Our first virtual conference will cover topics requested by our community, including

- Diagnosis
- Decision-Making
- Surgical and Non-Surgical Treatment
- Pain Management
- Medical Marijuana, Acupuncture
- Mental Health and Coping
- FPA Young Patients Committee
- … and more!

This year, the world’s largest facial pain conference goes virtual, allowing you to learn safely from the comfort of your home. Suggested Registration fee $25.00
Read about FPA’s new book on page 5
Visit facepain.org to find out how you can Purchase a copy

IN THIS EDITION OF THE Q

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I hope you are well. Most everyone I know is a bit stressed given the events of this year. And those of us with a difficult medical condition may be feeling it a bit more than others. Hang in there. Things will get better.

Fortunately, these difficult times have not hindered the Facial Pain Association (FPA) and our ability to provide information and support. In fact, in curious ways it has helped us accomplish some important things and pushed us in ways that are likely to benefit you and the rest of our community for years to come.

To begin, we were lucky. At the end of last year we decided to move to a more virtual organization, so as Covid-19 disrupted the operations of many organizations in the spring, our staff was already working from home and our systems were in place. Then, one of our priorities for this year was to publish the most comprehensive book about trigeminal neuropathic pain in the world. (It’s been in the works for a few years now.) One of the important challenges we had in the past was getting the time needed from world-class medical professionals to complete their sections of the book. Since many non-Covid-19 activities were suspended, our authors had the time to complete their work. This 300+ page book, authored by 30 experts, *Facial Pain: A 21st Century Guide*, will be launched in the fall. Dr. Jeffrey Brown, our Medical Advisory Board Chairman, and Anne Ciemnecki, a member of our board, led this huge project.

The planned Fall National Conference at Johns Hopkins had to be cancelled. However, there was even a silver lining in this as well. Our new CEO, Allison Feldman, created a task force composed of board members, staff and outside experts to create a Virtual Conference, which is scheduled for November 7th. Anyone, anywhere in the world, will be able to “attend” the conference from their computers. The expense will be minimal, no travel is needed, it will take much less time, and many more people in our community can “attend”. We want to return to hosting in-person conferences, but we can imagine supplementing these meetings with virtual conferences in the future, and Covid-19 pushed us to create these capabilities faster.

FPA’s progress this year reminds me of the adage, “When life gives you lemons, make lemonade.” Kudos to the staff, Medical Advisory Board, Board of Directors and others who have pitched in.

On a more somber note, Dr. Henry Gremillion, Dean of the LSU Dental School, one of our board members, and a great champion for those with facial pain recently passed away. He will be sorely missed.

Finally, this is the FPA’s 30th year. This organization started at Claire Patterson’s kitchen table and now serves thousands of people in our community each year. For all of you who contribute your time, energy or treasure, thank you. It’s important work and we are striving to do it even better.

David Meyers, Chairman of the Board
The Facial Pain Association
250 years ago a French doctor, Nicolaus André, described his technique of using “mercury water and cauterizing stones” to decompress branches of the trigeminal nerve as a cure for a peculiar disease. “I was telling myself that the nerve was pinched,” he wrote. We don’t remember him for that, but we do know of the term that he coined for that disease, “tic douloureux,” now (mistakenly) called trigeminal neuralgia.

Flash ahead another 180 years to 1932, when America’s second neurosurgeon, Walter Dandy, wrote of his experience treating trigeminal neuralgia by sectioning the trigeminal nerve near the brainstem.

“Aside from tumors the two common causes are arterial loops which lift the sensory root from the brain stem, and the venous branches which cross the nerve, sometimes dividing it into two parts.”

Dandy repeated this comment two years later in a second publication:

“And in almost every additional case, a large arterial branch of the anterior inferior artery lies upon or under the sensory root. In many instances, the nerve is grooved or bent in an angle by the artery. This I believe is the cause of tic douloureux.”

Dr. Peter Jannetta read this comment, published in the Annals of Surgery (there were no neurosurgery journals then) and went on to perform the first modern microvascular decompression for trigeminal neuralgia using the operating microscope in 1967-35 years after Dandy’s observation.

But, it is written in Ecclesiastes, as translated from the Hebrew:

“Not all new beneath the sun”

The world’s first neurosurgeon, a British man knighted as Sir Victor Horsley, published a description of his first (unsuccessful) attempt to cut the root of the trigeminal nerve near the brainstem—the predecessor to Dandy’s successful approach—in 1891. This was 35 years before Dandy.

“Who came first?” Continued on page 4
Horsley wrote, “On exploring the nerve in the canal behind the ganglion I passed a small blunt hook around it, and it then occurred to me that the small branch of the basilar artery which accompanies the nerve might give some trouble. I therefore thought one might safely attempt avulsion of the nerve from its attachment to the pons, and on gently drawing on it with a hook this was easily accomplished, and without even noteworthy oozing.”

Horsley did not specifically identify the arterial branch of the basilar artery, but it had to be the superior cerebellar artery. Horsley assumed that this vessel normally “accompanies” the trigeminal nerve. It does not. The superior cerebellar artery, slides around the brainstem on the way to the cerebellum. But, sometimes it winds up abutting the trigeminal nerve.

When it does, there can be a problem.

What Horsley identified for the first time, without understanding what he observed, was a vascular cause of trigeminal neuralgia.

Its treatment is to decompress the nerve by moving away the artery, as Dandy, Jannetta and countless others since then have observed.

Horsley hadn’t realized what he was seeing, but he had the genius to observe and record it.

Confucious wrote “study the past if you wish to define the future.” Who came first, Confucious or the author of Ecclesiastes? In the race backward to set a flag defining a place in the history of firsts, there is really no end to the distance one must travel.

As it is written more poetically, “There is nothing new under the sun.”

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**Who came first?** Continued from page 3

“As a third generation woman with trigeminal neuralgia, the Facial Pain Association has helped my ancestors. I joined the Legacy Society to be sure the association can continue to educate and advocate for future generations.”

— A.Ciemnecki

If you would like more information on joining the FPA Legacy Society, please call 800-923-3608 or email noscarson@tna-support.org.

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Our Legacy Society members are an instrumental group of supporters who have included a gift to FPA in their estate planning. Planned gifts ensure FPA continues to remain the premier resource for education, support and advocacy for years to come. Extend your caring for the facial pain community beyond your lifetime by choosing to include the Facial Pain Association in your estate plan.

By including us in your will or living trust, naming us as a beneficiary under an individual retirement account or otherwise including us in your estate plan, you will secure the future of the FPA mission and become a member of our Legacy Society.

Please consult with your attorney about your options for charitable giving.

**Legacy Society Members**

Ann B. Ciemnecki  
Doris Gibson  
Carlin Lagrutta  
Jody and David Meyers  
Mary-Ann Neri  
Paula Rosenfeld  
Ann and Arthur Schwartz

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FPA exists to serve all those affected by trigeminal neuropathic pain.

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FACIALPAINASSOCIATION
We are pleased to tell you about a book for people with trigeminal neuropathic pain (TNP) that will be available from the Facial Pain Association in late October. This 46-chapter and 300+ page state-of-the-art book offers the most up-to-date information available about trigeminal neuralgia (TN) and other TNP. It is a curation of articles, written in recent years, by a broad range of experts in diagnosing and treating TN pain. Some of the articles are from the FPA Quarterly. Others were invited specifically for this volume.

As editors, we like to think of this book as a Hop-On Hop-Off Tour Bus in a city you are visiting. You have an all-day pass, and you can start at the beginning of the route or any place along the way. You can ride around and look at everything superficially or get off, explore, and hop on again. You do not have to see attractions, or read chapters, in any order. Start at whatever topic interests you and continue wherever you like.

The book is different from previous volumes because it presents not just one point of view, but advice from experts in many aspects of your life with TNP. In the first half of this book, you will find chapters about getting the right diagnosis, finding the best doctor, assuring that you get proper MRIs, managing medications, and surgical solutions such as microvascular decompression, radiofrequency rhizotomy, balloon compression, radiosurgery, and repeat surgery. There is also a chapter on what to do when nothing seems to help. The second half of the book is devoted to complementary and alternative medicine and living well despite the condition. There are chapters on acupuncture, medical marijuana, upper cervical chiropractic, and how the weather affects pain. Finally, there is a chapter on the future of care for TNP.

Another way this book is different is that it uses a publish-on-demand model of distribution. This model allows us to continually update and improve the book’s content in the way your phone software updates. Finally, we have tried to make this volume into something that communicates and does not obfuscate. We use positive, people-first language. In every section, it conveys that you are more than your pain. If you are newly diagnosed, misdiagnosed, in need of another solution, a friend or family member, young or old, or doing well but wish to know more, then this book has been written for you.

All proceeds from the sale of this book will benefit the FPA so it can continue to educate and advocate for people with TNP.
By Mark E. Linskey, M.D.

Dr. Linskey is a Professor of Neurological Surgery at UC Irvine in California. He is also the Western Regional Director of the Medical Advisory Board of the Facial Pain Association, the “Smart Medicine” training module editor for the Trigeminal Neuralgia module for the American College of Physicians, and an Editor for the British Medical Association, British Medical Journal, “Clinical Evidence” manual module on Trigeminal Neuralgia.

I currently have the honor to serve as the faculty advisor for the Orange County (OC) Facial Pain Association (FPA) support group, which is the oldest Trigeminal Neuralgia Association (FPA) support group in continuous existence in the U.S. In that role I was asked in the Fall of 2017, by the then support group leader, Deborah Kurilchyk, to help them by coming up with a one-page “Advice Sheet” for trigeminal neuralgia patients and emergency room (ER) physicians on how to approach treating patients with acute attacks of neuropathic pain from trigeminal neuralgia needing to go to the ER. This one page sheet approved by the support group board April 6, 2018, was originally intended for use only by the OCTNA (now OCFPA) support group members. However, it soon found its way in various modified, and second-hand, forms onto the internet via various Face Book trigeminal neuralgia (TN) support groups and has “made the rounds”, so to speak. I have since been asked to write this article for the FPA to more completely address the real need to educate patients and ER physicians in what to do when faced with a TN patient with an acute neuropathic pain crisis.

Before we begin, it is important to note that in this article we are not focused on all forms of trigeminal neuropathic pain. In our practice we divide neuropathic pain into typical and “atypical” varieties. When we use the term “typical” neuropathic pain we are specifically referring to pain that is sudden in onset and resolution, lasts seconds to minutes, is described as intense sharp, stabbing or electric in character and is not associated with pain between the episodes. When we use the term “atypical” neuropathic pain we are specifically referring to pain that is described as dull,
aching, burning, throbbing and/or pressure in character. It may be present only intermittently, present all the time, or present all the time with intermittent severity “flares.” In our practice we view trigeminal neuropathic pain as falling on a continuous spectrum where the patient’s position on that spectrum can change over time with syndrome evolution as well as effects of therapeutic interventions (Figure 1). On one end of the spectrum we define “classic TN” as consisting of typical neuralgic pain only. We then define two hybrid syndromes where both types of neuralgic pain are present, but in different dominance ratios (typical pain >51% - TN1, and atypical pain >51% - TN2). We then define two syndromes on the other end of the clinical spectrum where only atypical pain is present (no typical pain component). The first where the atypical pain is intermittent with pain-free episodes present, we define as “Atypical TN.” The second where some atypical pain is always present we refer to as “Trigeminal Neuropathic Pain of Unknown (or obscure) Etiology (TNPUE).” The interventions described in this article are focused on acute crises of typical trigeminal neuralgic pain. That means that they will predictably work best for patients with classical TN and for the typical pain components of their syndrome for patients with either hybrid syndrome of TN1 or TN2. While patients with atypical neuralgic pain also have severe acute pain flares, the interventions described herein are less likely to help this type of pain which often requires standard pain pharmacological interventions such as narcotics, and more recently, ketamine.

**Standard treatments** that are the mainstay for treating patients with pain in general include, among others, acetaminophen (Tylenol), non-steroidal anti-inflammatory drugs (NSAIDS), narcotics and ketamine. All of them can now be administered both orally and intravenously. These medications may prove useful for treating acute flares of atypical trigeminal neuralgic pain. However, one of the unique characteristics of typical trigeminal neuralgic pain is that it generally does not respond well to these agents.  

**One of the unique features** of typical trigeminal neuralgic pain is that it characteristically responds best to anti-epileptic drugs (AED) treatment. These typically include the first line TN agents in the carbamazepine family including Tegretol and oxcarbazepine (Trileptal) as well as agents in the Gamma Aminobutyric Acid (GABA) analogue family which includes gabapentin (Neurontin) and pregabalin (Lyrica). Unfortunately these agents suffer from several major drawbacks during an acute flare of typical trigeminal neuralgic pain:

- First, TN is characterized by tactile triggers in the trigeminal nerve innervation distribution, and these agents can only be administered orally. If opening your mouth, taking pills, having liquid in your mouth, or swallowing are tactile triggers for a given patient, they may not be able to take the medication orally.

- Second, these agents have pharmacokinetic half-lives that require several days of consistent oral dosing for drug levels to reach a steady state. The longer tactile trigger concerns lead to missed oral doses, the lower the circulating blood levels get and the worse the acute pain flare becomes. It becomes an accelerating “vicious circle” over time.

- Third, Even if the patient could somehow take the medication orally during the acute crisis, depending on how many doses had already been missed, the
medication may take too long, or take too many doses over time, for an effective blood steady state level to be re-achieved.

What is needed to break the acute typical trigeminal neuropathic pain crisis are AEDs that can be administered intravenously (IV) in a loading dose that can immediately achieve a therapeutic drug level. The mainstay and most proven IV agent for TN is phenytoin (Dilantin) and now its newer cousin fosphenytoin (Cerebyx). Phenytoin has a long history of use in TN and in fact was the first AED to be shown to be effective for TN.3,4 It can be loaded to full therapeutic drug blood level if administered intravenously over 20-60 minutes with telemetry monitoring for safety reasons for possible cardiac heart rhythm and hemodynamic blood pressure effects. Fosphenytoin is newer and safer to load and along with phenytoin has been effectively used for acute attacks of typical trigeminal neuropathic pain.5,7 Once the pain cycle is broken by intravenous drug load administration, the patient can once again resume taking their better oral AED medications and “catch up” with re-establishing therapeutic drug levels of these better drugs. If additional time is needed for several oral AED doses to occur, the intravenous medication can be continued in a therapeutic maintenance dose regimen until the oral dosing/blood level goal is achieved, and the patient can then be sent home on their oral drug regimen.

It is also important to point out that patients who are in typical trigeminal neuropathic pain crisis where they cannot open their mouth, take pills, eat or drink, may also turn out to be significantly dehydrated by the time they finally resolve to go to the ER. In this setting intravenous hydration may also be an important component of helping to resuscitate them and helping them to feel better.

While there are no studies to date to assess their effect on an acute crisis of TN, we are constantly developing new AED’s for epilepsy. Two of these are of potential interest for the management of patients who are in typical trigeminal neuropathic pain crisis because they cannot only be administered intravenously, but can be fully loaded with the initial intravenous dose. These medications are levetiracetam (Keppra) and lacosamide (Vimpat). While neither has been properly evaluated yet for treating TN, as AED’s they retain that theoretic potential, and as drugs that can be loaded rapidly intravenously, they may be worth trying in the setting of trigeminal neuropathic pain crisis. This may be particularly relevant for patients who are allergic to phenytoin or fosphenytoin. An empiric trial of intravenous loading of one of these two agents if phenytoin or fosphenytoin do not work or cannot be administered due to drug allergy would seem to be a reasonable (though unproven) empiric option in these circumstances.

For patients with TN, we recommend that you carry with you, on your person at all times (wallet, purse, or cell phone), a sheet of paper or card that you can show to an ER healthcare provider if you are in such acute pain crisis that you cannot talk without triggering a pain attack. In Figure 2, we are also including a single page summary that you can/should also take with you to try and help in these crisis situations for communicating with your ER healthcare provider. I sincerely hope that these prove useful.

References:
4. BEnde, M. Diphenylhydantoin in tic douloreux and atypical facial pain. Va Med Mont (1918) 1957;84(7):358-9

Further Information:
B. Smart Medicine trigeminal neuralgia module from the American College of Physicians (http://smartmedicine.acponline.org/content.aspx?gbosid=299). Must be a member to access
C. Facial Pain Association https://fpa-support.org/
D. American Association of Neurological Surgeons (https://www.aans.org/Patients/Neurosurgical-Conditions-and-Treatments/Trigeminal-Neuralgia)

Disclaimer: This article discusses medical diagnoses and potential therapeutic interventions. It is intended for educational and background reference purposes only. It is not intended to prescribe any specific course of care or treatment. Actual care and/or treatment must always be prescribed by an appropriately licensed health professional in direct consultation with their patient in the setting of that specific patient-physician relationship taking into account their specific circumstance, as well as the risks and benefits of any intervention, which should be mutually reviewed and agreed upon onsite at that time.
To the Senior Emergency Room Physician:

The key drug to use is an anticonvulsant that can be loaded to full therapeutic blood levels intravenously (IV). Phenytoin (Dilantin) was the first anti-epileptic drug (AED) shown to work for trigeminal neuralgia (TN). Deliver a 1 gram load IV over 20-60 minutes with telemetry cardiac and blood pressure monitoring. This will break the acute pain cycle >90% of the time. Alternatively fosphenytoin (Cerebyx) may be used (1 gram phenytoin equivalent load) under the same monitoring conditions. Once the pain cycle is broken the patient can resume taking their better oral AED medications and you can even consider taking 1-2 extra doses, on a one-time basis, to catch up if they have previously missed a significant number of doses. If they are allergic to phenytoin or these medications do not work, two other AED’s (levetiracetam [Keppra] and lacosamide [Vimpat]) can be loaded IV and might help. They have not been tested and proven for treating TN, but they are in the same therapeutic drug class and can be safely loaded IV.

**KEY POINTS**

Neuropathic pain generally does not respond to standard analgesics including opioids (narcotics)

It is usually managed with PO AED’s that can take days to achieve therapeutic drug levels.

The patient has come to you because they are in acute neuropathic pain crisis, may have missed several PO AED doses as well as be unable to take PO AED’s in your ER due to oral tactile pain triggering, or may not be on the right medication to start with (usually carbamazepine, oxcarbazepine, gabapentin, pregabalin, baclofen, or a combination)

**Immediate Action Required:**

**Plan A:** administer a 1 gram load of phenytoin IV over 20-60 minutes with telemetry cardiac and blood pressure monitoring ( alternatively fosphenytoin may be used - 1 gram phenytoin equivalent load)

**Plan B:** administer a 1000mg load of levetiracetam IV over 5 minutes with telemetry cardiac and blood pressure monitoring

**Plan C:** administer a 200-400mg load of lacosamide IV with telemetry cardiac and blood pressure monitoring

**SUMMARY**

If the acute attack does not respond to an IV load of phenytoin or fosphenytoin, then it is reasonable to consider levetiracetam or lacosamide as alternatives in similar drug classes that can be safely loaded IV. Once the pain cycle is broken the better PO AED’s can be resumed.

**For more Information See:**


B. Smart Medicine trigeminal neuralgia module from the American College of Physicians (http://smartmedicine.acponline.org/content.aspx?gbosid=299). Must be a member to access

C. Facial Pain Association https://fpa-support.org/

D. American Association of Neurological Surgeons (https://www.aans.org/Patients/Neurosurgical-Conditions-and-Treatments/Trigeminal-Neuralgia)
Facial pain is one of the most challenging entities for physicians and healthcare providers. This is mostly due to a wide range of etiologies for facial pain. These include those that are neurological (e.g. trigeminal neuralgia, trigeminal autonomic cephalalgia), dental (e.g. temporomandibular joint disorders, tooth/gum issues), sinus and nose related, and those that are related to rheumatologic/autoimmune disorders.

Nerve supply of the face comes from the trigeminal nerve which is one of twelve cranial nerves in the human body. Trigeminal nerve starts from the brain and after it exits the brain, as the name indicates, is composed of three (tri) main divisions. Each division branches out to multiple small nerves as shown in the picture:

Those branches supply the sensation to different parts of the face, mouth, tongue, nose, and sinuses.

Any damage, injury or disease that affects trigeminal nerve, anywhere from its origin in the brain, to smallest branches on the face, can cause facial pain. It is important that physicians take every patient’s complaint of facial pain seriously. This includes gathering a thorough history plus examination of head, teeth, eyes, noses, throat, and even neck, since any of these structures can contribute to facial pain. Due to this heterogeneity of causes, patients with facial pain often need to consult with multiple providers in order to get the correct diagnosis and proper treatment. With an incorrect diagnosis and treatments, patients are very likely to experience a more intensified pain and discomfort.
Although most of the time, injury to the trigeminal nerve is due to trauma - like dental procedures, or compression of nerves by blood vessels or tumor, occasional medical disorders that affect the trigeminal nerve can be a source of the facial pain. Medical causes of trigeminal nerve injury are still not very known nor studied. In general, any pain that happens due to an injury to a nerve is referred to as a “neuropathic pain.” This definition is broad that covers over 100 conditions. When the injury to the trigeminal nerve happens in the brain due to compression by blood vessels, it is known as trigeminal neuralgia which has very classic symptoms.

The most challenging cases of trigeminal “neuropathic pain” involve patients with facial (trigeminal) pain who do not have classical trigeminal neuralgia. Most of these patients are labeled as having “atypical facial pain” or “atypical trigeminal neuralgia.” In practice, it reveals that some of these patients might have a “systemic medical disorder” which involves the trigeminal nerve, causing facial and trigeminal pain.

Among systemic medical causes, “inflammatory and autoimmune diseases” seem to be the most common disorders that can involve trigeminal nerves. Some of the autoimmune diseases such as Sjögren syndrome, scleroderma, lupus, and undifferentiated connective tissue disorder, can attack the trigeminal nerve and cause facial pain, sometimes similar to trigeminal neuralgia. We refer to this group of patients as “inflammatory trigeminal neuropathy” or “autoimmune trigeminal neuropathic pain.” It is critical to differentiate these groups from classical trigeminal neuralgia because the classical trigeminal neuralgia is treated with surgery called microvascular decompression that has shown to be the most effective treatment. If the two groups are not well differentiated and they are treated by performing the surgery, not only won’t the surgery make a difference, but it also might make the pain even worse and intractable to treatments.

Two autoimmune disorders that most likely affect trigeminal nerve are Sjögren syndrome and scleroderma:

Sjögren’s syndrome is a chronic systemic autoimmune disease and like most autoimmune disorders it is more common in women. It is one of the more prevalent autoimmune disorders which, since it’s symptoms sometime are mild, it might not even be diagnosed. The main target of Sjögren’s syndrome is exocrine glands, which causes dryness of the main mucosal surfaces and therefore dry eyes and dry mouth are the key features of this syndrome.

If Sjögren’s syndrome does not affect any other organs, it might not even be diagnosed just based on dry eyes or dry mouth symptoms since these symptoms are nonspecific and common in the general population. However, in Sjögren’s syndrome, a variety of systemic manifestations may occur, including fatigue, musculoskeletal symptoms, cutaneous lesions and internal organ and neurological involvement. Based on some reports, up to 70% of Sjögren’s patients may suffer from neurological manifestations. “Neuropathy” is a classic neurological manifestation of Sjögren’s syndrome, therefore trigeminal nerve involvement could happen as part of neurological manifestation of Sjögren’s patients. In fact, trigeminal nerve is the most common cranial nerve that can be involved in Sjögren’s syndrome. As a result, in patients who have trigeminal neuropathy due to Sjögren’s syndrome, with no other cranial nerve involvement, facial and trigeminal pain will be the only major symptoms of the Sjögren’s syndrome since dry eyes or dry mouth symptoms could be mild.

In patients with facial and trigeminal pain who do not have classic trigeminal neuralgia, presence of some nonspecific symptoms could suggest the possibility of Sjögren’s syndrome. These symptoms could be:

- Unexplained fatigue or tiredness
- Severe dry eyes that require treatment. Complaints that can happen due to dry eyes are broad and could be feelings of stinging, burning or itchy eyes, feeling of sand in the eyes, sore and swollen eyelids, discomfort when looking at light or even blurry vision.
- Severe dry mouth which can present with tongue sticking to the roof of mouth, feeling that food stuck in the mouth or throat, specifically dry food even changes in how food tastes.
- Frequent dental cavities despite keeping good dental hygiene
- Dry skin or vaginal dryness
- Rashes (especially after being in the sun)
- History of multiple unexplained miscarriages
- Muscle and joint pain with stiffness and swelling

These are the symptoms that are usually not asked about by physicians if patients present with facial and trigeminal pain. Therefore, patients need to be aware of this disease and pay attention to those nonspecific symptoms, particularly when they’re diagnosed as “atypical trigeminal neuralgia” or “atypical facial pain”.

“Medical Causes” Continued on page 12
Diagnosis of Sjögren’s syndrome is not always easy since the blood test that is for Sjögren’s could be negative in up to 40-50% of patients with this syndrome. Particularly in the patients who are in the beginning of the disease process and their body probably did not make enough antibody to be detected. Therefore, in patients with facial pain for whom there is a question of Sjögren’s syndrome as the reason for their trigeminal neuropathic pain, consultation with an expert physician in this field (usually rheumatologist) might help to clear the potential Sjögren diagnosis and lead to proper treatment.

Scleroderma has been described as a chronic autoimmune disorder which is much less common compared to Sjögren’s syndrome. However, since neurological and particularly trigeminal nerve involvement is one of the most common manifestations in this autoimmune disease, it’s worth to mention it as a potential differential diagnosis of facial pain.

Scleroderma like Sjögren’s syndrome is more common in women and in young to middle age, with peak onset in individuals aged 30-50 years.

Patients with scleroderma, experience progressive skin tightness and induration, often preceded by swelling and puffiness.

The other important symptom that can be suggestive of scleroderma is “Raynaud’s phenomenon”. Raynaud’s phenomenon is pale to blue to red sequence of color changes of the fingers or toes, most commonly after exposure to cold. (see picture)

Raynaud’s is more characteristic of scleroderma but can be seen in other autoimmune disorders.

Raynaud's phenomenon that is not associated with systemic sclerosis or other autoimmune diseases is known as primary Raynaud phenomenon. It occurs in 5-15% of the general population.

Beside skin manifestation, scleroderma, like Sjögren’s syndrome has lots of nonspecific symptoms including:

- Gastrointestinal symptoms which can range from dyspepsia, bloating, reflux to difficulty swallowing
- Respiratory symptoms like progressive shortness of breath, chest pain and dry persistent cough
- Musculoskeletal symptoms like severe muscle pain and fatigue and even muscle weakness, joint pain with loss in joint range of motion
- Kidney involvement, which usually presents with early onset hypertension, usually resistant to regular treatment which sometimes can cause renal failure

We need to keep in mind that since the symptoms in Sjögren’s syndrome and scleroderma as well as other autoimmune disorders that can attack trigeminal nerve are nonspecific, the entire clinical picture needs to be considered before suggesting these possibilities as the reason for facial pain. The most important factor is “age of the onset” of trigeminal pain. Since classical trigeminal neuralgia, which is the most well-known etiology for facial pain, never starts before the age of 40 and rarely before the age of 50. Patients with facial pain in that age group need to be aware of the possibility of autoimmune disorder as a differential. Particularly because it is noted that those age groups (between 20-50 years) are the most common age for autoimmune disorders.
**Did You Know?**

- There are twelve pairs of cranial nerves.
- The cranial nerves lead directly from the brain to various parts of the head, neck, and trunk. Some of the cranial nerves are involved in the special senses (such as seeing, hearing, and taste), and others control muscles in the face or regulate glands.
- The pairs of cranial nerves emerge from the underside of the brain, pass through openings in the skull, and lead to parts of the head, neck, and trunk.
- The fifth (VI) cranial nerve is the trigeminal nerve and supplies sensation to the face, part of the scalp, eyes, nose, lips and inside the mouth.
- The seventh (VII) cranial nerve is the facial nerve that supplies muscle movement to the face.

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<tr>
<th>#</th>
<th>Name</th>
<th>Function</th>
<th>Commonly Encountered Disorders</th>
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<tbody>
<tr>
<td>I</td>
<td>Olfactory Nerve</td>
<td>Smell</td>
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<td>II</td>
<td>Optic</td>
<td>Vision</td>
<td></td>
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<tr>
<td>III</td>
<td>Oculomotor Nerve</td>
<td>Eye movement, pupil constriction, Eyelid &amp; eyeball movement</td>
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<tr>
<td>IV</td>
<td>Trochlear</td>
<td>Eye movement - turns eye downward &amp; laterally</td>
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<tr>
<td>V</td>
<td>Trigeminal</td>
<td>Somatosensory information (touch, pain) from the face and head; muscles for chewing. largest cranial nerve three main branches that are ophthalmic, maxillary and mandibular nerve</td>
<td>Trigeminal neuralgia</td>
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<td>Neuropathic facial pain</td>
</tr>
<tr>
<td>VI</td>
<td>Abducens</td>
<td>Eye Movement</td>
<td></td>
</tr>
<tr>
<td>VII</td>
<td>Facial</td>
<td>Taste (anterior 2/3 of tongue); somatosensory information from ear; controls muscles used in facial expression.</td>
<td>Bell’s Palsy, Hemifacial Spasm</td>
</tr>
<tr>
<td>VIII</td>
<td>Vestibulocochlear</td>
<td>Hearing, Balance - Turns eye laterally</td>
<td>Acoustic Neuroma</td>
</tr>
<tr>
<td>IX</td>
<td>Glossopharyngeal</td>
<td>Taste (posterior 1/3 of tongue); Somatosensory information from tongue, tonsil, pharynx; controls some muscles used in swallowing.</td>
<td>Glossopharyngeal neuralgia</td>
</tr>
<tr>
<td>X</td>
<td>Vagus</td>
<td>Sensory, motor and autonomic functions of viscera (glands, digestion, heart rate)</td>
<td></td>
</tr>
<tr>
<td>XI</td>
<td>Spinal Accessory</td>
<td>Controls muscles used in head movement.</td>
<td></td>
</tr>
<tr>
<td>XII</td>
<td>Hypoglossal</td>
<td>Controls muscles of tongue</td>
<td></td>
</tr>
</tbody>
</table>
PROTECTIVE FACE MASKS TO PROMOTE TN AWARENESS

Article contributed by the YPC

When the COVID-19 virus came into the US this past spring, the Young Patients Committee (YPC) started thinking of ways they could provide more support to the community. Experts were starting to talk about requiring people to wear masks, a thought that makes anyone with facial pain cringe. Even so, the YPC thought there was opportunity to promote awareness and offer protection if masks were becoming the new normal. The committee of six put on their thinking caps and began creating designs that offered uplifting thoughts and could bring awareness by incorporating the color teal and the teal awareness ribbon we all associate with facial pain.

Since the inception of the idea, board members Lindsey Thacker and Stephanie Blough have been hard at work crafting this thought into a reality and are selling their creations on the YPC’s Etsy store.

Lindsey wanted to offer a way to ease the discomfort of the masks around our ears. With help from her boyfriend, Taylor, she was able to create ear savers with a 3D printer. These plastic straps can help minimize pain for some people since the ear loops of a mask connect to the strap as opposed to touching one’s ears. Since listing in the store, Lindsey and Taylor have made and sold over 50 ear savers!

Using her love to craft with vinyl, Stephanie has been hard at work putting designs on masks and, to date, has sold over 400. “I am so proud to be able to use my ability to help others in this time of need”, Stephanie said. “Even more, I appreciate the opportunity to craft my stresses away while making things that bring awareness to something so near and dear to my heart.”

Interested in supporting the Young Patients Committee and bringing more awareness to facial pain? Visit Etsy.com/shop/TealRibbonCrafts. All proceeds are used in supporting young patients with finding support, attending FPA conferences, and participation in other facial pain events.
Nine Books to Read if You Have Chronic Illness

Below are nine books listed (in no particular order) that have helped us through our experience with trigeminal neuralgia and chronic illness. Each of these books has helped us improve our outlook on life and also in choosing friends who uplift and support us. We hope that you find answers and joy in one of these books. Happy reading!

Guts by Raina Telgemeier
This book is a graphic novel that dramatizes the author’s fears and anxieties about her chronic illness, but it also focuses on her triumph over those fears. This book also destigmatizes the use of therapy to understand your personal experience with chronic illness. *Guts* is an excellent read for children with chronic diseases. It primarily focuses on the use of healthy childhood friendships to overcome fears and anxieties. Telgemeier uses imagery to emphasize the importance of friendship throughout a chronic pain experience.

The Book of Joy by Dalai Lama, Desmond Tutu and Douglas Carlton Abrams
The Book of Joy focuses on how to find joy amidst times of suffering. As those who live with chronic pain, this can be a question to which we thought we might never find the answer. Though we understand real suffering because of our chronic pain, this book also shows you how to relate to those around you who are going through different forms of suffering. Find friends who are willing to listen and understand what you are experiencing. And then find ways together to look for joy.

Tales of a Spoonie Warrior by Saidee Wynn
Wynn uses a collection of short essays to describe the highs and lows that come with living with chronic illness. She uses humor and honesty to portray what life is life accurately. When choosing friends to have in your inner circle of confidants, you want someone willing to hear about the highs and the lows of your life. This book shows one way in which you can share your own experience with those closest to you. Allow your friends to see the lower side of life with trigeminal neuralgia, and allow them to help you. It can be scary to share those intimate snapshots of living with chronic illness, but a true friend will help you.
**The Courage to be Disliked by Ichiro Kishimi and Fumitake Koga**

One of the hardest parts of living with a chronic illness is the societal expectation of being always “okay.” This book challenges that ideal and encourages you to live life authentically—to do what makes you happy. You can never please everyone in life, so you need to live for yourself. Life with a chronic illness means you may have to do things differently from others, but it doesn’t make you do things any less relevant or meaningful. Find friends who push you to live authentically and are excited to try new ways of doing things!

**Girl, Wash Your Face by Rachel Hollis**

A self-help book full of real-life insight and Hollis’ self-deprecating humor means you feel like you’re talking to a friend. Hollis wants to show you how to become who you are meant to be rather than having you focus on the lies you believe about yourself. This book teaches you how to count the positives in life, even the small ones, and start to see how they can add up to make significant changes in your life. Girl, Wash Your Face would be an excellent book to read with a friend to help each other focus on all of the positives in life.

**The Boy, The Mole, The Fox, and the Horse by Charlie Mackesy**

A story of four unlikely friends who share one unbreakable bond, this book reminds us that though we may all look different, we are all the same inside. Mackesy uses universal truths and wisdom to celebrate our differences. Our friends might not always experience life the same way that we do, but they can still be there to share in our successes. Full of short, but profound conversations between the friends, this book provides hope.

**Surviving and Thriving with an Invisible Chronic Illness by Ilana Jacqueline**

We all know living with a chronic illness is challenging enough, but when our pain is invisible, we can be left isolated and alone. Jacqueline writes about real-world examples of people who face invisible illnesses daily. With so many real-world cases, this book can begin to help you feel less isolated in your experience. Because our friends and family cannot always see the pain we are in, they may not still understand the severity of what we are feeling. The friends you surround yourself with should be willing to learn about the invisible aspect of trigeminal neuralgia, and this book can help you shape your experience into words.

**Everything I Need to Know I Learned from Mister Rogers’ Neighborhood by Melissa Wagner**

Everyone knows Mister Rogers, and this book compiles all of the wisdom he shared over the years. From seeing the good in ourselves to seeing the good in the world, this book reminds us that there is much to celebrate in life. Remember: you are special, and all kinds of feelings are okay.

**Happy by Fearne Cotton**

We often live in a state of confusion and pain, but Cotton wants her readers to know that they are not alone. She uses her personal experiences with feelings of isolation and sadness to relate to her readers. Her stories, when paired with expert advice, offer practical ways to find happiness in the mundane moments of life. Just like Cotton’s book reminds us, many people experience feelings of sadness too often, which is vital for us to remember. As much as we need our friends to be there for us, we must also be there for them. Friendship such as this will create lasting feelings of happiness and companionship.
FPA MOURNS
THE PASSING OF
DR. HENRY GREMILLION

Dr. Henry Gremillion, Dean of LSU Health New Orleans School of Dentistry passed away on Monday, May 18 at age 68 after a brief illness. Dr. Gremillion was an active member of the Facial Pain Association Board for decades, providing education to thousands of people affected by facial pain. He presented at FPA Conferences, spoke to support groups and authored articles about orofacial pain. Dr. Gremillion contributed a great deal to advance the knowledge of the FPA and patients in matters of orofacial pain.

Immediate past FPA Chairman, Jeff Bodington said, “Henry was capable, professional and a pleasure to work with. He cared about people with trigeminal neuropathic pain. Attendees at FPA conferences found his presentations clear and compassionate, and he worked to increase the importance of correctly diagnosing TN in dental school curriculums and in dental continuing education. We appreciate his efforts and send our condolences to his family and colleagues.”

Roger Levy, past FPA Chairman said, “Henry was a good friend to TNA/FPA. I could always rely on him for wisdom and action. People found it hard to resist Henry — he was simply a thoroughly decent human being.”

Dr. Gremillion was a Louisiana native who graduated in 1977 from the LSU Health New Orleans School of Dentistry and went on to become a leader in oral health at the local, state and national levels. He received many honors for his work as an educator and dental practitioner. Dr. Gremillion returned to Louisiana to lead his alma mater in 2008. Despite his national stature, Henry easily related to people from all walks of life. Students, faculty, patients, members of the community, elected officials, local, state and national leaders all found him approachable, respectful, caring, engaged and down to earth.

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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 facial pain surgery.

Dr. Brisman has served as Chief of Neurosurgery at NYU Winthrop Hospital, Mineola, NY, and is Co-Medical Director of the Long Island Gamma Knife® Center at Mount Sinai South Nassau in Oceanside, NY.

Dr. Brown is the chairman of the Medical Advisory Board of TNA-The Facial Pain Association. He serves as the Neurosurgery Director of the NYU Winthrop Hospital CyberKnife® Program in Mineola, NY.

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

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