

Page 8 - Dr. Mark Linskey on Avoiding the
Common Myths of TNA Diagnosis

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After 20 years of excruciating lower jaw pain and many unsuccessful treatments, I had neurosurgery at Mayo Clinic for trigeminal neuralgia. Now, the pain is completely gone. My only regret is that I didn't go to Mayo years ago. My answer was Mayo Clinic.



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From the Chairman of the Board

In my previous letter, I referred to the winds of change as a force for good and I'm pleased to say that those winds continue to blow. First, I am pleased to report that, following the departure of Susan Cupp, the Board has confirmed John Koff as our new CEO. John has been with TNA for over 5 years and has been responsible for many of our recent initiatives and for managing our business. The Board looks forward to John's continuing success in his new role. If you have not yet met him, you are likely to do so at one of our upcoming conferences

I am also pleased to report the addition of two new Board members, both facial pain patients: Jeff Bodington and Art McHaffie. Jeff is an investment banker in the electric power industry and Art has been engaged in management in the oil industry, domestically and internationally. Both have experience in nonprofit organizations and I am delighted that they are bringing that experience to bear for your benefit.

We will continue to expand our Board to add people who have a passion for our cause and the ability and desire to advance our mission. This will also allow us to develop new leadership and new approaches to meeting the needs of patients. With this in mind, I'm also pleased to announce the creation of a Young Patients' Committee. This Committee will advise the Board on issues and ideas that are of concern to our growing population of patients under 40 and, perhaps, represent the leadership of tomorrow. The inaugural Chair of the Committee is Tiffany Smith, an attorney in Washington, DC, whose experience with facial pain is chronicled on the website of our Facial Pain Research Foundation, www.facingfacialpain.org. Tiffany's zest for life, compassion and desire to succeed, notwithstanding her pain, are exemplified by the word "perseverance," now a tattoo engraved on her wrist. Tiffany will be seeking members for her committee and if anyone has an interest in participating please contact John Koff at our National Office.

Change has a bad reputation in our society, especially today. But change is a good thing for our Association when it serves the needs of our constituents and enjoys support from those who can either oppose it or help to make it work. I hope that we will always embrace change that makes our cause more visible or more attainable. I am confident that the changes I have announced represent such change and I hope you will continue to read this column for changes to come.

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



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INTRODUCING: The Facial Pain Research Foundation

Grassroots effort aimed at finding a cure in 10 years for the world's most excruciating human pain

By Arline Phillips-Han

Imagine you're an Army veteran, decorated for the combat missions you flew as a helicopter pilot in Vietnam, and now your retirement life is disrupted by full-magnum attacks of trigeminal neuralgia.

Imagine you have a tiny daughter, who suffered agonizing facial pain for almost four years before you found out she has TN, and although surgery ended her pain, you fear the risk of recurrence.

Imagine you live with burning, aching facial pain that at any moment strikes with an electrical force that leaves you unable to work and unable to get home without help.

For thousands of people in every corner of the world, TN and other nerve-related facial pain disorders hover like a cruel intruder over daily life, hindering efforts to work, attend school, enjoy a vacation, talk, eat, sleep or socialize with people. Medications and/or surgery relieve the pain for some, but not for others, and all face the chance that pain will come back. The severity of the disease and the lack of a cure signal a need for in-depth research.

Now go beyond imagination to an international campaign for a cure.

Founding trustees of The Facial Pain Research Foundation aim to find a cure in ten years through an international consortium of basic scientists focused on identifying how nerve damage occurs and how to repair nerves or protect them from injury. Seven accomplished professionals across the nation activated the Foundation at their first Board of Trustees meeting Jan. 7, 2011 in Gainesville, FL. See their Website at www.facingfacialpain.org.

Michael Pasternak, Ph.D., of Gainesville, a founding trustee who provided years of creative leadership to the TNA-Facial Pain Association before launching the research foundation, puts the game plan in focus. The Association, in its 21st year of service, will continue as the nation's leading source of education, patient support, and dialogue between patients and health-care professionals. The Foundation is a division dedicated solely to a scientific search for a cure.

Pasternak, who suffered several years of stunning, knee-buckling TN pain before he underwent successful microvascular decompression surgery in 1992, spends most of his workweeks, Monday to Friday, nurturing the Foundation. He consults with co-founders and volunteers from coast to coast, renewing friendships at scientific

conferences and meeting new patients. Through new connections, people who've never suffered any form of facial pain are signing on as corporate partners and fund-raisers. Among them: Brent Maher, six-time Grammy Award-winning writer and producer (see MoraineMusic.com) and Leonard Finz, author of the best-selling mystery thriller, *Paragon Connection*.

Myron (Mike) Hirsch of Naples, FL., also a charter trustee, is investing decades of experience in book printing, electronic publishing, graphic design and business development to boost the research he hopes will improve the lives of thousands around the world, including family and close friends. He is devoting extensive time to the foundation website and other public promotions, and to encouraging support for the research consortium.

"My family heritage instilled in me the necessity to help others," said Hirsch, who formerly served as president of the TNA-FPA Board for nine years. "Just as America put a man on the moon only seven years after President John F. Kennedy announced we should go there, I believe the Foundation can achieve a cure for trigeminal neuralgia in 10 years through the collaborative teamwork of premier basic scientists working toward the goal."

Trustee **Suzanne N. Grenell**, MBA, of Scottsdale, AZ., a creative writer, inspirational speaker and former business executive who frequently lost her ability to talk during a five-year siege of trigeminal neuralgia, is grateful for a pain-free life today, and has boundless empathy for people in pain. In her view, contemporary treatment for TN is dismal.

"I am backing this Foundation out of angry indignation!" she said. "This is the 21st century and we're talking about a disease known for thousands of years, affecting people worldwide, yet we still have no cure! I am mad at the laziness of scientists, who should be on this with greater effort. Patients today, as in years past, despite the great scientific technology that has been developed, are offered band-aid treatments, not a lasting solution."

Grenell said she has heard from world experts like Neurosurgeon Albert Rhoton Jr. (also a Foundation trustee) that no significant improvement has been made in the treatment of facial pain in over 40 years. "Other neuroscientists have told me treating trigeminal neuralgia should be easier than most other types of brain damage because it involves only one nerve. As I see it, the United States, which is no longer competitive in much of anything on the world stage, has a chance to be the world leader in brain science and the treatment of brain diseases like trigeminal neuralgia. We need to face the challenge smarter and faster. We need to lead an international effort to fix the trigeminal nerve, and if we can do that, we can repair other nerves and cure other nerve diseases."

Grenell said she welcomed the chance to help create the Foundation from the ground up and "to work with people as passionate as I am about finding a cure." (For 23 years, she served as a business

executive with Intel Corporation, leading its technology build-up and worldwide expansion, creating and implementing strategies for worldwide sales and customer relations.)

Pasternak said the Foundation's research initiative is guided by cues from patients who fail to benefit from existing remedies, and from medical experts at the frontline of diagnosis and treatment. For example, Dr. Rhoton has recommended expanded studies of the waxy myelin that protectively coats all nerves in the body. When the myelin sheath is eroded or chipped away from the trigeminal nerve, it sets the stage for electrical shocks of facial pain.

Pasternak said the scientists working with the Foundation at the University of California San Francisco, the University of Florida's McKnight Brain Institute and the University of London are optimistic that if a cure can be found for neuropathic facial pain, it is not an enormous stretch to be able to fix damaged nerves in other parts of the body and cure other diseases.

"Where will we find the solutions?" Pasternak asks rhetorically.

"Will it be possible to stop the progressive nerve damage involved in TN by repairing or regenerating myelin? University of Florida neuroscientists **Dr. Lucia Notterpek** and **Dr. Andrew Ahn** hope to find out through studies of myelin damage and repair in mice. Or can we stop the pain by transplanting, into brain areas influenced by nerve damage, healthy nerve cells that will inhibit pain signals from traveling to the brain? Right now, pain expert Dr. Allan Basbaum, Professor and Chairman of Anatomy at the UCSF, is investigating cell transplants in genetically altered mice."

Notterpek, who has been appointed chair of the FPRF Scientific Consortium, is working to expand the coalition of eminent basic scientists concentrating on nerve damage and repair.

In London, Dr. Joanna Zakrzewska, popularly known as Dr. Zak, director of the largest orofacial pain clinic in the United Kingdom, is working to expand the Scientific Consortium in her role as the Foundation's International Neuroscience Coordinator.

In Gainesville, FL., Foundation trustee **Douglas K. Anderson**, Ph.D., Eminent Scholar, Professor and Chairman Emeritus of Neuroscience at the UF College of Medicine, serves as the consortium's Scientific Advisor, a role aimed at targeting basic research toward application in human medicine, i.e. the treatment of neuropathic facial pain. Anderson is well known in neuroscience for pioneering laboratory research that led to the first implantation of human embryonic nerve tissue in patients with a type of spinal cord injury.

Roger L. Levy, Esq., an investment attorney in Scottsdale, AZ. and chairman of the TNA-FPA Board of Directors since 2000, also has joined the Foundation's charter trustees to bring worldwide attention to the relative rare problem of TN and other nerve-related facial pain. Levy's extensive leadership with the Association began after he suffered eight years in "a wilderness of pain" that shut down his legal career and forced him into a dark corner of silence. Now pain free, he has devoted much of the past decade to championing the need for research. Educated in England, he is CEO of Cambridge Fiduciary Services LLC in Scottsdale.

continued on page 4



Research Foundation Board of Directors. Top row: Roger L. Levy, Michael Pasternak, Myron A. Hirsch, Jay Winer, Dr. Albert Rhoton, Jr., seated: Suzanne N. Grenell, Douglas K. Anderson.

... "Research Foundation" cont.

Jay Winer of Asheville, N.C. and Indialantic, FL., an independent public relations/marketing consultant and fund-raiser, is unique among the Foundation trustees, having no history of facial pain in his family. But while producing videotaped interviews with TN patients at several TNA conferences, Winer said he was "hooked" on the cause of helping people in pain. A former director of public relations and community affairs for The Grove Park Inn Resort and Spa in Asheville, he is now treasurer of the Foundation and is applying his talents in videography, photography and PR/marketing to its development.

The Foundation aims to succeed on its grassroots fund-raising initiatives, which have expanded in only four months to include: Elizabeth Cilker Smith of Los Gatos, CA., West Coast Coordinator; Karen Burris of Leesburg, FL., Florida Coordinator; and Pam Unverzart of Brandon, FL., point of contact for volunteers from around the world through her e-mail address, Pam@facingfacialpain.org. And in Parachute, Colo., Joann Alam, who has never suffered facial pain, provides secretarial services.

The Foundation Website notes many ways to help: *Stay At Home for the Cure; *A Circle of Friends for small business owners; *Support Research by Hours or Minutes; *Students End The Pain Program; Honor or Memorial gifts, corporate gifts, and even a chance to sponsor a fund-raiser.

Stories on people behind the Foundation and the research underway are featured on the Website at www.facingfacialpain.org.



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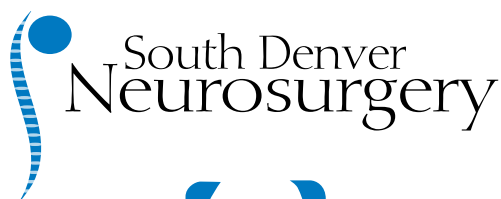


Dr. Thomas Kopitnik moved to Wyoming from Dallas, Texas where he was a Professor of Neurological Surgery at Southwestern Medical School. He helped start the North Texas chapter of the Trigeminal Neuralgia Association. He has treated Trigeminal Neuralgia for 25 years and continues to serve those patients with this disease process.



Dr. Todd Thompson joined the Trigeminal Neuralgia team at Mountain View Regional Hospital in 2010. Dr Thompson originally mastered the microvascular, percutaneous and radiosurgery skills needed for TGN while training at the University of Pittsburgh with Drs. Jannetta and Lunsford. With 10 years of private practice experience, Dr. Thompson tailors the multiple therapeutic options available to suit each patient's unique needs.

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Offers several types of surgical treatment for Trigeminal Neuralgia, including microvascular decompression, balloon microcompression and radiosurgery



Peggy Glass and her niece Katie

Thanks to aggressive medical care, Peggy Glass achieves TN pain relief

By Arline Phillips-Han

Peggy Glass of Roseville, MN., a former Catholic nun and Chicago attorney, knows the devastating toll of trigeminal neuralgia's hit-and-run pain after 20 years experience. Although free of facial pain today, she is realistic about the chances of recurrence. She shares the disappointments and successes of her search for pain relief in the hope of helping others.

Six surgical procedures, all aimed at stopping pain signals from traveling through the trigeminal nerve to the right side of her face, preceded the operation that ultimately stopped Peggy's pain on April 22, 2010. That scenario gives a clue to the complicated nature of her disease, which actually is two diseases: multiple sclerosis, diagnosed in 1984, and trigeminal neuralgia that began in 1991 and proved to be highly resistant to conventional medical treatments.

"I have TN because of multiple sclerosis, which makes my situation unusual," Peggy said. "Three percent of TN patients have it because of MS, and for me, the facial pain is my worst MS complication."

As she learned with the help of health professionals, TN and MS share an important common denominator. MS involves progressive damage to the waxy coating known as myelin, which surrounds and protects all nerves, and it is this demyelinating process that injured her trigeminal nerve, resulting in stunning shocks of facial pain.

Among the few fortunate aspects of her health problems was a fairly quick and accurate diagnosis. In 1991, Peggy requested that her endodontist repeat a root canal procedure, since her tooth pain was still intolerable. Upon reexamination, Dr. Claron Edwards suspected trigeminal neuralgia and recommended a neurological evaluation. A neurologist confirmed she had TN and prescribed Tegretol, which effectively controlled her pain for three years. But as the pain returned and struck more often, she needed higher doses to keep the pain at a tolerable level, taking up to 24 pills a day.

At that time, with little knowledge of TN, she was afraid to undergo any surgical treatment. She feared surgery might leave her with facial damage such as the "dropped face" that afflicted a friend with Bell's palsy, and that this disfigurement would impair her career as a trial attorney. She held on until 1994 when an accidental injury changed everything. She tripped and fell on a Chicago street, loosening some of her teeth and triggering new episodes of shock-like pain in her right cheek and jaw. The sharp pain worsened rapidly to the point she could barely swallow food or beverage. Within six months, she lost 32 pounds.

Peggy describes the attacks "like eight demons fighting for control of my cheek and jaw." Through most of her days, she tried to stay quiet in a useless effort to ward off pain. Desperate to find relief, she underwent her first, and ultimately successful operative procedure known as radiofrequency (RF) lesioning in 1994.

Chicago neurosurgeon Martin G. Luken III applied the radiofrequency heat, which damaged the trigeminal nerve in the affected area.

"It was like magic," she said. "The RF procedure left me numb in the cheek and jaw, but brought lasting pain relief. Today, I have no pain in this part of my face and minimal numbness!"

Shortly after the successful treatment, Peggy joined a Chicago-based trigeminal neuralgia support group that was being established in affiliation with the national Trigeminal Neuralgia Association. Glass became coordinator of the Chicago group, which served some 200 facial pain patients from Illinois, Wisconsin and Indiana. She remained active in Chicago TNA educational programs until 2002 when she moved back to St. Paul, MN. to rejoin her widowed mother. For seven years, she lived with her mother, enjoyed restaurant jaunts, travel and extended family events.

Peggy was pain-free at the time of her relocation, but in 2004 she began to experience sharp attacks of pain in her right forehead and eye area. Daily use of Trileptol, prescribed by a neurologist, temporarily provided relief. Early on, the pain occurred in quick bursts, but in time, the increasing pain lasted longer, with shorter and shorter spells of relief.

Her situation grew complicated as her aging mother became wheelchair-bound following hip replacement surgery, and she was unable to help her. Mother and daughter made it through difficult days



with round-the-clock personal care assistants. When a new bout of pain would start, Peggy would retreat to her room to read, watch TV and try to rest so that her mother would not see her suffer attacks of pain that sometimes knocked her to her knees. The medication no longer curbed the pain.

Thereafter, she underwent numerous surgical procedures. Since the 1994 RF treatment had been so successful to her cheek and jaw, she underwent the same procedure in December 2007 for the pain in her forehead. Dr. Stephen Haines, Chief of Neurosurgery at the University of Minnesota in Minneapolis, performed the surgery, which brought minimal pain relief. Haines repeated RF on Jan. 14, 2008 without success. On Jan. 17, he treated her with balloon compression, in which a needle is inserted through the cheek, carrying with it a tiny balloon that is inflated at a selected site to compress the nerve. Once more, there was no relief of pain.

On Jan. 22, 2008, Haines performed a procedure called supra-orbital nerve avulsion, in which he removed two segments of her trigeminal nerve. This relieved the pain for only a short time. Almost five months later, on June 12, 2008, Peggy underwent Gamma Knife treatment, a knifeless procedure in which finely focused beams of radiation were aimed at the trigeminal nerve close to where it connects to the brainstem. The radiation damaged the nerve and halted her facial pain for two years, until the pain returned full throttle, again striking the right side of her forehead and eye.

Only four days after this Gamma Knife surgery, she confronted a very different problem when she again entered the operating room for removal of malignancy in her right breast. With the aid of daily medication, she is recovering well after the lumpectomy and 36 radiation treatments. In light of her complicated health problems, she considers the cancer “a rather minor demon,” hopefully behind her.

Long-Awaited Success

The highlight of her journey with TN occurred April 22, 2010—another day at the University of Minnesota where she underwent balloon compression surgery for the second time. Having tried all her surgical options, she chose to have balloon compression performed again by Haines, a former member of the TNA Medical Advisory Board. This time, he compressed the trigeminal nerve in two strategically selected sites, rather than just one, with excellent results. The procedure obviously damaged the nerve sufficiently to disrupt misguided pain signals. Peggy said her only complication is numbness on the right side of her forehead and very slight numbness in her right eye. With 10 milliliters of liquid Trileptol every day, she is free of pain!

Peggy has a medical history that evokes disbelief, but today she cherishes the recovery of opportunities to try new travel adventures and activities with family and friends. She is optimistic about the future, especially since her MS is under control, leaving her with few problems other than weakness on her left side. She walks well with a cane, attends weekly physical therapy sessions, and has served as a volunteer at the nursing home where her mother lived for the last two of her 94 years. Mrs. Glass passed away peacefully on Feb. 12, 2011.

Today Peggy Glass celebrates her mother’s long productive life and her own pain-free life.

“With TN, you know it is always in the background,” she said. “The demon is sleeping, but can awaken again anytime. Every day I wake up pain-free, I thank my God, Dr. Luken and Dr. Haines.” ●



Avoiding Mythical Traps and Seductive Diversions

By **Mark E. Linskey, MD**, Western Regional Director, TNA Medical Advisory Board, Department of Neurological Surgery, University of California, Irvine.



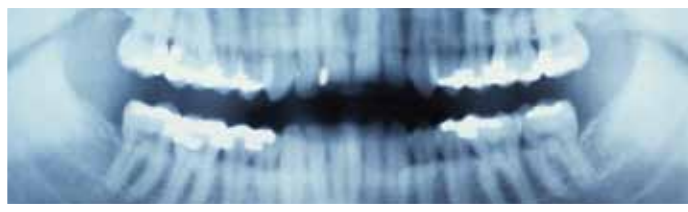
Developing, and then struggling with, a facial pain syndrome can be one of the most frightening and desperate times in a person's life. The possible syndromes at fault are rare enough where many primary care doctors, dentists, or other allied health professionals may have seen very few in their personal practice, and may themselves have to rely on researching reference materials, to try and guide their patients. Where is a patient to turn for experienced expert advice, and how are they to judge the accuracy, or degree of certainty attached to the advice they receive? This article tries to address two fundamental areas where there are common pitfalls and landmines that can lead patients down the wrong path. The first focuses on three common myths related to trigeminal neuralgia (TN) diagnosis, and the second focuses on three common seductive rationales that can lead patients down a less-than-optimal TN therapy.

Unfortunately, both medical and surgical therapies for facial pain syndromes other than TN are not nearly as successful as those for TN. Indeed, many clinicians would argue that most TN-proven surgical interventions should not even be considered in the early therapy of patients with non-TN facial pain. Thus, it becomes critically important, for the patient's sake, not to make the mistake of categorizing a patient with TN as having a non-TN facial pain syndrome. Missing the diagnosis of TN can have significant negative impact on patients through prolonging their suffering, failing to apply optimal medical TN treatments, or even failing to refer medically refractory patients for potentially beneficial operative intervention. In our experience, there are at least three myths circulating among health practitioners, and even repeatedly published in general TN reference literature, that can

mislead well-intentioned practitioners into failing to recognize that their patient actually has TN, rather than one of the other facial pain syndromes.

Myth 1: A Patient with a Detectable Trigeminal Sensory Deficit Does Not Have Trigeminal Neuralgia. It is very unfortunate that the International Headache Society (IHS) in their publication International Classification of Headache and Related Disorders (ICHD-II) 2004 defined TN as having no detectable sensory deficit on examination. They thus, by definition, excluded a subset of true TN patients from correct diagnosis and referral for potentially beneficial therapy. It should be obvious that many patients who have undergone trigeminal destructive procedures for TN, such as radiofrequency thermoablation, glycerol rhizotomy, percutaneous balloon compression, or stereotactic radiosurgery, will have sensory loss related to their destructive procedure, even if the procedure fails and their TN persists or recurs. However, this assertion is problematic even for a subset of patients who have never undergone a palliative destructive procedure.

Abundant evidence suggests that a subset of TN patients have subtle sensory deficits that can be picked up by either careful and thorough neurological examination, or by trigeminal sensory-evoked potential study. In our experience, we find subtle sensory deficits, usually detectable in the medial aspect of the V2, or less commonly V3 divisions, in up to 30% of TN cases. Interestingly, these findings appear to be more common in patients with a longer history of TN, lending support to hypotheses suggesting an ongoing nerve damage process at the root cause of TN. We also find subtle sensory deficits more commonly in patients who remain predominantly typical in their pain features (>70% of their



syndrome), but who are starting to develop minor background (<30% of their syndrome) atypical pain features, such as persisting dull or burning pain between neuralgic episodes. This observation would seem to support the hypothesis first noted by Jannetta and put forward by Burchiel, that TN type 1 (TN1) patients can evolve into TN type 2 (TN2) patients over time.

Myth 2: Patients Who Do Not Initially Respond to a Trial of an Appropriate Antiepileptic Drug for Trigeminal Neuralgia Do Not Have Trigeminal Neuralgia. Now it is certainly true that most true TN patients will at least initially show improvement with a therapeutic trial of one of the common and proven antiepileptic drugs (AEDs) used to treat TN (carbamazepine, oxcarbazepine, gabapentin, phenytoin, etc.). Unfortunately, the impression persists that this therapeutic trial is diagnostic for TN and, if the patient does not improve at all with the trial of one or two agents, then the diagnosis of TN is incorrect. The finding of a response to AED treatment is overwhelmingly common, and this should certainly reassure the practitioner that his diagnosis is correct. The absence of response, should also lead to very careful reconsideration of the other non-TN facial pain syndromes. However, this finding of non-response is not universal: If the patient has purely typical TN pain features (brief, sharp, electric, stabbing pain; tactile triggers; no pain between episodes), then he or she still likely has TN. In our experience, up to 5% of TN patients who go on to respond to surgical TN interventions never responded to AED therapy.

Myth 3: A Patient with Bilateral Symptoms Does Not Have Trigeminal Neuralgia. Bilateral TN symptoms are much more common in the setting of multiple sclerosis (MS)-related TN. While less common in the setting of non-MS TN, in our own experience approximately 2% – 4% of TN patients have bilateral symptoms. Nevertheless, bilateral symptoms should lead to a thorough evaluation to rule out MS. In our practices, this involves not just magnetic resonance (MR) scanning to identify and rule out demyelination plaques, it also includes cerebrospinal fluid (CSF) examination to assess myelin basic protein and rule out oligoclonal bands. When typical TN is bilateral, it almost always begins sequentially and not simultaneously on both sides, with often years between developing symptoms on the other side.

Assuming that you are not mis-characterized as a non-TN facial pain syndrome or an “atypical TN” patient, you still face the task of deciding among several potential TN surgeries with varying pain relief, numbness, and recurrence rates. The most ideal situation is to seek out guidance from experienced TN surgeons who routinely perform all, or most of the procedures for a balanced recommendation leading to an informed decision. Unfortunately, most TN surgeons perform only one procedure on a regular basis, and the old adage that, “when all you have is a hammer, everything tends to look like a nail”, tends to be true even for surgeons. Patients may not even be aware that there are multiple potential surgical procedures for TN. Their referring non-surgeon may have already decided themselves (rightly or wrongly) what they wish their patient to have, and guide their referral accordingly. In our experience seeing patients for second or third opinions, or even seeing them after an initial surgical intervention has already been tried and either failed, or

“Avoiding Mythical Traps” continues on page 10

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“Avoiding Mythical Traps...” cont.

worked only temporarily, three seductive rationales tend to emerge as reasons why they came to us already leaning in a particular direction, or had previously chosen to have a procedure prior to talking with someone who performs some of the other possible TN surgeries. These seductive rationales also turn out to be the main reasons that referring non-surgeons initially refer patients away from microsurgeons.

Seduction #1: Quotation of seemingly wonderful percentage rates with poorly defined, or even concealed, endpoints.

As a patient you must, yourself, be very clear on the goals you wish to achieve. For some patients even temporary partial relief of pain would be an acceptable outcome. For others temporary complete relief of pain even if it required continuation of their medications would be acceptable. For still others, only permanent complete relief of pain without the need for their TN medications will do. Every patient is different. Which are you?

The statement from the former Prime Minister of England, Benjamin Disraeli, that “there are three kinds of lies: lies, dam lies, and statistics” is particularly true when referring to unqualified percentages. Telling you that a procedure has a 90-95% success rate does not tell you whether the pain relief is partial (if so, how much), complete requiring medications, or

compete off all medications. It also does not tell if the success is immediate or delayed, or what the success rate is at 5-years, 10-years and 20-years. The same exact procedure can have a 90-95% chance of $\geq 50\%$ pain relief, a 63% chance of $\geq 75\%$ pain relief, and a 33% chance of complete pain relief off all medications, by year five after the procedure. Three surgeons quoting you a (A) 90-95% success rate, a (B) 63-70% success rate, and a (C) 33-50% success rate at five years for the same procedure would all be telling you the truth. You would not have a better outcome if you went to surgeon “A” over surgeon “C”. The results would be the same. However, surgeon “A” would likely be more successful in convincing you to have the procedure.

This problem is particularly rampant on the internet, where there is “no truth in advertising,” and where the buyer must beware. Many websites use the commonly accepted TN drug study success endpoint of only $\geq 50\%$ pain relief, without making this clear in their “literature”. The most accepted assessment endpoint among microvascular decompression (MVD) surgeons is being pain-free, off of all TN medication. It is the most objective and unequivocal endpoint. In our experience, it tends to be the most desired endpoint for patients, particularly if they are relatively young and healthy. In addition, durability of response is a crucial consideration. In the US, life insurance actuarial tables tell us that a US citizen aged 70 has ~15 more years, a 60-year-

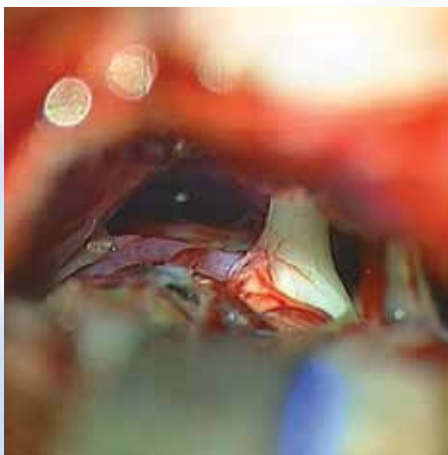
old an additional 22 years, and a 51-year old an additional 31 years, to live. Since palliative destructive procedures (such as Gamma Knife stereotactic radiosurgery [GKSR], radiofrequency lesion, balloon compression, and glycerol rhizotomy) have only a ~50% chance of leaving a TN patient pain free after 5 years, while MVD has an ~70% chance of leaving a TN patient pain-free both 10-, and 20-years after surgery, these factors must be properly taken into account.

Seductions #2 and #3: (2) *There is no downside to beginning with the least invasive procedure first and then moving on to those with increased risk if this fails, and (3) If GKSR doesn’t work, you can always do more, you haven’t lost anything.* These two seductive rationales will be considered together since they are related. Recommending a palliative destructive procedure such as GKSR as the initial treatment for young healthy patients with classic TN must be considered with caution and careful informed consent.

First, it must be kept in mind that time is a very important factor in success for MVD for TN. Dr. Jannetta’s observation that MVD results significantly diminish after 8 years of suffering with TN have now been confirmed and augmented by others, suggesting that the statistically significant cut point for worsened outcome may be as soon as 3 years. These statistics are for populations of TN patients undergoing MVD. Since the severity of vascular compression, as well as the inherent ability of an individual’s nerve to resist ill



effects from this compression are likely to vary individual-to-individual, the critical timing for transition from reversible damage to potentially irreversible damage, is also likely to vary a good deal. Whether the inflection point for you will be 2 years, 5 years, 8 years, or 10 years, is unknowable. However, a time will eventually be reached where completely reversible damage to the trigeminal nerve from ongoing vascular compression will transition to damage that can only be partially repaired, and clinical results



MVD Intraoperative Microscope

after subsequent MVD will be reduced accordingly. None of the four palliative destructive procedures mentioned above eliminate the progressive damage being caused by ongoing vascular compression which remains un-addressed. If the palliative destructive procedure eventually fails (~50% chance at 5 years), the time lost may have important negative consequences for results after a subsequent MVD.

Second, major MVD series have clearly shown that prior history of a palliative destructive procedure significantly worsens outcome of any subsequent MVD. Even if a second, or a repeat, palliative destructive procedure is chosen, not only are pain relief results worse the second time, but numbness rates significantly increase due to the accumulation of damage within the trigeminal system. It seems that a structural lesion in the trigeminal system, whether derived from natural pathology (such as a multiple sclerosis plaque or a small stroke), or an artificial lesion created on purpose in the trigeminal system from a palliative destructive procedure, predisposes the patient to worse outcome regardless of the subsequent procedure attempted.

We constantly tell patients who are early in their TN course (e.g. <3 years), that the time to get the best information possible and seek out multiple professional opinions is when their pain is initially relatively well controlled with medications. To wait until medications fail, to absorb and consider information as well as try and judge between differing opinions, is a potential formula for disaster. When you are in severe pain, you are desperate for relief and time-pressured to make a quick decision rather than a correct one. The urge to “do something”, and “do it quickly” can be overwhelming. At the same time the high doses of antiepileptic drugs (AED) and potentially narcotic pain medications resorted to when a patient is in extremis,

can both significantly impair learning and memory as well as cloud analytical judgment and decision-making. The time to consider surgical contingency plans is when the pain is controlled on relatively lower doses of AED's.

Microvascular decompression achieves significantly better pain control results for TN than GKSR or other palliative destructive procedures. Ultimately, it must be kept in mind that as a patient, you will never be younger, will never be a better risk for general anesthesia, and will never have a greater chance for a positive therapeutic result from MVD than at the present. However, not all patients are candidates for MVD, or choose to undergo the procedure. In our practice, GKSR is the TN surgical procedure of choice for patients who are elderly, medically infirm, or at high risk for general anesthesia; have surgical contraindications; or who have extremely low up-front risk tolerance. Microvascular decompression remains our preferred procedure recommendation for young, healthy patients, willing to accept the anesthetic and microsurgical risk. The truth is that both MVD and palliative destructive procedures are needed for the optimal care of our full spectrum of TN patients. Improving pain control and lowering the dose of cognitively and functionally debilitating medicines in our elderly and infirm patient pool is a very laudable endpoint, even when complete or permanent relief of pain is not a realistic goal. ●



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Ask the Doctor

Featuring Cindy Ezell and Dr. Ken Casey, Ms. Ezell is in charge of patient services for TNA and Dr. Casey is Chairman of TNA's Medical Advisory Board.



Q: What is Pseudotumor Cerebri and when/how does it cause neuropathic facial pain?

A: Pseudotumor Cerebri is more properly called Idiopathic Intracranial Hypertension.

It is a disorder of intracranial pressure regulation with chronically elevated Intracranial Pressure as the source of the headaches, visual complaints, and other manifestations.

Q: How does a nerve block by a pain management doctor differ from balloon compression, glycerol injection and radiofrequency?

A: The pain physicians (usually anesthesiologists) are offering a block designed to temporarily alleviate pain and sometimes to make a diagnosis, by seeing what the block affords the patient in the way of relief. The neurosurgical procedures are designed to effect longer

term pain control, on the order of 24 -36 months, when using glycerol or balloon or both. The surgeon is aiming to partially injure the nerve, permanently, to alleviate pain. We know that a destructive block, for example alcohol, is no longer considered a mainstream treatment.

Q: What exactly is neuropathic face pain?

A: Dr. Burchiel has proposed that there are 7 types of face pains. TNA and other organizations often refer to all seven types as neuropathic facial pain.

- Trigeminal neuralgia, type 1, (TN1): facial pain of spontaneous onset with greater than 50% limited to the duration of an episode of pain (temporary pain).
- Trigeminal neuralgia, type 2, (TN2): facial pain of spontaneous onset with greater than 50% as a constant pain.
- Trigeminal neuropathic pain, (TNP): facial pain resulting from unintentional injury to the trigeminal system from facial

trauma, oral surgery, ear, nose and throat (ENT) surgery, root injury from posterior fossa or skull base surgery, stroke, etc.

- Trigeminal deafferentation pain, (TDP): facial pain in a region of trigeminal numbness resulting from intentional injury to the trigeminal system from neurectomy, gangliolysis, rhizotomy, nucleotomy, tractotomy, or other denervating procedures.
- Symptomatic trigeminal neuralgia, (STN): pain resulting from multiple sclerosis.
- Postherpetic neuralgia, (PHN): pain resulting from trigeminal Herpes zoster outbreak. (SHINGLES)
- Atypical facial pain, (AFP): if facial pain is not diagnosed by any of the categories above, it falls into the AFP category, which is pain that has no known physical cause and is thought to be psychogenic—generated by the brain itself.

Submit a Question:

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



The following individuals joined or renewed their TNA membership

March 2011

Pat Akerberg
Robert Brenner
Patrick John Canta
Arlene Groden Cohen
Troy Croom
Terry Doremus
Thomas Espineda
Maria Glenn
Henry Goldenberg
Mary Ann Harrison
Susan Hassenbusch
Joanne E Hetherington
Joseph Klosek
Norman R. Long
Angela Martin
Edward McAninch
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Ken McNeil
John Moore
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Larry Overstreet
Lynn Phillips
Carolyn Richter
John Sexton
Katy Shearer
Shirley Thomas
Dee Diane Wood
Janice Zacherl
George Zack
Scott Ziegler

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Christa Bolton
Maynard Brun
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Nancy Clark-Locklin
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Fred DeMoro

Dennis Dore
Janet Dover
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Arthur Schwartz
Leslie Single
Michelle Soriton
Jennifer Taylor
Phyllis Teiko
William Tomlinson
Carol Warren
Jan Williams

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Margo Blevin-Denton
Billie-Jean Caperelli
Yvonne Chaplin
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Kellyann Desser
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Domenick Rose
Sheila B Rovner
Marion Savage
Brenda Sharp
Debra Shein
Kathleen Stack
Richard Stephens
Jennifer Stiller
Wayne Swanson
Chris Topp
Annette Washburn
Mary Welz
Dennis Wenger
Cynthia Woods
Margaret Hitchon

The following individuals are Lifetime members

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

TNA's Memorial Tribute Fund

There are special people in our lives we treasure. TNA supporters often make gifts in honor or in memory of such people. These thoughtful gifts are acknowledged with a special letter of thanks, are tax-deductible, and support TNA's initiatives on behalf of face pain patients. We are delighted to share recent Memorial Tribute gifts received in March, April and May of 2011.

In Memory of :

All Who Have Suffered with TN:

Pearline Francois

George Abbott

Alberta Abbott

Helen Baker

Jacqueline Bixel

Carmelia Barranco

Joseph Barranco

Genevieve Boyle

Mr. and Mrs. Gerald Boyd

Brad Browning

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Peggy Conrad

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TNA Western Regional Conference

By Mark E. Linskey, MD, Conference Course Director



Just how does one go about getting the most complete, accurate and up-to-date information needed to make informed decisions regarding treatment for facial pain syndromes?

Well just reading the TNA Quarterly is a good start. Other important steps include visiting the TNA website, www.tna-support.org where there is a tremendous wealth of information, where balanced publications providing information and empowerment for patients and their supporters can be found. However, probably the most efficient way to rapidly obtain the most accurate complete and up-to-date information regarding facial pain syndromes is to attend a national or regional TNA conference.

On Saturday, September 24, 2011, TNA-The Facial Pain Association will hold its Western Regional Conference for healthcare providers, patients and their supporters. Co-sponsored by the University of CA, Irvine and held at the Doubletree hotel in Orange, CA, right next to Disneyland and other fun southern CA destinations, this conference is designed to provide an efficient and informative, "one stop shopping" approach for everyone.

Healthcare experts in diagnosing and treating facial pain, including neurologists, neurosurgeons, dentists, anesthesiologists, internists, acupuncturists, nutritionists, hypnotherapists, physical therapists, and facial pain advocates from all over the US will all converge in Orange, CA for this important event. A special program on diagnosing and treating facial pain syndromes for medical and dental CME as well as nursing CEU educational credit for healthcare providers compliments a program orienting participants to TNA-The Facial Pain Association, their local TNA support groups, learning how to find the right experts and providers, as well as learning how to navigate and deal with their insurance companies. There will be a special symposium on mind-body interface focusing on complementary and alternative means for treating and coping with facial pain organized by the UC Irvine Susan Samueli Center for Integrative Medicine. There will be a special talk on current research into facial pain syndromes with a glimpse into the future. During lunch, there will be a workshop, Chaired by the founder of the TNA, Claire Patterson, for current and aspiring TNA support group leaders focusing on sharing resources, developing a western regional support group network and communication

infrastructure, benchmarking best practices, and sharing issues as well as trouble shooting successes. In the afternoon patient and supporter participants will have the opportunity not only to learn about all currently most-successful procedures for facial pain syndromes, but will have a chance to present their cases to both non-surgical as well as surgical expert faculty panels for feedback and recommendation. During lunch you will have the opportunity to sit with and talk one-on-one with these same expert faculty.

In terms of concentrated access to multiple facial pain experts from all fields of healthcare, nothing beats attending a TNA conference. The September Western Regional Conference in Orange County, CA promises to be one of our best yet. Be sure to mark your calendar and register early. Further information regarding the conference as well as registration can be found by going to www.tna-support.org. Be sure to watch your email for further TNA-The Facial Pain Association announcements regarding this important conference. ●

TNA WESTERN REGIONAL CONFERENCE • ORANGE, CALIFORNIA
SEPTEMBER 24, 2011



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Registration fee includes; welcome
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If you want to become a member before you register please visit **tna-support.org** or call 800-923-3608

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

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

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



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