

Please note that the sites currently enrolling subjects include Kaizen Brain Center - La Jolla, California; University of South Florida - Tampa, Florida; University of Cincinnati — Cincinnati, Ohio; and Columbia University Irving Medical Center - New York, NY this time.

### SPONSOR SPOTLIGHT

# Face Pain?



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# From the Board Chair

• The FPA's fourth annual virtual conference will be held this April, and it will include a great deal of information, empowering you to more effectively navigate your care whenever and wherever you

Helping You Where You Are will be our focus this year, but we will also be working hard to connect with those who we aren't effectively reaching, primarily those with lower education levels and lower income. Sadly, the entire healthcare system has been ineffective in reaching this community. Simply put, we can't help someone "where they are" if we're not even reaching them. To that end, I'm pleased to report that the FPA recently received its first grant — a grant to help us reach those in rural and other underserved communities.

In closing, I hope the overarching thought you take away from this letter is the sense that the FPA is working diligently to be helpful to everyone living with facial pain. For those of you who donated to our organization last year, I hope you can clearly see that your investment in the FPA is yielding big things. Without your generous help, we simply couldn't be doing these things. Thank you for supporting our mission of reaching every person with facial pain, wherever they are.

We are a community because we share some very important things: We either share the experience of having this terrible pain or helping someone who does; we share the need to find help to eliminate or manage the pain; we often either need support from others or are in a position to provide that support; and we share the need to simply know that we are not alone.

Although we have some shared experiences, we are not exactly the same. In addition to our differences geographically, demographically, medically and more, we are all in different places dealing with facial pain. Most of us at the FPA know this – because we are also dealing with this pain. So, the theme for the FPA this year is "Helping You Where You Are."

That's a snazzy theme, but what does it mean? It will mean many different things to you, but here are some examples to reassure you that this effort is real:

- The Quarterly journal is going to periodically deliver resources in the forms of inserts and tear-outs you can keep until you need them (e.g., recommendations for emergency room physicians about the best care for a person with trigeminal neuralgia (TN) or other neuropathic facial pain).
- Improvements to the FPA's mobile website so you'll have quick information at your fingertips when you need it.
- The FPA has redoubled its efforts to ensure that all ~200,000 dentists in the U.S. are aware of TN and other neuropathic facial pain so that unnecessary dental procedures are avoided, and proper treatment is delivered faster.
- The FPA has also started to ensure that the ~16,000 neurologists in the U.S. are even more aware of all the medications and procedures that are available to help you.

**David Mevers Board Chair** 

need to.

The Facial Pain Association

# A Message From the CEO



Every January, many people look forward to the new year with hopes and dreams, goals and objectives. The Facial Pain Association (FPA) is no different. We have spent the last several months thinking and planning for the best ways to fulfill our mission, to serve everyone living with facial pain.

That is a tall order. We are all on different paths, in different places in our journeys. Some have just been diagnosed. Others have been living with pain for many years. Many people care for someone who has facial pain and still others are managing their pain or are pain free. The needs for each of these groups are unique, and the FPA is committed to addressing all of them.

Our focus this year is ensuring we meet you where you are, providing support how and when you need it most. So, within the different paths and all of the experiences lived by those with facial pain, the Facial Pain Association has educational opportunities, options for support, and ways to advocate for one another. You'll see this theme throughout the year. The cover of this magazine shows a maze with the sun shining down on all of the different paths. The FPA is that light, reaching you where you are. We're planning another virtual conference for late April 2024, and our new conference logo shows a maze inside the circle representing the faces of those living with facial pain - it shows that we are with you on your journey with facial pain, no matter where you are on your path.

We have several initiatives that will help us accomplish our goals.

### Accessibility

We are working on our website to make it more accessible, adding a better mobile experience, multilingual materials, and new navigation to make resources easier to find and access.

### **Dentists & Neurologists**

An initiative to educate dentists that was launched in 2022 will continue and expand to educating neurologists as well. While our primary goal with the dentist initiative is to educate dental professionals in an effort to avoid unnecessary dental procedures for people with neuropathic facial pain, our neurologist initiative will have a different focus. To be clear, we understand that many neurologists already know a great deal about trigeminal neuralgia, but it is still a relatively rare condition. Some specialists may only see a few cases of facial pain in their careers. Our goal is to expand the knowledge of neurologists, so they know the breadth of treatment options available to people who live with facial pain every day.

### **Patient Registry**

Earlier this year, the FPA joined the National Organization for Rare Diseases (NORD) and we are closer than ever to launching our patient registry. NORD's IAMRARE platform supports the registries of many nonprofits and offers the benefit of a proven partner to help us build this incredible resource. With your contributions to the registry, we will build a collection of data that will benefit researchers and inform our efforts to affect change in the facial pain community.

#### Inclusiveness

A generous donor asked about the FPA's efforts to be inclusive - to reach communities that are typically underserved. While we have made efforts to increase our representation, to add accessibility to our resources, to make our educational opportunities available to everyone, regardless of their location, we need to go further. We need to reach those in rural areas, who not only don't have a facial pain specialist available to them but may not have a primary care physician; they may not have access to the internet. We want to make our resources consumable for everyone, regardless of education level or exposure to medical terminology. We know that people in

pain need accessibility and ease in their search for resources. We need to meet them where they are.

I hope you'll join our growing corps of dedicated volunteers, our amazing staff, and our medical and research partners as we band together to achieve these goals. Whether it is through our efforts to educate, support, or advocate for those living with facial pain, we are here for you, no matter where you are in the maze of your facial pain journey.

Muliera Baumbick

Melissa Baumbick

Chief Executive Officer. The Facial Pain Association

# Save the Date



The 2024 FPA Conference will be a two-day virtual event connecting the worldwide facial pain community with experts who diagnose and treat people affected by neuropathic facial pain.

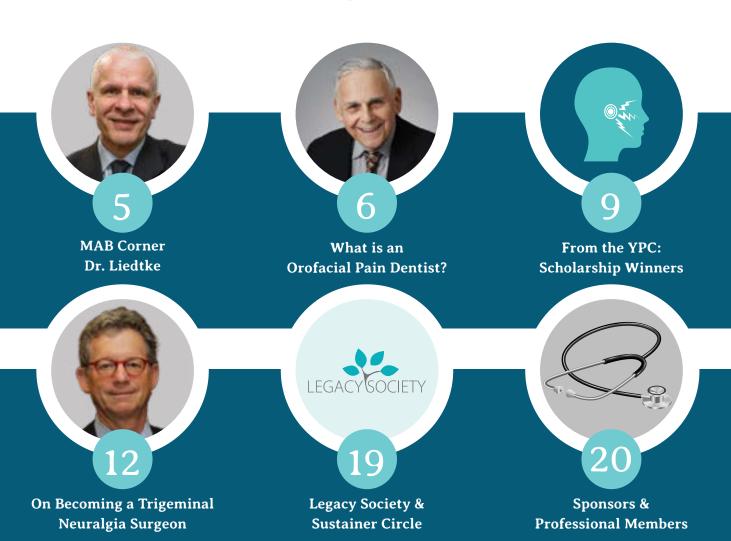
### Registration will open in February 2024.

Send an email to info@facepain.org or visit www.facepain.org to join the FPA's mailing list. Be the first to know when registration opens and receive the most up-to-date information on presenters and topics.





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Art and Design

# The MAB Corner

The FPA congratulates Dr. Liedtke on his election to the American Clinical and Climatological Association



Wolfgang Liedtke, MD, PhD

"Wow I'm in!" — it immediately hit me when I recently opened an e-mail from the American Clinical and Climatological Association (ACCA). Sounds like an unusual society —is this a recently founded group concerned with climate change?

Not at all — the American Clinical and Climatological Association was founded in 1884. As such, it is one of the oldest medical societies. At that time, there were no antibiotics, the world was on the cusp of discovering the bacterial cause of tuberculosis

(1890), inhalation anesthesia had only been around since 1846 (intravenous anesthesia was invented in 1934), there were no psychiatric medicines, no insulin, no anti thrombotic therapy, no modern-day analgesics, and no anti-

inflammatories — doctors took advantage of ambient climatic conditions to control chronic disease, e.g. tuberculosis. Tuberculosis was a pressing un-met medical need in the latter half of the 19th century —patients became increasingly frail, gradually lost weight, and became anemic. Leading doctors aimed to enhance the resilience of chronic tuberculosis sufferers by exposing them to preferred climatic conditions and enhancing their nourishment. These doctors, at the time, represented an elite cadre of clinicians who tried to more rationally understand chronic disease and enhance their understanding by forming a dedicated association — sort of teaming up against disease.

The American Clinical and Climatological Association has kept its original name, and although it introduces a whiff of double-entendre, the organization has withstood the test of time with flying colors. It is a medical organization dedicated to rationale-based yet empathy-centered clinical care, with a strategic centerpiece of keeping membership highly restricted. This brings together 250 leading medical minds from the US and some from abroad. I am very proud to have been elected to the ACCA.

The American Clinical and Climatological Association is not obscure — members are publicly announced in their Transactions of the American Clinical and Climatological Association. At a glance, it is an eclectic crowd. Upon closer inspection, the robust cadre of internal medicine physicians at the heart of the association cannot be missed, a persistent principle since its inauguration. Clinical neuroscience and pain medicine are not palpably represented. I am part of that latter crowd, coming from the "neuro

corner" of science. Since the American Clinical and Climatological Association appears to adhere to their time-tested principles, how come a candidate from left field like me got in? There must have been some good luck and a fabulous presentation by my nominators. But in

terms of substance that carried my nomination over the finish line, I know that my nominators stressed my foundational discovery of TRPV4 ion channels with their general medical and physiological relevance (e.g. not only in sensory function and pain, but also in physiology and diseases of the heart, lung, skin, immune system, and so many more), together with my equally strong leg as a caring doctor who leverages experience, intuition, and scientific understanding to make a difference in my clinics.

As a member of the American Clinical and Climatological Association, I will make new friends in the medical field, enhance my network, always be mindful of patients suffering from trigeminal neuropathic pain, and hold up their flag resolutely.

My best,

Wolfgang Liedtke, MD, PhD

FPA Medical Advisory Board Member Chair of Neurology, Psychiatry, Pain Medicine, and Sensory Systems at Regeneron Pharmaceuticals Member of the Global Development Scientific Council

Please Note: Opinions expressed here do not represent the view of Dr. Liedtke's employer, Regeneron Pharmaceuticals nor of his academic affiliates, Duke University and New York University College of Dentistry.

# What is an **Orofacial Pain Dentist?**



Stanley Markman DDS, DABOP, FACD, FAGD, FOFP

Decades ago, when I started my dental practice, I occasionally encountered perplexing patient pain issues. More than once I completed what I believed to be a successful root canal treatment, but the patient reported severe postoperative pain. Naturally, I repeated the treatment, for if the patient had pain, there must have been something wrong with my technique—though I had no idea what it could be. When the pain did not subside, I referred the patient to an endodontist who repeated the treatment and later did an apicoectomy. Ultimately, the tooth was extracted. In one case, the pain disappeared after the extraction, and in another case, the pain remained after tooth removal. I assumed from those experiences that root canal therapy does not work for everyone.

Orofacial pain specialists can help dentists solve the mystery of unexplained facial pain. They can provide relief to patients who might otherwise go undiagnosed and untreated or improperly treated.

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Another time a patient presented with tooth pain. A clinical exam of the tooth and surrounding area and a radiograph indicated that there was no dental pathology. The only time she experienced tooth pain was when she was chewing food. I assumed that the patient had some psychological problems, but I did refer her to an endodontist, who later informed me that he could find no reason for the pain.

Another remembrance is the patient who presented with complaints of a burning tongue. She had burning pain when she awoke, which gradually worsened as the day progressed. She reported that food no longer had a normal taste. As I did not know how to manage the problem, I suggested she see a physician. She said that she had already seen five and none had offered a treatment solution.

"Those were the ones I remember. There must have been others whose pain I could not resolve."



Thirty or more years later, while screening patients in a dental school with a colleague, I encountered a patient who would be a candidate for a partial denture except that she had issues with opening her mouth. I told my fellow examiner that this patient could not be seen by an undergraduate because of a TMJ problem. He said she should be sent to the orofacial pain department for treatment. I had been teaching in the school for two years and did not know there was such a department. I was curious about what that department did and arranged to spend some time there. It turned out to be an eye-opening experience for me.

I was intrigued with the treatments that I saw. In the clinic, they were treating patients not only for TMD but also for a variety of pain issues involving the neck, face, and head. I enrolled in a training program, became a teacher, and later took the Academic Orofacial Pain Boards to become a credentialed specialist. Now I have the designation diplomate of the American Board of Orofacial Pain.

What to call an orofacial pain specialist is actually a dilemma that our association is attempting to figure out. Neurodontist? Cephalodontist? Orofacialdontist? Other suggested names are orofacialist, orodontist, ododorist, OFPainist, and an OFDolorist.

# What preparation is required to become an orofacial pain specialist?

The orofacial pain curriculum focuses on pharmacology, neuroanatomy, neuronal pain pathways, neurology, muscle physiology, structural knowledge of brain stem and the brain, the somatosensory nervous system, continuing updates on pharmacology, and common orofacial pain diseases.

There is significant emphasis on clinical diagnoses in order to identify obscure orofacial diseases. We learn about pulmonology so we can treat obstructive sleep apnea with appliance therapy. We learn about diagnostic medical and CPT coding. The curriculum covers the location of the cranial nerves and their function and how the body creates spinal fluid and melatonin.

There is constant review of physiology and the functions of the sympathetic and parasympathetic autonomic systems. Clinical training on the treatment of trigeminal neuralgia and TMD issues—especially those associated with muscle pain—is included. There is training on differential diagnosis to distinguish between the many varieties of headache, including migraine, and how to diagnose so-called "dental phantom pain," where there is tooth pain but no diagnosable tooth pathology.

### What do OFP specialists do?

When dentists hear about an orofacial pain specialist, they are likely to think of a dentist who specializes in TMD issues or someone who makes appliances. However, OFP specialists do much more, including prescribing antivirus and analgesic cortisone-type medications. We provide trigger point injections, nerve block injections, neuropathy treatment with medications, and Botox injections for muscle pain, and we diagnose systemic conditions that mimic TMD pain. Patients receive prescriptions for blood work, which are reviewed by orofacial pain dentists.

We are kind of like neurologists of the face. Our practice is much like medical practice. Medical insurance forms are completed for the patients. Dental insurance is not used, as it does not apply for what we do. Some of our offices are set up without traditional dental equipment.

A common type of patient we see is one who has been treated for what appears to be dental pain, incorrectly diagnosed. Some have had multiple root canal treatments on one side of their jaw for the purpose of eliminating pain. The problem is that the patient had non-odontogenic pain, unrecognized, or rather, undiagnosed. Such pain is referred to as neuropathic pain and will not respond to regular dental treatment. Dental procedures ameliorate somatic pain.

We can help general dentists a great deal by giving a name to the pain they see that does not make sense. As an example, a patient, medicated for trigeminal neuralgia by a neurologist, was seen by a dentist who could not treat a lower posterior tooth because the

"Orofacial Pain Dentist" continued on page 8



"Orofacial Pain Dentist" continued from page 7

patient felt severe shocking pain when the dentist attempted to retract her cheek. He did not realize that he was activating a trigger zone by pulling on her cheek. The inner aspect of the patient's cheek was painted with a topical anesthetic, which muted the trigger zone's response. Pulling on the cheek now caused no problem, and we informed the dentist what to do to help the patient.

Orofacial pain specialists understand the many physiological aspects of pain. They can help you with diagnosing what appears to be the weird facial and head pains your patients may experience. When your patient's pain is eerie, mystifying, or strange, avoid doing dental procedures and refer the patient to an orofacial pain specialist.

Dentists in North America are eligible for a complimentary print subscription from Dental Economics.

# Some conditions that OFP specialists diagnose or treat include:

- Trigeminal neuralgia
- Glossopharyngeal neuralgia
- Occipital neuralgia
- Geniculate neuralgia
- Facial shingles
- Postherpetic neuralgia
- Facial myalgia
- Myofascial pain
- Phantom dental pain
- Obstructive sleep apnea

- TMD treatment for myalgia
- TMD treatment for skeletal pain
- Migraine headache
- Tension-type headache
- Headache induced by referred muscle trigger points
- Toothlike pain from a mid-face migraine
- Toothlike pain from a sinus infection
- Lateral nasal numbness when the sinus membrane thickens due to a bacterial or viral infiltration

#### **Medical Editor Glossary of Terms:**

- Apicoectomy wherein more of the tooth is removed Odontogenic dental
- TMD temproromandibular disorders

- We orofacial pain specialists





# Bennett Decker

As an incoming rabbinical student, I think a great deal about how to contextualize my experience of chronic pain within a Jewish context. Judaism plays a central role in my life, and the way I experience the world is always reflected through the lens of Judaism... My trigeminal neuralgia has, despite, or perhaps because of my pain, offered me new opportunities to reexamine pieces of Jewish text or theology in ways that able-bodied people might not. Where is my tradition speaking to me in a way that it hasn't spoken to others? Where is it ignoring me? In this way, my trigeminal neuralgia has taught me to understand my religion – its texts, vernacular, culture, and identity – in ways that those without

TN, or chronic pain at large, might not. This lens has equipped me with a unique opportunity to examine a particular example of Jewish parlance, its inadequacies in speaking to those with chronic pain, and where Jewish theology and tradition must grow in order to talk to Jews of all bodies and experiences... It is difficult to transfer meaning from one term to another without anything lost in the exchange. No other term can easily substitute for the weight of "refuah shlema," and yet "refuah shlema" lacks the power needed to meet the needs that the full spectrum of human illness demands of our compassion. The communal norms we perform simply are not as wide as our communities... As I think about what I want my rabbinate to look like, I want to sharpen my capacity as a religious leader to create more expansive Jewish language that speaks to the whole of the Jewish community. With my own chronic facial pain in mind, I will endeavor to expand Jewish rituals to include a broad range of Jewish experiences and individuals. Particularly, I want to have a hand in creating healing rituals and language for people who won't experience an end to their illness life.

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### Facial Pain Resiliency Scholarship Recipients continued from page 9



# Sarah Salvatierra

Due to my experiences navigating the complexities of the healthcare system and living with occipital neuralgia, I'd like to think I'm no longer as cocky as my younger self. Rather, facial pain has humbled me and given me new insight into how patients with chronic health conditions struggle. I no longer want to bend the world but instead mold my own heart towards the capacity for suffering—I hope to become a therapist who bridges the specialization gap in mental health services for people with chronic conditions and pain (and I would love to one day treat patients

with facial pain!). On top of that, my spark has returned, and I seek to become a fierce advocate for my clients, especially those who are part of low-income communities of color, are LGBTQ+, or are experiencing homelessness.

For other young patients affected by facial pain, especially those feeling like they are at the end of their rope, I would like you to know that you are not alone. There is a community out there of people just like you who are willing to listen, share their experiences, and offer resources. While it's true that facial pain has impacted the trajectory of my life, I've remained resilient because of the help of people in the FPA, especially the Young Patients Committee. Joy has gradually found its way back into my life as I carefully rebuild new, steadier foundations with the support of others. I used to be terrified of asking for help, thinking it meant that I was weak, but there is profound strength and bravery in reaching out to people and being honest with your feelings.

The Young Patients Committee Facial Pain Resiliency Academic Scholarship is available to students in the US between the ages of 18-40 attending school, college, or university that have facial pain. An exception to age will be made if you are 17 and entering college in the semester following the application. Applicants must complete this application in full, including upload requests, to be deemed eligible for award consideration. Be on the lookout for the next application round!



## Connect with the FPA Young Patients Committee!









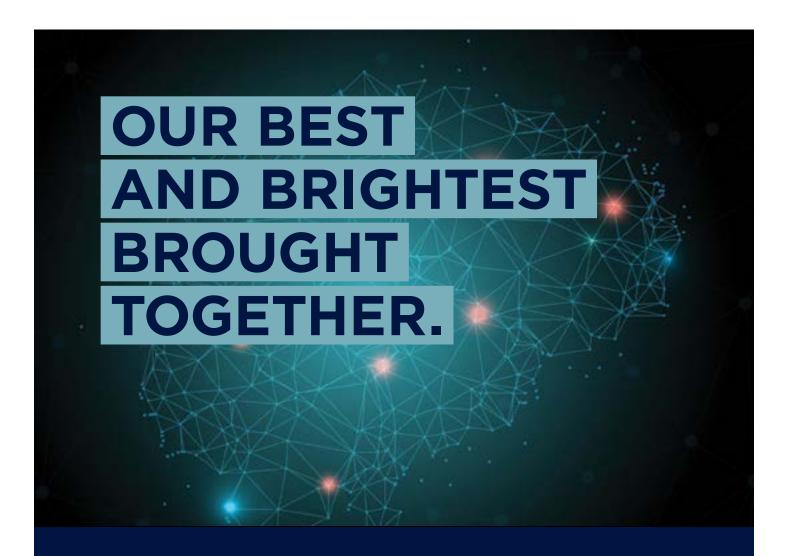


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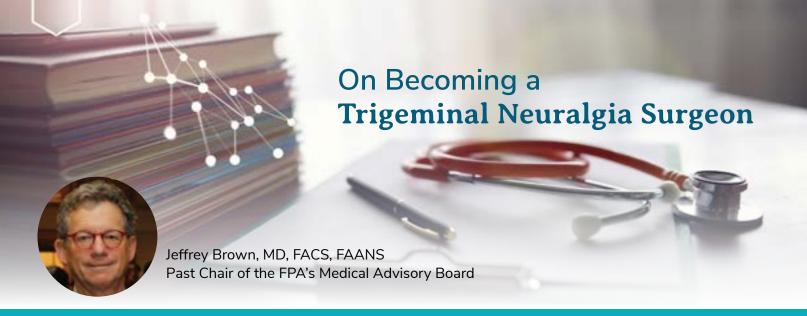
The Brain and Spine Institute at UConn Health provides exceptional care for patients suffering from disorders of the brain and spine. Our world-renowned experts from neurology, cranial neurosurgery, spine surgery, non-operative spine care, and neuroradiology collaborate to offer you comprehensive, personalized care.

The team at The Brain and Spine Institute provides support and resources for patients through every step of their journey. Our providers offer compassionate care for you from diagnosis to treatment and ensure you understand all of your care options.



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# The FPA congratulates Dr. Brown on his retirement and thanks him for his decades of service to the facial pain community.

When I chose to do a residency in neurosurgery, it had a well-deserved reputation for being a brutally intense experience. In a class of one hundred medical student graduates, on average, only one would even

apply. When I started my training, computed tomography (CT) scans were just coming into the world of medicine: few were available. Magnetic resonance imaging (MRI) scans did not exist. There were no physician assistants to share in the workload. Every other night, hospital calls were routine. Fellowship programs and sub-specialties did not exist in the field, so neurosurgeons were expected to be experts in all areas — pediatrics, spine, peripheral

nerve, brain and spinal tumors, vascular and pain surgery. The rigor continued for six years, each year bringing more responsibility.

The resident selected to follow me in my training program developed a bleeding ulcer during his first neurosurgery rotation. He resigned. His replacement decided to become a pathologist. He resigned. The next resident selected was a woman — there were only a handful of courageous women in neurosurgery then. Neurosurgeons modeled themselves after the father of the field, Dr. Harvey Cushing, who was a brutal taskmaster and had never trained a woman.

The highly competent woman resigned after her first year.

We had only cerebral angiography to guide us in the

decision-making process of whether a blood clot, brain tumor, or aneurysm was present. We did our own cerebral angiography for emergencies, and on the south side of Chicago, there were many. We did not depend on the few neuroradiologists available to interpret them. The process of identifying lesions deep in the brain, and the ultimate decision to operate, was dependent on your ability to interpolate the location and nature of the lesion without absolute confirmation by any means.

"Are you ready to face the reality that there is often a destiny beyond your ability to determine?"

> One cannot truly comprehend the self-confidence necessary to be able to triangulate the location of a hidden tumor that may not actually be one, and to penetrate inches of functional brain to reach it. There is no terror in life that can match that experience. Are you on the correct side; the correct lobe? Are you avoiding injury to vital areas of the brain that control speech, movement, and sensation? Are you ready to face the reality that there is often a destiny beyond your ability to determine?

At the end of the years of intense training, the next hurdle was a three-hour oral board examination in which case stories, chosen by the examiners, were presented for evaluation. You were expected to solve the conundrums of the brief history delivered, request the proper imaging studies, interpret them when they were offered to you, then describe the surgery required or not required. Examiners acted as blank walls while listening, gave no feedback, then graded you on your responses. Failures occurred and applicants had to wait another year to reapply. Passing allowed you to become a member of the national society, of which there were then only a few thousand.

The brutality of the training has been criticized, and since eliminated, but I imagine an equivalent experience would be that of preparing your mind for the battles of war. People die from your mistakes and misjudgments. The development of advanced imaging techniques in medicine has changed the need for all that, and the experience of neurosurgical training has changed with it.



J. Koff, J Boddington, Dr. Babu, Dr. Brown — NY 2015



Dr. Slavin, Dr. Babu, Dr. Brown — NY, 2015

The department chair and program director of my residency program in neurosurgery at The University of Chicago, Sean Mullan, was a creative genius years ahead of his time, much like another of my mentors, Peter Jannetta.

Sean Mullan believed that much that could be done by major open surgery could instead be done with the much simpler insertion of a needle. Most great men are known for a single innovation — Sean Mullan devised three over the course of his career. His first involved the injury to pain fibers in the cervical spinal cord with a radiation bead, inserted by a needle, instead of by open surgery. For patients enfeebled by hemibody pain from lung cancer, this was a godsend.

The last of his conceptions came decades later out of his ongoing interest in pain neurosurgery.

### That's where I came in.

"Trigeminal Neuralgia Surgeon" continued on page 14



Dr. Linskey, Dr. Brown



Dr. Brown, two attendees — NY, 2015

"On Becoming a TN Surgeon" continued from page 13

The operating microscope had been used in neurosurgery for only several years. Few neurosurgeons had been trained to use it. As I began my final clinical year of training, I insisted that Dr. Mullan send me to attend a course in Gainesville directed by Dr. Al Rhoton on the techniques of doing surgery under the microscope. Dr. Rhoton was the next link in my connection to trigeminal neuralgia (TN) surgery.

During a break in the course, in the dense heat of July in Florida, I was in the hotel pool. A young boy was there by himself (I thought). I worried about that, entertained him, played games with him, and watched after him. I did not realize that Dr. Tom Milhorat was watching me (and the boy, his son) the whole time. When he stepped out of the pool, Dr. Milhorat thanked me for looking out for his son and explained that he, too, was taking the course. It was in preparation for starting a neurosurgery program in

Brooklyn, New York. He was already a renowned pediatric neurosurgeon, and my interest then was in treating children.

### This would turn out to be a rather unusual job interview.

It was during the ensuing year that Dr. Mullan conceived of the technique of percutaneous balloon compression for trigeminal neuralgia. With a needle inserted through the cheek and a balloon catheter, he could squeeze the

trigeminal nerve and ganglion just enough to stop the pain of TN. By doing this he transformed a many-hour operation being done by open craniotomy to one done using minimal access.

# I had a year of research yet to finish. One option was to do the research at another program.

Dr. Peter Jannetta was one of the few program directors advertising a fellowship program, so I wrote to him about it. In the frigid, grey Chicago days of February, there was an intense ten-day, twelvehour-a-day review course required for neurosurgery residents preparing for their written examination. Dr. Jannetta came to the city to deliver one of the lectures.

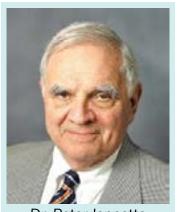
On a typically chilly Saturday afternoon, he knocked on the door of my apartment in the south side of Chicago, hoping to recruit me. I was not home. I was 10 miles away, downtown, at the course. My wife was home, however, because she was pregnant, and the doctors were limiting her activity. Dr. Jannetta spent several hours warmly recruiting my wife to convince me to join him in Pittsburgh.

# Another unusual way to offer one a job. I turned him down.

Instead, I went with Dr. Milhorat, who had offered me a position as chief of neurosurgery at King's County Hospital in Brooklyn. The pay was better. The work was harder. My wife was from New York. I knew I needed the experience.

King's County Hospital served a population of 10

million people. Working there was the equivalent of being in a wartime MASH unit. During my training, I learned how to think about performing surgery. In Brooklyn, I did it — day after day, night after night. I became a surgeon, albeit an exhausted one.



Dr. Peter Jannetta

### Within a year, I left to return to the Midwest.

In Ohio, I was able to focus on treating children, which is what I wanted to do. I ran a busy spina bifida clinic, treating

children born with devastating spinal deformities, and others with terrible brain tumors. Some of these tumors were deep in the brain in a central switching station for brain function called the thalamus. I sent such patients to Dr. Ben Carson at Johns Hopkins University who had a well-deserved reputation in the field for operating in this dangerous area. This was the next link in my TN career.

# Why?

### A quarter of a century later, our careers would collide for a different reason.

The neurosurgery oral board examinations were taken only after several years of practice. I was now just outside of Ann Arbor, Michigan. To prepare myself,

I regularly attended Wednesday evening neurosurgery conferences at The University of Michigan. I sought out the chair of the department, Dr. Julian Hoff, to help in my preparation for it. He would be another important link. I also sought out the chair of another program in Cincinnati, Dr. John Tew. I brought patients with difficult lesions of the skull base adjacent to the trigeminal nerve to him to operate on. This was his expertise.

Dr. Tew and Dr. Rhoton were appointed by Dr. Janetta as advisory board members of a new organization called the Trigeminal Neuralgia Association (TNA)

founded by Claire Patterson, who was living with facial pain and looking for resources and support. Dr. Tew was also an expert in the technique and teaching of radiofrequency (RF) rhizotomy for TN. Dr. Rhoton was renowned as an expert on the anatomy of the trigeminal nerve.

After a presentation by Dr. Jannetta at a national conference, I approached him and inquired why he had never mentioned balloon compression as an option to treat TN. He answered me with classic Jannetta speak:

"I am not familiar with the procedure, but I look forward to reading about your results from it when you publish them in the journal."

In other words, put your results up for analysis, and he would seriously consider them and the procedure. That's what he did with his own work.

I noticed something unusual when doing the balloon operation. When I squeezed the trigeminal nerve root, the heart rate would slow, sometimes dramatically, and along with that, the blood pressure would temporarily drop. I sent an abstract of my research findings regarding bradycardia and hypotension during balloon compression for TN to the national

meeting of the American Association of Neurological Surgeons. It was accepted for an oral presentation on the opening morning of the meeting, when 500 neurosurgeons would be in the audience and the most important papers of the year would be heard.

This was going to be the first presentation of my own work. What I had to say directly contradicted the standard teaching about what happens during injury to the trigeminal nerve. When the technique of radiofrequency rhizotomy heats the nerve, the blood pressure and the heart rate shoot up, sometimes enough to cause a brain hemorrhage. RF rhizotomy

> then was the most common way of treating TN, even more than MVD.

Oral presentations were scheduled for 7 minutes. Three minutes were reserved for questions from the audience.

I was petrified of the potential questions. I put a fix in.

Ahead of the presentation, I asked Dr. Mullan if he would pose a question. I approached the session moderator before it started and asked him to call on Dr. Mullan when I finished talking

and there was a call for questions. Dr. Mullan did one better. When called upon, he spoke for three minutes about his experience with the operation and never asked a question. I got off the podium unscathed, published my paper six months later, and then another with my results.

Next, I put together a research laboratory team at my medical school, now called Toledo University School of Medicine. With a PhD neuroscientist and anatomists to help me, we set out to investigate balloon compression — How did it work? Why did it work? What were the neural pathways that led to the drop in heart rate upon compression?

"On Becoming a TN Surgeon" continued on page 16



"On Becoming a TN Surgeon" continued from page 15

# It was tedious work. I published it seven years after beginning my practice. What was so curious about my findings?

Through electron microscopy imaging of the trigeminal nerve and ganglion in an animal model of balloon compression, I learned that the operation selectively preserved pain fibers and only injured what are described as large-myelinated fibers. These are fibers in the nerve that transmit sensations of light touch. The operation works by injuring the myelin fibers, which act as insulation. This reduces the electrical input to the short circuit in the trigeminal nerve at the site of Dr. Jannetta's vascular compression that leads to the severe electrical shocks of TN. This input comes from just the lightest touch to one's face. Everyone with TN knows to avoid anyone touching their face! That is why.

One very important consequence of that discovery was that balloon compression is safer to do on patients with stabbing pain in the eye, because the fibers that deal with the eye's ability to blink when touched are preserved. Curiously, these are the fibers known to transmit pain. They are preserved! The eye must be protected. Sensations that trigger blinking must be preserved, otherwise the cornea can be injured, and vision lost.

I sought to present my findings in the Pain Section of the national organization. Its leadership wasn't responding. Dr. Hoff, now president of the national association, was able to get their attention for me.

I became chair of the neurosurgery department in Toledo, but I had cases that needed expertise I felt I did not have. I sent some of those patients to Cincinnati and joined Dr. John Tew and Dr. Harry van Loveren while they performed the surgery.

Now that my research on balloon compression was becoming known, Dr. Jannetta invited me to join him, Dr. Tew, and Dr. Rhoton with Dr. Casey to participate in the first national meeting of the Trigeminal Neuralgia Association. My purpose was to describe balloon compression to support group leaders from around the country. In the first national meetings, there were no other patients present.

Based on my promising results and dedication to research on the subject, Dr. Jannetta appointed me to the Medical Advisory Board. This was a quarter of a century ago.

Due to my involvement with TNA, I began to treat patients from around the country. Many of them had the more difficult dilemma of constant burning pain associated with numbness in the face, often from injury due to surgery on the nerve. These patients did not typically respond to repeat MVD surgery. Balloon compression and RF rhizotomy would only worsen the injury to the nerve.

While dealing with a particularly difficult-totreat patient, one with constant burning pain, not stabbing pain, I read about a procedure called motor cortex stimulation. It was being done in Paris by a neurosurgeon, Yves Keravel. I then had a fellow working with me who had trained with Dr. Keravel. He encouraged me to contact him about the

operation. We developed an ongoing relationship along with other neurosurgeons doing that surgery and exchanged the knowledge we gleaned from doing it. I reviewed my results and presented them in conferences and papers.

I participated in TNA national conferences and soon organized them. I realized that a large number of the attendees looking for help were individuals who suffered from this constant, burning pain; these patients had what is called neuropathic facial pain, not trigeminal neuralgia. I promoted enlarging the focus of TNA to acknowledge this large group of patients. The new chair of the board, Roger Levy, agreed with me. There was a vote in favor, and this vastly expanded the reach of an organization limited to the "orphan" disease, trigeminal neuralgia. TNA became "The Facial Pain Association."

I moved back to New York and joined a small private group with opportunities to grow. We ultimately built it to include 16 neurosurgeons, covering all of Long Island.

Dr. Jannetta stepped away from chairing the MAB, and, with his and Dr. Tew's support, I was elected chair. My personal goal was to convince the neurosurgical community, who treated trigeminal neuralgia, that TN was just one manifestation of a form of neuropathic facial pain derived from injury to the trigeminal nerve. It could present as the intermittent stabs that have been described for hundreds of years; it could present as a mixture of stabs and constant, burning pain; or it could consist of a predominance of constant burning pain. This is still an ongoing discussion.

The final link in my career occurred when Dr. Ben Carson began referring patients whom he believed he could not help. Like me, he had moved away from a primary focus on pediatric surgery and now had the largest practice of trigeminal neuralgia patients in the country. If he had a difficult patient whom he could not help, or who did not improve with his two-pronged approach of combining glycerol and RF rhizotomy, or MVD alone, he asked me to see these

patients. I realized that I could help. We developed an ongoing relationship until his retirement and entrance into the political fray. My relationship with his immediate successor, Dr. Michael Lim, who has since moved to the distinguished helm of the neurosurgery department at Stanford University, continued as we tried to solve the conundrums of the patients who did not get better.

### These are the challenges of the next generation of neurosurgeons and neurologists.

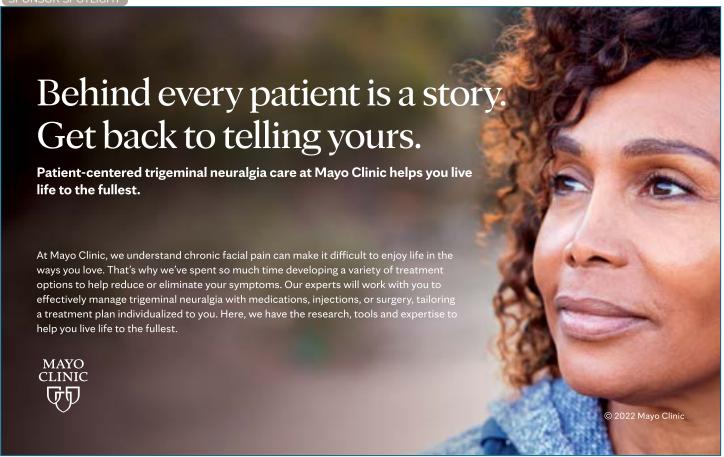
As MAB chair, and with the support of the new Board chair, Jeff Bodington, regional meetings were developed across the country to supplant biannual "national" meetings. The FPA began to use the internet to broadcast webinars in which I interviewed other neurosurgeons and neurologists about their approach to the care of TN. These were placed on our website as resources.

After COVID, we morphed our national meeting to the next step beyond individual webinars and held a completely virtual conference. By this means, we moved from reaching half a hundred to more than 500 viewers from across the world in one or two days of lectures, and countless others by placing the lectures on the web afterwards.

After two terms as chair of the MAB, Dr. Ray Sekula, now at Columbia University in New York and a remarkable protégé of Dr. Jannetta, has succeeded me as the MAB chair of an organization now named simply "The Facial Pain Association."

I completed 45 years of practice, finished my last MVD, and retired from the active practice of neurosurgery in October of this year. I retain a teaching position at NYU Long Island School of Medicine, but no longer treat patients.

It has been a good run. As I wrote in my note to my patients, I wish to thank each of you for granting me the great privilege of caring for you.



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Dr. Michael Brisman performs a variety of procedures, including MVD, percutaneous rhizotomy (radiofrequency, glycerol and balloon techniques) and Gamma Knife radiosurgery, to treat Trigeminal Neuralgia and other chronic facial pain conditions.



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. Brisman is the author of Put Down the Knife (Springer Publishing), a textbook on adult brain surgery which promotes the importance of minimally invasive surgical procedures and conservative treatment options.





