TNA Quarterly

The Journal of
The Facial Pain Association

Winter 2012
Volume 1 Issue 4

TNA's newest book with foreward by Dr. Oz

Dental Care and Facial Pain

New Face Pain Classification

Support Group News

International Consultant Joins TNA Board

TNA
The
Facial Pain
Association

From the Chairman of the Board

I am composing this letter in November 2011 so that it is ready to go to press in time for a January 2012 publication and I have been reflecting on the fact that the first Thanksgiving in North America was held in Canada to celebrate an English seaman's survival of the transatlantic crossing, not in the US to celebrate a successful harvest. In my last Chairman's letter, I mentioned that our Association had suffered a significant decline in charitable contributions but I am glad to report that, as we approach the 2011 Holiday Season, we have more to celebrate than our survival.

Since our last Quarterly Magazine, there have been many positive outcomes. First we have held a very successful conference at the University of California, Irvine Medical Center. Host, Dr. Mark Linskey, welcomed over 200 patients who had the opportunity to participate in sessions on medical and surgical treatment of facial pain as well as sessions on complementary and alternative therapies. Since facial pain is a chronic condition for many patients, we recognize the importance of these therapies and will strive to include them as topics in future conferences. Our next one will be held in New York City in May this year and I will look forward to seeing many of you there. Please keep an eye on our website for more details.

We have also participated in a pilot Webinar program in which Dr. Cohen-Godal spoke of microvascular decompression surgery. This attracted 98 participants and the feedback has been very positive. Accordingly, you may expect to see more Webinars on different topics announced on our Website. In a similar vein, Dr. Ken Casey, Chairman of our Medical Advisory Board, was a featured guest on Dr. Paul Christo's radio show, "Aches and Gains." Dr. Casey described TN and its possible causes as well as available treatments. This is a wonderful way not only to reach patients but also to increase public awareness of TN and facial pain in general.

What's in a name? For many facial pain patients with complex cases, the term "atypical facial pain" has carried the stigma of involving psychological origins. As reported elsewhere in this edition, under the leadership of Dr. Peter Jannetta and our Medical Advisory Board, we are witnessing a change. From now on, the Association and the Advisory Board will refer to pain for which the origin is unknown as "facepain of obscure etiology." This is a major breakthrough and we will try to persuade others in the medical community to adopt a similar, enlightened approach.

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Emmit "Art" McHaffie, international consultant on energy resources, brings global experience to the TNA-FPA Board of Directors

By Arline Phillips-Han

International energy consultant Emmit Richard "Art" McHaffie of Santa Fe, NM, who has helped expand oil and gas production in key areas of the world, joins the TNA-Facial Pain Association Board of Directors with a clear aim to boost its search for a cure for facial pain.

McHaffie currently serves as Honorary Consul to the Republic of Azerbaijan, with responsibilities covering the State of New Mexico. He served in the 1990s as a senior representative for Amoco International Oil Company, sent to Baku, Azerbaijan to start the first international operating company in the region. As executive vice president of the company, he led the development of a 4 billion-barrel oil field in the Caspian Sea and directed the delivery of energy resources to the world market.

He is a member of the Board of the World Affairs Councils of America in Washington, D.C., a national non-partisan network of 93 local councils dedicated to educating and engaging Americans in international affairs. For 27 years, he held leadership positions with various branches of Amoco International Oil Company in Houston, Chicago, Libya, Egypt and Azerbaijan. By the time he retired in 2000, he had completed more than 30 years in global business development, finance and planning related to oil and gas production.

McHaffie brings to the Board of TNA-FPA a driving interest in solving the mysteries of trigeminal neuralgia, which impaired his life for almost a decade prior to successful neurosurgery in April 2011. In the midst of his trials with pain that started in 1999 and evolved into uncontrollable stabs of pain on the right side of his face, he recalls, "My general practitioner said he hoped it was not "tic" (slang for tic doloreux or trigeminal neuralgia), but in 2007, CT scans confirmed this was what I had. I started out trying to control the pain with medications, including Neurontin, which virtually destroyed my ability to play bridge. In March 2011, the pain in my right eye became much worse; I could not turn my eye or even look up!"

He happily talks about his treatment at the Mayo Clinic in Scottsdale, AZ., where neurosurgeon Richard Zimmerman ended the pain by repairing two different areas of arterial compression on the trigeminal nerve. During the six-hour operation, Zimmerman corrected both problems by separating the artery from the nerve. In one affected area, he performed conventional microvascular decompression (MVD), and in the other space, he glued the offending artery to the base of the skull.

While reading everything he could find on severe facial pain, McHaffie said, "The most knowledge I gained came from the TNA-FPA through the Internet and through listening to the lectures and discussions at the 2008 TNA national conference in Dearborn, Mich. I decided, based on the data that was presented, not to consider Gamma Knife treatment." (He decided that when the prescribed medicines no longer relieved his pain, he would be ready to consider MVD surgery.)

McHaffie said his decision to serve on the TNA-FPA governing Board is based largely on his gratitude for becoming pain-free, and his desire to help find a cure for the thousands of people who still suffer with facial pain. He is interested in helping the Facial Pain Research Foundation (a division of the TNA-FPA) achieve its grand goal of finding a cure (or cures) for trigeminal neuralgia and other nerve-related facial pain disorders by the year 2020. Details of the Foundation's research programs are on the Web at www.facingfacialpain.org.

"I consider myself very fortunate to benefit from the medical professionals who came before me, including Dr. Peter Jannetta, who developed MVD surgery and trained other neurosurgeons," McHaffie said.

Today, at home in Santa Fe, NM, he is back to enjoying games of bridge and planning travel with his wife, Joy. The couple has three adult children.

Dr. OZ Introduces TNA's New Book on Managing Face Pain

The following is the foreword to "Facing Facial Pain" written by Dr. Mehmet Oz. Dr. Oz, besides his television celebrity, is professor and Vice-Chairman of the Department of Surgery at Columbia University/New York Medical Center. He is also the authors' son-in-law.

Here is the story of how a new treatment for trigeminal neuralgia was born. It is a story of love and science, of life experience and theory. But most important, it is a story of hope for those who suffer with TN and other neurological face pain.

Mehmet Oz, MD

John Fothergill gave the first full and accurate description of trigeminal neuralgia in 1773, but earlier descriptions of TN (Fothergill's disease) can be inferred from the writings of Galen in Asia Minor two thousand. years ago and in the 11th century by Avicenna, who called TN "tortura oris." Undoubtedly, some images depicting "toothache" suffers from remote eras actually represented patients with this ailment, since dental caries were uncommon until modern times.

So why has such an ancient malady remained uncured in a time where modern medicine has made remarkable advances in understanding the molecular mechanisms of diseases and offering high tech solutions? This is the challenge that Dr. Gerald Lemole embarks upon with this wonderful summary of trigeminal neuralgia—the ailment, its causes, and its potential treatments. What makes this "owner's manual" for trigeminal neuralgia so valuable is its comprehensive holistic approach to treating a chronic illness that has multiple avenues of recovery and relapse.

Although he's an internationally renowned cardiac surgeon, Dr. Lemole would not be the most likely candidate to create a book that will serve many trigeminal neuralgia sufferers, their families and their caregivers so admirably. He does not have the ailment himself. He has not specialized in neurologic ailments in the past. But over the course of 40 years as a healer, Dr. Lemole began identifying fundamental, recurrent problems that cause many of the chronic illnesses that afflict so many Americans.

The inflammation that precipitates heart disease is also an underlying problem in many neurologic conditions. Think of inflammation as the rusting of our bodies, accelerated by oxidation and other natural processes that usually are naturally kept in

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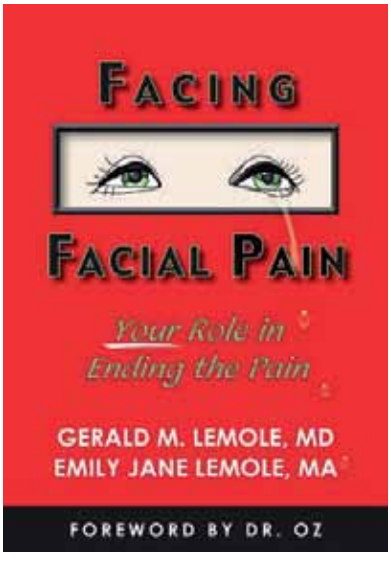
Facing Facial Pain: Your Role in Ending the Pain



The Lemole Recovery Program – designed for those suffering with facial pain. From specific nutrition to the most beneficial exercise, the Lemoles guide the reader through a life changing plan for facing and controlling facial pain.

Here is the story of how a new treatment for trigeminal neuralgia was born. It is a story of love and science, of life experience and theory. But most important, it is a story of hope for those who suffer with TN and other neurological face pain.

- Mehmet Oz, MD

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"Dr. Oz Introduces . . ." cont.

check. For example, when you cut an apple in half, the browning process that ensues over 20 minutes is caused by oxidation. Squeezing a lemon over the half apple will retard the color change because lemon juice contains the anti-oxidant vitamin C. When we consume vitamin C, we also slow the oxidation process within our bodies.

Abnormally functioning regulatory processes like inflammation and oxidation are worsened by toxins and by the inability of our lymphatic systems to support a dysfunctional immune system that mistakenly begins to bring "friendly fire" onto our own tissues. Lymphatics are particularly interesting because most of us know little of this essential system of waste removal from the body. Your lymph nodes are the lumps that form in your neck when you get a sore throat. They connect the lymph channels throughout the body, and their tiny muscles "milk" the fluid back toward your heart when you are active. Massage will stimulate lymph drainage as well, which may explain why a massage is so soothing - and is such a darn good idea.

Once we understand the basics regarding trigeminal neuralgia, we can launch into the recovery program designed by Dr. Lemole. To explain the fundaments, please allow me a brief autobiographical segue.

I made the smartest decision of my life 25 years ago by marrying Dr. Lemole's eldest daughter Lisa. At the time, I was a traditional medical student, studying pharmacology and physiology with our conventional textbooks and memorizing established rules for treating illness. On my first visit to his home, I was struck by the remarkable insight that the Lemole family had somehow bottled "wellness". The six children looked and behaved healthily. The secret seemed to be that Mrs. Lemole had created a sanctuary for healthy living, including herb gardens, a vegetarian lifestyle and an appropriate skepticism of long-established medical rules.

Dr. Lemole was already famous for developing numerous innovative solutions in treating advanced heart disease surgically. After graduating from Temple University medical school, he was trained at the remarkable Baylor cardiac surgical training program in Houston with Drs. DeBakey and Cooley. Dr. Lemole participated in the first human heart transplant in the country, then returned to the Northeast as the youngest chief of cardiac surgery ever. He performed the first coronary artery bypass in the area and invented devices to repair torn aortas and complete other complex operative procedures. His many contributions to the field earned him numerous academic accolades, including membership in the most prestigious heart-surgery societies.

Despite all these successes within conventional medicine, Dr. Lemole was increasingly open-minded to innovative healing approaches. Once while playing a heated game of Trivial Pursuit with the family, 1 was stumped by the question, "Which famous surgeon earned the nick name 'Rock-a-doc' by being the first to play rock music in the operating room". My father-in-law won the point — and game — by offering his own name. Dr. Lemole had permitted the playing of music in his operating theatre in order to help the team and patient relax so all could participate most effectively. He brought this same openness to alternative and complementary healing approaches.

Throughout my adult life, 1 have enjoyed enormously watching Dr. and Mrs. Lemole (AKA my "in-laws") battle over the best path for healing friends and family. One discussion surrounded their sister-in-law Gwen, who was suffering from trigeminal neuralgia with no clear course of treatment yet identified within conventional medicine. Over the course of several months, the Lemoles offered solutions that dramatically reduced Gwen's symptoms of TN, and the experience awakened the sleeping giant of an idea. Could many of our chronic illnesses be treated with a simple recovery program which we know is effective in other well-studied ailments like atherosclerotic heart disease and certain cancers?

This brings me back to the Lemole Recovery Program, which is the heart and soul of this book.

We must understand that when we walk into a grocery store, we are really walking into a pharmacy. The powerful nutrients found in colorful vegetables and fruits were created to protect these products from the sun and other oxidizing stimuli. We share these healing nutrients by consuming this produce. The Lemole Food Pyramid outlines this insight elegantly and offers a logistically simple pathway to making the correct food choices. Adding the micronutrients and herbs described to the mix reinforces the healing power of food. As a side benefit, you get to lose weight effortlessly with the 14-day diet plan, supported by the many recipes in chapter 10. Adding effective management of the stress of modern life, and doing smart exercises—including the aforementioned massage—helps keep the immune system functioning at full speed and playing for the right team—yours.'

Part III of this comprehensive survey helps all of us understand the underlying science behind many of Dr. Lemole's insights, and much of this material will be of more importance to your healers than to you—orthomolecular medicine, vitamin D science, antioxidant details, the myths of cholesterol, and the deeper insights that explain healthy aging. Why is this foundation of science included in a book designed for patients and their loved ones? All too often, ground-changing books like this sit on a patient's bookshelf without ever being digested by the doctors and nurses who treat trigeminal neuralgia.

The one request that I have for each reader of this book is that they share Part III with their healers so we can all spread the word. You are now in the army that will carry this banner for a smart treatment approach that actually can help those suffering from trigeminal neuralgia. By being one of the bumble bees that fertilizes the pods of learning from which your healers feed, you are helping modern medicine treat this and other chronic illness.

Bless you for doing this, despite your own suffering.

Mehmet Oz, M.D. Host, "The Dr. Oz Show" Professor and Vice Chair, Department of Surgery, Columbia University/New York Presbyterian Medical Center

"From the Chairman . . ." cont.

By the time you read this, we will have launched the first phase of our revamped Patient Registry. This is an opportunity to collect much needed patient data on treatments and their cost and I encourage all patients to participate. Knowledge is power and you can help us understand the cost of treating facial pain so that we can be a more effective voice on your behalf as the nation struggles to find a mechanism to achieve cost effective healthcare.

Finally, we are proud of our new book, "Facing Facial Pain" by Dr. Jerry Lemole and his wife Janie. Related to Gwen Asplundh, a former Board member, the Lemoles are well known to many of our patients as frequent speakers at our national conferences. This book, as described elsewhere in this edition, expands on the theme of their conference presentations and is a welcome addition to our publishing list.

So, we have much to celebrate as 2011 draws to a close and we face the New Year in which this letter will be published. I would like to take this opportunity to thank our Board members for their unstinting support and hard work to ensure that we stay on mission. I would also like to thank John Koff for his leadership as CEO and all members of the staff for continuing to deliver the effective services which are so important to our patients. To our Support Group Leaders, Telephone Contacts and other volunteers, TNA is a grass roots organization and know that the TNA family is stronger because of you and your efforts.

On behalf of the board and staff at TNA-The Facial Pain Association I'd like to wish you all a very happy new year.

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

Be On the Look Out (BOLO)

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

There are many claims on the internet offering to cure the pain of Trigeminal Neuralgia. When we are in such pain these claims sound very good to us. We just want to be out of pain and don't want to leave any stone unturned. During these times of intense pain, it is difficult to weed out the good information from the bad. In order to help with this task of evaluating these treatment claims, TNA has found this information from The Mayo Clinic Website to be very helpful.

Complementary and alternative medicine: Evaluate treatment claims

Don't take all CAM claims at face value. Do your homework when considering CAM therapies.
Complementary and alternative medicine treatments, such as herbal remedies and acupuncture, have become more popular as people seek greater control of their own health. But while complementary and alternative medicine, called CAM for short, offers you more options, not all CAM treatments have been proved safe or effective.

When considering CAM treatments, it pays to be a savvy consumer. Be open-minded yet skeptical. Learn about the potential benefits and risks. Gather information from a variety of sources and check the credentials of CAM practitioners. And be sure to talk with your doctor before trying any treatment — especially if you take medications or have chronic health problems.

Although scientific studies are the best way to evaluate whether a treatment is safe and effective, it isn't always possible to find good studies about alternative medicine practices. Keep in mind that a lack of evidence doesn't necessarily mean a treatment doesn't work — but it does mean it hasn't been proved. Don't hesitate to talk with your doctor if you have questions

How to evaluate claims of treatment success
Look for solid scientific studies

When researching CAM treatments, do like doctors do. Look for high-quality clinical studies. These large, controlled and randomized trials are published in peer-reviewed journals — journals that only publish articles reviewed by independent experts. The results of these studies are more likely to be solid.

Be cautious about studies in animals, laboratory studies or studies that include only a small number of people. Their results may or may not hold up when tested in larger clinical trials. Finally, remember that sound health advice is generally based on a body of research, not a single study.

Weed out misinformation
The Internet is full of information about alternative medicine treatments, but not all of it is accurate. To weed out the good information from the bad, use the three D's:

- Dates. Check the creation or update date for each article. If you don't see a date, don't assume the article is recent. Older material may be outdated and not include recent findings, such as newly discovered side effects or advances in the field.

- Documentation. Check sources. Are qualified health professionals creating and reviewing the information? Is advertising clearly identified? Look for the logo from the Health on the Net (HON) Foundation, which means that the site follows HON's principles for reliability and credibility of information.

- Double-check. Gather as much information as you can. Visit several health sites and compare the information they offer. If you can't find supporting evidence to back up the claims of a CAM product, be skeptical. And before you follow any advice you read on the Internet, check with your conventional doctor for guidance.

Supplements: 'Natural' doesn't always mean safe

- Herbal remedies, vitamins and minerals, and all types of dietary supplements are marketed as "natural" products, but they can have drug-like effects that can be dangerous. Even some vitamins and minerals can cause problems when taken in excessive amounts. So it's important to do your homework and investigate potential benefits and side effects of dietary and herbal supplements. Play it safe with these tips: Talk to your doctor before taking a dietary supplement. This is especially important if you are pregnant, nursing a baby, or if you have a chronic medical condition such as diabetes or heart disease.

- Avoid drug interactions. Prescription and over-the-counter medications can interact with certain dietary supplements. For example, the herbal supplement ginkgo can interact with the blood-thinning medication warfarin and increase the risk of serious bleeding complications.

- Before surgery, tell your doctor about supplements you take. Some supplements can cause problems during surgery, such as changes in heart rate or blood pressure or increased bleeding. You may need to stop taking these supplements at least two to three weeks before your procedure.

Watch out for CAM scams

Scammers have perfected ways to convince you that their alternative medicine products are the best. These opportunists often target people who are overweight or who have medical conditions for which there is no cure, such as multiple sclerosis, diabetes, Alzheimer's disease, cancer, HIV/AIDS and arthritis. Remember if it sounds too good to be true, it probably is. Be alert for these red flags:

- **Big promises.** Advertisements call the product a "miracle cure" or "revolutionary discovery." If that were true, it would be widely reported in the media and your doctor would recommend it.

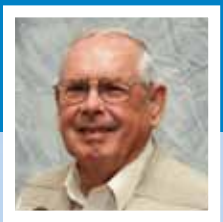
- **Pseudomedical jargon.** Although terms such as "purify", "detoxify" and "energize" may sound impressive and may even have an element of truth, they are not scientific terms and their meanings may vary.

- **Cure-alls**. The manufacturer claims that the product can treat a wide range of symptoms, or cure or prevent a number of diseases. No single product can do all this.

- **Testimonials**. Anecdotes from individuals who have used the product are no substitute for scientific proof. If the product's claims were backed up with hard evidence, the manufacturer would say so.

- **Guarantees and limited offers**. These pitches are intended to get you to buy before you can evaluate the product's claims.

For more information go to Mayo Clinic Website: http://www.mayoclinic.com/health/alternative-medicine/SA00078



Support Group News

By Ron Irons

Enjoying a soothing shower and then you experience an electric shot to the face that has brought you to your knees or pain in your forehead that won't go away. "What was that," you ask yourself. You talk with friends and family and they are bewildered as to what it could be. What to do? You need answers. "Please give me relief, I will go anywhere, just make the pain go away!"

Rob who was experiencing facial pain traveled over 350 miles with his wife Linda. After driving about 6 hours they attended the Ocala TNA Support Group meeting in Ocala, FL. Talking with the Pain Specialist at the meeting Rob was diagnosed with Facial Migraines and given the name of a doctor that could help him. Rob and Linda said they were thankful the support group was there when they needed it and despite the long drive, it was well worth the effort to get there.

TNA is working hard so you don't have to travel as far as Rob and Linda to find a Support Group. Since July, 2011 TNA has added new support groups. Palm Desert, California, Kathy Kempken; Central North Carolina in the Raleigh, Durham area, John Galligan; Oklahoma City, OK, Ralph and Chris Craig; Greater Panhandle in Amarillo, TX, Carol Murray. We wish them much success and thank them for stepping forward and helping others find answers for their facial pain.

Many thanks to the Kansas City Missouri Support Group. They received a rather nice donation and contributed a good portion of it to The Facial Pain Association's National Office.

Support Groups do make a difference for those in pain. If you have found a cure for your pain please attend a TNA/FPA Support Group and share your success with others who are looking for answers! Please contact me if you would like to have a TNA Support Group close to you! E-mail: rirons@tna-support.org or Phone: 352-272-3915.

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John Pollina, Jr., MD, FACS

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Drs. Moreland and Pollina perform Gamma Knife Radiosurgery procedures at the Gamma Knife Center located at Roswell Park Cancer Institute.

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Ask the Doctor

Featuring Cindy Ezell and Steven Graff-Radford, DDS , *Ms. Ezell is in charge of patient services for TNA. Dr. Graff-Radford, is a member of TNA's Medical Advisory Board and is Director of the Program for Headache and Orofacial Pain at The Pain Center at Cedars-Sinai. In addition, he serves as an Adjunct Professor in the Oral Medicine and Orofacial Pain Section of the UCLA School of Dentistry and is a Clinical Professor at the University of Southern California School of Dentistry.*

Q. If you were the patient with neuropathic facial pain what steps would you take to help alleviate the pain

A. Neuropathic facial pain has many mechanisms that create it. Understanding the mechanisms can help choose a treatment direction. Broadly, neuropathic pain can be intermittent as in trigeminal neuralgia or glossopharangeal neuralgia, or continuous as in traumatic neuralgia (complex regional pain syndrome, CRPS) post herpetic neuralgia, or diabetic neuropathy. Starting peripherally treatment can be aimed topically with the application of anesthetic agents (benzocaine), substance P depleters (capsaicin), or other topical pain relievers (tricyclic antidepressants, klonopin, clonidine, antiepileptic agents). The topicals are applied intraorally with the use of a stent or "neurosensory shield". This is an acrylic piece made to fit over the site of the pain. The topical agent is applied to the pain location multiple times per day. Outside the mouth the application can go directly on the skin. The pain can also be relieved with neural blockade. If the pain is sympathetically maintained, that is after sympathetic block the pain is decreased, then repeat block (stellate ganglion block or sphenopalatine ganglion block) may reduce the pain. Destructive procedures to the sphenopalatine ganglion, (radiofrequency ablation or gamma knife ablation) may provide longer lasting results. Pharmacologic therapy is the mainstay for control of neuropathic pain. If the pain is continuous the use of tricyclic antidepressants, selective serotonin norepinepherine reuptake blockers or antiepileptic drugs such as gabapentin, pregabalin, phenytoin, zonisamide, topiramate, levetiracetam may be helpful. If the pain is intermittent as in trigeminal or glossopharangeal neuralgia, the use of antiepileptic drugs such as carbamazepine, oxcarbazepine or phenytoin is best.

Q. If you were the patient with neuropathic facial pain what would you avoid doing?

A. In neuropathic pain further destruction of the sensory nerves may trigger further pain. It is described that patients with intermittent neuralgias who have either rhizotomy, glycerol gangliolysis, balloon gangliolysis or gamma knife may develop anesthesia dolorosa. Although the incidence is low (3-7 %) consideration should be given before proceeding with any destructive procedure. Patients often inquire about having cosmetic facial procedures or dental therapies when they have neuropathic pain. We advise that any procedure to the trigeminal nerve can aggravate their symptoms, but the use of good local anesthetic at the time of procedure is often protective. In continuous neuropathy we avoid sensory destructive procedures at all costs.

Q. What advice would you give others with neuropathic facial pain that have tried medications and the pain still prevents them from living a normal life?

A. There are medications and physical therapies that are less commonly thought of in patients who fail traditional therapy. It is best to be evaluated by an orofacial pain specialist or physician familiar with less common agents. Some of which could include, memantine, mexiletine, alpha blockers, tizanidine, and ketamine. It is very important to look at dosing of medications that failed. Often too small a dose was used or perhaps the drug was escalated too quickly and side effects could have prevented an appropriate trial. There are a number of procedures that help differentiate if the sympathetic nervous system may contribute to the pain. If so, repeat blockade of the stellate ganglion or sphenopalatine ganglion and possible destructive procedures to the sphenopalatine ganglia may be useful. Stimulation of the sensory nerves with implantable devices may offer relief in a select group of patients.

One of the biggest concerns is the appropriate diagnosis. The most common missed diagnosis involving the face are dental pathologies. Evaluation for an additional missed canal in the tooth that has undergone root canal therapy, or assessment for a crack must be considered. It is recommended a Morita tomographic scan be considered in these cases.

Q. What do you see on the Horizon for treatment of neuropathic facial pain.

A. As we begin to understand which patients likely develop neuropathic pain, we see the high risk group for the face as being 40 year old females. There is clearly a link to the presence of estrogen and the initiation of the pain. Hopefully with time we can predict with better accuracy who may be at risk and how to prevent the pain from starting. Another area of research that is promising understands the role glial cells may have in neuropathic pain. Hopefully this cell will become a target for pain relief in the future.

TNA's Mission, in part, is to empower patients through education

Dr. Graff-Radford sites one of the biggest concerns in treating neuropathic facial pain is the appropriate diagnosis. As neuropathic facial pain patients, one of our best tools is to educate ourselves on the appropriate diagnosis and treatment.

Educate Yourself – Strike Back – Never Give Up

Familiarize yourself with the difference in classic trigeminal neuralgia versus neuropathic facial pain, or deafferentation pain.

Visit the "Knowledge Base" on TNA's website at www.tna-support.org

Talk to others with similar symptoms - We recommended TNA's Facial Pain Network fpa-support.ning.com or your local TNA Support Group, or TNA conferences.

Read "Striking Back"

Read all available medical literature such as this TNA Quarterly

Seek out a medical professional that is well informed about neuropathic facial pain, check out the healthcare providers on the TNA website

Many of the treatments for classic trigeminal neuralgia are not effective for other types of facial pain and could even make the pain worse.

Know that in neuropathic pain further destruction of the sensory nerves may trigger further pain!

Let us hear from you; submit a question:

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

Facial Pain Experts Establish a New Pain Classification

The Facial Pain Association and its Medical Advisory Board under the guidance of Dr. Peter J. Jannetta have concluded that the term atypical facial pain be replaced with the term facial pain of obscure etiology

The senior author spent over five months wrestling with the quandary of how to classify our ignorance regarding facial pain as seen by neurologists and neurosurgeons. In his attempt to do this, he enlisted the help of the Medical Advisory Board of the TNA Facial Pain Association. Their input was thoughtful and usually profound and always helpful.

In days of yore, things we did not understand, both good and bad, were attributed to the workings of the gods in the trees, seas and mountains. This gradually settled onto one Supreme Being before being ascribed, parascientifically, to the psyche. The unknown became psychological and this has become pejorative in most minds.

On a personal note, as I was combing my way through the literature on the primary etiology of various cranial nerve problems and more recently brain stem vascular compression syndromes, I found that authors did one of two things when they were ignorant. The first (more common) was to expostulate long and hard, confusing etiology with mechanism. This was and is usually unintelligible. The true savant, on the other hand, recognized his ignorance and simply and briefly noted, "we do not know the primary etiology of such and such."

Rather than rewriting the Burchiel classification, our consensus was that we should just admit our ignorance. A group of face problems exist without a known primary cause. As optimists, we believe these etiologies will be classified over time. For the present, we should discard the terms atypical and functional from our lexicon. Idiopathic, from the Greek, "it comes from within itself," implies only that we are ignorant. So be it. We admit this. We need only a non-pejorative term to apply to this group of unclassified problems.

The term "atypical facial neuralgia or pain" was a wastebasket term applied by a serious contributor of a former era to a group of patients he did not understand. Many of these patients were our trigeminal neuralgia type 2 patients. It is unfortunate that many of these people were told they had psychological problems. Many developed psychological problems after the fact when told by everyone that such was their problem. Over the years, our areas of ignorance have progressively narrowed.

A non-pejorative and, hopefully, reasonable term for the ever-narrowing group of undiagnosed face pain problems: Face pain of Obscure Etiology (FOE or POE) to replace atypical facial pain in the Burchiel classification.

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Potato-Leek Soup

T'is the season to curl up with a homemade cup of soup

3 tablespoons butter

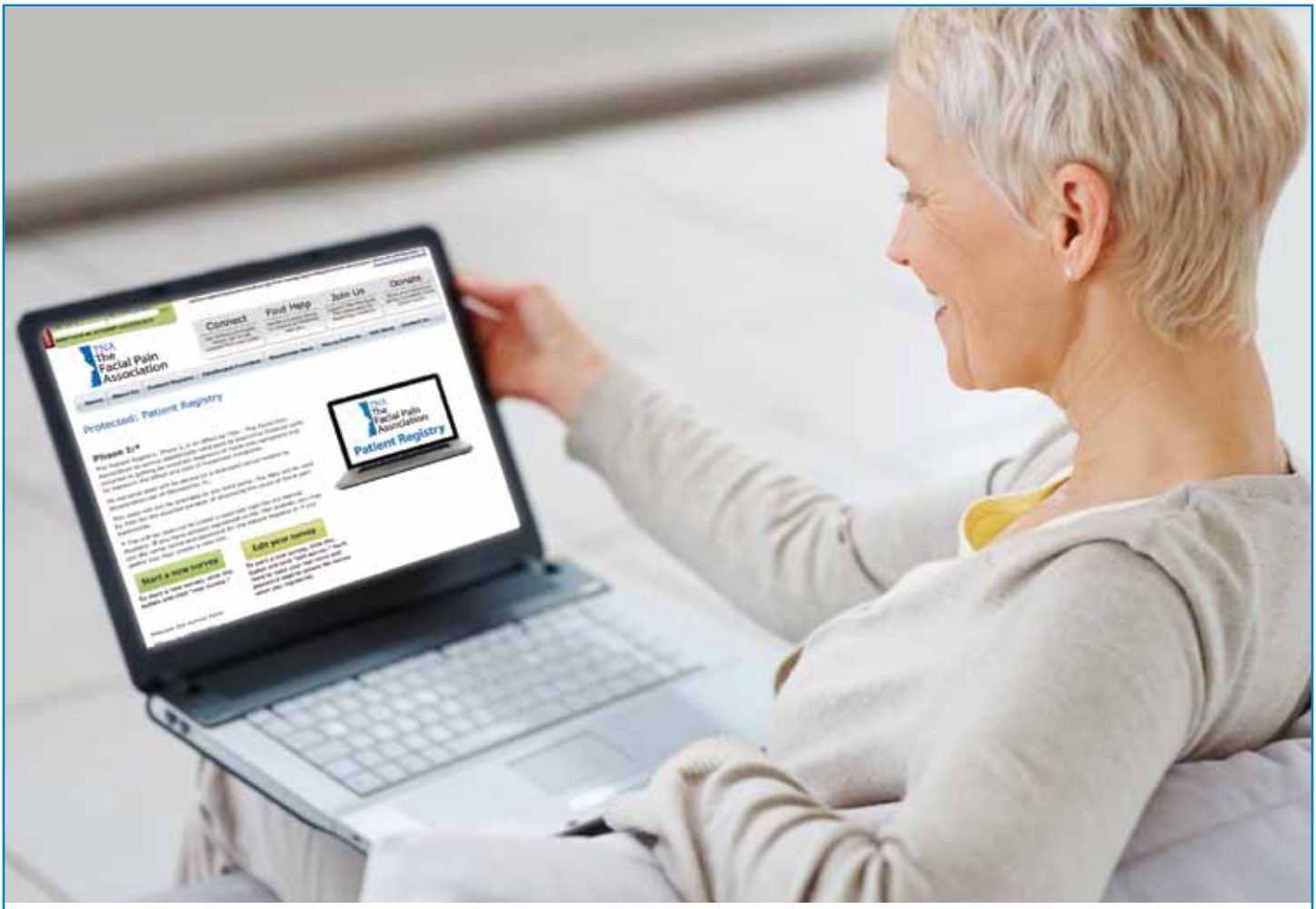
6 leeks (white part only) cleaned thoroughly and chopped

3 medium baking potatoes, peeled and thinly sliced

5 cups chicken or vegetable stock. Melt butter in a heavy soup pot. Add leeks and stir until tender but not browned, about 20 minutes. Stir in remaining ingredients. Bring to boil, reduce heat and simmer until the potatoes are soft, about 30 minutes. Puree, using food processor or mill, until smooth.

Salt to taste. Thin if necessary with additional stock or water.

* To create velvety bisque, push soup through a sieve after it is pureed, add a cup of cream. This soup can be served hot or cold.



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Help us learn the real cost of this disease.

If you are a face pain patient, please go to **www.fpa-support.org** and click on the **Patient Registry** link at the top on the page to complete the Patient Registry Questionnaire.

This simple action will take only minutes of your time, but will help us gather definitive data to measure the effectiveness and cost of various treatment modalities.

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Complete the TNA Patient Registry Questionnaire today and take an active role in the battle against trigeminal neuralgia and related face pain conditions.

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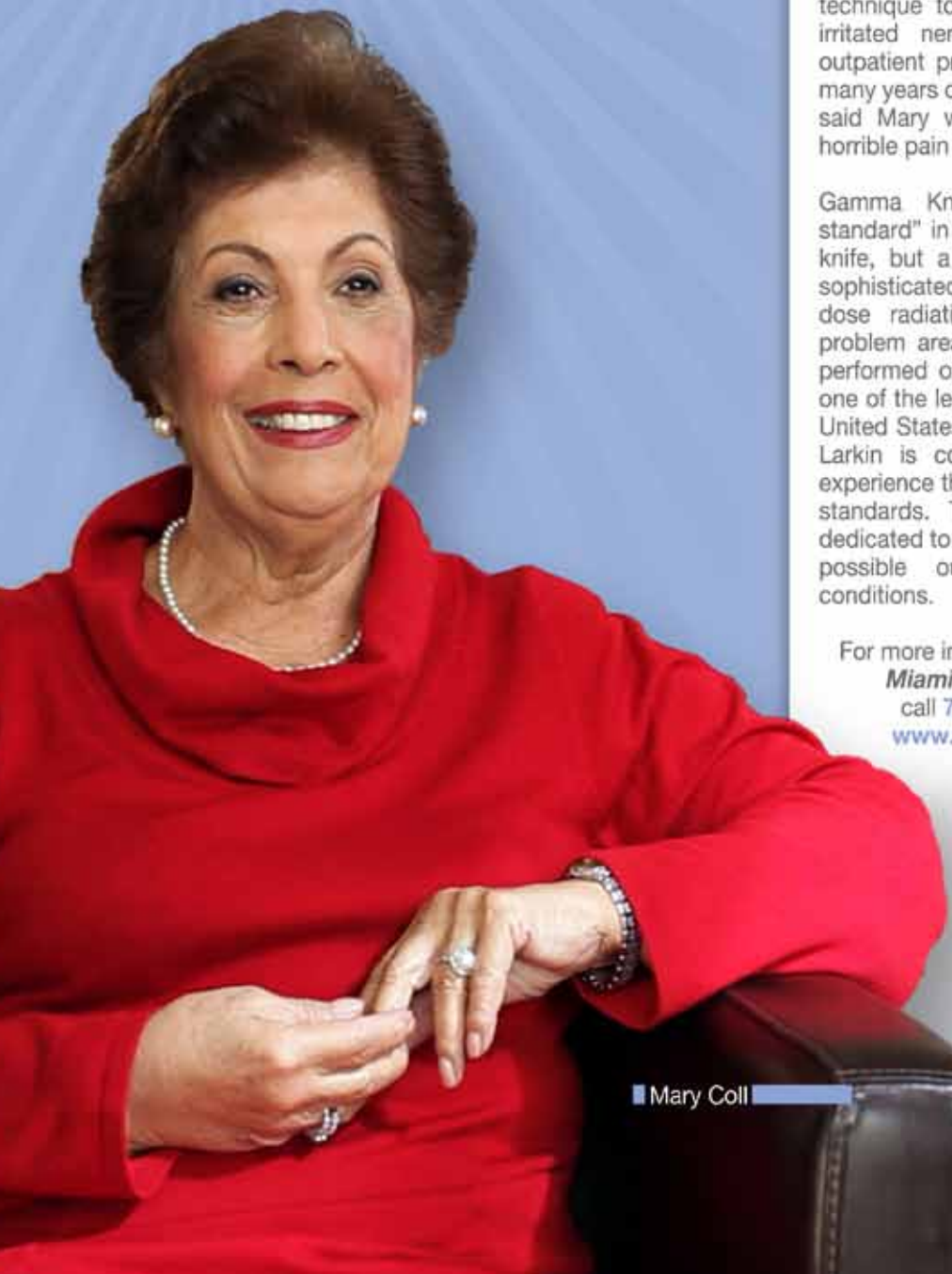

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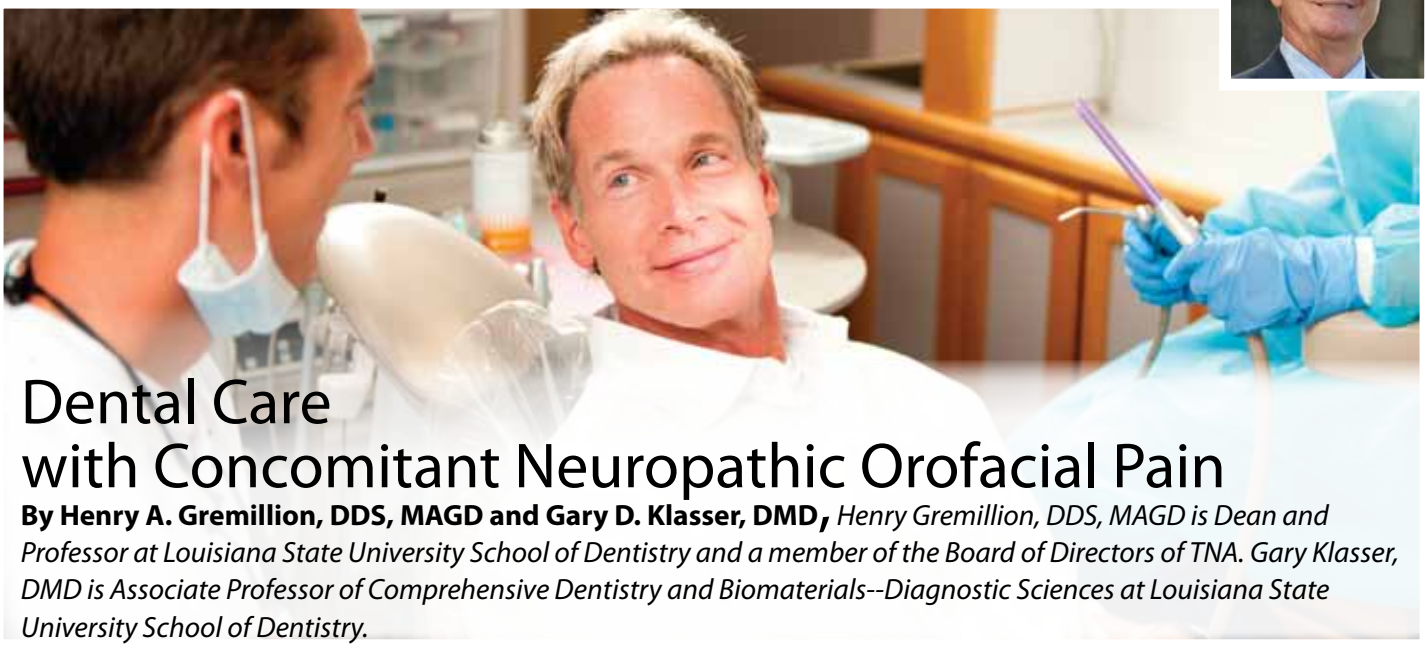

Dental Care with Concomitant Neuropathic Orofacial Pain

By Henry A. Gremillion, DDS, MAGD and Gary D. Klasser, DMD, *Henry Gremillion, DDS, MAGD is Dean and Professor at Louisiana State University School of Dentistry and a member of the Board of Directors of TNA. Gary Klasser, DMD is Associate Professor of Comprehensive Dentistry and Biomaterials--Diagnostic Sciences at Louisiana State University School of Dentistry.*

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".[1] 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 incompleteness of these descriptions a new classification scheme based upon suspected mechanism(s) is being considered. Revisions should be forthcoming.[2]

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

"Dental care . . ." continued on page 18

Dental care ... continued

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.[8, 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 [20, 21]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 anesthetic 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 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

"Dental care . . ." continued on next page

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 multi-dimensional 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.

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TNA California Conference . . . . maybe the best yet!

The Facial Pain Association's regional conference this past September in Orange, CA, sponsored by the University of California, Irvine School of Medicine, was a huge success. The conference was attended by more than 200 patients and medical professionals and offered a wide ranging agenda.

The morning session, for patients, focused on the integration of eastern medicine and alternative therapies into an overall treatment plan. Lunch was a special treat, with medical experts in facial pain seated at each table to discuss patient issues and answer their questions. The afternoon sessions were devoted to surgical options, case presentations and extensive question and answer sessions between patients and presenters.

Our sincere thanks to our host Dr. Mark Linskey and his staff, the TNA staff and volunteers, the UCI School of Medicine and of course all the conference presenters and attendees.

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Kathleen Warren
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October

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Jason Cable
Susanne Eberle
Richard Elam
Hilary Hardin
Jonathan H. Lustgarten
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Judy Randolph
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November

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

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

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

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

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

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253 East 77th Street • New York • NY 10021	(855) 263-0000
112-03 Queens Blvd. • Suite 200 • Forest Hills • NY 11375	(718) 263-1414
353 Veterans Memorial Hwy. • Suite 303 • Commack • NY 11725	(631) 864-3900
500 Montauk Hwy. • Suite K • West Islip • NY 11795	(631) 983-8400
1500-8A Route 112 • Port Jefferson Station • NY 11776	(631) 828-3001
55 Medford ave. / Route 112 • Patchogue • NY 11772	(631) 569-8325