

Facial Pain Association REGIONAL Conference Program Minneapolis

SEPTEMBER 10, 2016

Meet the Oral Facial Pain team from the University of Minnesota

The Fifth Annual
Matt Redwine
TNA Charity
Golf Tournament





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FEATURES



FPA recognizes the passing of Dr. Peter Jannetta, one of the most renown neurosurgeons of his generation.



A reprise of a feature article by **Don Nixdorf, DDS and Flavia Kapos, DDS** on how to prepare for an orofacial pain diagnosis.



From the Editor's Desk.



Looking for alternative treatment options? A comprehensive guide to selecting a CAM practitioner.



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Memorial and Honorary Tribute Fund, New Members



From the Chairman of the Board

Much is underway at the FPA.

First, the fifth Matt Redwine TNA Golf Tournament on April 2, 2016 in Tampa was a record success. Over 200 golfers filled two courses. This event is an important source of operating funds for the TNA- The Facial Pain Association (FPA for short here) and it raises awareness of facial nerve pain disease too. Gary and Madeline Redwine organize this tournament and they not only raised a record amount this year but they also seem to have made the mid-day rain go away to ensure that participants had a dry and good time out on the course. Thank you to Gary and Madeline for your efforts and support.

FPA's Regional Conferences are a way for people with facial nerve pain to hear from experts in diagnosis and treatment and to talk with each other about managing life outside a doctor's office. We thank Mr. Brett Frankel for funding two Regional Conferences per year for three years. The first conference was in Pittsburg on April 24. It was hosted by the University of Pittsburg Medical Center and Dr. Raymond Sekula was the Faculty Director. Physician speakers included Drs. Sekula and Ramesh Babu, Jeffrey Brown and Kenneth Casey. The FPA Support Group Leader speakers were Anne Ciemnecki and Rohn Harmer. That conference sold out and the over 150 attendees report that it was very useful and in some cases life changing. Those results are why FPA does what it does, we are here to help. The next Regional Conference will take place near Minneapolis on September 10, 2016. Organized by Donald Nixdorf, DDS this conference is hosted by the Orofacial Pain team at the University of Minnesota.

Next, FPA's plan to offer webinars has now been realized thanks to the initiative of FPA Medical Advisory Board Chairman Jeffrey Brown, MD. Webinars are a means of reaching people who cannot attend a conference, and

FPA is building a library of webinars that people can download to watch when they have time and at no cost. Our first webinar was on April 25th by Dr. Brown with FPA's Young Patients Committee. Focusing on the needs of those under 40 years old, over 60 participants logged on to view an initial presentation by Dr. Brown and then a period of live guestions and answers. The second FPA webinar to date took place on June 15th. Dr. Brown interviewed John M. Tew, Jr., MD. Dr. Tew was a pioneer in microneurosurgery, helped to develop a steerable radio frequency electrode for thermal rhizotomy and has treated many people with facial nerve pain. We thank Drs. Brown and Tew for the interesting and informative webinar. Stay tuned for announcements about upcoming FPA webinars.

I close this Chairman's Letter with a sad note and a happy note. Dr. Peter Jannetta passed away on April 11, 2016. He and Dr. John Alksne developed the microvascular decompression surgery that remains the most effective long-term treatment for facial nerve pain, and he both inspired and trained many surgeons who now help thousands of patients. He was key support for Ms. Claire Patterson who founded the FPA, he chaired the Medical Advisory Board, and he was a member of our Board of Directors too. We mourn the loss of Dr. Jannetta and are grateful for his contributions. On a happy note, we say congratulations to YPC President Allyson Castellano who married Daniel Kubik on May 14, 2016. Ally, we are happy for you and glad to have your leadership of the YPC and your participation in the FPA.

Jeff Bodington, Chairman of the Board TNA – The Facial Pain Association

Peter Jannetta, MD

April 5, 1932 - April 11, 2016



With profound regret the Facial Pain
Association announces the passing of Peter
Jannetta, MD. Dr. Jannetta was one of the most
renown neurosurgeons of his generation and
developer of the MVD surgical procedure that
ended the pain for thousands of TN patients.

The following is an excerpt from an article published in the 2015 Fall edition of the FPA Quarterly magazine.

Peter J. Jannetta, MD, Vision and Perseverance

As TNA marks 25 years of providing support, information and education, we recognize the unparalleled contributions of the Medical Advisory Board and Dr. Peter Jannetta.

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

Although Dr. Jannetta's scientific and leadership contributions are significant, perhaps his greatest achievement is the legacy of outstanding international leaders he trained in neurosurgery. During his 25 year tenure as Chairman of the Department of Neurosurgery at the University of Pittsburgh, he trained 150 residents—22 of whom went on to be Department Chairs. Dr. Jannetta was honored with an endowed professorship, appropriately named after Walter E. Dandy—considered one of the founding fathers of neurosurgery.

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



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QUARTERLY

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SPOTLIGHT ON THE DOCTOR

FRANK P.K. HSU, MD, PHD

Professor and Chair, Department of Neurological Surgery Director of Functional, Epilepsy and Pain Neurosurgery Surgical Director, Comprehensive Brain Tumor Program Co-Director of Cerebrovascular and Skull Base Surgery

Dr. Frank P.K. Hsu specializes in cerebrovascular minimally invasive and open skull base surgery. He has extensive expertise in radiosurgery and functional surgery for movement disorders, deep brain simulations, epilepsy, trigeminal neuralgia and pain. Hsu also treats patients with aneurysms, arteriovenous malformations and cavernous malformations, as well as malignant and benign tumors of the brain and spine.

Hsu offers a comprehensive treatment program for patients with facial pain. For the more common cases of trigeminal neuralgia, procedures offered include microvascular decompression, percutaneous radio-frequency gangliolysis, and stereotactic radiosurgery (i.e. Gamma Knife®). More difficult cases are treated with percutaneous peripheral nerve stimulation, and for the most severe cases failing prior treatment modalities, Hsu offers nucleus caudalis DREZ and motor cortex stimulations. Some of these procedures are performed

by only a handful of surgeons in the world. The entire spectrum of surgical procedures is offered at UC Irvine Health.

Hsu received his medical degree from the University of Maryland, where he also earned a PhD in mechanical engineering. He completed a general surgery internship, a neurosurgical residency and a fellowship in functional, stereotactic and pain neurosurgery at Oregon Health Sciences University in Oregon. Hsu completed an additional fellowship in cerebrovascular and skull base neurosurgery at the Barrow Neurological Institute in Phoenix.

After his fellowships, Hsu joined Loma Linda University Medical Center, as professor in the departments of neurosurgery, otolaryngology and physical medicine and rehabilitation, as well as vice-chair of neurosurgery and director of the Cerebrovascular and Skull Base Center. He joined UC Irvine Health in 2012.

Hsu has received numerous awards including the Research Fellowship in Cerebrovascular Disease from the American Heart Association and the Short Term Research Fellowship from the University of Maryland. He is a member of several professional societies, among them the American Association of Neurological Surgeons and Congress of Neurological Surgeons. Hsu has more than 20 publications and book chapters to his name and has been invited to speak at dozens of lectures and workshops.

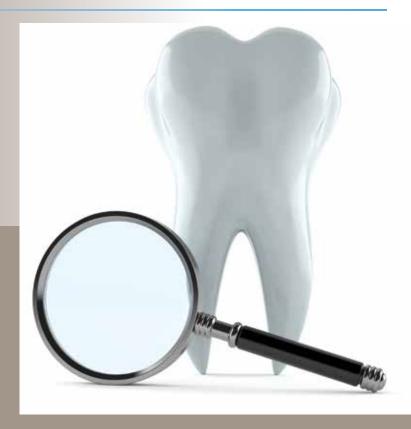
OROFACIAL PAIN DIAGNOSIS

How to prepare when seeking a diagnosis for orofacial pain

Donald R. Nixdorf, DDS Flavia P. Kapos, DDS

Donald R. Nixdorf, DDS is an Associate Professor at the University of Minnesota School of Dentistry and Director of the Advanced Education Program in Orofacial Pain.

Flavia P. Kapos, DDS is a Research Assistant at the University of Minnesota School of Dentistry



This article has been written to outline the components of a comprehensive orofacial pain evaluation; to empower you as a patient (and your loved ones) to more adeptly participate in this diagnostic process. Please keep in mind that different healthcare specialties have scopes of practice and may define a "complete" evaluation differently.

Importance of a good diagnosis: finding the target before shooting it.

The underlying reason for someone's pain is best described by the diagnosis, which is a name given to a certain disorder or disease process. Ideally, the diagnosis should give us information about what is going on, which would consequently derive a conclusion on how to address it. It is important to keep in mind though, that many times there are multiple factors playing a role in a single condition. Elements that serve to bring on the problem, called initiating factors, may not stay and therefore may not be observable along the course of time. The illness, however, may persist due to other influences, called perpetuating factors, or even worsen due to aggravating factors. Note that these might as well have been present before the onset of the problem without major issues, making it hard for the person to identify them as potentially negative, but they could definitely be harmful in this new context of dysfunction.

A simple example is walking on a sprained ankle. The injury may have been caused by a different event, and walking may have never been a struggle, but under those circumstances, the affected joint may need to be guarded

"Nixdorf"...continued on page 7

"Nixdorf"...continued from page 6

from the activity or otherwise the lesion could be made worse or be prolonged. This complex puzzle needs to be carefully studied so all of the pieces fit together and hopefully lead to a resolution or adequate management.

To make the investigation even more challenging, pain conditions in the trigeminal innervation territory often present referral patterns; meaning that the location where the pain is felt is not the actual origin of the painful symptoms. Thus, treating the site of the referral will not address the true source of the problem and will very likely

after a good response to treatment by the classic component of the pain. As an analogy, when a person has a sprained ankle, they may develop a limp to avoid putting weight on the injured limb when walking. If this becomes a habit, the other structures being overloaded in that process, such as back, hip and knees, may become painful as a result of the imbalanced use. The cause for these pains are separate and different, though related. Making a parallel back to TN, patients with intense pain in their face, frequently develop regional muscle guarding, tightening the muscles in the affected area as a natural response and making them sore as a result. Treatment directed to

the TN, in the uncontrolled jaw muscled may not che component related to it not changed multiple synlikely explaid process, the there has to occurring a superior occurring a furthermore procedures the condition because the unsatisfactor and negative as worry, feed to the control of the total control of

the TN, in the presence of an uncontrolled daily constant jaw muscle pain, unfortunately may not change the muscular component, if the behavior related to its development has not changed. Even though multiple symptoms are most likely explained by a single process, there is no rule that there has to be only one problem occurring at a time.

Furthermore, misapplied procedures increase the risk of the condition becoming chronic, because the pain remains unsatisfactorily managed longer and negative thoughts, such as worry, fear, and anger, set in becoming new contributing factors.

be ineffective. A key part of the diagnostic process is to unveil these potentially misleading clues and identify proper targets for treatment. For example, trigeminal neuralgia (TN) pain may be perceived as a "toothache" (since the innervation of the teeth is part of the trigeminal distribution), but dental care will not be helpful and may even make things worse.

When there is a classic presentation of TN as well as a concomitant continuous "background" pain; it would be hasty to assume that the latter is part of a TN without first considering a range of differential diagnoses, especially

An orofacial pain evaluation should consist of the following steps, in order of importance; (i) history taking, (ii) physical examination, (iii) obtaining diagnostic testing, such as imaging or laboratory tests, as needed.

a) History: Getting to a differential diagnosis

The most important step in the diagnostic process is the history taking, which leads the clinician to develop an initial differential diagnosis. In other words, by talking to the patient and collecting the right information, the provider narrows down the list of all the possible conditions to a

few more likely ones. For example, knowing the patient's age and gender already provide a good pointer towards conditions that may be more or less frequent in that specific demographics group.

Signs and symptoms teach us about the underlying condition and its nature. When preparing for a medical appointment, be ready to answer many questions about the characteristics of the pain and the context in which it presents. Your answers probably hold the most valuable diagnostic information. An astute clinician is not only interested in what you are saying, but also how you are saying it. For patients seeking care for pain, the pain itself

will be called the chief complaint and the details of its history are often referred to by providers as history of present illness, including:

- -Location: Where is the pain felt? Is it always on the same place? Is it punctual or affects a broader region? Is there a spreading or movement component to it? Is it easily localized or is it more diffuse? Does it feel superficial, on the surface of the skin, or deep, "in the bone"?
- **-Onset:** When did it first start and in which circumstances? Were there any initiating factors? Was it a sudden or gradual onset?
- -Progression: Has it changed since the onset? Is it getting better, worse or staying the same? Is it always the same when it occurs, or does it change?
- **-Frequency:** Is it constant or intermittent? How often does it occur?
- **-Duration:** How long does it stay when it is there?
- **-Timing:** Is there a time of the day when it is usually worse? Does it present "on the clock"? Are there periods of remission, times when you feel nothing?
- **-Quality**: What does the pain feel like? Which words could be used to describe it? (i.e. sharp, dull, throbbing, shooting, electric shock-like, burning, etc.) Is there an emotional component?

- -Intensity: Is it mild, moderate or severe? How would it be rated on a scale of 0 to 10, being 0 no pain and 10 the worst pain possible?
- **-Interference:** Does it disrupt sleep? Does it affect the ability to perform daily activities?
- -Aggravating/Alleviating factors: What makes it better and what makes it worse? Is it affected by physical activity, light, noises, jaw movements, body position, temperature, touch, sneezing/coughing, etc.? Does it respond to over-the-counter analgesics or other medications?



- -Associated features: Are there other signs or symptoms present before, during or after the pain? Are there any appearance changes, for instance redness, swelling, tearing or sweating? Is it predictable? Can you feel or sense it coming on? Are there other changes in vision, movements, sensation?
- -Prior Treatments/Tests: Were there other providers consulted? What therapies have been tried and what were the results? Are there any prior imaging, labs, etc. and what were their findings? What medications have you taken, at what dose, for how long, and what were the effects?

"Nixdorf"...continued on page 9

"Nixdorf"...continued from page 8

It is clear that the pain itself is where most of the attention of the patient will tend to focus; however, it is important to think of the whole person and the conditions in which the problem is presenting. The history can also uncover contributing factors that can help to understand the origin of the pain as well as to guide the therapy. Fundamental pieces of the puzzle are also frequently found "thinking outside of the box":

- -Medical history: Are there any other medical conditions? How are they being addressed? Are there any medications, vitamins or supplements being taken, at what doses and for how long have they been taken? Has there been any trauma? Are there any other pains throughout the body?
- **-Family history:** Are there other cases of similar problems in the family? Are there any cases of auto-immune disorders, cancer, pain disorders?
- -Habits: General exercise, diet, water, tobacco, caffeine? Oral parafunctional habits (i.e. teeth clenching and grinding, biting objects, fingernail, lips, cheeks, gum chewing, etc.)?

-Sleep: What is the typical sleeping routine? How long? Is it restorative? Is there difficulty falling or staying asleep? What is the sleeping position?

-Psychosocial history: What is the patient's occupation, marital status, family dynamics? What is the level of psychosocial stress? Does the patient have a support system, coping strategies? Are there diagnoses of anxiety, depression or other mood disorders and how are they being addressed? Have there been traumatic life events? Is there ongoing litigation?

b) Physical Exam: Refining the list

After the history taking, the clinician should have generated a mental list of the possible conditions that could be going on. The physical examination will serve to confirm or refute such hypotheses and guide the process of diagnosis. The trained professional may be able to gather further information beyond what is volunteered by the patient, starting from general appearance, affect, posture, gait, speech and non-verbal communication.

One of the major goals of the physical exam is to duplicate the chief complaint, as to better understand its origin

> and response to stimuli. For instance, dental pain of pulpal origin is expected to be elicited or changed in a predictable manner by application of cold to the surface of the tooth, therefore a dentist uses a cold test and is trained to interpret the response as within normal limits or altered. To further illustrate this concept, in order to render the diagnosis of temporomandibular disorders (TMD), there should be a positive finding of familiar tenderness to palpation or range of motion of the involved muscles and/or temporomandibular joints (TMJ) on exam.

> Since pain is a very personal and subjective experience, even during the exam, part of the findings will be subjective and dependent on patients' reports. If at any point during the



exam pain is provoked, it is of crucial importance to discuss how the provoked pain is the same or different than what is typically experienced. The exam maneuvers may provoke pain; however the pain which is familiar to them, fully or partially reproducing their usual symptoms is the one of interest.

Regional head and neck exam should include visual inspection and palpation of masticatory and cervical muscles, TMJs, face, thyroid gland, lymph nodes, teeth, mouth, and oropharyngeal mucosa. Changes in symmetry, shape, size, consistence, color and texture should be noted. Range of motion of the head and neck should be evaluated for limitations and coordination, as well as associated pain or noises. Cranial nerve screening evaluation is also valuable to evaluate motor and sensory functions of the major nerves supplying the face and neck. The teeth and supporting tissues should also be inspected for signs of disease, attrition, fractures and occlusion.

c) Imaging and other diagnostic tools: Taking a closer look

No tests or exams to date have been able to depict or objectively confirm the source or even the presence of pain. In the greatest majority of the cases, comprehensive history and examination will reach a diagnosis; however there are clinical findings that require further investigation of the causes of specific signs or symptoms, especially to rule out disease or pathology underlying these features. For instance, neuralgia-type pains or neurologic deficits should trigger a request for brain imaging to rule out intracranial processes that could be causing the symptoms.

In a few conditions, diagnostic imaging can be used to confirm a clinical diagnosis, but in order to avoid unnecessary costs, exposure to procedure risks and delay of therapy, it should only be indicated if the results will determine treatment recommendations. For example, in a typical case of TMJ, osteoarthritis the prognosis with conservative treatment is usually very good, and the clinical evaluation can assess with a reasonable degree of

confidence that the condition is present. By the means of a computer tomography (CT), the diagnosis could be confirmed and graded in severity. Nevertheless, the initial treatment strategy would be the same as if no imaging was done, but the patient would have been exposed to a dose of ionizing radiation and there would be associated costs to the healthcare system.



It is also important to keep in mind that all tests have their particular ability to accurately detect the target condition. No test is perfect and a certain degree of false positives (test indicates disease being present when it is not there) and/or false negatives (test indicates disease not present when it is there) is expected. The practical conclusion is that tests ordered without previous clinical contextualization and indication can generate misleading and meaningless results. Going back to the orteoarthritis example, is it known that radiographic findings of degenerative changes in joints are very common and increase with age, but only a small minority of cases will present symptoms. In addition, there is no evidence of treatments that can prevent progression. Thus, treatment based on the imaging findings alone is not adequate.

The response to treatment is also sometimes diagnostic. Based on the disease mechanism, there are specific drugs that seem to work so well that a significant response tells much about what is going on. It is the case of

carbamazepine for Trigeminal Neuralgia or steroidal antiinflammatories for autoimmune conditions. The rates of improvement in those cases are so high that it makes a diagnosis very unlikely if there is no significant response to the medication. Another type of test that would have diagnostic and potential therapeutic benefit is nerve blocks, which help to locate the source of the pain and may provide relief as well.

There are also other tests such as nerve conduction and quantitative sensory testing (QST), as well as many others that may come, which at this time have not yet been demonstrated valid and reliable for clinical use, but research is being developed to explore their value in the diagnosis of pain conditions. Based on the rationale presented, it is always important to put it in a clinical context, compare risks and benefits before running any tests.

Final Considerations

Once the information is collected, your doctor develops a list of diagnoses that are the most likely reasons for your pain. Often times there is a single diagnosis, one that fits the information that you are presenting. Other times the information is not clear or the doctor is unsure, so a list of possible diagnoses or a general diagnostic category is given. This list or general category is reviewed, and revised accordingly, as your doctor obtains more information about you over time, such as your symptoms change and how you respond to initial treatments.

While the goal is to obtain the correct diagnosis right away, it can be a reiterative process occurring over a couple visits for more rare conditions that are not frequently encountered or chameleons in their presentation. Whatever the process is to derive a diagnosis, getting there is a very important step because one would not expect a treatment being applied to address the wrong diagnosis to be helpful. Rather, it tends to be expensive, time consuming, and sometimes harmful.



Advanced Treatment for Facial Pain

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



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

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

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FROM THE EDITOR'S DESK

To the best of our knowledge the description of trigeminal neuralgia as the suicide disease originated in the late 19th century. During this time general brain surgery incurred a mortality rate of 90% and it was considered tantamount to suicide by many. It goes without saying that brain surgery for TN was crude and dangerous, with doctors advocating either brain surgery or suicide as the only treatment options for desperate patients.

In 1900 the famed London neurologist David Ferrier, discussing the "ganglion operation" with a TN patient described it "as a last desperate resort a polite way of committing suicide."

So there you have it, a label born from the limitations and desperation of 19th century medicine that has managed to survive today's arsenal of pharmaceutical, surgical and non-invasive treatment modalities.

Well it doesn't have to be called the suicide disease any more. Medical professionals who are experts at treating TN can offer a myriad of treatments and pain management techniques. While every treatment plan does not work for every patient, to quote a renowned expert, "there are always options".

Let's leave the description "the suicide disease" where it belongs . . . back in the 19th century.



Ramesh Babu MD, Associate Professor of Clinical Neurosurgery



- · Specializing in atypical facial pain
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NYU Medical Center 530 First Ave. Suite 7W New York, NY 10016 212-263-7481 From the National Center for Complimentary and Alternative Medicine

Selecting a Complementary and Alternative Medicine Practitioner



Introduction

Selecting a health care practitioner is an important decision and can be essential to ensuring that you are receiving the best possible care. This fact sheet provides information on selecting a practitioner whose services are part of complementary and alternative medicine (CAM), such as acupuncture, chiropractic, and naturopathy. It also suggests sources for additional information.

Key Points

- Talk to your primary health care providers if you are considering a CAM therapy. They may be able to answer questions and/or refer you to a practitioner. Also, be aware that there are other resources for locating a CAM practitioner, such as professional organizations for specific practitioner groups.
- Gather basic information on the CAM practitioners you are considering, such as education, experience, and cost, and interview them in person or by telephone. Make your selection based on their answers to your questions, and your level of comfort during the interview.

- Evaluate your practitioner after the initial treatment visit—including what you have been told to expect in terms of therapy outcomes, time, and costs—and decide if the practitioner is right for you.
- Tell all of your health care providers about any complementary and alternative practices you use. Give them a full picture of what you do to manage your health. This will help ensure coordinated and safe care. For tips about talking with your health care providers about CAM, see NCCAM's Time to Talk campaign.

About Complementary and Alternative Medicine

CAM is a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine. Conventional medicine is medicine as practiced by holders of M.D. (medical doctor) or D.O. (doctor of osteopathic medicine;) degrees and by their allied health professionals, such as physical therapists, psychologists, and registered nurses.

"Alternative Medicine" . . . continued from page 13

Complementary medicine is used together with conventional medicine, and alternative medicine is used in place of conventional medicine. Integrative medicine combines conventional and CAM treatments for which there is evidence of safety and effectiveness. For more about these terms, see the NCCAM fact sheet What Is CAM?

Time To Talk

It is always a good idea to discuss any health options you are considering, including CAM options, with your trusted health professionals. Before selecting a CAM therapy or practitioner, talk with all your health care providers. Tell them about the therapy you are considering and ask any questions you may have. They may know about the therapy and be able to advise you on its safety, use, and effectiveness, or possible interactions with medications.

Finding Complementary and Alternative Medicine Practitioners

Several resources are available to help you find CAM practitioners:

- Your doctor or other health care provider may be able to give a referral.
- A nearby hospital or a medical school may have a list of local CAM practitioners or may be able to make a specific recommendation. Some regional medical centers may have CAM centers or CAM practitioners on staff.
- Professional organizations for CAM therapists often provide referrals to practitioners as well as information on therapies, standards of practice and training, and state licensing requirements. These organizations can be located by searching the Internet or directories in libraries (ask the librarian). One source is the National Library of Medicine's Directory of Health Organizations Online (https://goo.gl/vs9QZ3). Some professions may be represented by more than one organization.
- State regulatory agencies or licensing boards for health care professionals may provide information regarding practitioners in your area. Your state, county, or city health department may also refer you to such agencies or boards.

Even if a friend recommends a CAM practitioner, or if you have found a practitioner through your local Yellow

Pages, looking into the resources suggested above can give you confidence that you have considered all the best possibilities.

Choosing a Practitioner

As when choosing any health care provider, contact the practitioners you are considering to gather some basic information. Although you can do this over the phone, consider asking for a brief, in-person consultation (which may or may not involve a charge). Practitioners may also have a Web site or brochure. Before you make your contacts, think about what is important to you—what you need to know to make your decision. You might ask about:

- Education, training, licenses, and certifications. If you have information from a professional organization, compare the practitioner's qualifications with the training and licensing standards for that profession.
- Areas of specialization, experience treating patients with problems similar to your own, and his or her philosophy of care.
- Any scientific research studies that support the treatment's use for your condition.
- The number of patients the practitioner sees in a typical day and average time spent with each patient.
- Treatment costs, including charges per session, charges for cancelled appointments, payment options, and participation in your insurance plan (see box below).
- Office hours, how far in advance you need to schedule an appointment and typical waiting time in the office.
- Office locations—for example, accessibility to public transportation, parking, and elevators.
- What to expect during the first visit or assessment.

After making your contacts, think about how comfortable you felt during your initial conversations with the practitioners and their staff, and review the information they provided. How do they measure up in terms of what is most important to you? Now, you are ready to decide which practitioner will most likely meet your needs.

"Alternative Medicine" . . . continued on page 15



1. Make a list of questions before your visit.

(some people bring a recording device).

2. Bring a notepad to record the answers

3. Consider asking a family member or

compare notes after your visit.

friend to accompany you, so you can

Insurance Coverage

If you have health insurance, it may not cover your CAM therapy. Even if it covers the therapy, you may have to pay for part of the cost. Before agreeing to any CAM treatment, ask your insurer what percentage of the cost, if any, will be covered. Also find out whether the practitioner participates in your insurance plan. The NCCAM fact sheet Paying for CAM Treatment has additional information.

The First Visit to the **Practitioner**

The first visit is important. Come prepared to answer questions about your health—past and present. Bring a written list of surgeries, injuries, and major illnesses, as well as the prescription medications, over-the-counter drugs, and vitamins and other supplements you take. Also

come prepared to ask questions, for example:

- Are there any scientific research studies that show that this therapy may be helpful?
- What benefits can I expect from the therapy?
- What are the risks associated with the therapy?
- Do the known benefits outweigh the risks for my disease or condition?

- What side effects can be expected?
- Will the therapy interfere with any of my daily activities?
- How long will I need to undergo treatment, or how many office visits will I need? How often will my progress or treatment plan be assessed?
- What are the costs for the recommended treatments? Will I
 - need to buy any equipment or supplies?
 - Could the therapy interfere with conventional treatments?
 - Are there any conditions for which this treatment should not be used?

Make a list of questions before your visit. Bring a notepad to record the answers (some people bring a recording

device). Consider asking a family member or friend to accompany you, so you can compare notes after your visit.

Evaluating the Practitioner

After your first visit, ask yourself:

- Was the practitioner easy to talk to? Did I feel comfortable?
- Was the practitioner willing to answer all my questions? Was I satisfied with the answers?

Summer 2016 —

- Was the practitioner open to considering how CAM therapy and conventional medicine might work together for my benefit?
- Did the practitioner get to know me and ask me about my health condition?
- Did the practitioner seem knowledgeable about my specific health condition?
- Does the recommended treatment seem reasonable to me?
- Was the practitioner clear about the time and costs associated with treatment?

Building a relationship with a new practitioner takes time. Nevertheless, if at any time you are not satisfied or comfortable, you should discuss your concerns with the practitioner and feel free to stop treatment or look for a different practitioner. Before deciding to stop treatment, however, ask if doing so is safe. If you do stop treatment, tell your other health care providers so they can continue to make fully informed decisions about your care.

NCCAM's Role

The National Center for Complementary and Alternative Medicine (NCCAM) is the Federal Government's lead

agency for scientific research on CAM. NCCAM's mission is to explore CAM healing practices in the context of rigorous science, train CAM researchers, and disseminate authoritative information to the public and professionals.

Although NCCAM does not provide referrals to CAM practitioners, its Web site offers useful resources for people considering a CAM therapy. The Health Information page of the NCCAM Web site provides access to a variety of fact sheets and other resources to help people be informed consumers of CAM services and products. The Clinical Trials page has information on NCCAM-supported clinical trials (studies in people) on CAM therapies, including studies that are recruiting participants.

NCCAM Clearinghouse

The NCCAM Clearinghouse provides information on NCCAM and complementary health practices, including publications and searches of Federal databases of scientific and medical literature. The Clearinghouse does not provide medical advice, treatment recommendations, or referrals to practitioners.

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MY STORY WITH FACIAL PAIN

Winnie Oguta a TN patient from Kenya. Her story in her own words, from the onset of pain through diagnosis and treatment support provided by the Facial Pain Association.

Photo at left: Winnie with NJ Support Group Leader and FPA Board Member, Anne Ciemnecki

I remember it all started in 2006 with constant aching pain on my right eye. I was six months' expectant with my second born child. It was aching constant pain, I took so much medication which did not help. Upon delivery the pain was still there, but not as much as it was when I was expectant.

In 2009 when I was expectant with my last kid, I went through the same torture as before. I was working in a hospital by then as a hospital accountant. I recall one of my colleagues who was a clinical officer who had seen me suffer before say, "Winnie, the pain you are feeling could be nerve pain, why not try carbamazepine". I told her to give me a prescription, I give it a try. I started using it immediately and it really helped. I was happy and I knew I had nerve problem but did not know exactly which nerve.

In 2011, I started getting frequent attacks, with severe pain on my teeth and right eye. I booked an appointment with a neurologist. MRI was done and the diagnosis then was blood clots in the brain. I took blood thinners for six months but there was no change. The severe pain persisted.

In 2013, I was referred to a neurosurgeon who examined me.

The neurosurgeon recommended that I undergo a MRA-Magneto Resource Angiogram- test. The doctor came back with a report confirming that it was Trigeminal Neuralgia-TN. He explained to me about TN and what could be done to help. He told me about MVD-Micro Vascular Decompression- surgery and stated that he was able to perform the surgery.

He then put me on tegretol 200mg twice a day and Lyrica 75mg twice a day. I felt relief with the medication. I was later booked for brain surgery which was done on 19th August 2014. I had unbearable pain after the first operation and went for a second surgery, a week later.

Another week later I was discharged home. While at home, I had this awful headaches, vibrations at the back of the head, loss of hearing on the right ear and different kind of pain just next to my left ear.

"Patient Story"...continued on page 18

"Patient Story"...continued from page 17

I went back to the office in January 2015, six months after my surgery. I was still tensed up with what I was going through. I then decided to come out and look for moral support from any part of the world. I did this through the internet.

First, I googled for the Trigeminal Neuralgia Association and managed to receive the contact details of the association's CEO-Mr. John Koff. My first email to John was on 25th February 2015. I introduced myself, where I come from and the kind of help I needed.

I was assisted with a list of support group contacts. Since I could not manage to write to all at once, I did it bit by bit from the time I got the list.



On the 30th March 2015-my 35th birthday- I wrote a mail to Anne Ciemnecki and few other people. Fortunately, Anne responded positively on 2nd April 2015. She asked me if we could talk. I gave her my mobile number and she called me the next day. I was more than happy to hear from Anne who really encouraged me. We became good friends and were always in touch with each other. Anne changed

my life from a depressed mum to a jovial mum with her positive and encouraging words.

I got back to John Koff and informed him that I already got response from Anne Ciemnecki. I thanked him because he made this happen.

Anne was determined to help me, one day she suggested that I needed to visit the United States. I was so happy when I heard this. We worked on my trip plans together and it finally took place on 16th April 2016. It may have happened earlier, but Anne scheduled the trip to coincide with the conference in Pittsburg on 23th April 2016.

During my trip to the US, I learnt a lot, got answers to my questions, met my friend Anne Ciemnecki face to face. I went to US with an MRI which was done back in Kenya. Dr. Heir looked at it and says the damage is outside the brain, the pain I had was muscle pain and not TN. His diagnosis is cervicogenic headaches and masticatory myofascial pain.

I don't really know if what I had before my MVD was trigeminal neuralgia, but all I know is that the terrible aching constant pain I had around my right eye and my right teeth vanished after the MVD. The pain I had after MVD is a bit different.

He recommends physical therapy and muscle relaxants which Anne ensured I had few sessions while in the US and I saw much difference. I also got a second opinion from Dr. Mammies who after seeing the MRI said there is no compression. Dr. Mammies also says the noise I hear at the back of my head after the surgery is cervico-spinal fluid, it is audible because the skull fragment was not replaced after the surgery. Dr. Sekula also confirmed this in Pittsburgh.

I give thanks to the Trigeminal Neuralgia Association as a whole, the doctors I met while in the US, the physical therapists, my family who prayed and supported me during my time with pain and most of all to The TNA CEO John Koff and my friend Anne Ciemnecki. Anne I may forget my injuries but I cannot forget your kindness. Thanks

— Winnie Oguta, Kenya.



The Fifth Annual Matt Redwine TNA Charity Golf Tournament

Madeline and Gary Redwine

Over the past 22 years I have attended many TNA events, helped to increase awareness of TN and other forms of neuropathic facial pain, helped to educate patients and medical professionals and provided support and encouragement. One of my proudest moments occurred recently at the Annual Matt Redwine TNA Charity Golf Tournament. My husband has played in the tournament since its inception, but this year we were fortunate to have our friends accompany us. I was able to look at the "TNA/ FPA World" from their perspective and what I saw brought both pride and appreciation. I saw first-hand, Gary and Madeline Redwine, their family and friends taking up the torch to continue the mission of TNA/FPA. Even though Gary Redwine, is a busy Tampa area businessman, he still finds time to serve as a member of the FPA Board of Directors. He founded the golf tournament five years ago, along with his wife Madeline, in honor of their son Matt who suffers from trigeminal neuralgia. On April 2, the Fifth Annual Matt Redwine TNA Charity Golf Tournament was held at the Eagles Golf Club in Tampa, FL. This year \$70,000 was raised, bringing the five year total to \$226,000.

Even though the day started with clouds and rain, spirits were not dampened. After only an hour weather delay, 214 of 224 registered golfers were able to complete the tournament. Among those golfers were sponsored teams of active duty personnel along with teams of Wounded Warriors.

This event would not be possible without the generous support of the sponsors and volunteers. There were over 50 sponsors and the more than 170 raffle and auction prizes were the cause of much laughter and cheers by the winners. Many of the volunteers return year after year to give of their time for registration, set up, clean-up, beverage tents, photos, lunch, and awards. Several TN patients were part of the event as well.

Many thanks go to the Redwine family, the volunteers, sponsors and golfers for the money raised at another successful golf tournament. This generous donation ensures that the Facial Pain Association will continue its mission of providing support and accurate information to facial pain patients, their families and medical professionals.

Join everyone for next year's tournament.



Matt and Amy Redwine with their daughters, Madison and Alexis













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For more information and current site status, please go to www.clinicaltrials.gov:

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TN IS NOT INVITED TO THE BIGGEST DAY OF YOUR LIFE

By Ally Kubik, Chris Nolze and Kenzie Winslow



Winslow, Mountain Vista High School Class of 2016

We all know that coping with TN can be difficult, even after treatment. As my high school graduation neared, I found myself becoming more and more stressed, which unfortunately caused more and more burning "healing pain" that I still experience even after an MVD. I wanted

my graduation to be special, memorable and not tainted by the same pain that was present during most of my high school career. That meant recognizing the stress I felt and finding ways to manage it.

I was lucky in that I had live-in distractions: the 11 out-of-town relatives staying at my house. Instead of focusing on my own problems and anxieties, I threw myself into helping my mom with my nana, who was recently diagnosed with ALS. I also focused my attention on graduation festivities

including parties, dinners and shopping. I found that if I shifted my mind to others, I had less time to stress and therefore less healing pain. I had to find creative ways to distract myself.

When it comes to managing pain, being resourceful can take on a lot of shapes. It doesn't always mean finding the medication that's going to help. Sometimes it means going to the grocery store to shop for the 15 people living in your house. I realized that these people were here because they love me so much and if I could just channel some of their positive vibes, I could revel in my accomplishments for a moment. Because, let's face it, accomplishing anything when battling TN is a victory and I'm pretty proud of mine.

I also found time for myself. When you're going through something big it's important to designate some time for quiet thoughts and relaxation. So, I simply used the lock on my door every now and then. My family understood that I was under a lot of stress and they respected my need for alone time. I used this time to sit and think, listen to music and take little naps. When pairing TN with a big life event you have to remember that time to yourself doesn't make you selfish, it makes you human.

Trigeminal neuralgia sure has a way of interfering with daily life. Missing work or school, canceling plans with loved ones and having to plan your schedule around TN are all constant reminders that the beast is an unwelcome, albeit constant, presence in one's life.

But sometimes, just sometimes, facial pain doesn't get an invitation to the party. Three board members of the Young Patients Committee recently celebrated major milestones in their lives, and here they share how they got to the finish line both despite of and because of their facial pain.

I got to - and through - my high school graduation because I was resourceful, found distractions to take my attention off of the pain, and carved out time to take care of myself first. Next stop: Pepperdine University!

hris Nolze, Ocean County College Class of 2016



It can be very difficult to hear a doctor tell you, "you have trigeminal neuralgia." It can be a longawaited answer to the previously unnamed pain, a diagnosis for the burning, stabbing or electric pain rushing through your face. You may go through the process of trying multiple treatment options, some of which will help

while others won't. Wondering if you will ever find relief can be the hardest part. It can make you want to stop what you've been working toward and just give up.

My experience with TN knocked me to my knees, and there were times that I believed I would never find relief. Medicine after medicine, procedure after procedure, and still my face felt like electricity was running through it. There were times that I looked in the mirror and wondered why I was still fighting when I could easily just give in to

the pain and let it consume me. But I looked to my friends and family and saw how much they were fighting by my side. I knew that just as much as I was fighting for myself, I was fighting for them as well

No matter how bad times may be, how bad the pain may become, always remember your goals, motivations and reasons for fighting. I always have remembered mine, and it was because of my friends and family that I found the strength to keep moving forward. Both figuratively and literally. Weather changes are a big trigger of my pain and my college graduation day was especially hot. I didn't have to walk - my diploma would have been sent to me anyway. But I was determined to walk across that stage and receive my (faux) diploma because I wasn't just walking for me.

Whether it was friends, family, or the younger TN patients looking to me for guidance in battling the monster, I knew everything I pushed through made an impact on somebody. Never give up, fight through the pain, and cherish the victories you achieve throughout that time. Never quit fighting, because the people that stay by your side won't quit fighting for you.

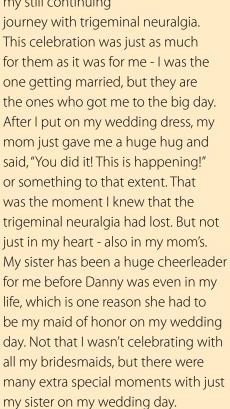
I got to my college graduation date despite my battles with TN because I kept moving forward and never forgot the reasons for fighting. Next stop: Kean University

nd I now pronounce you Mrs. Ally Kubik

When you have trigeminal neuralgia, you learn to celebrate even

the smallest things that the average person may not acknowledge, like going to get dinner with friends. On those big days that call for a real celebration, like a wedding or a graduation, it is important to celebrate with those who are there for you when you are in excruciating pain.

My mom and sister have always been my biggest supporters (along with Danny, my now husband) through my still continuing



Every TN patient needs a support system in the TN community, and mine was represented at my wedding. One of my TN friends attended, sporting a teal ribbon, and I was especially fortunate to have



my surgeon (Dr. Casey) join in the festivities. I turn to my TN family when in pain, so it was meaningful to me to have them witness my big day.

And of course Danny, my husband, couldn't be more supportive of me in all of the fights I have had with trigeminal neuralgia over the years. To be honest, I wondered if I would ever get married. Vows were said, so it happened! TN has been a major factor in our relationship - it taught us the meaning of "in sickness and in health" before we ever said "I do." Trigeminal neuralgia taught us both

that we need to celebrate our love and celebrate when we are able to do the things we love, despite the pain.

I walked down the aisle in spite of and because of my TN, thanks to the continued love and support of those who stand beside me every day. The celebration was just as much for them as for me. Next stop: my honeymoon!

Pain is a part of life, especially for a TN Warrior. It causes us to celebrate the little things on a daily basis. But living with chronic pain makes celebrating life's major accomplishments that

much more important - not just to the TN Warrior, but to their family and friends as well. Nobody wants this beast to win.

Sorry, TN, but your invitation to this party has been lost in the mail. We will all celebrate when there is a cure.

For more information about the YPC, visit ypc.tna-support.org /tnaypc

FPA's Memorial Tribute Fund

There are special people in our lives we treasure. Increasingly, FPA 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 FPA's growing initiatives on behalf of TN patients and families. We are delighted to share recent Memorial Tribute gifts received as of March -May 2016:

Honorary Tributes

John Alksne, M.D. Katherine Stevens

Kelley Bergman Douglas Weeks

Cindy Colon Cindy Colon

Miriam Day Denise Wood

Dan & Ally Kubik Melissa Anchan

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Name: Aimee Champion

Current age: 34

Where do you live? Syracuse, NY

How old were you when you first experienced facial pain? 29

How old were you when you were diagnosed? Just turned 30

What was your diagnosis? Originally, they thought I had TMJ, dental issues, etc. Was then diagnosed with Trigeminal Neuralgia

What do you do for fun? Swim, hike, take long walks, play with my daughter, spend time with my spouse, play softball/catch. Anything outdoors, in the warm weather.

What has TN taught you? TN has taught me to live in the moment. To look at what is in front of me with more vivid detail. Prior to TN, I was a

Young Patient Profile

fast paced individual, always on the go, moving with time at a fast rate. Now, I'm more cautious. Life is more beautiful. I'm more slower paced. I look at my daughter and analyze every detail of her, so that I don't forget and so that I enjoy her more. It has taught me to be more compassionate to those in need, to listen cautiously. I love deeper. I appreciate my loved ones, they give me strength.

What treatments (non-surgical) have you tried? Gamma knife radiation; Nerve blocks; Numerous medications.

Have you had any procedures? MVD in 2014 in Boston, Mass; and a redo MVD in 2016. Today, I'm in less facial pain and am 100% grateful!

How has your facial pain changed you? I try not to sweat the small stuff. Who has time for that, anymore? I

learned that it's ok to take care of myself. I've learned to accept help from others. I've learned to look at the world around me in deeper content. To soak in the good days, and take full advantage of them! I have more appreciation for life and the determination to pick myself up no matter the outcome. Facing this every day of my life has made me more passionate and compassionate toward those with medical issues. But it has shaped me into who I am today. I listen better to those in need. My senses are more heightened to those around me.

What tips do you have for other young patients? You are loved. You are strong. You're not alone. You are brave and courageous. You deserve to live! Don't give up! This is not your fault! And besides, you're perfectly you!! Develop a strong support system and utilize it. Communicate with your loved ones - they are hurting too!



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The following individuals joined or renewed their FPA membership between March 1 and May 31, 2016

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Martha Bertrand
Marc Blough
Joan Cannelli
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Dr. Brisman is Chief of Neurosurgery at Winthrop-University Hospital and Co-Medical Director of the Long Island Gamma Knife® at South Nassau Communities Hospital.

Dr. Brown is the chairman of the Medical Advisory Board of TNA-The Facial Pain Association. He is the Neurosurgery Director of the Winthrop-University Hospital CyberKnife® Program and Chief of Neurosurgery at Mercy Medical Center, Rockville Centre, New York.

Dr. Mechanic served as Chief of Neurosurgery at Huntington Hospital, in Huntington, NY, from 1996 to 2014. He is Chairman of the Nassau Surgical Society Section of Neurosurgery.



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