pain care. TNA also offers one-day regional conferences to make it easier for attendees to meet each other and hear from experts. We are thankful to TNA-member Brett Frankel who will sponsor two regional conferences each year during each of the next three years. Watch TNA’s website, emails and mailings for details on those conferences.

However great the conferences and Support Groups are, the Internet is a very low cost method of delivering information and having a conversation. TNA’s website is getting several million visits per year from all over the world, the TNA Newswire provides a bi-weekly news update, the TNA Quarterly is distributed via email in addition to mail, TNA is active on Facebook, and our Video Project conveys the impact of the disease. TNA is also working to provide more information as downloads too.

Looking forward to the next 25 years in a changing world, TNA will work to keep the balance of conference and internet resources just right, to manage shifts from physical support group attendance by some toward internet-based interaction, from physical books for some to downloads, and from reliance on existing healthcare contacts by some to consulting “Dr. Google” before actually meeting with an expert. TNA will work to stay the go-to credible source of information in a sea that sometimes contains sources with a narrow or agenda-driven view. After 25 years, we remain devoted to providing proactive and personal assistance.

Again, welcome to TNA’s 25th Anniversary National Conference and I know that you will find it useful.

Jeff Bodington, Chairman of the Board
TNA – The Facial Pain Association
Getting a Better Understanding of Neuropathic Facial Pain – Dr. Jeffrey Brown discusses how gaining a better understanding of the classifications of facial pain can help patients receive better treatment.

Founder Claire Patterson charted the course for the Trigeminal Neuralgia Association.

Brett Frankel – Facial pain patient Brett Frankel has found relief from his pain, and now he wants to give back to help other TN patients.

The New TNA Regional Conference Program.

Trigeminal Internal Neurolysis – Kim Burchiel, M.D. comments on the research he and his team have conducted regarding a new surgical treatment for TN.

Peter J. Janetta, MD: Vision and Perseverance – Leaders in the field of Neurosurgery look back at the impact Dr. Janetta has had upon their careers and the field as a whole.

Science 2015 Meeting – Elizabeth Cilker Smith, West Coast Coordinator for the Facial Pain Research Foundation, shares details from the 2015 research conference held in Naples this past March.
Fall 2015

TNA Past and Future! – A look at the history of the treatment and support options available for facial pain patients.

What We Learned Along the Way: Four long-time TNA support group leaders discuss their search for information since they were diagnosed.

TNA Through the Years – A look back at the past 25 years of TNA through pictures.

Decision Making, Dr. Raymond Sekula’s thoughts on making treatment decisions.

Dental Care with Concomitant Neuropathic Orofacial Pain

Back to school with the YPC. Our first young patient profile.

TNA salutes all members of the Board of Directors and Medical Advisory Board.

Please look for regular features such as the Memberships, Honorary and Memorial Tributes in the Winter Quarterly

TNA Video Project

BE HEARD • RAISE AWARENESS • JOIN THE VIDEO PROJECT

Look for the VP Logo in the conference agenda for the where and the when
For generations now textbooks of medicine, neurology and neurosurgery have included chapters on “trigeminal neuralgia,” repeatedly referencing descriptions of untreated “lancinating” pains in tortured patients from the 1600’s. Though the history is interesting, the time has come to move away from such historical considerations into a more modern understanding of the nature of neuropathic facial pain.

Whereas patients will often speak of “stabbing” and “electrical” pain, “lancinating” is a word often seen in the literature but seldom used or understood by patients in this era. “Classical” and “typical” refer to patients who are briefly pain free in the intervals between occurrences of their neuropathic face pain. TN2 refers to patients with constant neuropathic pain. It is time to retire the historical terms “classical,” “typical” and “atypical.” “Typical” and “atypical” have an emotional content to them that unnecessarily complicates the diagnosis. There is nothing inherently typical about patients with intermittent stabbing pain, or atypical about patients with constant pain. The terms only reflect the experience of the neurosurgeon performing the evaluation.

Taking the thought one step further, the term “trigeminal neuralgia” itself has inherent limitations. Patients with neuropathic facial pain may or may not fit into the historical category of “trigeminal neuralgia.” For example, a patient who has developed severe, intermittent, stabbing facial pain in the cheek may also have sensory loss in the jaw after having had an ablative procedure in the past. The area of numbness may cause a minor element of constant burning pain. Is this TN1? Is this TN2? Is this atypical pain? Is this still “trigeminal neuralgia?” None of these terms is adequate to the situation. Does the presence of numbness in one trigeminal division obviate ablative treatment for severe stabbing pain in another?

For the patient who wishes to know, “Do I have trigeminal neuralgia?” the answer should be, “That’s not the right question.”

“Dr. Brown” . . . continued on page 5
The question should be: “Do I have neuropathic facial pain with predominantly paresthesias, with predominantly dysesthesias or with a mixed entity consisting of both types?” Even simpler is to phrase the question as “Is the pain paroxysmal or not?” If it is not then the treatment options change. If it is constant with paroxysmal intervals, then the next question is whether the constant pain is electrical in nature. If so, then one needs to know whether the paroxysmal pain predominates. If it does, then the surgical treatment could be either ablative or decompressive. If the paroxysms are not the predominant issue, then the surgical treatment may be limited to peripheral stimulation or motor cortex stimulation.

Confusing?

The route to the correct treatment for facial pain is not straight and direct like an interstate highway. But, the one to New York City and the upcoming Bi Annual national meeting of our organization in New York City on October 10-11, 2015 might be your best move. It is there that you will have the opportunity to hear the world’s experts provide you with their thoughts on the most up to date treatment for facial pain. Listen, question and decide yourselves what is best. The mission of TNA—the facial pain organization is to provide that information for you. Take advantage. 🌻

Congratulations to
TNA-The Facial Pain Association on the 25th Anniversary and 10th National Conference.

Ramesh Babu MD,  
Associate Professor of Clinical Neurosurgery

NYU Medical Center  
530First Ave., Suite 7W  
New York, NY 10016  
212-263-7481

• Specializing in atypical facial pain  
• Microvascular decompression  
• Glycerol rhizotomy  
• Comprehensive management of facial pain
“Once, we were the only ‘port in the storm’ for providing basic navigation to people stricken by the shocking facial pain of trigeminal neuralgia,” says Claire Patterson, founder of the Trigeminal Neuralgia Association that has since been renamed TNA-The Facial Pain Association.

Patterson refers to the Association’s formative years in the early 1990s when the “port” was her home overlooking a lagoon in the seaside borough of Barnegat Light, N.J. Like the keepers of the historic lighthouse guarding the coastline at Barnegat Inlet, Patterson was a beacon of guidance for people struggling to find an accurate definition of the mysterious hit-and-run pain. She seemed always ready for the calls that came from people in pain, who had no inkling that her office was her kitchen counter, equipped with telephone and fax machine.

At this early point in the Association’s history, trigeminal neuralgia had no public recognition and scant description in medical literature or popular press. Typically, a person stricken by TN pain had to search for years to obtain an accurate diagnosis and find knowledgeable experts to treat the disease. Against that backdrop, the Association evolved dramatically as Patterson worked her way through the process.

COMPASSIONATE, VISIONARY CLAIRE PATTERSON CHARTED THE FIRST COURSE FOR TRIGEMINAL NEURALGIA ASSOCIATION

By Arline Phillips-Han
of incorporation in the State of New Jersey in 1990, succeeded in obtaining IRS 501 (c)3 nonprofit tax-exempt status in 1991, and enlisted other volunteers in seeking private funding.

Today, TNA-FPA uses high-tech communications to reach patients and health professionals worldwide, and is a leading resource for the education, counseling and support of facial pain patients, as well as for frequent dialogue between patients and the health professionals who treat them. Scientific research—a third dimension of service—is supported by gifts and grants channeled through its new division, The Facial Pain Research Foundation, whose ambition is to find cures for TN and other neuropathic facial pain by the year 2020.

The Association began with an address list of 75 individuals; it now has a mailing list of 35,000 and an international registry of over 4,000 patients. The national office provides personal assistance to facial pain patients and their families through 50 support groups, and fields e-mail requests from people of all ages throughout the world. Sister organizations in the United Kingdom, Canada, Australia and Western Australia reach thousands through their own educational programs and patient support groups.

Patterson, backed by the first Board of Directors and Medical Advisory Board, laid a foundation for that growth. During her 13 years at the helm, the first printed patient education materials were developed, including a newsletter, TNALERT, and a booklet, TN: A Primer for Physicians and Patients, published in English and Spanish, later translated into Russian for distribution to physicians in Russia.

Doors were opened for research through TNA exhibits at neuroscience meetings and increased interaction between the leadership of TNA and pain researchers at the National Institutes of Health (NIH).

Among high points of TNA expansion, Patterson cites a special event in September 1999 when several pain-related institutes and offices of the NIH sponsored the first scientific conference on trigeminal neuralgia, and developed a priority list of topics for future research.

“Claire Patterson” continued on page 8
In July 2003, the national office was relocated from Barnegat Light to Gainesville, FL. Patterson stepped down as president and served on the Board of Directors for two years while also serving as Director of Institutional Relations and Research. When she retired in January 2005, the Board appointed her Honorary Founder/President Emeritus.

It has been more than 25 years since the entire left side of her face was stricken by intense, repetitive pain, which gradually destroyed her abilities to eat, talk or brush her teeth. She endured a succession of medication failures before she heard about Neurosurgeon Peter Jannetta, M.D. and the microvascular decompression (MVD) surgery he had developed at Allegheny General Hospital in Pittsburgh. She traveled to Pittsburgh to undergo the operation.

Not long after the surgery, Patterson asked Dr. Jannetta why wasn’t there an organization to assist patients with TN? He replied by asking her pointblank, “Why don’t you start one?”

“On the way home from the hospital, my husband, Buck, encouraged me to go for it, and later our daughter provided amazing encouragement at a time when she was undergoing treatment for breast cancer,” she recalls. “There were days when I wondered whether the organization would survive.”

Publicity was needed, and it finally came in 1992 when The New York Times ran an article about TN and the new association, prompting 5,000 letters to the TNA office. Patterson scrambled and found eight volunteers from her church to help answer the letters from her kitchen table. Her phone began to ring often as people in pain called from coast to coast, many of them asking how to find medical help. One urgent call came from a woman aboard a sailboat near Fiji, whose husband was stricken by terrifying bolts of facial pain. Patterson helped her contact a TNA Medical Advisory Board member in Hawaii.

Demands for service grew, and the Association grew to meet the needs, aided by the international influence and personal contributions of Patterson’s neurosurgeon.

“Doctor Jannetta enthusiastically agreed to chair our first TNA Medical Advisory Board, and introduced us to the first funding source—the Richard King Mellon Foundation in Pittsburgh,”

“Claire Patterson” continued on page 41

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“Claire Patterson” continued on page 41
Four years ago, Brett Frankel was celebrating with friends at a weekend bachelor party when he started experiencing pain he believed to be a toothache. When he returned home, he made a trip to the dentist who prescribed him antibiotics and sent him on his way. When the pain had still not subsided, Brett was given a root canal, and then another, but the pain still remained. He was then directed to an oral surgeon who proceeded to pull nine of his teeth: “I never had the classic shocks like everyone else had. I just had constant mouth and teeth pain.” After multiple root canals and tooth extractions that did not relieve his pain, he was finally directed to a neurologist, who immediately recognized that Brett’s pain could in fact be trigeminal neuralgia. He was then recommended to an ear, nose, and throat doctor who confirmed that Brett was suffering from type 2 trigeminal neuralgia.

He was put on Neurontin for the pain, but he did not like the way the medication was affecting him. “At the time I was 36 years old, running a business, I had two small children, it just made me a zombie. It took away the pain but I couldn’t have a life.” Unhappy with the effects of the medication, but not willing to give up, Brett headed online to do research about what he could do to alleviate his pain. Through online forums and message boards, including The Facial Pain Association’s website (www.facepain.org) and Facial Pain Network (www.facepainhelp.com), Brett found Dr. Ben Carson, who was known for his treatment of TN. However, Dr. Carson was getting ready to retire so his office was directing patients elsewhere to begin their care. This led Brett to Dr. Jeffrey Brown, who is one of the world’s leading experts in the diagnosis and treatment of neuropathic facial pain and a Regional Director of the FPA’s Medical Advisory Board. Brett was fortunate to find Dr. Brown not only for his specialty in treating TN type 2, but also because he was located close to his home. It only took 30 minutes for Dr. Brown to diagnose Brett’s type 2 TN; he also told him that he would be a good candidate for a microvascular decompression. “I went from a few months of tooth pain to realizing I had to have brain surgery.” Brett had a successful MVD in June 2012, and is still pain free today, although he now has partial numbness. He has also been working with Dr. David Sirois for the past two years to fix his teeth.

“I went from a few months of tooth pain to realizing I had to have brain surgery.”

“I’m on no medications, no anything. And I just hope and pray that my life is good and that we can help other people learn about this because the one thing I really learned from those message boards is that most people that have a good outcome don’t really come back and talk about it.” Because of this, Brett was motivated to make a donation to the Facial Pain Association. Over the next three years, he will be donating a total of $100,000 that will allow FPA to host numerous regional conferences that will bring information and resources to countless new patients. “I want to give back and help people that can’t help themselves,” not only with a financial donation, but also with the donation of his time and experience.

It is the generosity of individuals like Brett Frankel that allows FPA to continue to educate and support patients by providing a range of free information, including: treatment options, pain management techniques, health care providers, and a support group network that includes one-on-one telephone support.
Through the generous sponsorship of TN patient Brett Frankel, The Facial Pain Association will be presenting two regional conferences each year for the next three years. The first conference in the program will be in the Spring of 2016 at the University of Pittsburgh Medical Center, Faculty Director, Raymond Sekula, M.D.

Mr. Frankel is committed to giving back to TNA and the facial pain patients that supported him when he was diagnosed with TN. The goal of the Regional Conference Program is to make face pain conferences accessible to a greater number of patients across the country. By hosting smaller regional conferences twice a year, TNA will be able to reach patients and caregivers in locations that we’ve never been before! Be sure to go to www.facepain.org for announcements of future conference dates and locations.
Editor’s note: Below is an abstract of research conducted by Dr. Burchiel, et al, on a treatment for trigeminal neuralgia when no neurovascular compression is present. Following on page 13 are Dr. Burchiel's comments on their findings.

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CLINICAL ARTICLE
Long-term efficacy and safety of internal neurolysis for trigeminal neuralgia without neurovascular compression
Andrew L. Ko, MD, Alp Ozpinar, BA, Albert Lee, MD, Ahmed M. Raslan, MD, Shirley McCartney, PhD, and Kim J. Burchiel, MD

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DISCLOSURE The authors report no conflict of interest concerning the materials or methods used in this study or the findings specified in this paper.

METHODS
This was a retrospective review of all cases of Type 1 TN involving all patients 18 years of age or older who underwent evaluation (and surgery when appropriate) at Oregon Health & Science University between July 2006 and February 2013. Chart reviews and telephone interviews were conducted to assess patient outcomes. Pain intensity was evaluated with the Barrow Neurological Institute (BNI) Pain Intensity scale, and the Brief Pain Inventory–Facial (BPI-Facial) was used to assess general and face-specific activity. Pain-free survival and durability of successful pain relief (BNI pain scores of 1 or 2) were statistically

Abstract
OBJECT
Trigeminal neuralgia (TN) occurs and recurs in the absence of neurovascular compression (NVC). While microvascular decompression (MVD) is the most effective treatment for TN, it is not possible when NVC is not present. Therefore, the authors sought to evaluate the safety, efficacy, and durability of internal neurolysis (IN), or “nerve combing,” as a treatment for TN without NVC.

ABBREVIATIONS
BAEP: brainstem auditory evoked potential
BNI: Barrow Neurological Institute
BPI: Brief Pain Inventory
GKS: Gamma Knife surgery
HR: hazard ratio
IN: internal neurolysis
MVD: microvascular decompression
NVC: neurovascular compression
PSR: partial sensory rhizotomy
QOL: quality of life
REZ: root entry zone
RFL: radiofrequency gangliolysis
TN: trigeminal neuralgia

“JNS” . . .continued on page 12
evaluated with Kaplan-Meier analysis. Prognostic factors were identified and analyzed using Cox proportional hazards regression.

RESULTS
A total of 177 patients with Type 1 TN were identified. A subgroup of 27 was found to have no NVC on high-resolution MRI/MR angiography or at surgery. These patients were significantly younger than patients with classic Type 1 TN. Long-term follow-up was available for 26 of 27 patients, and 23 responded to the telephone survey. The median follow-up duration was 43.4 months. Immediate postoperative results were comparable to MVD, with 85% of patients pain free and 96% of patients with successful pain relief. At 1 year and 5 years, the rate of pain-free survival was 58% and 47%, respectively. Successful pain relief at those intervals was maintained in 77% and 72% of patients. Almost all patients experienced some degree of numbness or hypesthesia (96%), but in patients with successful pain relief, this numbness did not significantly impact their quality of life. There was 1 patient with a CSF leak and 1 patient with anesthesia dolorosa. Previous treatment for TN was identified as a poor prognostic factor for successful outcome.

CONCLUSIONS
This is the first report of IN with meaningful outcomes data. This study demonstrated that IN is a safe, effective, and durable treatment for TN in the absence of NVC. Pain-free outcomes with IN appeared to be more durable than radiofrequency gangliolysis, and IN appears to be more effective than stereotactic radiosurgery, 2 alternatives to posterior fossa exploration in cases of TN without NVC. Given the younger age distribution of patients in this group, consideration should be given to performing IN as an initial treatment. Accrual of further outcomes data is warranted.

The origins of trigeminal neuralgia are currently being reassessed. The concept that neurovascular compression (NVC) is the origin of TN in almost all TN patients is being challenged. For example, in our patient population we find that approximately one third of our newly diagnosed, classic TN1 patients have no demonstrable NVC either by imaging, or at the time of surgery. Further, it appears that younger patients with TN1 are less likely to have NVC than their older counterparts, and younger female patients are even less likely to have NVC.

Although microvascular decompression (MVD) produces the best surgical outcomes for TN1, in many cases it is not a cure. There is a steady recurrence rate of TN after MVD, which averages about 4% per year. This means that some patients will seek further surgery, after TN has recurred after MVD.
These two TN populations, i.e., those who do not have NVC, and those with recurrent pain after MVD, ideally should have some surgical options. For TN1 patients in whom no NVC can be demonstrated by imaging at the time of initial diagnosis of medically intractable pain, a question arises as to which surgery might be most appropriate. Radiofrequency rhizotomy (RFL), and stereotactic radiosurgery (SRS) are possibilities, but pain generally recurs in a relatively few years after these procedures. Glycerol injection and balloon compression can also be considered, but these procedures also generally do not produce long-lasting pain relief.

For patients with recurrent pain after MVD, repeat MVD has been performed. This can be a difficult procedure, and it almost certainly is partially destructive to the nerve. It is likely that the trigeminal nerve damage which occurs after repeat MVD is responsible for the prolonged pain relief that can be seen after a second “MVD”.

An additional surgical option for patients without demonstrable NVC at the time of initial diagnosis and imaging, or for those in whom pain has recurred after MVD, is “trigeminal internal neurolysis” (TIN). This is in some ways an older operation that involves “stroking” or “combing” the nerve. In the past this has also been referred to as the “Taarnhoj Procedure”. Variations on this surgical theme have actually been used in patients with TN since the last part of the nineteenth century. Most experienced MVD surgeons, in fact, do “stroke” the nerve prior to completing an MVD, and TIN may simply be a more overt attempt at injuring the nerve. TIN is an alternative to another older procedure, i.e., cutting part of the nerve (rhizotomy), and is probably a variation on the rhizotomy theme.

In our practice TIN involves a surgical approach to the nerve, much like an MVD, visualizing the nerve under the operative microscope, then taking a microinstrument and combing through the filaments of the nerve. This is clearly disruptive to the nerve, and patients do have some numbness on the face after surgery, which seems to lessen over the first few postoperative weeks. We have now looked at the outcome from TIN and found that this procedure produces lasting pain relief comparable to MVD. Our TIN patients have not generally indicated dissatisfaction with the facial numbness, and have told us that it is much preferred over their TN pain.

TIN represents an additional surgical option for patients in whom no NVC is found either on imaging (MRI) or in whom no NVC can be identified intraoperatively. Some numbness does result from the procedure, but the pain relief is long lasting. Over time, the clinical outcome from TIN, and its role in the treatment of TN will become much clearer.
As TNA marks 25 years of providing support, information and education, we recognize the unparalleled contributions of the Medical Advisory Board and Dr. Peter Jannetta.

Dr. Jannetta’s microvascular decompression surgery, commonly called MVD, is widely regarded as one of the most important modern-day breakthroughs in the field of neurological disease. Over the years, it has been improved and simplified with better surgical instruments and refined techniques. To date, it remains the most effective means of ending the devastating pain of trigeminal neuralgia for those patients diagnosed with classic TN who fail to gain relief with standard prescription drugs.

Although Dr. Jannetta’s scientific and leadership contributions are significant, perhaps his greatest achievement is the legacy of outstanding international leaders he trained in neurosurgery. During his 25 year tenure as Chairman of the Department of Neurosurgery at the University of Pittsburgh, he trained 49 residents—including four future department chairmen—and was honored with an endowed professorship, appropriately named after Walter E. Dandy—considered one of the founding fathers of neurosurgery.

Through Dr. Jannetta’s guidance, the MAB has provided TNA with both support and timely information on TN and other neuropathic facial pain. Dr. Jannetta’s work has transformed the way trigeminal neuralgia is perceived and treated today, insuring effective treatment for thousands of patients and impacting the lives of his fellow doctors.

A tribute in quotes from Ken Casey, MD, Chief of Neurosurgery at Oakwood Southshore Hospital

You only live once, but if you do it right, once is enough. — Mae West

On being part of the program at Pittsburgh: Find out what you like to do best, then get someone to pay you to do it. — Katharine Whitehorn

On the concept of the MVD: There is only one way to avoid criticism: Do nothing, say nothing, and be nothing. — Aristotle

A mind that is stretched by new experiences can never go back to its old dimensions. — Oliver Wendell Holmes, Jr.

The comment after almost every MVD: The harder I practice, the luckier I get. — Gary Player

On our experience of residency: If you are going through hell, keep going. — Winston Churchill

Regarding his life’s works: The best answer to our critics is massive success. — Frank Sinatra

On the lives we all lead, thanks to him: Go where you are celebrated—not tolerated. If they can’t see the real value of you, it’s time for a new start.

How I regard patients: You treat a disease, you win, you lose. You treat a person, I guarantee you, you’ll win, no matter what the outcome. — Patch Adams

I always learned to treat the patient, not the disease.

Casey on P.J. Jannetta: You cannot stop a great teacher, they just keep doing.

Morale of our story: It does not matter how slowly you go,as long as you do not stop.

— Confucius
Dr. Jannetta welcomed me to the Medical Advisory Board of TNA in 1998. He sparked and nurtured my continued interest in the medical treatment of TN. Without Dr. Jannetta’s influence, I probably would not have contributed to the scientific literature of TN. My clinical practice of Neurology also changed course, as I began to care for more and more patients with intractable facial pain. I remember that at my first National TN meeting, he impressively held court at the Saturday evening dinner and entertained all with his singing and his banjo. Like so many other Physicians in the TN community, Dr. Jannetta’s presence has always been a guiding force.

Jeffrey Cohen, MD
National Medical Director, SpecialtyCare

I first met Peter Jannetta in a confrontational situation at the 2nd TNA conference when sitting on a panel answering questions from patients. He thought I had incited a patient to say that an MVD she had done at his centre had resulted in unilateral deafness and loss of a job as a musician. Once we clarified that it had been a spontaneous remark and that I was from the UK Peter realised that my interest as a physician treating TN patients was to understand all the pros and cons of MVD. Peter helped me to appreciate that in the correctly diagnosed patient MVD provided the best results. His efforts to help Claire set up such a thriving patient support group provided me with the model of how this could be done elsewhere. I went on to set up the UK TNA along the same lines after Peter and Claire Patterson found me a patient that he had operated on to become our first UK chairperson. I have since attended every single national meeting in the USA and our UK TNA has been growing from strength to strength which highlights Peter’s vision that TN patients needed a voice and support from healthcare professionals. Thank you Peter for all your hard work for patients with TN.

— Joanna Zakrzewska, MD
Professor Eastman Dental Hospital
University College London

Dr. Jannetta is one of the greatest neurosurgeons on this earth. He is a world-class researcher, teacher, and clinician and is one of my most respected and treasured friends. He brought a magnificent contribution to the treatment of trigeminal neuralgia, hemifacial spasm, and other conditions. His contribution on microvascular decompression for trigeminal neuralgia is one of the greatest steps forward in the treatment of this condition. Initially, MVD was considered controversial but with persistence and his excellent teaching it became a standard part of the treatment of trigeminal neuralgia for selected patients. His contributions to neurosurgery have been great and in the area of trigeminal neuralgia have been transformative. He has my highest praise, congratulations, and applause on this 25th anniversary of the Trigeminal Neuralgia Association.

— Al Rhoton, MD, Past President
American Association of Neurological Surgeons

For years, I worked alongside Dr. Peter Jannetta. He was a wonderful mentor and partner. He helped countless patients suffering with facial pain through his own hands and the hands of others.

Raymond F. Sekula, Jr., MD
Director, Cranial Nerve Disorders Program
University of Pittsburgh Medical Center

I trained with Peter Jannetta at the University of Pittsburgh for seven years from 1986-1993. He is my chairman, my mentor, and in many ways, a surrogate or second father. He taught me about cranial nerve syndromes, microsurgery, patient care, leadership, innovation, and personal integrity under adversity. His overwhelming impact on my career as well as professional life and personal life is unmeasurable. It has been a tremendous honor to try and carry on in the footsteps of this unique and great man, trying to extend the trail he initially cut from the wilderness. Congratulations Dr. Jannetta on your well-deserved recognition.

— Mark Linskey, MD
Professor of Neurological Surgery, UC Irvine
Western Regional Director, Medical Advisory Board, TNA
I first worked up the courage to approach Peter Jannetta after he finished speaking at a luncheon seminar during one of the national meetings. I asked him if he knew about balloon compression as a surgical treatment for trigeminal neuralgia. He said that he hadn’t but he “looked forward to reading about my results in future publications in the journal.” Thus he had given me my challenge. Publish my work and prove its worth. And so my journey through the field of facial pain began. Dr. Jannetta said one other thing that struck me on that day. He said that if you are truly serious about learning to perform microvascular decompression you need to watch Dr. Fukushima work in Tokyo. I did that and of course I went to watch Dr. Jannetta in Pittsburgh and later Dr. John Tew in Cincinnati. I had already learned about balloon compression from Dr. Sean Mullan who trained me through residency, but it was the force and clarity of Dr. Jannetta’s outline for success that mobilized my unanticipated career pathway.

In the end I learned that, like a writer who reads the masters one must develop a style that is true to oneself and not another. In ensuing years I came to lean on Dr. Jannetta’s sage advice on issues far afield from surgical decision making. His depth of good judgement and assuredness of purpose is not limited to things medical. I had the good fortune of being mentored at a distance, never a resident, nor a fellow, nor a faculty member, but a colleague and later a friend.

Jeff Brown, MD
Chief of Surgery, Mercy Medical Center

I was inspired by Peter Jannetta when I first met him at UCLA. I was a new faculty member having just completed my neurosurgery residency at University of Washington, and Peter was a neurosurgery resident at UCLA. I enjoyed talking to him about Trigeminal Neuralgia and was amazed by his knowledge of its history, its anatomy, and the observations of Dr. Dandy. As a result it was easy for me to invite him to join me and do a posterior fossa exploration when I had a patient with trigeminal neuralgia as I was only trained to do sub-temporal exposure of the Gasserian Ganglion for section of the sensory root. The rest is history and what an inspiration!

— Nicholas Barbaro, MD
Chairman Dept. of Neurological Surgery
Indiana University School of Medicine

Even though I have been trained by many people of great stature over the years, I consider Dr. Jannetta to be the most influential person in shaping my career. He is not only a great surgeon but a compassionate physician and wonderful teacher. Every time I work in that small space which I call CP angle I think of him.

— Ramesh Babu, MD
Associate Professor of Clinical Neurosurgery
NYU School of Medicine

Dr. Jannetta was the Neurosurgery Department Chair when I was a medical student at the University of Pittsburgh. Although I thought that neurosurgery might be the right career for me, it was after watching a video and hearing a lecture from him that I knew it was exactly what I wanted to do. I had the opportunity to observe him on rounds, in the operating room and in educational conferences during my time as a medical student. No one was better at communicating with patients. He was a master micro-surgeon and was impossible to rattle while doing the most complex cases. The weekly grand rounds attended by Dr. Jannetta and leaders of related neuroscience departments were the best example of multi-disciplinary teaching that I have ever experienced. Dr. Jannetta was very supportive of me and gave me an excellent recommendation that other programs commented on every time I interviewed.

Throughout my career, he has been a wonderful mentor. It took years before I could address him as “Peter” and now I consider him a great friend and advisor.

— John F. Alksne MD
Professor of Neurological Surgery
UCSD School of Medicine
Neurosurgeons at UPMC have pioneered the treatment of trigeminal neuralgia and other cranial nerve disorders for more than 25 years. Our team offers expertise in the full array of treatments:

- **Microvascular Decompression (MVD):** UPMC is one of the nation’s leading centers for this minimally invasive surgical procedure that treats the cause of cranial nerve disorders, offers the most long-lasting relief, and minimizes risk of postoperative side effects.

- **Gamma Knife® Radiosurgery:** This painless outpatient procedure uses up to 201 highly focused radiation beams to target facial nerves and block transmission of pain signals. UPMC’s experts have treated more than 13,500 patients using the Gamma Knife. No incisions are required.

- **Percutaneous Glycerol Rhizotomy:** This needle-based procedure has been performed more than 1,200 times on patients at UPMC, often on an outpatient basis with the use of local anesthesia and sedation.

**Meet Our Experts**

**Raymond F. Sekula Jr., MD, MBA**  
**Director, UPMC Cranial Nerve Disorders Program**

Dr. Sekula is known nationally and internationally for his refinement of microvascular techniques that may provide patients with improved outcomes, reduced complications, and easier recoveries. He has performed more than 1,000 MVD procedures for patients with trigeminal neuralgia, hemifacial spasm, and other cranial nerve disorders. Dr. Sekula’s clinical research also has shown that MVD can be safely and effectively performed in select older patients, giving them a new option for pain relief.

**L. Dade Lunsford, MD**  
**Director, UPMC Center for Image-Guided Neurosurgery**

Dr. Lunsford is an internationally recognized authority on stereotactic surgery, radiosurgery, and minimally invasive surgery. In 1982 he established the first U.S. operating room with a dedicated CT scanner for intraoperative imaging. In 1987 he brought the Gamma Knife® to UPMC, which was the first center in North America to offer this state-of-the-art, minimally invasive form of brain surgery. Dr. Lunsford has treated more than 2,000 patients with trigeminal neuralgia since 1981, and his team has published extensively about the outcomes of minimally invasive procedures for trigeminal neuralgia.

Learn more about our nationally renowned experts and treatment options at UPMC.com/CranialNerve. Or, call us at 1-877-986-9862.
SCIENCE 2015 MEETING
March 2015 Naples Science Meeting

Sitting around a large parquet conference table on a sunny March morning in Naples, Florida were an artist who has commissions for large fountains in Israel, a UCLA graduate and a mother of two high school daughters - one applying to colleges in the fall, a world traveler whose favorite country is Turkey, an avid hiker just returning from Peru, a tri-athlete whose son holds the tennis junior state championship, a grower of olives, grapes and almonds, and a member of the United Kingdom’s Royal Society.

As fascinating as each of these individuals are, what brought them from around the world to lean over this table to share excited challenges, new insights and passionate dialogue was one simple but profound question: “How can we stop the pain?”

Each of these people is an expert in individual areas of pain research. Each one was reporting on their “piece of the puzzle” searching to find the cause and cure to the world’s most terrific pain, Trigeminal Neuralgia. To be invited to sit in the same room as these researchers reported the current status of their projects is an honor at any time.

But when the subject is familiar and the experience is personal, I found myself riveted.

Even as I write this, my pulse beats faster with the hope provided by the researchers’ tireless work. For six years I suffered from Trigeminal Neuralgia. The pain started with an innocuous tic and grew to be intolerable. The fear, depression, helplessness and drug dependency snuck into my days. It changed my life and worried my family.

Finally, after a successful micro-vascular decompression surgery by Dr. John Alksne in 2001, I felt I had to make a decision: to turn away from this torturous experience or to turn toward it, walking through the fear to try to help others. As many of you know, the easy way out often feels like a relief, an escape. But my father always said, “If you borrow something, give it back in better shape.”

It may seem crazy, but my TN world now appears “borrowed” and I long to change the lives of other sufferers. Of course I am fully aware of how incredibly fortunate I am to be pain free for these past years. And the thought, “Why me?” has played in my mind and heart as I hear and read so many of your TN stories.

As West Coast Coordinator for The Facial Pain Research Foundation (FPRF), I was invited to listen to the researchers the foundation is supporting. I’d like to share with you a bit of what I heard in each presenter’s own words and in some instances what the conference meant to them:

Dr. Allan Basbaum, University of California at San Francisco, reviewed results of cell transplant studies in models of neuropathic pain in mice. His laboratory has now demonstrated that the transplants are effective in neuropathic pain models following both traumatic nerve injury as well as chemotherapy-induced mechanical and thermal hypersensitivity. Soon information from models of facial pain can hopefully be extrapolated to facial pain conditions that would include Trigeminal Neuralgia. An avid discussion followed.

“Research”...continued on page 19
Dr. Lucia Notterpek, McKnight Brain Institute, University of Florida, discussed studies concerning myelin biology and its relationship to nerve damage in neuropathies which include the pathobiology of Trigeminal Neuralgia.

Why myelin in certain individuals is prone to degeneration is unclear, but genetic and metabolic factors may play a role. Myelin is enriched in specific lipids, including cholesterol.

The Notterpek lab uses mice whose nerves are genetically deficient in myelin lipids, which affords them the opportunity to study why cholesterol is critical for healthy myelin. Current experiments may allow for the design of novel and effective therapies for disorders such as TN that involve myelin damage.

Dr. John K. Neubert and Dr. Mingzhou Ding, McKnight Brain Institute, University of Florida, spoke on their project to identify neurophysiologic signatures of Trigeminal Neuralgia pain. The primary goal is to acquire a neural signature or “map” of the brain in individuals with TN pain. This study is being carried out simultaneously in animals and in humans.

Professor Zakrzewska, Eastman Dental Hospital, London, gave a talk on diagnosis of Trigeminal Neuralgia. Although it seems that this is a relatively straightforward diagnosis, it is not the case. Patients describe a wide range of symptoms. It is very important that as much detail as possible be collected on these patients for the genetics study. This collection process is called phenotyping.

Another talk by Professor Zakrzewska described the preliminary results from a new drug for management of Trigeminal Neuralgia. The news is encouraging and further studies in USA and Europe are being planned.

Professor “Zak” stated that the meeting gave her a “superb opportunity to exchange information with other scientists and clinicians that will help further understand the complexity of Trigeminal Neuralgia.”

Dr. Ze’ev Seltzer, University of Toronto Center for the Study of Pain, presented the particulars of his and Dr. Zakrzewska’s set of questionnaires that were sent to all participants of the genetic study. These questionnaires include details such as where in the face/mouth the pain is felt; how it is described; how often do these attacks appear; how long do they last, etc.

The data provided will be used as follows: (1) to deepen familiarity with the expression of TN in our large study group that is currently aimed to include 1,000 patients, the largest of its kind to date; and (2) to extract traits associated with genotypes that identify genetic variants at risk for developing Trigeminal Neuralgia.

Dr. Scott Diehl, Rutgers University, New Jersey, presented early results for the genetic study team including a genome analysis of 94 TN1 patients. This was a part of a total sample of 500 patients now being recruited with support provided by the Foundation.

He cautioned that we need to wait for the complete analysis before drawing any solid conclusions. However one gene region suggested by early data appears interesting because the gene is known to be important for nerve development.

Dr. Diehl emphasized the importance of large numbers of subjects and endorsed the recommendation for increasing our sample to 1,000 patients.
Dr. Marshall Devor, Hebrew University, Jerusalem, is project coordinator of the project to find the genes that predispose to Trigeminal Neuralgia. He and Dr. Kim Burchiel, Oregon Health and Science University, discussed the current collection of 500 TN patients DNA from around the world.

In Dr. Burchiel’s words, “The Meeting was a rare opportunity to spend time with world leaders in Facial Pain Research. The environment of discussion, inquiry and innovation was personally very invigorating. We have made amazing progress towards identifying the genes that predispose individuals to Trigeminal Neuralgia in a very short time.

We have done this in an efficient and cost–effective manner since the three-legged stool of our research effort is based on scientific curiosity, volunteerism, and a motivated organization, The Facial Pain Research Foundation. It is an honor to participate in this effort, and it is a model of what a dedicated team can accomplish."

There were other participants at the Scientific Meeting. For a comprehensive review of the projects and their goals please read Dr. Doug Anderson’s fascinating March 2015 Report to the Board of The Facial Pain Research Foundation on the Research Foundation’s Web Newspaper at www.facingfacialpain.org.

The message from the meeting is urgent and clear. The researchers cannot sit at the table alone. We must all sit at the table – each of us who has this terrible disease and lean forward with our talents, interests but most of all our passion. If we don’t now, who will?

The researchers are unable to do it without our cry for the impossible, our stories, and our dollars. We press them to hurry and find the answer to “How do we stop the Pain?”

---

Break Free of Facial Pain

Neurosurgeon Stephen E. Griffith, M.D., tailors surgical and nonsurgical treatments for trigeminal neuralgia. This includes:

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- Internal neurolysis
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Trust Dr. Griffith and the experts at Saint Luke’s Marion Bloch Neuroscience Institute for world-class care to help you live life without pain.

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Welcome

We would like to extend a warm welcome to all patients, caregivers, and medical professionals who are attending this 10th National Conference of TNA-The Facial Pain Association in New York City. For the past 25 years, TNA-FPA has been dedicated to providing support and education to those afflicted with trigeminal neuralgia and related neuropathic facial pain.

This conference has drawn the world’s leading experts in facial pain for two days of sessions, with topics covering diagnosis, treatment, and research.

One of the highlights of this year’s conference is Saturday’s lunch with the conference faculty and Sunday’s brunch with experts. Both of these events present the opportunity to connect with medical professionals in a relaxed informal environment. An added benefit of the Lunch & Brunch events is the invaluable experience of connecting with other patients and caregivers from across the country.

As many of you are aware, we have been commemorating the Association’s 25th year with the TNA Video Project. We will have volunteers available throughout the conference to record your face pain story. We encourage patients, caregivers and medical professionals to participate in the project.

We will also be active on Twitter and Facebook throughout the conference. If you aren’t already doing so, follow us on Twitter (@FacialPainAssoc) and like us on Facebook (The Facial Pain Association) to join in the conversation. We will be using the hashtag #TNAinNYC for all conference tweets, so you will easily be able to find them.

Have a great conference and be sure to let us know what you think. If you have the time, try to enjoy some of New York’s world famous attractions.

John Koff, CEO
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<th>Time</th>
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<tr>
<td>7:00 am - 8:00 am</td>
<td>Registration &amp; Breakfast</td>
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<tr>
<td>8:00 am - 8:15 am</td>
<td><strong>FPA Welcome:</strong> Jeff Bodington, TNA Board Chairman, Peter Jannetta, MD and John Alksne, MD</td>
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<td>8:15 am - 9:00 am</td>
<td><strong>Dental Origins of Facial Pain:</strong> Dave Sirois, DMD</td>
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<td>9:00 am - 9:45 am</td>
<td><strong>Overview-The Surgical Treatment of Neuropathic Facial Pain:</strong> Jeffrey Brown, MD</td>
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<td>9:45 am - 10:15 am</td>
<td><strong>Diagnosis and Treatment of Neuropathic Face Pain:</strong> Jeffrey Cohen, MD, PhD</td>
<td><strong>Social Media for Face Pain Patients</strong></td>
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| 10:30 am - 11:15 am| **Roundtable:** MVD for Neuropathic Facial Pain  
**Moderator:** Jeffrey Brown, MD;  
**Pediatric TN:** Mark Linskey, MD;  
**Recurrent TN:** Ken Casey, MD;  
**The Mayo Approach:** Richard Zimmerman, MD |    |
| 11:15 am - 11:30 am| **Facial Pain Research Initiative:** Michael Pasternak, PhD |    |
| 11:30 am - 12:00 pm| **Finding the Genes that Predispose to Trigeminal Neuralgia:** Scott Diehl, PhD | **YPC Meeting:** Ally Castellano, YPC Chair |
| 12:00 pm - 1:00 pm| **Lunch with the Experts** in the Downstairs Café |    |
| 1:00 pm - 1:20 pm| **What Do I Do Now?** John Alksne, MD |    |
| 1:20 pm - 2:00 pm| **Psychology of Facial Pain:** Leesa Morrow, PhD |    |
| 2:00 pm - 3:00 pm| **Roundtable:** Ablative Procedures  
**CyberKnife:** Jonathan Haas, MD;  
**Balloon:** Jeffrey Brown, MD;  
**Glycerol:** Michael Brisman, MD;  
**Gammaknife:** John Alksne, MD;  
**Radio Frequency Rhizotomy:** TBA |    |
| 3:00 pm - 3:15 pm| **Break**                                           |    |
| 3:15 pm - 4:00 pm| **Motor Cortex Stimulation:** Ken Casey, MD  
**Peripheral Stimulation:** Konstantin Slavin, MD | **Social Media for Face Pain Patients** |
| 4:00 pm - 5:00 pm| **Failed Surgery and Returned Pain:**  
**Introduction:** Jeffrey Brown, MD;  
**Venous Compression:** Ramesh Babu, MD;  
**Recurrent MVD:** Mark Linskey, MD;  
**Complex MVD:** Ken Casey, MD |    |
Thank You to Our Conference Sponsor

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Your Health Means Everything.

Sunday Brunch Highlight

Sunday Brunch and Conference Ticket Giveaway

Don’t Forget! Sunday we will be having “Brunch with the Experts” to commemorate TNA’s 25th Anniversary.

This is your chance to connect with the leading experts on facial pain, as well as other patients and caregivers.

Win tickets to a New Regional Conference near you!

Win a drawing for one of three pairs of tickets good for any of our upcoming conferences in the new Regional Conference Program. Three people will win a pair of tickets, good for them and a guest to attend a regional conference of their choosing.

You must be present at Sunday Brunch to win. We hope to see you there!

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<th>Time</th>
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<td>8:30 am - 9:30 am</td>
<td><strong>Brunch with the Experts</strong> in the Downstairs Café</td>
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<td>9:30 am - 10:00 am</td>
<td><strong>Welcome to Our Special Sunday Session:</strong> Peter Jannetta, MD</td>
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<td>10:00 am - 10:45 am</td>
<td><strong>Persistent Symptoms Despite Surgical Intervention for TN, an Orofacial Pain Perspective:</strong> Gary Heir, DMD</td>
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<td>10:45 am - 11:00 am</td>
<td><strong>Break</strong> in the Lobby</td>
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<tr>
<td>11:00 am - 11:45 am</td>
<td><strong>Discussion: Living With Facial Pain</strong></td>
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<td><strong>Moderator:</strong> Anne Ciemnecki</td>
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<td><strong>Panel:</strong> Gary Heir, DMD; Leesa Morrow, PhD; Ally Castellano, Young Patients Committee; Joe Runyan, Patient</td>
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<tr>
<td>11:45 am - 12:30 pm</td>
<td><strong>New Treatment for TN:</strong> Joanna Zakrzewska, MD</td>
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Jeffrey A. Brown, MD, neurosurgeon is the conference host and Eastern Director of TNA’s Medical Advisory Board. Dr. Brown has published more than 35 articles in peer-reviewed neurosurgery journals on the treatment of chronic pain, especially facial pain, as well as in the areas of spinal, vascular, tumor and trauma neurosurgery. He has been selected as one of America’s Top Doctors in the 2003 and 2004 editions of the Castle-Connolly Directory.

John Alksne, MD, is professor of neurological surgery at the UCSD School of Medicine and member of TNA’s Medical Advisory Board. Dr. Alksne’s clinical practice focuses on the care of patients suffering from trigeminal neuralgia, glossopharyngeal neuralgia, and acoustic neuroma. Dr. Alksne has pioneered new surgical techniques and technologies to advance the treatment of diseases and disorders of the central nervous system.

Michael H. Brisman, MD, FACS, is a Board Certified Neurosurgeon who is proficient in adult neurological surgery. He specializes in stereotactic and radiosurgery techniques for the treatment of brain tumors and trigeminal neuralgia. He is Chief of the Division of Neurosurgery and Co-Director of the Neuroscience Institute at Winthrop University Hospital in Mineola. Dr. Brisman has authored numerous articles and book chapters in the field of neurosurgery. He serves on the Board of Directors of the New York State Neurosurgical Society.

Kenneth F. Casey, MD, is chief of neurosurgery at Oakwood Southshore Hospital in Michigan, Associate Professor at Michigan State University and Chairman of TNA’s Medical Advisory Board. Dr. Casey is co-author of Striking Back! The Trigeminal Neuralgia and Face Pain Handbook. He is currently developing new techniques involving transcranial magnetic stimulators, infrared light, and topical therapies.

Jeffrey Cohen, MD, PhD is a member of the TNA Medical Advisory Board and is also an international lecturer, author, researcher and teacher. Dr. Cohen is currently the National Medical Director for SpecialtyCare.net.

Scott R. Diehl, PhD is a Professor in the Department of Oral Biology and Director of the Center for Pharmacogenomics and Complex Disease Research (CPCDR) at the Rutgers School of Dental Medicine of RBHS. Dr. Diehl is the Lead Consultant on The Facial Pain Research Foundation’s International Research to Find A Cure “Finding the Genes that Predispose to Trigeminal Neuralgia”

Jonathon Haas, MD is the Chief of Radiation Oncology at Winthrop Hospital. Dr. Haas is a recognized international expert in CyberKnife, having been an invited lecturer to medical centers throughout the country and the world on its use. Dr. Haas has been named a Castle Connolly New York Metropolitan Top Doctor as well as New York Newsday Top Doctor and was the youngest doctor to receive these awards.

Gary Heir, DMD is Clinical Professor, Director of Division of Temporomandibular Disorders and Orofacial Pain, Department of Diagnostic Sciences at Rutgers School of Dental Medicine. Dr. Heir is Past President and a Fellow of the American Academy of Orofacial Pain and has published papers, chapters and abstracts on topics related to the field of temporomandibular disorders and orofacial pain.

Mark E. Linskey, MD is Professor of Neurological Surgery at the University of California, Irvine, Western Regional Director of TNA’s Medical Advisory Board, and physician advisor for the Orange County TNA support group. He is the editor for the American College of Physicians (ACP), Physician Information Education Resource (PIER) module for trigeminal neuralgia and co-editor for the British Medical Journal Clinical Evidence module for trigeminal neuralgia. His clinical interests include microvascular decompression and Gamma Knife stereotactic radiosurgery for trigeminal neuralgia and
other facial pain syndromes. He has published extensively on trigeminal neuralgia, Gamma Knife radiosurgery, skull base microsurgery and surgical neuro-oncology.

**Leesa Morrow, Ph.D., JD, LP**, is a Health Psychologist and Clinical Assistant Professor, Division of TMD and Orofacial Pain, Department of Diagnostic and Biological Sciences, University of Minnesota, School of Dentistry. Dr. Morrow maintains a private practice in clinical health psychology treating chronic pain disorders. In 1999, after many years practicing psychology, and she began the full-time study of law, graduating with a degree in law from Indiana University. Dr. Morrow now practices psychology and conducts research at the UM School of Dentistry.

**Donald R. Nixdorf, DDS** is an Associate Professor at the University of Minnesota in the Division of TMD & Orofacial Pain, adjunct Assistant Professor in the Department of Neurology and a member of the TNA Medical Advisory Board. His clinical interests include neuropathic orofacial pains including trigeminal neuralgia, as well as deafferentation pain and headache management. Dr. Nixdorf’s research includes functional imaging of chronic orofacial pain conditions and classification of orofacial pain disorders.

**Michael Pasternak, PhD** is a TN patient, entrepreneur and fundraiser for face pain research. Dr. Pasternak is the former President of the TNA Board of Directors and is currently one of the founding trustees of the Facial Pain Research Foundation, whose mission is to fund research to find a cure for neuropathic face pain in the next ten years.

**Raymond F. Sekula, Jr., MD** is a member of the TNA Medical Advisory Board and is Assistant Professor of Neurological Surgery and the Director of Cranial Nerve Disorders Program at UPMC. Dr. Sekula is known internationally and nationally for his development of microvascular techniques, which provide patients with improved outcomes, reduced complications, and easier recoveries. He has been recognized with numerous honors, including The American Association of Neurological Surgeon’s Young Investigator Award and The Trigeminal Neuralgia Association Fellowship Award.

**David A Sirois, DMD, PhD** is Associate Professor of Oral and Maxillofacial Pathology, Radiology and Medicine at New York University and a member of the TNA Medical Advisory Board. Dr. Sirois’s current major research efforts are focused on developing clinical research programs which explore the neurophysiology and psychophysical aspects of chronic human pain and intervention strategies to prevent or relieve that pain.

**Konstantin Slavin, MD** is an Associate Professor and the Chief of Stereotactic and Functional Neurosurgery at the University of Illinois in Chicago, Illinois. Dr. Slavin has conducted research in facial pain, the surgical management of pain and deep brain stimulation. His clinical interest is in trigeminal neuralgia and facial pain.

**Joanna M. Zakrzewska, MD** is Professor and consultant at the Eastman Dental Hospital, University College London Hospitals NHS Foundation Trust, London UK where she heads up the largest UK multidisciplinary orofacial pain clinic. As the chair of the Medical Advisory for the UK Trigeminal Neuralgia Association she has been active in promoting patient involvement in research studies and acting as their advocate. “Dr. Zak” has published more than 100 peer-reviewed articles, four books on facial pain and 12 chapters. She is the author of Insights – facts and stories behind trigeminal neuralgia which relied heavily on contributions from members of TNA associations in the US, UK and Australia and has received excellent reviews by both sufferers and healthcare professionals.

**Richard S. Zimmerman, MD** is Associate Professor of Neurosurgery at the Mayo Clinic in Phoenix, AZ and a member of the TNA Medical Advisory Board. Dr. Zimmerman’s clinical interests include epilepsy surgery, he is a member of the Comprehensive Epilepsy Center, microneurosurgery for trigeminal neuralgia and hemifacial spasm, brain tumor and skull-base surgery, facial pain and trigeminal neuralgia.
This year TNA - The Facial Pain Association celebrates 25 years of providing support, education, and outreach programs. Over the years great strides have been made in identifying and treating trigeminal neuralgia. Treatment has become more effective with fewer side effects. While current treatments for TN are often criticized as being ineffective and/or having too many side effects, let’s take a moment to look at some early treatment modalities for patients suffering with trigeminal neuralgia.

- Powder of gelsemium soaked in a pint of spirits. This treatment was thought to be effective if it caused the patient to experience symptoms such as loss of sight, double vision, headaches, or paralysis.

- Blistering

- Camphorated mercurial ointment

- Ether

- Opium

- Arsenic in gruel

- Inhalations of trichloroethylene

- Intravenous stilbamidine

- Alcohol injection into the gasserian ganglion

In the last 100 years we have seen much advancement in treatment of TN.

- The anticonvulsants, such as phenytoin (Dilantin) and carbamazepine were introduced in the treatment of TN and found effective in treating TN.

- Walter Dandy, MD devised an alternative surgical approach for partial sectioning of the trigeminal nerve via a lateral suboccipital craniectomy and discovered compression of the trigeminal nerve by a blood vessel. Later, the operating microscope made it possible to explore the 5th nerve via a suboccipital craniectomy and Dr. Walter Dandy’s idea of neurovascular compression was revived and the treatment of this problem by Microvascular decompression was developed by Peter Jannetta, MD of TNA’s BOD and Founding member and Chairman of TNA’s Medical Advisory Board

- Radiofrequency lesioning was used in the treatment of TN. Later; John Tew, MD, founding member of TNA’s MAB was instrumental in developing the curved electrode that is currently used in RF.

- Glycerol injection to treat TN was developed by chance in Sweden by Dr. Lars Leksell.

Since 1990

- The Trigeminal Neuralgia Association was founded by TN patient Claire Patterson, with the mission to improve the quality of life of TN patients through: programs that empower patients and their families to become knowledgeable about their condition and treatment options; reduce isolation of those affected
by TN; increase public awareness and to encourage relevant medical research.

• Medical Advisory Board was developed.
• TNA published its first newsletter - The TNAlert
• Balloon Compression technique was refined by Dr Jeffrey Brown of TNA’s MAB, and is now widely used to treat TN.
• Stereotactic Radiosurgery (Gamma Knife) was used to treat TN as well as brain tumors.
• In 1996 TNA held its First National Conference in Cincinnati, OH -hosted by Dr. John Tew of TNA’s Medical Advisory Board, bringing together experts in the field of treating TN and support group leaders around the country.
• TNA’s first website was developed
• In 1998 TNA held its Second National Conference in Orlando, FL - hosted by Dr. Albert Rhoton, Jr., a founding member of TNA’s medical advisory board and trustee of Facial Pain Research Foundation. This conference included FP patients and experts in the field. Sponsored by University of Florida.
• In 1999 TNA established a satellite office in Florida to provide patients with one on one support and information
• “Striking Back! The Trigeminal Neuralgia Handbook” was published. Written for patients in plain English by TN patient George Weigel and Dr. Ken Casey of TNA’s MAB.
• In 2000 TNA held its Third National Conference, Pittsburgh, PA hosted by Peter Jannetta, MD of TNA’s BOD and Founding member and Chairman of TNA’s MAB Sponsored by Allegheny General Hospital
• MRI techniques improved to show blood vessels that are compressing the nerve
• Over 17,000 people in TNA’s database
• In 2002 TNA relocates to Florida
• Alternative and complementary treatments are explored and found effective in treating TN/Facial Pain.

• In 2002 TNA held its Fourth National Conference held in San Diego, CA hosted by Dr. John Alksne, Member of TNA’s Medical Advisory Board Sponsored by University of California-San Diego, Division of Neurosurgery
• Transdermal creams by compounding pharmacist are added to the armamentarium
• New Classification Scheme for facial pain purposed by Dr. Kim Burchiel of TNA’s MAB. This classification provides both the patient and the doctor with the information necessary to properly diagnose and treat neuropathic facial pain.
• TNA’s mission statement is expanded to include facial pain related to TN.
• In 2004 TNA held its Fifth National Conference held in Orlando, FL – hosted again by Dr. Albert Rhoton, Jr, and sponsored by The University of Florida
• Motor Cortex Stimulation is also used to treat intractable neuropathic facial pain
• Founder of TNA Claire Patterson steps down and Roger Levy steps forward to continue TNA’s mission.
• In 2006 TNA held its Sixth National Conference-Portland, OR - hosted by Dr. Kim Burchiel, Member of TNA’s Medical Advisory Board Sponsored by the Oregon Health & Science University, Dept of Neurological Surgery
• “Insights: Facts and Stories Behind Trigeminal Neuralgia” published - Dr. Joanna Zakrzewska (Dr. Zak) of London, Medical Advisory Board of US and UK
• In 2008 TNA held its Seventh National Conference held in Dearborn, MI hosted by Dr. Kenneth Casey, current chairman of TNA’s Medical Advisory Board Sponsored by Wayne State University Dept of Neurosurgery and University Physician Group
• TNA changes name to reflect its mission to include other forms of neuropathic facial pain to TNA - The Facial Pain Association
• In 2010 TNA – The Facial Pain Association celebrated 20 years held a special event at the Eighth National Conference – Rochester, MN – hosted by Dr. Bruce Pollock of TNA’s MAB – Sponsored by Mayo Clinic

“Future” . . . continued on page 28
Advanced Treatment for Facial Pain

Expert, integrated care for patients with trigeminal neuralgia
Addressing both your physical and emotional needs

Offering a full roster of advanced options for treatment, including:

- Microvascular Decompression
- Stereotactic Radiofrequency Lesion
- Stereotactic Radiosurgery
- Neurostimulation

The Facial Pain Program at Weill Cornell Brain and Spine Center is an innovative program that focuses on the diagnosis and treatment of trigeminal neuralgia, one of the most disabling causes of facial pain. Our team includes top specialists in vascular neurosurgery and pain disorders—internationally recognized experts in the field who have advanced training in the very latest minimally invasive procedures used to treat facial pain. Find out more at weillcornellbrainandspine.org or call 212-746-4684 to make an appointment.

The Facial Pain Program at Weill Cornell is directed by Dr. Philip E. Stieg, professor and chairman of the Department of Neurological surgery (left) and Dr. Michael Kaplitt, vice chairman, who specializes in advanced treatments for movement disorders and pain.

The Facial Pain Research Foundation was formed—Michael Pasternak, Ph.D., TN Patient, Mike Hirsch, spouse of TN patient, Roger Levy, Esq., TN Patient, Suzanne Grennell, TN patient, Albert Rhoton, MD, founding member of TNA’s Medical Advisory Board, Douglas K. Anderson, Ph.D., chairman emeritus of neuroscience at the University of Florida’s McKnight Brain Institute and Jay Winer, friend to TNA.

In 2011 TNA enhanced their social media presence by creating an interactive patient site, Facial Pain Network. Over 5000 members share information.

In 2013 TNA held its Ninth National Conference – in San Diego, CA, again hosted by Dr. John Alksne and sponsored by University of California-San Diego, Division of Neurosurgery.

Today, with the guidance of the Board of Directors, the support of a prestigious Medical Advisory Board and a dedicated staff, The Facial Pain Association serves tens of thousands of face pain patients and their families throughout the world.

“Future” . . .continued from page 27
WHAT WE LEARNED ALONG THE WAY: The Search for Facial Pain Information & Support

Four long-time TNA support group leaders discuss how the search for information about facial pain has changed since they were diagnosed.

by Carly Kosmacki

For those with Trigeminal Neuralgia and other neuropathic facial pains, the search for information has always been a difficult task. TN is classified as a rare disorder, affecting just 4.3 of every 100,000 people in the U.S. Before the creation of the Trigeminal Neuralgia Association in 1990, there was no organization that provided comprehensive information on TN which made it considerably harder for patients to access proper diagnoses and treatment, let alone support. Four current and former TNA support group leaders got together for a conference call to discuss how things have changed since they were diagnosed, and where they see the association in the coming years. On the panel were Cindy Ezell, Patient Services Coordinator at TNA-FPA; Rohn Harmer, current Support Group Leader; Kathy Hays, current Support Group Leader; and George Weigl, former Support Group Leader and author of Striking Back!

There was a consensus among the panelists that the biggest change has been the amount of information that is available, for both patients and doctors. When Cindy was diagnosed in 1982, the only option that was presented to her was medication for the pain. However, she wanted to have a child, which led her to research other options, which led her to find out about MVD surgery. Rohn had a similar experience to Cindy when he was diagnosed sixteen years later in 1998; he was told he would have to take medications for the rest of his life, which he said was “discouraging.” George was diagnosed by a doctor in 1990 who specialized in root canals, but he obtained the majority of his information about TN from medical libraries. When Kathy’s TN struck for the first time in 2002, she went to a dentist as many commonly do. Luckily, she was told there was nothing wrong with her teeth, so she went to her family doctor for a second opinion. She found TNA on the internet, and eventually had an MVD for her TN pain.

“TNA has made a remarkable impact on individual’s lives”
– Rohn Harmer

Although our four panelists were diagnosed ten to twenty years ago, they all had a somewhat similar experience regarding the lack of information that was available to them. The growth of the internet over the past two decades has allowed a greater number of people access to information that was once limited. Doctors are now more informed than ever when they encounter a TN patient, and patients have access to information to help guide them when choosing treatment.

The internet also allows TN patients to connect with one another like never before. Patients who once had never
met or spoke to another person with TN are now able to connect with others with the click of their mouse. In addition to traditional support groups, TNA now has active Facebook and Twitter pages, as well as a patient forum called The Facial Pain Network, specifically created for face pain patients and caregivers. These three resources, in addition to email and the FPA website, offer round-the-clock information and support to patients across the world. Rohn pointed out that the internet has changed the way people interact: “I think that negates the real need for people to travel and spend time in a room. And they can get the social aspect of it as well as the technical aspect of trigeminal neuralgia from home.” However, Rohn still gets phone calls from new TN patients looking for support and advice, and this is an interaction he feels the internet could not replace.

Our panelists were asked where they would go if they were diagnosed with TN today, and surprisingly they all had varying answers. George said he would go right online to get information, and given the resources available, he’s not sure he would ever have to reach out to a live person at all. There was no information available when George was diagnosed, which is what led him to write Striking Back, which is now considered the handbook for facial pain patients. However, Kathy felt differently; she said she would find what she could online, but would also want to talk to someone one-on-one about having TN.

The panelists were asked if they have seen more awareness in the general public over the years. All four agreed that they do not think there is any more awareness within the general public, but there is a greater awareness in the medical community. Kathy, who has attended dental conferences to provide informational resources to dentists, says she saw a difference in a very short time. “The first time we did it, most of them didn’t know anything about it. I went to a big dental conference, and nobody came by. The next time I went, we ran out of materials by the time it was over.”

While there may not be greater public awareness, Rohn made the point that “The mission of the Association is fulfilled through the medical community, not the general public.” All four panelists agreed that educating doctors and hospitals is the best way to help patients, ensuring that they know where to direct new patients for information and support. George highlighted the importance of being aware of the changing needs of current and future patients: “What information do people want, and where are they going to look for it? So if you figure that out first, and then get there, you’re in good shape.” As we discovered in the discussion, the place most patients are heading for information on TN is the internet, but there still remains a want and need for personal interactions with other patients. Because of this, support contacts and TN conferences will have a place within the community for years to come.

It is remarkable how much things have changed since the founding of TNA in 1990. Not only is there more information available to patients with facial pain, but it is also easier than ever to access the information online. Patients who once attended small support group meetings are now connected with thousands of other patients across the world through the Facial Pain Network. Information that was once only available in medical libraries is now easily accessed on the TNA Website. The one thing that hasn’t changed though is the need for education and support for facial pain patients. With any disease, especially one as rare as TN, it is invaluable to know that you are not alone. It is because of this need that TNA continues to maintain and strengthen its current support network, and it continues to develop new and innovative ways to support patients well into the future. As Kathy, Cindy, Rohn, and George discovered, TNA has changed in many ways, but these changes have allowed us to reach more patients and places than ever before.

“People make the information relevant”
– Kathy Hays
Face Pain Patients:

To date, nearly 4,000 patients have completed the Patient Registry, making it the most comprehensive collection of data on facial pain patients. By providing your answers, you can help us to empower patients and educate policymakers.

If you are a face pain patient, please go to www.facepain.org and click on the Patient Registry link on the right side of the page under “Highlights” to complete the Patient Registry Questionnaire.

Your information will be stored securely, and you can save a questionnaire in progress. Return as many times as needed to finish and update answers.

It is crucial to gather data so that we can play an important role as an advocate for facial pain issues, and to help us measure the effectiveness and cost of various treatment modalities.

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THROUGH THE YEARS
MAKING TREATMENT DECISIONS

“If all you have is a hammer, everything looks like a nail.”

This quote, known as Maslow’s hammer, is from Abraham Maslow’s The Psychology of Science, published in 1966. It implies that people who possess just one tool, a hammer, see problems narrowly. People with a full tool kit approach problems from broader perspective. They examine the problem, select the most appropriate tool or solution, and develop back-up strategies in case their initial approach does not result in the desired outcome.

Dr. Raymond Sekula, Associate Professor of Neurological Surgery and Director of the Cranial Nerve Disorders Program at the University Of Pittsburgh School Of Medicine, could not agree more. He recommends that doctors care for patients by using a broad approach to resolving their facial pain. Though Dr. Sekula is a world-renowned neurosurgeon, performing a variety of operative procedures to alleviate facial pain, his aim is to take patients to the operating room only when the surgery will improve their pain and leave them with few or no complications. Although his hammer, the operative interventions, treat some types of facial pain, the surgeries are not panaceas for all patients. Some people find that over time the pain returns. Others have intolerable side effects. If used inappropriately, surgeries can cause pain to worsen.

Dr. Sekula and Rohn Harmer, leader of the Greater Tampa Bay Support Group, developed a diagram to help patients make treatment decisions. They recognize that patients might rush into less than optimal decisions when they are desperately seeking relief. Sekula and Harmer recommend that patients work with their physicians to identify the cause of their pain and have a toolkit of solutions: pharmaceutical, surgical, and complementary and alternative medical (CAM) options available. Sekula and Harmer hope that as patients consider all options, they make decisions based on their doctors’ expertise and the best available external clinical evidence from systematic research.

The decision tree on the next page offers some optimal solutions based on the cause of pain. The questions on the left hand side of the tree ask about pain, test results, and treatments. Answer the questions and follow the “yes” and “no” arrows. Doctor Sekula and Mr. Harmer expect that the chart should simplify the decision process, especially for people who are newly diagnosed with facial pain. They warn that the chart cannot possibly predict the correct treatment for each and every patient and may not address every situation patients grapple with. For that reason, professional medical consultations should still be the foundation of medical decisions.
Can you answer “yes” to most of the following questions?
Do you recall the time/place of your 1st pain episode?
- Does your pain get worse with talking, eating, brushing teeth, cold wind, etc.?
- Do the attacks last only a few seconds and occur intermittently?
- Would you describe your pain as a “tic”, sharp, electric, or instantaneous?
- Does your pain respond to oxcarbazepine (Trileptal) or carbamazepine (Tegretol)?
- Is the pain on one side of your face?1

Can you answer “yes” to any of the following?
- Have you had an MVD, gamma knife, or other surgery for facial pain?
- Have you had other surgeries around your head or face that were not intended to damage the trigeminal nerve?
- Have you experienced a trauma to your face or head such as whiplash, sports injuries, fall, back pain, or poor posture?

Was your surgery intended to damage the nerve, i.e. intended to cause numbness, to treat facial pain?

Do you feel pain through numbness?

Have you recently had shingles (herpes zoster)?

Does a thin slice, high resolution, or 3D MRI show a blood vessel compressing the trigeminal nerve?

Does an MRI show that you have MS or a tumor?

Your facial pain is likely due to a blood vessel compressing the trigeminal nerve. You have many options: medication, MVD, or other ablative surgeries. MVD is likely the best option for you.

There are special treatments for facial pain caused by MS or a tumor. Your best option may be to treat your primary condition.

It is unlikely that your facial pain is due to a blood vessel compressing the trigeminal nerve. For this reason, the success rates for MVDs or ablative surgeries are relatively poor. Your best options may be anti-epileptic drugs, anti-depressants or muscle relaxants. Also consider Upper Cervical Chiropractic or CAM therapies.

Your best option may be to continue to manage your pain with medications such anti-epileptic drugs, anti-depressants or muscle relaxants. CAM therapies, alone or along with your drugs, may also be helpful.

While this pain can be difficult to treat, your best options may be medication management and/or CAM therapies. Medications include anti-epileptic drugs, anti-depressants or muscle relaxants.

Your facial pain is likely post-herpetic neuralgia. It may go away in time. Medication management and/or CAM therapies may provide relief. Topical analgesics such as lidocaine patches may also be helpful.

1 Only two percent of people with facial pain have bilateral pain. You may need an MRI to check for MS or a brain tumor.
Introduction

Neuropathic pain is currently defined by the International Association for the Study of Pain (IASP) as “pain caused by a lesion or disease of the somatosensory nervous system”. It is further explained that neuropathic pain is a clinical description (and not a diagnosis) which requires a demonstrable lesion or a disease that satisfies established neurological diagnostic criteria.

The term lesion is commonly used when diagnostic investigations (e.g. imaging, neurophysiology, biopsies, lab tests) reveal an abnormality or when there was obvious trauma. The term disease is commonly used when the underlying cause of the lesion is known (e.g. stroke, vasculitis, diabetes mellitus, genetic abnormality). Somatosensory refers to information about the body per se including visceral organs, rather than information about the external world (e.g., vision, hearing, or smell). The presence of symptoms or signs (e.g., touch-evoked pain) alone does not justify the use of the term “neuropathic”. Furthermore, the IASP classifies neuropathic pain into 2 distinct entities, depending upon the location of the lesion or disease. Hence, central neuropathic pain is defined as “pain caused by a lesion or disease of the central somatosensory nervous system” and peripheral neuropathic pain is considered “pain caused by a lesion or disease of the peripheral somatosensory nervous system”. Due to the

“Dental”…continued on page 37
For simplicity and clinical purposes another classification for neuropathic pain may be based upon a temporal component and therefore divided into continuous and episodic. Continuous neuropathic pains are pain disorders that have their origin in neural structures and are manifested as a constant, ongoing and unremitting pain. Patients usually experience varying and fluctuating intensities of pain, often without total remission. This pain is commonly felt in dental structures and has been referred to as atypical odontalgia \(^3\)\(^4\) or sometimes phantom toothache. \(^5\)\(^6\) In some cases there may be a sympathetic component associated with this pain. \(^7\) Patients experiencing continuous neuropathic orofacial pain often report a history of trauma or ineffective dental treatment in the area. \(^8\)\(^9\) Episodic neuropathic pain is characterized by sudden volleys of electric-like, severe, shooting pain that lasts only a few seconds to several minutes and is referred to as neuralgia. \(^10\) The classical example of this type of pain is trigeminal neuralgia. Often with episodic neuropathic orofacial pain there exists a perioral trigger zone that, when lightly stimulated, provokes the severe paroxysmal pain. \(^10\) Interestingly, anesthetic blocking of the trigger zone may completely eliminate the paroxysmal episodes during the period of anesthesia.

**Epidemiology**

The true prevalence of these conditions is unknown since both disorders are relatively uncommon in general population based studies. In one of the few general population based studies investigating neuropathic orofacial pain, prevalence rates of 0.03% for persistent idiopathic facial pain and 0.3% for trigeminal neuralgia were identified. \(^11\) Intriguingly, the diagnosis of neuropathic orofacial pain is much more common when patients present to a tertiary care orofacial pain center as prevalence rates have been reported to be between 25%-30%. (Gremillion, H. A. unpublished data, 2006)

**Pathophysiology**

The pathophysiology of neuropathic orofacial pain is yet to be fully elucidated; however, there are a number of mechanisms that have been suggested involving complex peripheral and central mechanisms in the initiation and maintenance of this pain. Briefly, changes in neural systems occur as a result of physiologic (peripheral and central)
events, influenced by neurochemicals, anatomic structures and genetic components. Initially, due to some form of tissue injury or inflammation (often etiology is unknown or not reported), there is a release of chemicals from the peripheral tissues or primary afferent nerve endings.

This can increase the excitability and decrease the activation threshold of peripheral nociceptors (peripheral sensitization) increasing nociceptive input into the central nervous system (CNS). This bombardment of input in the CNS induces spontaneous activity, expansion of receptive fields, lowering of activation thresholds, hyperexcitability of neurons in the CNS, anatomic alterations to inhibitory neurons and genetic alterations (central sensitization). 12, 13

Dental Diagnostic Considerations
Due to the complexities associated with neuropathic orofacial pain, it becomes easy to understand why the presentation of this pain condition may pose significant difficulties for the clinician since the structures the patient reports as painful appear clinically normal. This can often lead to misdiagnosis/incomplete diagnosis and result in misdirected/incomplete treatment.

Unfortunately, various invasive dental interventions are often implemented in the hope of effective treatment for both continuous and episodic neuropathic orofacial pain conditions. 6, 14-18 Ram et al. 19 in their retrospective study involving 64 patients reported that 71% had initially consulted a dentist for their pain complaint, and subsequently 79% of patients received dental treatment that did not resolve the pain.

To avoid this pitfall, diagnosis must begin with a comprehensive history and clinical/imaging examination. A differential diagnosis should be established to rule out pain of dental/soft tissue or pathological (peripheral or central) origin. Once the diagnosis of neuropathic orofacial pain is established, no further dental procedures should be performed unless very specific findings of dental pathosis(es) are identified. The dental professional must then determine whether to treat these individuals or provide a referral to a health care professional who has an understanding of these neuropathic conditions. However, another dilemma that may arise is the need to provide these patients with dental treatment for an existing dental problem or for routine maintenance of their dental health. It is of utmost importance that the individual who is suffering from neuropathic orofacial pain engage in appropriate preventive oral health care in order to avoid a progressive decline in oral health. Such a decline has the potential to exacerbate painful stimuli.

Dental Care Considerations
Dentists should be aware that neuropathic orofacial pain patients in need of invasive dental treatment may experience an exacerbation of their current pain condition due to the procedures performed as result of neural trauma, from the invasive nature of the procedure(s) and/or ischemia from the administration of local anesthesia. 22 The issue of neurotoxicity (all local anesthetics have some degree of neurotoxicity) as it relates to the administration of local anesthetic is dependent upon several factors including the potency of the local anesthetic as neurotoxicity parallels potency and the ability of the local anesthetic to create constriction of tiny blood vessels associated with peripheral nerves. 22 Another

“Dental”...continued on page 39
important factor which requires consideration involving local anesthetic and the potential for neurotoxic effects is the location of the pathology. Administration of local anesthetic to a neuropathic orofacial pain induced from peripheral trauma and resulting in a localized neuroma or neuralgia would be rather worrisome as the existing pain condition may be enhanced whereas a similar outcome would be of minimal concern if the pathology were located in the central nervous system such as that caused by a cerebral vascular compression. Additional important factors to be considered for choice of local anesthetic are related to its concentration and time of exposure of peripheral neural tissue.22

Dental procedures including dental hygiene appointments should be performed when medication used in the management of these conditions is at its peak level of effectiveness. Furthermore, since pain in these conditions often varies and fluctuates in intensity, an appreciation of the pain cycle is important as procedures should be instituted during periods of the lowest pain intensity or in periods of remission. The goal for the dentist is to provide the patient with maximum comfort during and following the procedure. Therefore, the use of pre-emptive analgesia by providing the patient with “booster” doses of “anti-neuropathic” medication and with the administration of long-acting anesthetic at end of the procedure should be considered. Another consideration may be to perform dental procedures with the use of general anesthesia with augmentation from local anesthetic.

Often, these patients are unable or reluctant to perform normal dental hygiene procedures as stimuli to these painful intraoral regions may stimulate or increase their current pain. Dental providers should not ignore this aspect of care as neglect may have detrimental dental and periodontal consequences. To best accommodate these patients, it is important for dental providers to consider the utilization of soft cleansing aides, antibacterial/antiplaque alcohol free mouth rinses, recalcifying agents, fluoride supplementation in the form of custom trays and/or pastes/gel/rinses and consideration to the use of anesthetic camouflage.

Conclusion
Dental practitioners need to recognize and understand the concept of neuropathic orofacial pain. Additionally, they need to understand that management of these patients requires a comprehensive multidisciplinary team approach utilizing multidimensional management strategies. The team must take into account the physiological, environmental, psychological and genetic dimensions of pain. The dental team may be called upon to provide restorative and preventive procedures for these individuals. With proper communication among all health practitioners and with a mutual understanding of concerns and tolerance levels and a clear set of goals outlined between the dental team and the patient, will a positive outcome be established to provide these patients with the best quality of care.
References


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she recalls. “I wrote a proposal for the $35,000 Mellon grant, which enabled us to rent and furnish 100 square feet of office space and hire a part-time office assistant.”

Fast forward to 1993 when Jannetta performed MVD surgery on popular singer Norma Zimmer, known as the “Champagne Lady” on the nationally televised Lawrence Welk music show. The operation ended her initial bout with disabling TN pain. Later that year, he invited Norma and her husband, Randy Zimmer, along with the Pattersons, to a dinner in his honor at the University of Pittsburgh Medical Center. After the dinner, he asked Norma if she would serve as Honorary Director of the Association.

Zimmer took her new role seriously and for years, until her sudden death on May 10, 2011 at home in Brea, CA., she counseled and comforted other people in pain. From the Welk stage, before she ended her singing career, she told TV viewers about her long bout with pain and successful treatment.

“Norma added a touch of inspiration to our organization,” Patterson said. “She spoke at several national conferences, shared her medical experience with individuals, answered questions and held moments of prayer with people in pain. She personally answered every letter received from patients, closing each letter with ‘God bless you.’ When she died, we lost our dear friend, and we lost an honorary board member who found special ways to reach out.”

Patterson says she is “really retired,” but she remains a busy advocate for people with facial pain. She volunteers time to both TNA-FPA and the American Chronic Pain Association, and serves as the ACPA Board’s liaison to the NIH. Her calendar tracks her travel to the national TNA-FPA conferences—from Cincinnati to Orlando, Pittsburg, San Diego, back to Orlando, to Portland, Dearborn and Rochester, MN, as well as to Sydney, Australia. People attending the meetings see Patterson as a “success story” and seek chances to talk with her.
Many of us on the YPC have gone back to school and we’re focused on our lessons in numbers. The numbers of today’s lesson: 3, 10, and 25.

In honor of the 3rd Annual Trigeminal Neuralgia Awareness Day, TNA-The Facial Pain Association’s 10th National Conference and 25th Anniversary, the Young Patients Committee presents a list of 3, 10, and 25 fun facts.

**3 things you should know about the YPC:**

1. **What we’re about:**

   The Young Patients Committee (YPC) assists in fulfilling the mission of TNA-The Facial Pain Association by representing the interests of neuropathic facial pain patients under the age of 40. The YPC makes recommendations to the Board of the Association pertaining to young patients and develops events, opportunities, and initiatives on behalf of young patients and their families.

2. **What we do:**

   The YPC aims to fulfill its mission by:
   - Providing support for young patients and their families
   - Advocating for young facial pain patients
   - Raising awareness about facial pain
   - Engaging with the TN community
   - Fundraising for programs that benefit young people with facial pain and the TNA as a whole

3. **How young patients thrive, despite TN**

   The YPC is pleased to present the inaugural edition of our Young Patient Profile, featuring a young person with facial pain who has demonstrated strength and perseverance despite a chronic health condition. To kick things off, we start with one of our own board members, Ally, who has been on the YPC since it was founded in 2011. Read Ally’s Young Patient Profile on page 44.
25 Ways to Spread Awareness about Trigeminal Neuralgia and other facial pain conditions

1. Sell teal merchandise.
2. Wear teal / TN awareness merchandise (you can find fun stuff from the YPC’s pages on CafePress and Zazzle).
3. Change your Facebook profile or cover photo to a teal ribbon, or something else to stand for Trigeminal Neuralgia.
4. Educate your family and friends about how TN impacts your life.
5. Share your story on social media.
6. Ask for a shout out on the radio.
7. Plan and/or attend events and fundraisers.
8. Share the YPC’s Facebook pages on your social media.
9. Shop at smile.amazon.com and devote proceeds to TNA.
10. Educate yourself about your condition.
11. Get your community to turn teal for October 7th.
12. Create arts or crafts! Think teal!
13. Share your story with local papers; write news stations to share your experience.
14. Hold local fundraisers in your community for TNA and/or the FPRF. Restaurants & other small businesses often donate a portion of proceeds to charity. Just help spread the word of the event!
15. Create a video and join the TNA Video Project.
16. Call your local radio station and ask for a shoutout about facial pain
17. Share information with local medical professionals & hospitals.
18. Organize a local walk for awareness.
19. Create a blog following your journey.
20. Share information with local schools. Rare or not #KidsGetTNToo!
21. Hold a car wash or bake sale & donate to the TNA.
22. Join local support groups and share your story with others you can find a list of groups on TNA’s website.
23. Hold a raffle online or in local stores/restaurants to support TNA & the FPRF.
24. Ask businesses to post awareness bulletins on their reader boards for October 7th.
Name: Ally Castellano

Current age: 26

Q: Where do you live?
A: Washington, NJ.

Q: How old were you when you first experienced facial pain?
A: I was 13. The pain woke me up at 3:33 am on October 7, 2002. I can remember that moment like it happened yesterday. I was diagnosed less than 2 weeks later when a neurologist told my parents, “either your daughter has been reading a medical textbook or she has Trigeminal Neuralgia.”

Q: What was your diagnosis?
A: My initial diagnosis TN2 or “atypical TN.” I was later diagnosed with bilateral TN2.

Q: What do you do for fun?
A: For fun I love to be outside (when the TN weather allows.) I love hiking, rock climbing, and mountain biking. I also love to dance! Finally, I am a special ed teacher (I love my job) and am planning my wedding!

Q: What has TN taught you?
A: Having TN has not been fun or easy, but it has taught me so much. It has taught me at an early age what really is important in life: taking care of myself, listening to my body, and not to stress about the small stuff! I’m still working on that last part. TN has also taught me to find the positive in each situation, which in itself has taught me to be a better person.

Q: What treatments (nonsurgical) have you tried?
A: Accupressure, acupuncture, uppercervical chiropractic, chiropractic, magnet therapy, TENS unit, biofeedback, limited saturated fat diet, nerve blocks, herbal oils, Lidocaine infusions, and many different medications.

Q: Have you had any procedures?
A: I have bilateral TN so I have had one MVD on the right, 3 on the left, and the Dorsal Root Entry Zone procedure (DREZ).

Q: How has your facial pain changed you?
A: I wouldn’t say my facial pain has changed me, I would say it changed the way I look at things. I look at a situation and think “how can I adapt to this,” as opposed to “I can’t do this.”

Q: What tips do you have for other young patients?
A: Stay positive! Having TN at any age is tough, but having TN as a young patient is another challenge in itself. Lean on your friends and family, they are there for you. Lastly, find a doctor you really trust and are comfortable with.

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