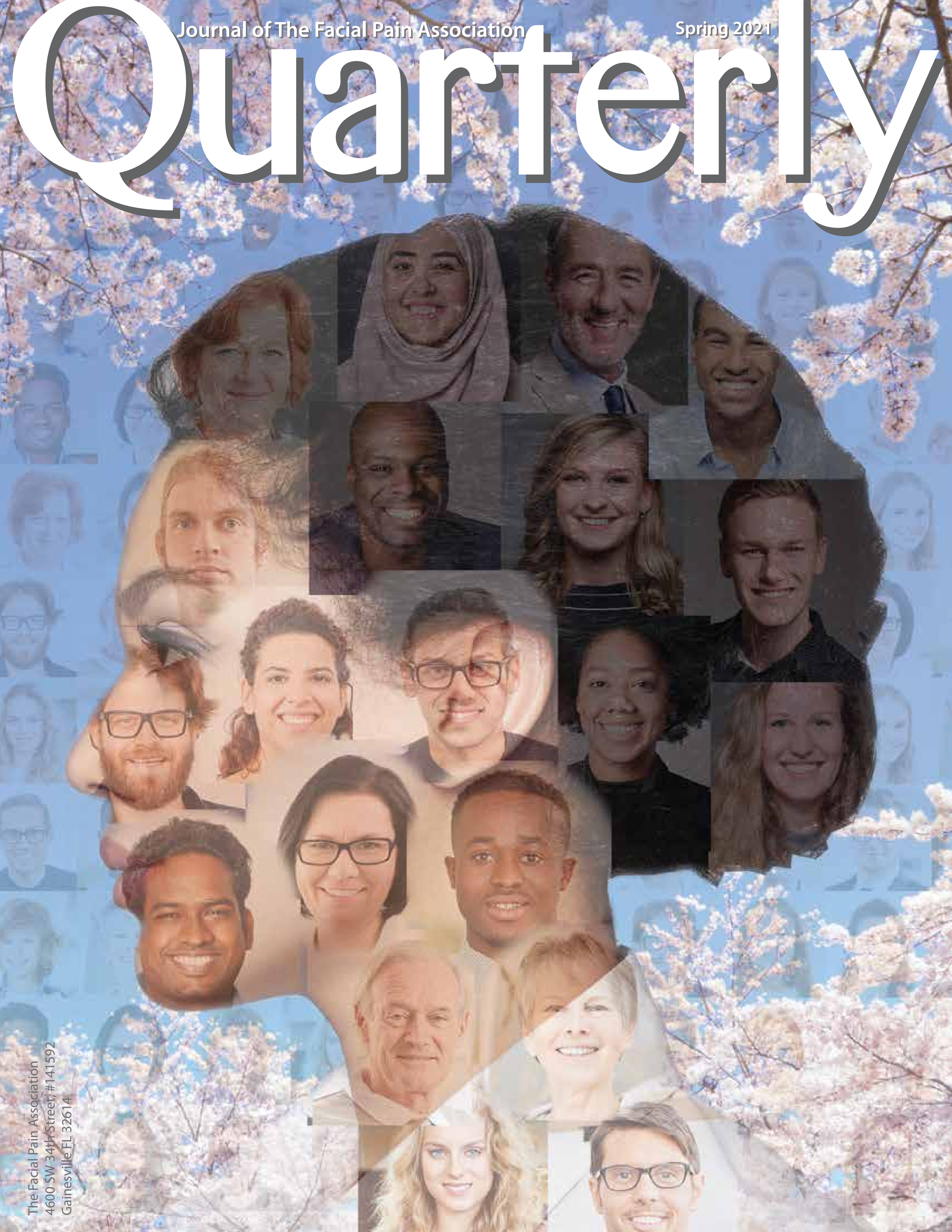
Journal of The Facial Pain Association

Spring 2021

Quarterly



The Facial Pain Association
4600 SW 34th Street #141592
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SO SHOULD THE **TREATMENT.**

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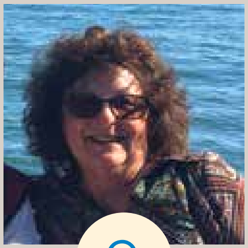
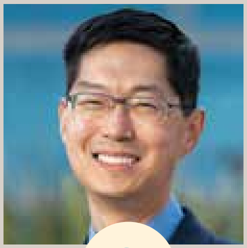
FPA is a diverse community with a common mission, to serve those with neuropathic facial pain through support, education, and advocacy. This year we seek to celebrate the many faces that comprise our community.

IN THIS EDITION OF THE Q



Q FEATURES



FACIALPAIN
ASSOCIATION

From the Chairman of the Board

Although this has been a difficult year for nearly everyone, I'm pleased to report that the FPA made great progress toward its mission of providing information and support to those with facial neuropathic pain, their caregivers and the medical community that supports us. And this terrific progress was due to many of you.

There were many FPA achievements this past year, and four that I'd like to highlight. First, the FPA transitioned to become a virtual organization (we started this before Covid hit), which allows us to lower costs and staff the organization with the best talent we can find regardless of their location. Second, a Peer Mentor Corps was created and staffed with 29 volunteers to add another important dimension to the breadth of support we are able to provide. Third, *Facial Pain: A 21st Century Guide For People With Trigeminal Neuropathic Pain* was published. It was three years in the making, and it is likely the most comprehensive book on this topic in the world. Finally, the FPA hosted its first Virtual Conference with close to 1,000 attendees from 47 states and 14 countries. Not only did this event receive outstanding praise from its attendees and participants, it was an incredibly important big, first step in developing our ability to reach more people in our community through this format.

Whew, I feel like I'm riding on the *Little Engine That Could!*

How did all of this happen? Our small staff led by our new CEO, Allison Feldman, deserves most of the credit. They work tirelessly for our community. On top of that, we have ~ 85 volunteers who are members of our Medical Advisory Board, Board of Directors, Support Group leaders, Peer Mentors, leaders of our Young Patient Committee and others. And last, but certainly not least, we are extremely fortunate to have had more than 1,500 people generously donate to our cause. Without these donations, we'd vanish.

As we enter 2021, we dream about being even more helpful and valuable to those in our community. For example, this past year we cataloged all of our important information assets (e.g., studies, articles, videos) by topic in a manner that allows staff, Support Group Leaders, and Peer Mentors to provide you with the resources you need. In 2021, we will launch a new FPA website that will enable you to retrieve some of this vital information directly and be even better at helping you answer your most pressing questions. (But remember, even with an improved website, we want to hear from you directly.)

Those of us with trigeminal neuropathic pain are in an unenviable position. But there are many world-class medical professionals dedicating their lives to helping us, and research is being conducted everyday to find new solutions to our problem. Furthermore, there are many things to try to stop, or at least reduce, the pain.

And always remember that you are not alone. We at the FPA stand ready to help, as do many other members of our community.

David J Meyers

David Meyers, Chairman of the Board
The Facial Pain Association

The MAB Corner

Michael Lim, MD

Science Innovation Technology

One silver lining of the current pandemic is the incredible display of science, innovation, and technology on display during the race to develop a COVID-19 vaccine. Remarkably, researchers were able to sequence the COVID-19 virus, understand its structure, and generate vaccines in under one year! Furthermore, the technology developed from this vaccine is now being applied to other diseases. However, this impressive feat is not a one-off. If we look at our scientific progress over this decade, the vaccine is one of several major medical advancements. In cancer, for example, we now have therapies able to cure advanced cancers by using a patient's own immune system to fight the disease. Furthermore, with new advanced sequencing technology, scientists have identified targetable mutations and created drugs that selectively block those mutations. As a result, we observed tumors melting away in patients with widespread disease. We are truly at an inflection point in science and as we look to facial pain, and pain in general, we have more reasons for hope than ever.

Progress occurred because of major advancements in our scientific technology. Some of the notable exciting advances in scientific tools include the ability to perform genetic sequencing now at the level of single cells rather than using large pieces of tissue. We can also extract genetic material from a simple blood draw to detect disease and monitor its progress. In addition, we can study how our immune system interacts with our body to cause pain or even cancer. These technologies are now being applied to all diseases, including pain. As a result, In TN, studies are now identifying new signaling genes and ion channels (that effect how nerves conduct signals) that have gone awry. These findings have implications for new classes of drugs. Others have also found alternative pain signals that could be responsible for facial pain and clinical trials are underway to target these and other signals in patients with TN and atypical TN. Furthermore, immune studies have better characterized the role of aberrant inflammation in pain. As we better understand the underlying mechanisms of pain and identify new targets, more effective therapeutics will be developed to treat these abnormal pathways and interactions. In some cases, we may be able to reverse these abnormalities as exciting new genetic technologies allow us to replace the faulty genes. Also, these technologies have the potential to be applied to conditions other than classical TN such as atypical facial pain.

We are inspired by the courage and strength of our patients in fighting their pain. This inspiration drives us to explore the biological basis of pain and discover new therapies. However, we know that progress is a team effort. Despite the amazing tools that we have at our fingertips, we could not have made these advancements without the participation of our patients (whether it be patients volunteering for a population study or donating samples). Together, we will overcome and cure facial pain. ■

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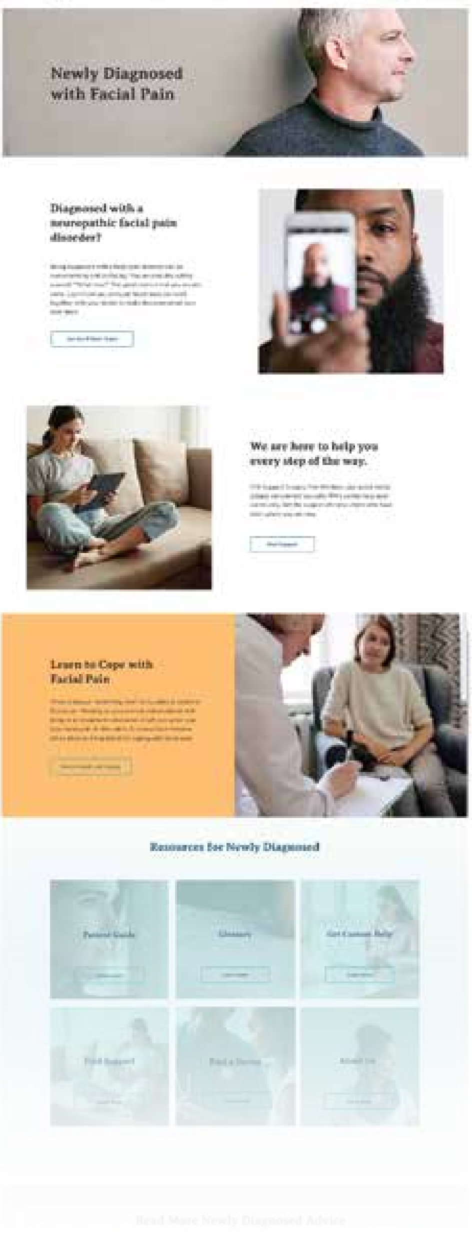


Newly Diagnosed with Facial Pain

Diagnosed with a neuropathic facial pain disorder?

We are here to help you every step of the way.

Learn to Cope with Facial Pain

Resources for Newly Diagnosed

Read More Newly Diagnosed Advice

We have a new logo

Facial pain management is complex. Over the last three decades, our outreach has expanded to include people with various symptoms, experiences, and facial pain diagnoses. If the challenges of 2020 have taught us anything, it is that FPA will continue to diversify our programs to meet the needs of the facial pain community. As we evolve, our mission to support, educate, and advocate for people living with neuropathic facial pain remains central to every decision we make.

As we turn our face towards the future, we have chosen a new logo that honors our legacy while communicating our ongoing commitment to inclusion.

Teal has become the color that represents awareness, and our new logo expresses our dedication to advocacy through awareness.

The three shades of teal represent the three core components of our mission: support, education, and advocacy.

The faces honor you, acknowledging your journey was likely not a direct path, but you are not alone.

The circle enclosing our logo's faces represents our commitment to providing access to everyone suffering from neuropathic facial pain regardless of diagnosis, age, or needs.

The Facial Pain Association continuously strives to be the most reliable and comprehensive resource for those affected by facial pain, their families, and healthcare professionals. Our new logo better aligns with this goal.

As we embark on this new era, we envision FPA reaching more people, better serving our community, and developing a large volunteer corps to support these efforts. In addition to our new logo, we will soon launch our new website. FPA's website will be faster, easier to navigate, and more accessible. We believe people with facial pain are best served when they are educated partners in their healthcare, and are supported by a caring network of others who have 'walked a mile in their shoes'. Our redesigned website (preview on left) will empower you to become educated about your condition and will connect you to the facial pain community.

Working hand-in-hand with medical experts treating neuropathic facial pain, our new website will be a hub for upcoming events, latest research, educational materials, and up to the minute information to help you live your best life. Your support makes all that we have accomplished possible.

Thank you for supporting the Facial Pain Association,

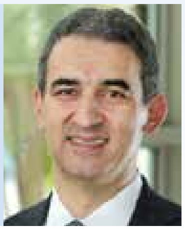
Allison Feldman
Chief Executive Officer

Shooting Pain in the Back of the Head: The Occipital Neuralgia

Konstantin V. Slavin, MD, FAANS

Professor, Department of Neurosurgery

University of Illinois at Chicago



It is not uncommon in a facial pain practice or in a headache clinic to hear from patients about pain in their face and head that originates, focuses, or culminates in the back of the head, the region that is called occiput. The patients' description of the pain location may – and usually does – help in making a correct diagnosis as most nerves in the head and neck region cover very specific anatomical distributions. The trigeminal nerve, for example, is the main provider of sensation to the entire half of one's face. Similarly, the sensation in the region behind the ear and above the hairline in the back of one's head is supplied by a very specific group of nerves, the occipital nerves. There are three occipital nerves on each side: the greater, the lesser, and the third occipital nerves, and all of them originate from the upper cervical spinal nerve roots, mainly from the second and third cervical levels (C2 and C3).

As the sensory information from the occiput is carried by the occipital nerves to the central nervous system, it travels through sensory ganglia and nerve roots and then enters the spinal cord in the upper part of the neck. There it is processed in the same area that is involved with sensation from the face and the rest of the head – the so called trigemino-cervical complex. These intricate connections explain frequent overlap of the occipital pain with various migraine and headache conditions as well as some instances of occipital pain radiating into the forehead or getting aggravated by the facial pain.

It is important to notice, however, that among many painful conditions that involve occipital region, the true occipital neuralgia – the subject of this paper – presents a very specific pain syndrome that can be successfully treated in most patients, as long it is properly diagnosed and addressed.

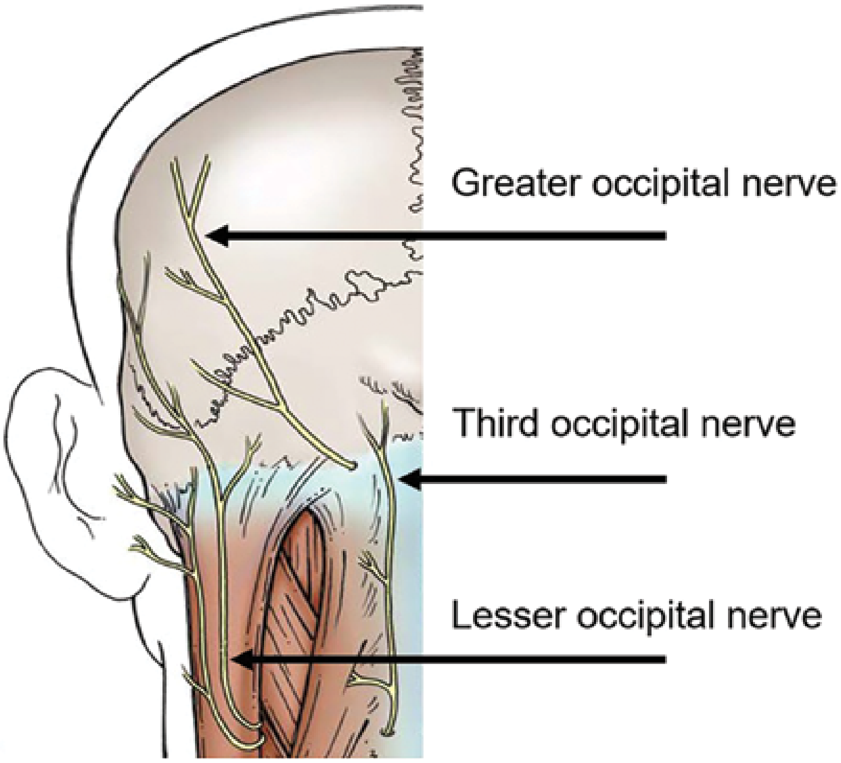
"Occipital Neuralgia" Continued on page 6

"Occipital Neuralgia" Continued from page 5

So what is the occipital neuralgia (ON)? It is a relatively rare condition that manifests itself with a pain on one or both sides of the head (unilateral ON is seen in 85% of cases). The pain usually starts in the back of the head and travels higher and toward the front, eventually reaching the very top of the head (the vertex). It is described as shooting, electric-shock like, or stabbing in nature (and this in medical terminology is referred to as paroxysmal lancinating pain). Very often there is also a dull aching pain between the shooting attacks located in the same general area. The duration of attacks lasting from few seconds to few minutes, the severe intensity of pain, presence of either tenderness over the course of the occipital nerves or trigger points within the occipital area, as well as pain or discomfort observed with innocuous stimulation of the scalp or hair (such as hair brushing or shampooing that would not normally cause pain) are all characteristic features of ON. Another classical feature that helps in making proper diagnosis is the improvement or disappearance of pain in response to numbing the nerve with an injection of local anesthetic in the vicinity of the nerve in question (nerve block). Such blocks are used to both diagnose and treat ON as the pain relief from a single injection may last quite long. In order to make diagnosis of ON, the patient is asked or tested for all of the above-mentioned features, keeping in mind that other conditions that present with pain in the occipital region (migraines, cluster headaches and hemicranias, tension headaches, cervicogenic headaches that arise from dysfunction of the joints within the spinal column and neighboring cervical muscles, etc.) have to be ruled out first.

Very frequently, in order to rule out associated anatomical pathology, it is necessary to perform appropriate imaging of the head and neck – this would usually include MRI of the brain and the cervical spine. The imaging would allow detection of Chiari malformations, cervical spondylosis, vascular, and neoplastic conditions; in most ON cases the MRI studies are read as normal or almost normal.

Interestingly enough, the exact source of pain in ON remains unknown – it is commonly accepted as a neuropathic pain condition, meaning that the underlying process is the malfunction of the nervous system. The occipital nerves, the culprit of ON, appear to be hyperactive and irritated but the reason for this irritation is often unclear. Multiple existing theories postulate compression or entrapment of the nerve or nerves anywhere along their course in the patient's neck and head, but there is no consensus or a universally accepted understanding of the underlying pathology.



As with all chronic pain syndromes, the treatment of ON is administered in systematic fashion – starting from conservative measures: medications, interventions, and ultimately, surgery. As the natural course of ON may be self-limiting and the pain may improve over time, it may be prudent to avoid risky interventions early on in the course of the disease, but medically-refractory cases (those not yielding to treatment) are often considered for invasive treatments as the pain may become disabling and making risks of interventional or surgical treatment justified.

The common initial treatments include application of cold and warm packs, massage, and physical therapy. Rest also frequently reduces the pain. Among available medications, initial preference is given to conventional anti-inflammatory drugs and muscle relaxants. The next level of treatment would include those commonly used for neuropathic pain conditions- anticonvulsants and antidepressants, including gabapentin, amitriptyline, pregabalin, carbamazepine, and nortriptyline. Although useful in relieving the pain, the opioid medications are to be avoided in ON and other neuropathic pain conditions.

The nerve blocks are considered next – and here one may use the block or blocks for diagnostic and for therapeutic purposes. Nerve blocks may include both short and long-lasting local anesthetics; the medications are injected in the vicinity of each suspected nerve, and as a result of injection the territory that the nerve supplies becomes temporarily numb. Along with numbness, patients experience improvement or complete relief of their ON pain, but duration of this relief tends to be longer than duration of numbness, and sometimes the pain relief may turn out to be long-lasting or even permanent. This course of events, however, is observed in only a small fraction of ON patients, and therefore the nerve blocks have to be repeated, usually with addition of corticosteroids to the local anesthetics, adding anti-inflammatory effect to the anesthesia.

Other interventional (non-surgical) ON treatment options include injections of botulinum toxin, pulsed radiofrequency treatments, and short-term electrical nerve stimulation (so called percutaneous electrical nerve stimulation or PENS). Each of these interventional modalities is able to provide significant reduction in pain intensity in a majority of ON patients, but the longevity of improvement varies from person to person and permanent pain relief is rarely seen.

Surgery is reserved for the most refractory patients who fail to respond to non-surgical treatments and those with intolerable pain who experience pain recurrence after the use of less invasive approaches. Although many specific surgical procedures are available for ON patients, all of them are divided into three main groups: decompression, neuromodulation, and neurodestruction.

Decompression surgery is based on a presumption that the pain comes from the occipital nerve(s) being compressed along their course through the muscles and fascial layers with additional aggravation from neighboring arteries that are expected to travel next to the nerves. During surgery, the nerves are released at one or several points, usually by cutting the adjacent muscle and fascia, and the additional compression points from the vessels are protected by physical separation of neural and vascular structures. In case of unsuccessful decompression or if the pain recurs due to scar formation, there is an option to interrupt transmission of painful signals or remove the hyperactive neural structures – this is accomplished by destructive interventions which include neurectomy or neurotomy, ganglionectomy, and rhizotomy that are aimed at the nerves, spinal ganglia, and spinal nerve roots, respectively. All of these interventions are considered established treatment options for ON, but the patients are expected to discuss with their surgeons the associated risks of complications and possibility of improvement, as well as contingency plans in cases of insufficient pain relief or pain recurrence.

A very different approach in treatment of ON is based on pain suppression with electrical stimulation that is delivered by an implanted device. This technique, called occipital nerve stimulation (ONS), was developed in the 1970's and perfected to its current shape in late 1990's. It is now considered a standard approach to the treatment of medically-refractory ON pain. Several years ago, practice guidelines backed by a national neurosurgical society (the Congress of Neurological Surgeons) recommended ONS for ON patients based on evidence gathered through multiple peer-reviewed publications. Despite this, however, ONS remains one of those procedures that require a complicated approval process from most insurance companies.

The surgery for ONS includes implantation of one or two electrodes in the immediate vicinity of the nerve so that the electrical pulses can reach the nerve when the device is activated. During the initial testing period (the trial), the electrodes are connected to an external device to check for the degree of improvement and presence of any side effects; these temporary (externalized) electrodes are usually removed at the end of the trial. Later on, the implantation of the permanent device involves insertion of both the electrodes and an internal pulse generator that

"Occipital Neuralgia" Continued on page 8

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serves as the power source and a "brain" of the ONS system. The devices available for ONS today allow patients to turn stimulation on and off, make it stronger and weaker, adjust settings, and switch between different programs based on pattern and severity of their pain. All of this is done with an external "remote control" that communicates with the implanted generator using telemetry. Among multiple generators and systems available for ONS today there are some devices that are rechargeable and can last, with proper recharging, up to 15 years.

No surgical treatment of ON is perfect – each modality has its own set of risks and limitations – but with proper diagnostic evaluation and clear expectations of treatment it is possible to achieve lasting pain relief, so the diagnosis of ON should not be considered a lifelong burden but rather a treatable condition that can be improved and potentially cured as long as there is a well-informed patient and a team of experienced and enthusiastic physicians and surgeons.

Disclaimer:
The FPA does not endorse any product, doctor, procedure, medical institution, or its staff.

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Volunteer Spotlight

My name is Susan Mills. I live in Sonoma, California. My trigeminal neuralgia pain started after a subepithelial connective tissue graft, an elective procedure used by periodontists to correct receding gums. After the procedure, I left the dental office feeling like something had gone wrong. I was in too much pain, too bruised, and too swollen for what was supposed to be a simple procedure. That day was October 18, 2012, and I have had constant burning pain ever since. Several months later, I was diagnosed by a neurologist who said, "I am so sorry this has happened to you."

I had never before heard the words "trigeminal neuralgia," and it has taken many years and too many doctors to count for me to understand the gravity of those two words. As I bounced from one doctor to another, I heard many more words to describe my condition... TN2, TN3, burning mouth syndrome, atypical facial pain, migraines, complex regional pain syndrome, neuralgia involving the distal branch of the maxillary nerve, chronic neuropathic facial pain following local anesthesia accident with pain in 2nd division, left branch of the 5th trigeminal nerve, trigeminal neuralgia, trigeminal neuropathy, chronic pain syndrome, and many others I cannot remember.

Prior to my periodontal injury, I was a healthy individual who worked out at the gym every day, did yoga on the beach, and walked 6 miles several days a week with my neighbor. On the weekends, I climbed mountains! Not anymore.

I have tried all the "tricks of the trade" typically prescribed by doctors for neuropathic pain including anticonvulsants, antidepressants, antispasmodics, nerve blocks, ketamine treatments, lidocaine infusions, acupuncture, chiropractic adjustments, photo-modulation, transcranial magnetic stimulation, cyberknife, and a radiofrequency rhizotomy, all with no relief. I recently completed an eight-week Chronic Pain Management Program. The only procedure I have not had is microvascular decompression surgery.

I felt all alone until one day I came across the FPA while searching on-line, determined to find a way out of this nightmare. I started attending a facial pain support group in the San Francisco/East Bay where I met others with the same or similar conditions. We shared our stories about doctors and procedures, medications and side effects, and how this condition had totally changed our lives.

I have attended three annual conferences. At the San Diego convention, I met Claire Patterson, who founded the FPA in 1990. I don't know where I would be today if I had not found the FPA. TN is considered an "orphan disease"; however, I seem to meet someone who has it or knows of someone who has it every week. I am a peer mentor

"Volunteer Spotlight" Continued on page 10

"Volunteer Spotlight" Continued from page 9

for the FPA and a co-leader for the San Francisco/East Bay support group that has recently merged with the Sacramento support group.

I am indebted to the FPA for all it has given me and I feel compelled to give back. You can too!

Start a support group in your community, or become a peer mentor. Attend support group meetings and annual conferences. Help fund raise.

Above all, spread the word to your medical community that there is help for their facial pain patients … and that is the Facial Pain Association. ■

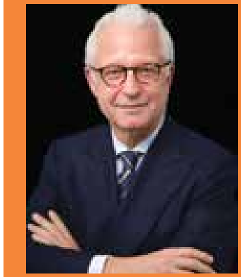
SPONSOR SPOTLIGHT

Weill Cornell Medicine
Brain & Spine Center

Our Facial Pain Program includes internationally recognized experts in the field who have advanced training in the very latest minimally invasive procedures used to treat TN.

Advanced Treatment for Facial Pain

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



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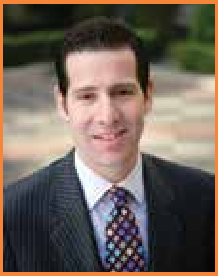

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Find out more at weillcornellbrainandspine.org/facial-pain-program or call one of our specialists to make an appointment.

Tips on How to Afford Your Prescription Medication

By Lindsey Thacker,
Certified Pharmacy Technician, YPC Committee Member

I was unprepared that the reality of having chronic health conditions would leave me in a state of financial insecurity. Over the past few years, I have learned to not only advocate for myself, but also for my patients. I wanted to share with you some of the most common questions we get from patients at the pharmacy that are struggling to afford their medication and what can be done to lower the cost.

What happens when the insurance rejects the claim for a medication?

- **Prior Authorization:** This is a term that nearly all of us have heard, however, many patients do not understand what it means or what the process is. If a medication requires a prior authorization, it could mean several things:
    1. The medication is not covered on your insurance plan.
    2. The medication is covered on your plan, but you must meet certain requirements for them to pay. When this happens, your doctor needs to submit information to insurance to prove that the medication is medically necessary.
    3. The medication is covered on your plan, but it requires step therapy. This means that the insurance would rather pay for cheaper alternatives. If you have tried alternative medications and they were not a good fit for you, your doctor can submit this information to insurance to get the medication covered.

The next big question is what needs to be done. When the rejection pops up at the pharmacy, the pharmacy will contact your doctor's office and inform them that a prior authorization needs to be completed. Your doctor's office will then contact your insurance and provide them with the information they need. Then, it is up to the insurance company to decide if they are going to cover the medication. Sometimes it will be an immediate response; however, it could take several days for them to make a decision. From the patient side, there is not much you can do during this process.

If the prior authorization is denied, there is still hope. Your doctor can appeal the prior authorization. If the appeal is denied, they can file a second level appeal. Finally, if that is denied, most insurance companies will let you do an external appeal through a third party.

What if a brand name medication is not covered?

- **Patient Assistance Programs**: The manufacturers want you on their brand name medications. They often have programs to help you get their medication. For example, if you are financially struggling or meet certain requirements, then you may be eligible for this. To see if you qualify, reach out to the manufacturer, and explain your situation. You never know how they might be able to help you until you reach out.
- **Independent Pharmacy Programs**: Some independent pharmacies are partnered with the manufacturers of brand name medication. They will sell the medication

"Prescription Medication Continued on page 12

“Prescription Medication Continued from page 11

for an extremely discounted “cash price”. This information should be listed on the medication’s website.

If a brand name medication is covered, how can I make it affordable?

- **Manufacturer Savings**: If you take brand name medication and have commercial insurance, these are your best friends. Nearly all brand name medications have a coupon from the manufacturer. There are two ways to get manufacturer coupons: looking online and your doctor’s office. If you go online, search the “name of the drug savings” and click on the medication’s website. It will have you fill out a quick form and then you email or download the card. Take this information to the pharmacy so they can apply the savings!

What if a generic medication is not covered?

- **Prescription Savings Cards**: If it is not a name brand medication, prescription savings cards and programs that can help you. There are websites like GoodRx and AmericasPharmacy where you can search the name of your medication and it will show you the price of the medication with their coupon card at different pharmacies. Not all pharmacies accept these, so reach out to your pharmacy before you decide to go this route.

- **Pharmacy Savings Programs:** Walmart, wholesale clubs and many retail pharmacies offer RX savings programs. Walmart has a list of medications that are $4 for a 30-day supply and $10 for a 90-day supply. Wholesale stores will offer a discount for those that pay for a membership to the club. Many retail pharmacies are starting to offer similar programs. If you pay a yearly fee, you can receive a discount on your prescriptions.

What if I cannot afford my medication?

- **Assistance Programs Run by the State:** If you are having a hard time affording your medication, some states offer Medicaid programs that you can use as a supplement. Requirements differ in every state.

- **Assistance Programs Run by Nonprofit Groups:** These programs will help pay for your prescriptions. There are several ways to find non-profit assistance programs. If you are religious, with your place of worship. Many will have assistance programs set up for their members and sometimes even can help people outside of the church. While I am unaware of a program for those with Trigeminal Neuralgia, there are some conditions that have assistance programs to help with copays. If you have other conditions, it could be worth looking into. There are also programs online for those with low income or on disability. If you need help, reach out to several programs, and see what you qualify for. They are here to help you.

- **RX Savings Cards and Programs:** Even if the medication is covered by your insurance, sometimes you can get it cheaper by utilizing these cards and programs as mentioned above.

If you have any additional questions, please do not hesitate to reach out. You can contact me through the Young Patients Committee of the Facial Pain Association. Our email is youngpatientscommittee@gmail.com

Disclaimer:
The FPA does not endorse any product, doctor, procedure, medical institution, or its staff.

Managing Pharmacy Costs

Awareness Conversation Starters

YPC Facial Pain Association
Young Patients Committee

Article contributed by the YPC

Living with a rare disease like trigeminal neuralgia or any of the many facial neuralgias we all experience can be isolating. One thing that 2020 taught the world is the importance of human interaction. This year, we encourage you to foster knowledge. For those who don't live with a rare disease, research leads to knowledge which breeds empathy.

Empathy is a very strong emotion that can help us to not feel as isolated in our pain. Having those difficult conversations can be a first step to bridge the gap between those of us who experience pain and those who do not.

Kickstarting these conversations can be challenging; they require us to lean into our vulnerabilities and share something that is very personal. We've come up with a few tips and conversation starters to help with these conversations.

Utilize Plural Pronouns

If you aren't comfortable sharing your own personal experience, use plural pronouns like 'us', 'they', or 'we' to share the experience of facial pain. Phrases like "when we feel pain it comes in the form of electrical shocks" or "taking lots of different types of medications is normal for us" can be just as powerful as "I feel electrical shocks" or "I take four types of medications for my pain." Using broad statements like this won't take away from the impact of what you're saying, but it does give you the opportunity to avoid complete vulnerability. We should have the choice what to share with the world about our pain while still being able to bring awareness to those around us.

Start with a Question

Questions are an easy way to start conversations and they give you a chance to see what they may already know about facial pain. When dealing with difficult conversations, you want to give the other party a chance to speak too. Asking questions pulls people into the conversation. It also gives the other person permission to ask questions.

You can start with, "Have you heard of Rare Disease Day?" or "Did you know that October 7th is International Trigeminal Neuralgia Awareness Day?" to start a broad conversation. But questions like, "Did you learn about facial pain in your college health class?" or "Have you ever noticed that sometimes I need to wear face coverings outside?" will draw the other party into more specific conversations about facial pain.

Lean Into Your Emotions

One of the hardest things to do when talking about difficult things is to have a constructive conversation while trying to hold in your emotions. Showing an emotional side of things, whether it be anger or tears, doesn't take away from the validity of your words. In fact, it only heightens the power you show. People will remember the conversations that made them feel something.

"Awareness" Continued on page 14

"Awareness" Continued from page 13

Allowing yourself to feel and show how you're feeling gives the other person a chance to step into a sphere of understanding. Facial pain is an emotional rollercoaster, lean into the rollercoaster and see where it takes you!

These tips will hopefully help you to share with those around you about facial pain and to help us bring awareness to our experience. Whether you lean into your emotions or choose to speak broadly about facial pain, speaking up is an empowering phenomenon. We are proud of your strength! ■

Useful links

- /tnypc
- /youngpatients
- /tnaypc
- /facialpainassociation
- www.facepain.org

YPC PROFILE:
Brian McNeal

YPC Facial Pain Association
Young Patients Committee

How old are you?

I am 34 years old.

Where do you live?

Delaware, Ohio- north of Columbus.

What is/are your diagnosis?

I have atypical trigeminal neuropathic pain from multiple dental traumas as well as 2 compressions against my trigeminal nerve causing classic TN shocking pain in addition to the constant pain.

When did you first experience neuropathic facial pain?

I first started having excruciating pain following a common root canal. They told me I likely just had an infection, and it would go away, it didn't. Two weeks later I was back at the ER in the same horrific pain and again they just told me to be patient and it would subside. Unfortunately, it took 2 years to determine something more substantial was the cause and I was diagnosed with Trigeminal Neuralgia. Another year after that I learned from Dr. Casey in Michigan my exact condition, and 4 months ago it was confirmed with Dr. Linskey's thorough evaluation.

What do you do in your free time?

I own a small business building custom furniture and décor. In my free time, I love to spend time with my wife and boys outdoors playing sports or riding bikes or going to a park playground.

What has TN taught you?

TN has taught me that no matter what my situation is, it can always be worse. Pain, discomfort, or dissatisfaction are all relative to what I tell myself I can endure. I must remind myself that no one will make my pain disappear, so I have to suck it up and fight to get through each day however I can.

What non-surgical procedures have you tried?

In the beginning when doctors did not trust the severity of my pain, I tried every non-prescription medication you can name. I went to multiple chiropractors, an acupuncturist, massage therapists and masseuses. I have had Botox, bought heating pads, ice, tens units, and muscle stimulators. I tried a dozen different topical creams including ketamine, CBD's with and without THC and even one with hydrocodone in it. My dentist friend tried typical numbing injections. I have taken oral, topical, and injectable steroids. The list of prescribed medications is enough to fill a pharmacy. I have taken 5 of the top TN antiseizure medications but because of my type 1 diabetes responding negatively was narrowed down to only oxcarbazepine. I have taken opioid medications, have tried marijuana in multiple forms, and have just recently began a series of stem cell injections. I am probably missing quite a few others, but these are many non-surgical treatments I have tried.

Have you had any surgical procedures?

Our insurance currently does not understand the complexity of my diagnosis and unfortunately is refusing to support our desires to get an MVD from someone qualified to do an "empirical" or "exploratory" MVD as opposed to a "classic MVD." Once we know that we will not have consequences from exploring surgery "out-of-network," we will try to find a way to financially pay to have Dr. Linskey do the MVD as a desperate attempt at gaining back a fraction of my normal life and work capacity.

How has your facial pain changed you?

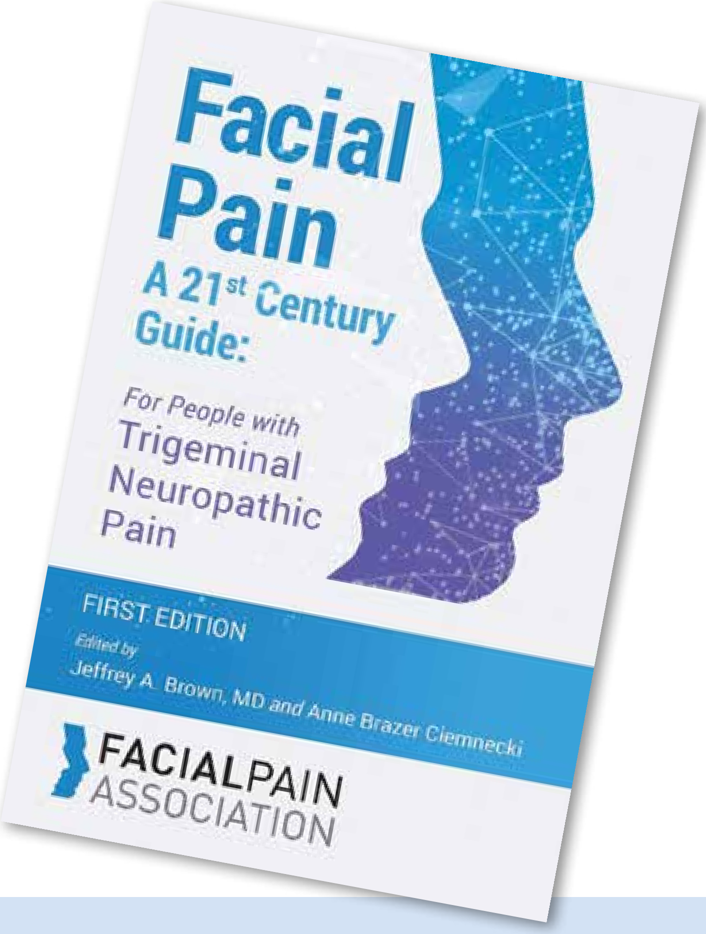
I won't lie, every day I look at the life I want to be living and acknowledge the gap that exists between that and reality. Then, I fight like crazy to fill my mind with the hope for each day and getting the most I can out of it. Some days that is harder than others to accomplish, but I have to fight it for my two boys, my marriage, and the rest of my friends and family that watch and pray for my survival. We are blessed to have so many people offer to help support us right now either in tangible physical form or just emotionally.

What tips do you have for other young patients?

My hope for each of us dealing with this lifestyle and struggle is continually to never give up, and never stop believing that one day something will change. This is not a journey we chose to endure, but it is our duty to fight and survive and to be an encouragement to the others battling to survive. God has a purpose for why I am dealing with this condition. And regardless of me knowing why that is, I must trust that good will come from it somehow, and I do. ■

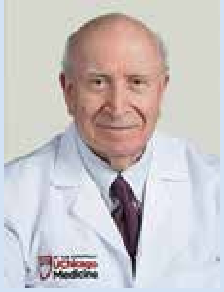
FPA Book and Webinar Series Offer Valuable Information

In October 2020, FPA published **Facial Pain: A 21st Century Guide**. Thirty world experts in the diagnosis, treatment, and management of trigeminal neuropathic pain contributed their expertise to cover the full breadth of knowledge in the field to this comprehensive book.


Facial Pain
A 21st Century Guide:
For People with Trigeminal Neuropathic Pain
FIRST EDITION
Edited by
Jeffrey A. Brown, MD and Anne Brazer Ciemnecki
FACIALPAIN ASSOCIATION

This year FPA launched a new webinar series based on topics covered in the book, including:


The Dialectic of Pain:
Synthesizing Acceptance and Change
Deborah Barrett , PhD, MSW, LCSW


Speaking with Your Doctor:
What Makes the Ideal Professional
Javad Hekmat-panah, MD


A Mindfulness-Based Approach for
Coping with Chronic Pain
Jonathan Greenberg, PhD

If you have not yet attended an FPA webinar, or it has been a while, we hope you will join us for this important series. Webinars provide you an opportunity to learn more about a variety of facial pain-related topics and allow you to interact directly with the experts.

One of the priorities of the FPA this year is to increase the information and education we provide about mental health and integrative health therapies, in addition to the medical content we have always offered.

All FPA webinars are broadcasted live, are free, and open to all!

Visit FPA's website, www.facepain.org, to view past webinars and register for upcoming webinars.

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CYNTHIA BENNETT, Sustainer Circle Member

I found our local support group 20 years and two procedures after facial pain began for me. If only I had known those years before then what I began to learn afterward, I might not have felt so alone or misunderstood. I consider the FPA and its website and literature to be true lifesavers. The national and regional conferences, where patients can have direct contact with the many supporting physicians, dentists and fellow facial pain patients have been particularly meaningful to me. I have the utmost admiration of and respect for those who keep the FPA afloat and consider them vital to all of us with facial pain. I am deeply grateful for the education and hope the FPA has provided to me. It is a privilege to give a few dollars each month to say thank you and to help sustain this crucial organization.

FACIALPAIN ASSOCIATION SUSTAINER CIRCLE

The Sustainer Circle is an incredible community of monthly givers who help ensure that FPA meets our mission of support, education and advocacy of the facial pain community.

This opportunity allows you to set up automatic monthly donations.

- **It's Convenient.** No need to write checks and no payments to remember.
- **It's Flexible.** You decide how much you want your monthly gift to be.
- **It's Rewarding.** Watch your monthly gifts add up and make an impact.
- **How Do I Join?** Visit facepain.org. Decide your gift level, click "DONATE," and start providing ongoing help to the facial pain community!

A monthly gift of $10, $20, $50 or more makes giving easy and often allows you to make a more generous gift to support the facial pain community by breaking it down into smaller increments. To join the FPA Sustainers Circle, go to the online giving form and indicate that you want to make a monthly gift and designate the amount.

We gratefully recognize all donors who have joined the Sustainers Circle, having funds directly charged to their credit card or withdrawn from their bank account automatically each month. These donations provide a reliable source of funding that allows us to sustain the initiatives of the Facial Pain Association while spending fewer resources on fundraising.

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FPA's Honorary and Memorial Tribute

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 people with neuropathic facial pain and their families. We are delighted to share recent Tribute gifts received from ***December 2020– February 2021***

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All Patients, Caregivers, Family & Friends
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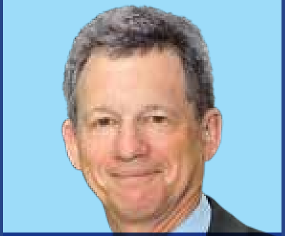

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Dr. Brown is the chairman of the Medical Advisory Board of the TNA-The Facial Pain Association. He serves as the Neurosurgery Director of the NYU Winthrop Hospital CyberKnife® Program in Mineola, NY.

Alan Mechanic,, M.D.

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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