

Quarterly



Facial Pain Association
REGIONAL
Conference Program
Kansas City, Kansas

IN THIS ISSUE

- **What to Expect from Medical Treatment for TN** by Jeffery Cohen, MD
- **Trigeminal Neuralgia without Neurovascular Compression** by Kim Burchiel, MD
- **Dr. John Alksne on the first MVD surgery performed**

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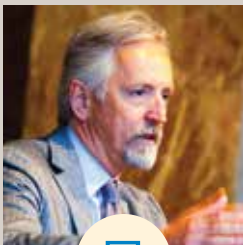
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Cover

Regional Conference hosted by the Kansas City Support Group

FEATURES



7

Kim Burchiel, MD reports on evidence that neurovascular compression is not necessary for the development of TN.



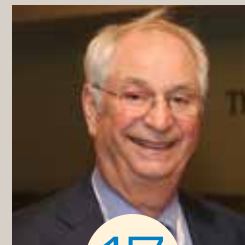
10

Neurologist Jeffrey Cohen, MD on the medical treatments available for TN.



14

John Alksne, MD talks to Mervyn Rothstein about what it was like to participate in the first MVD surgery ever performed.



17

Mervyn Rothstein interviews Michael Pasternak, PhD trustee of the Facial Pain Research Foundation.



21

Kansas Regional Conference information and faculty.

IN EVERY Q

2

From the Chairman of the Board

3

THE MAB CORNER with Jeffrey Brown, MD, National Chairman of FPA Medical Advisory Board.

24

Young Patients Committee: Summertime and TN

27

28

New Members, Memorial and Honorary Tributes

From the Chairman of the Board

Much is underway at the FPA. Support groups and conferences are critical to the support and services that we provide. So too is the internet that makes our website possible, that makes our Facebook page useful and that we use to deliver information to you, including the *NewsWire* and this *Quarterly*. What patients and caregivers want is changing, and the FPA is working to see that change and make sure that our mix and implementation of physical meetings and internet-based interaction are as useful as possible.

But wait, the changes that the FPA is working to address are not all about what the internet has made possible. Harvard psychologist Robert Putnam wrote *Bowling Alone* in 2000 about how people were participating less in community groups, clubs, scouting and many other organizations. And his findings applied to support groups too. It wasn't the internet then, he said it was television, other demands on peoples' time and a hard-to-understand disengagement. While some of the FPA's support groups thrive, others are examples of the trend that Putnam observed in *Bowling Alone*. The FPA has begun a new initiative to understand what makes our support groups and conferences both useful and successful. Regardless of age, participants in the FPA's programs are ecstatic about getting together and want more. They say that meeting others who have facial nerve pain provides invaluable comfort, support and information about managing life outside of a doctor's office. It was invaluable for me too.

OK, now add the internet. The access, information, and interaction that the internet makes possible are both good and highly disruptive. The internet is an invaluable tool, but it accelerated the adverse trend that Putnam observed. Attendees at FPA support group meetings and conferences want more. Those forces are pushing in

different directions at the same time. They may be part of the reason that some of our support groups struggle. In that environment, managing the FPA to keep it as useful as possible is an exciting task that I think our CEO John Koff, our staff and our Board of Directors are doing well. But the work is not done, it may never be done.

The job of managing our balance and implementation of support groups, conferences, website and internet-based support is not easy. It is more than a decision about how to allocate the FPA's resources, it is a research and development effort too. All of our programs need to take advantage of what technology is making possible, the highly-successful webinars run by our Medical Advisory Board Chairman Dr. Jeffrey Brown are an example. Our series of articles by topic experts, that are easy for you to download and easy for the expert to keep up to date, are another. While maximizing the use of technology, all of our programs need also to remember the value of getting together at support group meetings and conferences. How one thing effects another is not always clear, change is constant, experimentation and feedback are essential.

That brings this Letter back to the mission of the FPA. We are here to provide support, information and community to people with facial nerve pain and to their caregivers too. To make our mix of meetings, internet-based and other programs as useful as possible, we want your ideas and feedback. Call our office anytime, send us an email, your input will help to guide the decisions we make.



Jeff Bodington, Chairman of the Board
The Facial Pain Association

The MAB Corner



Jeffrey A. Brown, MD

Should you have a repeat MVD?

In Peter Jannetta's lifelong series of 1185 patients on whom he performed an MVD, he included 132 who required reoperation (11%). After a single operation 82% of patients had immediate relief and another 16% had at least partial relief. A year later, 75% were pain free and another 9% had partial relief. The percentage of patients pain free after ten years dropped by 11%, or by 1% per year to 64%..

What if a second operation was done?

In that series, 132 patients (11%) required reoperation, 58% of them within two years. Immediately after repeat surgery, about 60% of patients were pain free. After ten years, 47% were either free of pain or partially relieved.

Another study of repeat MVD was published in the US literature ten years later. This study was from the

Netherlands. These authors also had an 11% incidence of repeat MVD surgery. One year after surgery 66% were free of pain and off medicine and another 10% required some medicine. Their results were thus quite similar to those of Dr. Jannetta.

What were the causes of the recurrence?

Dr. Jannetta noted that veins and smaller arteries were the most common findings present at a second surgery. He also mentions that the presence of venous compression at the first surgery leads to a higher risk of recurrence. The Netherlands series noted that in 61% of repeat operations no compression was found. They removed the Teflon pad and suspected that the pad itself had devolved into a form of granuloma and was the cause of pain. When a cause was found, it was nearly equally divided between a new vein and artery. Success correlated with immediate relief after surgery. However, Dr. Jannetta noted

"MAB Corner"...continued on page 4



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Guest Contributor

Mervyn Rothstein was an editor and writer at *The New York Times* for 29 years. Mr. Rothstein now writes the monthly "Regional Theatre" column for *Playbill Magazine* and is a former member of the Tony Awards Nominating Committee. His first symptoms of trigeminal neuralgia occurred in 2005.

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that pain often persists for several weeks after surgery before resolution.

Repeat MVD was associated with a higher incidence of facial numbness (8%) than at the first operation (1%) in Dr. Jannetta's series. In the Netherlands series it was 27% because of more extensive exploration when, ultimately, no source of vascular compression was discovered.



What do we need to know that will help with the decision to proceed with repeat MVD?

Neither of these studies made use of sophisticated neuro imaging using FIESTA or CISS MRI techniques and multiple view planes. It is not always possible to see evidence of recurrent or persistent compression. However, as much as possible the effort must be made to avoid "exploratory" surgery. If pain recurs after an MVD, a repeat sophisticated MRI should be done. Understand clearly that not all MRIs are equal and it is not the power of the MRI alone that makes a difference. It is the power of the software program used to perform the study combined with the sophistication of the neuroradiologist and neurosurgeon evaluating it.

In these two series, other than the increase in facial sensory loss, the morbidity from the reoperation was not higher. Experienced sub specialists in the field performed the surgery. Repeat MVD surgery should only be recommended and performed by such an individual. ●



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Dr. Philip E. Stieg, professor and chairman of the Department of Neurological Surgery (center) directs the Facial Pain Program at Weill Cornell Medicine. Dr. Jared Knopman (left) and Dr. Michael Kaplitt also specialize in advanced treatments for trigeminal neuralgia and other conditions that can lead to facial pain.

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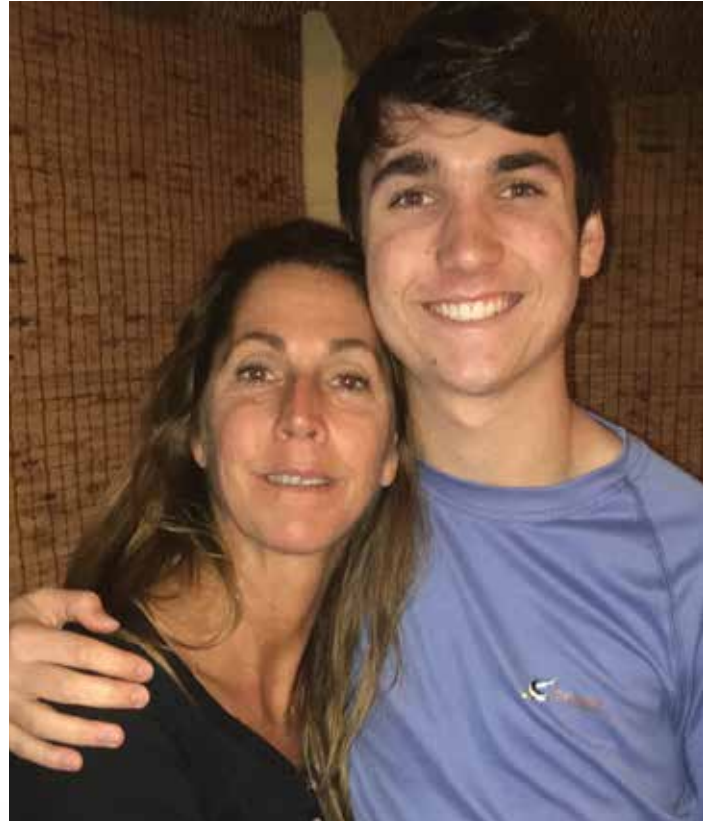
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FOLLOW UP

Student Helps Mom Deal with TN

In the spring issue of *The Quarterly* we shared Michael Brown's story about his mother Eileen, a TN patient. It was difficult for Michael to stand by when his mom was having a bout of TN induced pain. Michael decided to redirect his anguish and apply that emotion to his studies. The result was a yearlong research-based investigation to address and research the social impact of TN. More than a 1000 of our readers participated in the research study by completing and submitting Michael's questionnaire.



Exploring the Social Impacts of Trigeminal Neuralgia, a Neuropathic Chronic Pain Condition

by Michael Brown

Using a review of studies on analogous chronic pain conditions, a questionnaire was developed to explore how TN may impact a patient's social interactions. The questionnaire was distributed by the Facial Pain Association. The data obtained from the questionnaire was analyzed for any common trends or answers in the information. From here, specific conclusions were drawn in each of the social themes being explored, and it became evident that TN has a profound impact on a patient's social life.

For those of you who would like to read the paper that Michael submitted to his faculty advisor please visit **<http://bit.ly/2tTSnPc>**.

Trigeminal Neuralgia Without Neurovascular Compression

By Kim J. Burchiel, M.D. Department of Neurological Surgery, Oregon Health & Science University, Portland, Oregon, United States



Increasing evidence indicates that neurovascular compression (NVC) is not necessary for the development of trigeminal neuralgia (TN).

A retrospective chart review of patients 18 years of age and older presenting between 2007 and 2017 to Oregon Health and Science University (OHSU) to a single surgeon (KJB) was performed under OHSU Investigational Review Board approval.

Patients were diagnosed clinically based on the Burchiel classification of facial pain (Burchiel 2003). All patients had TN1 defined as idiopathic, episodic, lancinating pain lasting seconds, with pain-free episodes in between attacks. Patients with TN2, defined as predominant aching, throbbing, or burning pain for greater than 50% with minimal lancinating pain were excluded. Patients with

"Neurovascular Compression"...continued on page 8

"Neurovascular Compression"...continued from page 7

a diagnosis of multiple sclerosis or signs or symptoms indicative of multiple sclerosis were also excluded for the purposes of this study.

Patients considered potential candidates for microvascular decompression (MVD) underwent a diagnostic high-resolution 3T MRI/MR angiography (MRA). 3D reconstructions were generated from the MRI/MRA fusion to confirm or infer the presence of neurovascular compression (Miller et al. 2009; Ko et al. 2015) Intraoperative findings and video were used to confirm imaging results. Demographic data was collected including: gender, age at presentation to clinic, reported age of symptoms onset, symptom duration, neurovascular compression, medications for TN and reported response. Age at symptom onset was used to define the age distribution of our patient population.

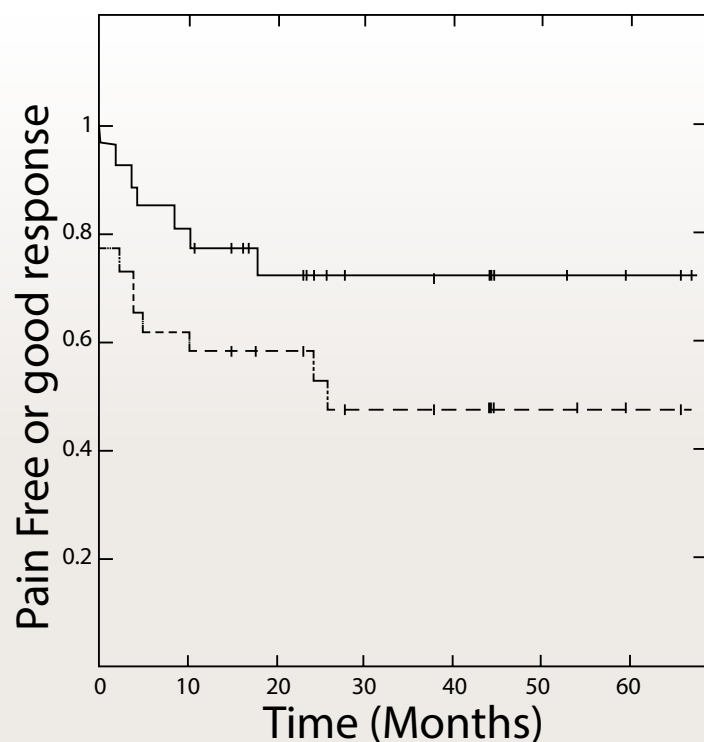


Figure 1: Results of a first-time internal neurolysis (IN) in patients with TN1.

Two hundred and forty-four patients with TN1 were seen between 2007 and 2017. Thirty-two percent of patients in the whole group did not have an arterial compression of the trigeminal nerve by MRI/MRA analysis. The age at symptom onset for patients without neurovascular

compression (WONVC) was 10.6 years younger than those with neurovascular compression (WNVC). This younger TN1 (less than 45 years old) population was composed of 46 patients WONVC (58% of the group) and 43 patients WNVC (26%) of this patient population. Age at symptom onset was 4 years younger for patients WONVC. The age of the patients at the time to their first consultation visit was 7.8 years younger for patients WONVC compared to those with WNVC. Symptom duration before referral to neurosurgery in patients WONVC was also significantly shorter by 44.7 months than for those with WNVC. In this group, patients WONVC were more likely to be women by a factor of 4.8:1.

Our results indicate that in the entire population of patients with TN, a substantial number do not have NVC. This is strikingly true in patients less than 45 years old, particularly females who out number males in this younger WONVC group by a factor of almost five to one. These data strongly suggest that TN has a major genetic component which predisposes individuals, particularly females, to develop TN.

The question that arises is what can surgery offer patients that continue to have pain on maximum medication, but who are found to not have NVC on MRI/MRA?

Over the last decade, we have offered these patients a procedure we call "internal neurolysis" (IN). This is effectively "combing" of the nerve, through an approach that is otherwise identical to microvascular decompression (MVD).

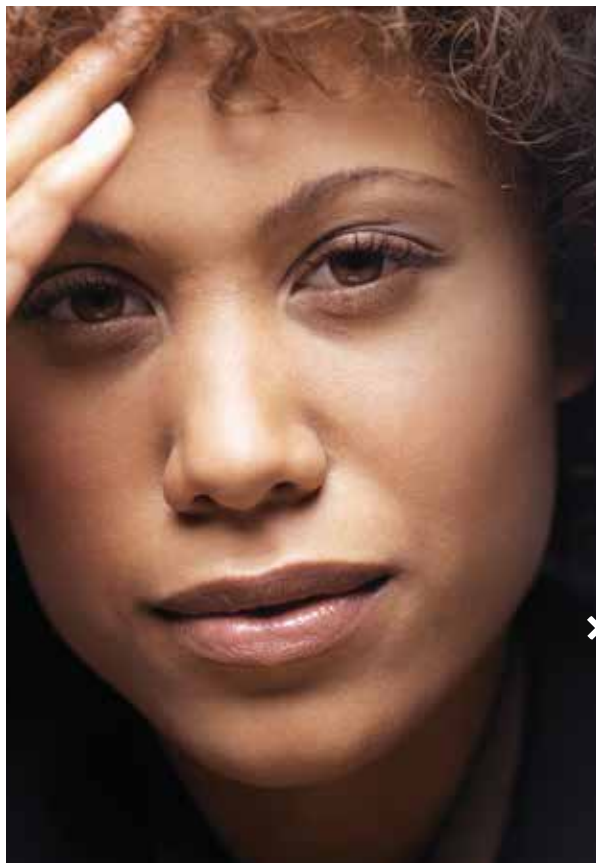
We now have enough data on this procedure to conclude that this procedure works for TN patients WONVC about as well as MVD works for patients with NVC. The difference being that after IN, patients will have mild numbness in the face, which is usually not uncomfortable or disabling. The results of first-time IN for our patients WONVC are shown in Figure 1. The chance of being completely pain-free and

off medication more than five years after IN is about 50%. To this result, if we add patients that continue to be pain-free, but require some medication, the chance of success at more than five years is about 75%.

Currently we are working with the Facial Pain Research Foundation to identify genes that are associated with the development of TN. Our hope is that this research will lead to a fundamental breakthrough in TN that will allow us to cure TN with gene therapy, or other innovative non-surgical approaches.

SOURCES


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Medical Treatment for Facial Pain

By Jeffrey Cohen, MD
Member of the FPA Medical Advisory Board



Medications are usually the first step in the approach to the treatment of facial pain. Anyone experiencing severe facial pain wants it to go away as quickly as possible. At the same time, everyone is wary about the potential adverse effects of medications that are used to treat pain. By making yourself knowledgeable about these treatments, you can make educated decisions about which medications to try, and how to minimize potential risks.

The choice of a medication for facial pain is dependent upon multiple factors; some of which are related to the specifics of the individual patient. While there is a growing trend to use “personalized medicine” in the treatment of a variety of conditions (which uses genetic information referred to as genomics), this approach has not yet reached the management of facial pain.

There are two main types of pain: nociceptive- which is caused by tissue damage, and neuropathic pain- which is caused by nerve damage. Facial pain belongs to the latter. This is an important concept, as certain medications work better for each type of pain.



Trigeminal neuralgia (TN) and other forms of neuropathic facial pain are mostly treated with classes of drugs referred to as antiepileptic medications (AEDs) or antidepressants (ADs). Drugs for nociceptive pain, such as acetaminophen or ibuprofen, usually are not effective for TN.

What to expect from medical treatment for TN and other neuropathic pain?

Ideally, the doctor and patient want the same thing: to control pain as quickly as possible with a safe medication that works at a low dose and doesn't cause any side effects. This may be achieved for some patients, at least at the outset; however, due to the refractory nature of TN, it is often necessary to work with the medication dose, trying to achieve a balance between pain control and safety.

There are relatively few studies in the literature that demonstrate that medications are effective for TN, and the studies that do exist are not of the quality consistent with what would be expected to show efficacy in painful conditions.

Selected Medications for Facial Pain: Guidelines for Use

Table 1

Class	Generic Name	Trade Name ²	Daily Dose ¹	Possible Adverse Events	Monitoring
Antiepileptic Medication (AED)	Carbamazepine	Tegretol	100 - 1200 mg/day	double vision, fatigue, balance, nausea	Blood work for sodium level, liver enzymes, white blood cell count
	Oxcarbazepine	Trileptal	300 - 1800 mg/day	double vision, fatigue, balance, nausea	Blood work for sodium level, liver enzymes, white blood cell count
	Eslicarbazepine	Aptiom	200 - 1600 mg/day	dizzy, balance, fatigue, double vision	Blood work for sodium level and white blood cell count
	Gabapentin	Neurontin	300 - 2400 mg/day	dizzy, drowsy, weakness, weight gain	Generally not indicated
	Pregabalin	Lyrica	150 - 600 mg/day	memory loss, reduced coordination, weight gain	Generally not indicated
	Phenytoin	Dilantin	100 - 500 mg/day	balance, drowsiness, slurred speech	Blood work for liver enzymes
	Topiramate	Topamax	50 - 300 mg/day	confusion, word finding difficulty, weight loss	Generally not indicated
	Lamotrigine	Lamictal	50 - 400 mg/day	dizzy, headache, fatigue	Blood work for white and red blood cell counts, platelets
	Levetiracetam	Keppra	500 - 3000 mg/day	fatigue, irritability, dizzy	Generally not indicated
	Clonazepam	Klonopin	0.5 - 20 mg/day	drowsiness, balance, confusion, dependence	Periodic blood counts and liver enzymes, if long term therapy
Antidepressant (AD)	Amytriptyline	Elavil	25 - 150 mg/day	drowsiness, confusion, dry mouth	ECG
	Nortriptyline	Pamelor	25 - 100 mg/day	dry mouth, confusion, nausea	ECG, lab work at higher doses
Skeletal Muscle Relaxants (SMR)	Baclofen	Lioresal	15 - 60 mg/day	drowsiness, nausea, weakness	Generally not indicated
Anesthetic (ANS)	Lidocaine	Xylocaine	5% nasal spray	stinging, burning, dizziness, numbness	Generally not indicated
Toxins (TOX)	Botulinum toxin	BOTOX	6 - 100 U/day	injection site pain, weakness	Generally not indicated

¹ Some medications have more than one trade formulation.

² Discuss with your doctor about how to dose these medications

Please note: Patients may be on higher/lower doses at different frequencies.

"Medical Treatment"...continued from page 11

As a result, Physicians must make medical decisions based upon incomplete medical evidence, and often use personal experience. At least through 2017, all medications used for the treatment of TN were developed for a variety of other medical conditions. Nonetheless, as their mechanisms of action are important to block the perception of pain in the brain, they are often effective for the treatment of the pain associated with TN.

Table 1 on the previous page lists a variety of medications that are in use for the treatment of TN (extensive, though not exclusive). For most, there are no clinical trials, and for others, there are a few case series in the literature. Nonetheless, many patients with TN state that they receive at least partial relief of their facial pain from them.

For first line therapy, carbamazepine, or one of its derivatives, is often chosen.

For first line therapy, carbamazepine, or one of its derivatives, is often chosen. About 70% of patients experience significant pain relief, at least for the short term. There are a variety of other AEDs that have been tried to relieve TN pain, and many of them have been effective in certain patients. These include gabapentin, pregabalin, phenytoin, lamotrigine and topiramate. Some other non AEDs that may be helpful include baclofen, nortriptyline and amitriptyline.

If pain is not controlled, or if control of pain is at the expense of unacceptable side effects, then a different medication should be tried. This could be done as another trial of monotherapy. Single drug therapy is preferable as there is less of a chance of adverse effects and also because it is less costly. However, there may be certain situations in which two drugs in combination might be beneficial for some patients.

The first drug in development for TN is making progress in clinical trials. This is the first time that a medication is being studied specifically for its ability to reduce TN pain



(as opposed to a medication being developed for another reason, and then tried for TN). It is a unique sodium channel blocker. Phase III studies are in planning to begin later this year.

What to look out for from medical treatment of TN and other neuropathic pain?

Adverse effects (AEs) may be divided into those that are dose dependent, and idiosyncratic (dose independent). In general, dose dependent AEs are more common and can be mitigated with either a reduction in total daily dose, spreading the total daily dose into more frequent intervals, or if it exists, using a longer acting version of the same medication. Idiosyncratic AEs may occur at any dose, at any time, and require that the medication be discontinued.

AEs can also be classified into those that occur acutely vs. those that develop chronically. By definition, acute AEs occur shortly after a medication is started, or when the dose is increased. Chronic AEs develop slowly, usually after long exposure to a medication. Interestingly, a study of AEs in a group of patients given AEDs revealed that the number and severity of acute AEs declined during the first 8 weeks of taking the medication, even when the dose was not changed, suggesting that many patients develop a tolerance to them over time.

Nervous system adverse effects may include dizziness, balance difficulties, double vision, memory problems or fatigue.

The most common dose dependent AEs from TN medications are those related to the nervous system and to the gastrointestinal system. Nervous system AEs may include dizziness, balance difficulties, double vision, memory problems or fatigue.

Idiosyncratic AEs are fortunately, rare. They are unpredictable, and while they are more common during the beginning of medication treatment, they may occur at any time. Some examples of these include: severe skin rashes, low blood cell counts, and liver problems.

What about opioids and medical marijuana?

Opioids and medical marijuana have received a lot of attention in the media, and not all of the information is positive. While a detailed discussion of these topics is beyond the scope of this article, some mention is important as these questions come up frequently. In 1980, a one paragraph letter to the editor of the New England Journal of Medicine reported that only 4 people out of 12,000 people prescribed an opioid developed an addiction to the drug. Although not a controlled clinical study, and although there was no long term follow up, this information became influential in stimulating the prescription of opioids for refractory pain as opioids were considered safe. We now know that opioids carry a significant risk of addiction, and should not be a standard therapy for painful conditions such as TN.

Medical marijuana has generated interest for a number of medical conditions. While there was recently a positive controlled clinical trial suggesting benefit of a marijuana metabolite for the treatment of a specific difficult to control epilepsy condition, there are no properly done controlled clinical trials of marijuana for facial pain. No

recommendations can be made at this point regarding a role for medical marijuana in the medical treatment of TN pain.

General strategies in the medical treatment of facial pain.

You should discuss your goals of treatment with your Doctor. While most patients want to be pain free, some may be satisfied with a significant pain reduction, if that is what it takes to not experience adverse events. Patients with TN often start with an AED, such as oxcarbazepine

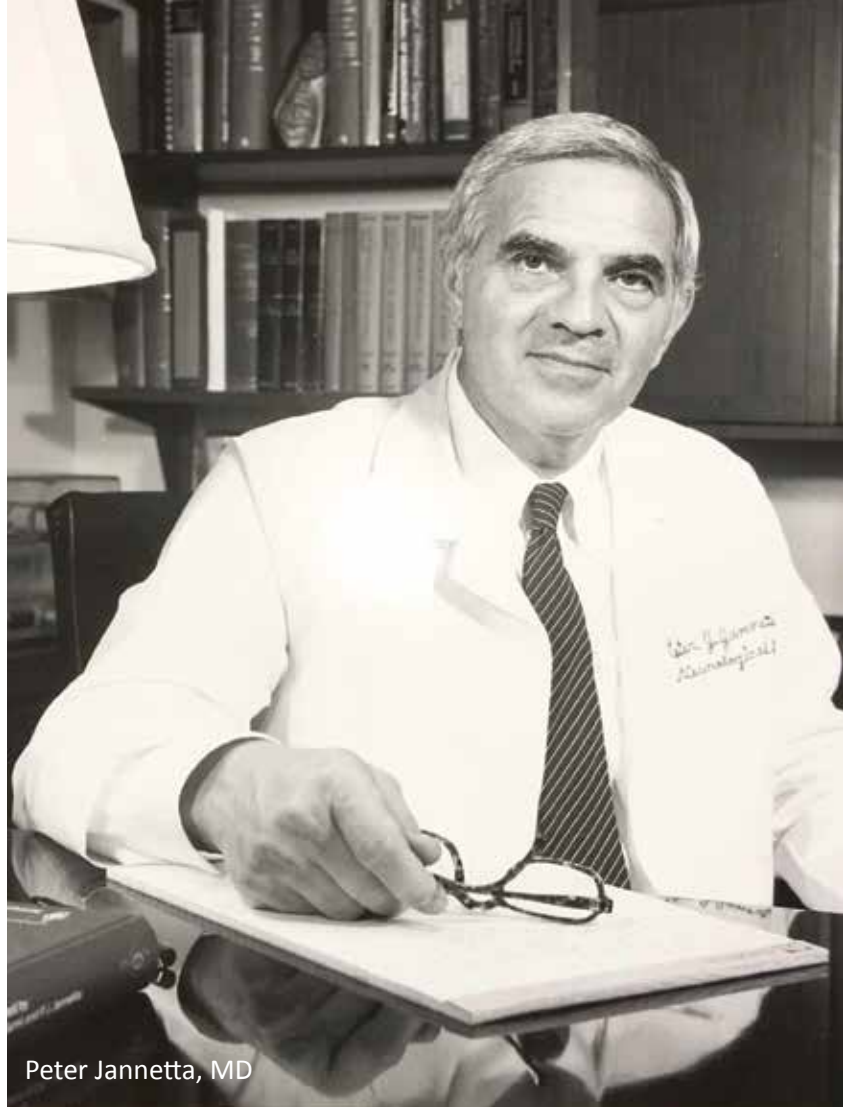


or carbamazepine, and if those don't work, they may try others, either as single drugs or in combination. The AEDs are often better at reducing the recurrent, sharp, lancinating pain attacks, while the antidepressants are often more effective at covering pain that is more constant, or lingering. Patients should discuss with their Doctor what doses they may take, and any guidelines for changing the dose or frequency of the medication.

These medications are different compared to those available over the counter; caution should be exhibited by the patient in making any change in how much or how frequently they take them. Patients should be informed about what AEs to look out for, as well as understand when they should have follow up. The need for blood work should be discussed. If medical treatment is successful, patient-Doctor conversation should include whether medication can be reduced or eliminated. Finally, when multiple medications fail to work, either due to lack of pain control, or AEs that cannot be reduced, surgical treatment should be considered. ●



John Alksne, MD, is a distinguished neurosurgeon and highly respected researcher in neurological disease. Dr. Alksne is the former Chairman of the Dept of Neurological Surgery at UCSD and a member of the FPA Medical Advisory Board.



Peter Jannetta, MD

A conversion with John Alksne, MD

about Dr. Jannetta's Historic First MVD surgery

By Mervyn Rothstein

"The patient woke up. And he had no face pain."

That's Dr. John Alksne, recalling the day in 1966 when he was the attending neurosurgeon for Dr. Peter Jannetta in the historic first microvascular decompression surgery, to treat patients suffering the excruciating pain of trigeminal neuralgia – a procedure in which an impinging blood vessel is separated from the trigeminal nerve and a Teflon sponge is placed between them.

Fifty years ago, Jannetta (who died last year at age 84) published his landmark first paper describing that pioneering surgical procedure, and Alksne is talking about that surgical moment – and how it came to be – in honor of that anniversary. Alksne, now 83 years old, is a famed neurosurgeon and researcher in neurological disease. He is a professor of surgery in the division of neurological surgery at the University of California, San Diego, School of Medicine; he was founding chief of the medical school's neurological surgery division as well as former dean and vice chancellor for health sciences at the medical school.

The first microvascular decompression surgery was performed at Harbor General Hospital, a county hospital in Torrance, California, in southwestern Los Angeles County, that was affiliated with the University of California, Los Angeles. "I was on the U.C.L.A. faculty, but I was based at Harbor General," Alksne remembers. "It was my first job. I had finished my residency in Seattle in 1963 and had been offered this position by the chairman of neurosurgery at U.C.L.A. Mostly I took care of neurosurgical problems that came in through the emergency room."

When he was a resident in Seattle, he was "interested in trigeminal neuralgia, because we knew that it was a founding signal of neurosurgery, because people were so desperate with this pain before there were good treatments, and we didn't have very good medicines at that time," Alksne says. "We were taught to do a sitting subtemporal extradural approach to the trigeminal nerve, and then follow it up to the base of the skull and then make a cut in the nerve to try to stop the pain. But that would produce a lot of numbness, so patients didn't particularly like it. When I was in Seattle, my chairman had

the idea, and talked me into it, to convert from cutting the nerve to traumatizing the nerve, the idea being that if we traumatize the nerve cells in the ganglion, then some of them would die and might cause some scattered numbness in the face but not as much as you get when you cut the nerve. So we had done those cases."

Trigeminal neuralgia, though, was still a mystery. "There was no other pain like this," he says. "It is triggered by a touch, a nonpainful touch, and it responds with this electric shock." Experimenters were trying to understand the neurophysiology of it; "we were trying to understand how to stop it."

When he got to California, even though he was younger than Jannetta, Alksne was an attending surgeon, and Jannetta was still a resident. The two would talk about trigeminal neuralgia, and "I was very impressed with him," Alksne says.

Jannetta rarely came to Harbor General. "The chief resident and the upper residents stayed at U.C.L.A., which had much more volume, much more diverse patient care," Alksne recalls. "But we had joint grand rounds every Saturday morning. Three Saturdays a month I would go up to U.C.L.A., one Saturday everybody would come down to Harbor General. There was no question in my mind that he was the most dedicated and well read of all the residents, and he was very interested in trigeminal neuralgia. He was quoting frequently the reports by Dr. Walter Dandy, back in the 1930s and 1940s, describing patients with trigeminal neuralgia."

Dandy's innovation "was the idea that instead of doing the standard subtemporal extradural approach, to do the posterior fossa approach, so you can see what's happening. His reasoning was that some of these patients had small tumors, small meningioma, and you could relieve their pain by removing the meningioma. But we never did it."

But Jannetta was very impressed. "There were diagrams, there were articles written by Dr. Dandy that were in the literature, but 90 percent of neurosurgery residents didn't read them. But Peter did."

When there wasn't a tumor, "Dr. Dandy had noticed that there were lots of blood vessels around the trigeminal nerve where it entered the brain and warned people about being very careful if you're going to do the posterior approach to get these arteries out of the way because you

could cause a stroke." Jannetta told Alksne that "he had done cadaver dissections on 'normal' patients and never found the abnormality that Dr. Dandy had described in his posterior fossa explorations." Jannetta decided that a blood vessel impinging on a trigeminal nerve might be the reason behind trigeminal neuralgia.

But the chairman of neurosurgery at U.C.L.A. refused to let Jannetta do a posterior fossa exploration on a trigeminal neuralgia patient. "Dr. Jannetta was complaining to me about that – the chairman is so rigid, he wants me to do it the old-fashioned way, the subtemporal extradural approach, but when you do that you don't see the part of the nerve that Dr. Dandy was talking about. All you see is the part that's in what we call Meckel's cave," the area that houses the trigeminal ganglion.



Jannetta was frustrated, Alksne recalls. "He was in his chief residency year, he had gone to all these meetings, he had given talks about his findings, and he wanted to explore a posterior fossa approach."

"Alksne"...continued on page 16



Then, one day, Alksne "had a patient with trigeminal neuralgia come in through the Harbor General emergency room, a county no-insurance patient, and the doctors in the emergency room called me to see him. I went down and he had excruciating trigeminal neuralgia. He was in his mid-50s and he would agree to anything to get rid of his pain. I called Peter and I said, I think we have a patient, you can join me and we can do a posterior fossa approach."

But Harbor General didn't have operating microscopes. "Harbor General was a poor man's hospital. The only person who had his own operating microscope at U.C.L.A. was Dr. Robert Rand. He was the son of a former neurosurgeon, and he had a busy practice and enough cash flow so that even though the hospital wouldn't buy him an operating microscope he bought one himself. Dr. Jannetta had to call him and say, Hey, this is an opportunity. Dr. Rand had to go to the U.C.L.A. hospital, get his microscope and put it in the back of his car. Which meant taking the microscope apart, because these come with stands and arms that reach out over the patient. It's not like your standard bench microscope. So it wouldn't have happened without Dr. Rand. We got it all put together, set up and ready to go."

The next day, Jannetta and Alksne "scrubbed in. I had consented the patient for partial section of his trigeminal nerve, because that was the standard of care and what we would have to do if we didn't find anything. But that was O.K., and the patient was quite happy with whatever approach we wanted, to take care of his pain."

Jannetta had devised his approach, "not what I would consider the standard posterior fossa approach. Sometimes

we did trigeminal sections for patients with cancer through the posterior fossa, but we were coming in under the cerebellum and working our way up. But Peter had developed this plan in the cadaver lab to start out as if you were doing it in a more traditional way and then open the tentorium so we would be able to go into the posterior fossa without exposing it in the temporal fossa. And we would see the trigeminal nerve come out of Meckel's cave and go across to the spinal fluid and into the pons," in the brain stem.

Alksne was scrubbed and helping, but Jannetta "was doing the procedure. I had never done one. And when we got to the trigeminal nerve, lo and behold there were looping vessels impinging and distorting it. I saw it, I remember it, I know it."

Jannetta "dissected the vessels off the nerve, and separated them away." (No Teflon sponge was used for this first procedure.) "He was very excited, because it was exactly what he expected, what Dr. Dandy had described and drawn pictures of in his article. But then he was nervous – what if the guy woke up and still had his trigeminal neuralgia? We talked about it and we agreed, that because the patient was consented for a partial trigeminal nerve section, we did a partial trigeminal nerve section, even though Jannetta had seen what he wanted to see and had done what he wanted to do."

The surgery was complete. And "the patient woke up. And he had no face pain. We knew that we had solved the problem by moving the vessel. But we also knew that we solved part of the problem by making a small cut in the nerve."

When Jannetta wrote his first papers, or gave talks at his first few conferences, Alksne recalls, "there was a negative reaction in the neurosurgical community, because people said you may have just been damaging the nerve by trying to move those vessels. That doesn't mean that those vessels caused trigeminal neuralgia."

But future surgeries, refining the procedure – adding the Teflon sponge – and eliminating cutting the nerve, and the success of those surgeries, proved that Jannetta was right. It all began more than 50 years ago, and microvascular decompression continues to eliminate devastating pain in thousands of victims of trigeminal neuralgia – and give people back their lives. ●

Watch Dr. Alksne discuss the first MVD performed with Dr. Jannetta <https://vimeo.com/153386512>

Michael Pasternak, Ph.D., is a founding trustee of the Facial Pain Research Foundation. Dr. Pasternak spoke by telephone from Florida with Mervyn Rothstein.

The Interview

By Mervyn Rothstein



Michael, how did the Facial Pain Research Foundation, a multimillion Dollar research foundation to find cures for trigeminal neuralgia and related neuropathic pain, become a reality?

I think, Merv, first I need to remind you that I had the pain. That I am a survivor of that facial pain. And I am in a very sought-after group to be in. Because there are few people of the thousands of trigeminal neuralgia sufferers I've known that have been as pain free for as many years as I've been. So I feel very special. And there was a moment when I realized that it was time for us to work toward finding a cure.

I'd been involved with the Facial Pain Association, formerly the Trigeminal Neuralgia Association, for many years as a volunteer and in leadership roles after I'd stopped having the pain. I was fortunate to have a successful microvascular decompression surgery with Dr. Peter Jannetta. I had been

a businessman and a college professor, and I always felt, because my mother had told me that I could, that I could be successful at whatever I wanted to do. Then, in 2009, two other members of my family got facial pain. It was at that moment that I felt that we really needed to have a cure.

For 50 years, the treatments that have been given to trigeminal neuralgia patients have worked for only some people and not for others. So I connected with several friends who had been with the Association for years – Roger Levy, who had been the chairman of the board, and Mike Hirsch, who had been the president of the association after me – and we went down to Marco Island in Florida and spent three or four days talking about how do we put together a research foundation to find a cure for TN, and for related neuropathic pain.

And that's what we did. We brainstormed – and there certainly wasn't a roadmap – and we decided to find some talented people, creative people, who were willing to admit they didn't know what they were doing but were willing

"Pasternak"...continued on page 18



"Pasternak"...continued from page 17

to pull together and create a foundation to find a cure. I approached Al Rhoton [Albert L. Rhoton Jr., M.D., founding chairman of the department of neurosurgery at the University of Florida College of Medicine], the most famous neurosurgeon in the world, and Doug Anderson [Douglas K. Anderson, Ph.D.], head of the McKnight Brain Institute at the University of Florida, and we continued to talk about what it would take to put together a foundation, and we grew it. The focus was we were going to find a cure.

How are we going to get rid of all this pain?

We're going to get rid of it because we have found the best consortium of scientists in the world to work on it. These are outstanding scientists whom we approached, and we pulled them together, and we said, "We need your help to do this." It's a hell of a challenge. Imagine saying we want you to work on the most difficult problem there is – how do you stop the worst pain known to humankind? Now we have five research projects, working on different approaches to finding a cure.*

The scientists in the consortium believe in the concept of synergy, that the whole is worth more than the parts, that each group's research supports, affects and benefits the other groups' research. These are great minds, and I believe they're going to do it. That's basically our motto – we can do this. There are hundreds of scientists working on these projects in the five locations. Our goal is believable. And it's going to happen.

Where does all the money come from to support the foundation's research projects? How much does the foundation receive each year?

That's a very, very good question. First, we have thousands of volunteers who have created opportunities for people to participate in fund-raising activities – everything from comedy shows to golf events to running and walking and wine-tasting, music events, the whole range. All of these are volunteer-based.

We have people who send us \$1 a month and many who send us thousands of dollars a year. We also have companies like IBM that send us money. We've had a number of people who have given large sums of money as matching grants. The Wasdin family has given \$120,000. A matching grant of half a million dollars came from the Cilker family.

There are many ways of raising money, and it's the first time in history that people have been asked to donate specifically to stop pain. We're going after pain. Pain is the disease here. Because if we could end the pain, we could stop the world's most painful condition – which is trigeminal neuralgia, and the conditions related to that.

How do you get people to volunteer?

Well, Merv, how did we get you to volunteer? We asked you, and you said yes. I would guess most of our volunteers are people who are in serious pain and have been unable to resolve it with surgeries or medications, or people who have experienced the pain but have been able to resolve it or ameliorate it with procedures or medicines. Family members and friends volunteer too. They all are doing the fund-raising hunting for us. And they find us on our web newspaper, The Afternoon Edition.

Tell me about The Afternoon Edition, which is at www.facingfacialpain.org. I understand it's the most visited of its kind. It has no advertising, and yet has so much information and is read worldwide. How does it get its stories?

The Afternoon Edition is really the brainchild of Mike Hirsch, who is the Chairman of Whitehall Printing Company. Mike had the belief that if he could create a newspaper that would speak in simple, lay person's terms, that would explain the science and the pain, that would tell the stories of the people in pain, and that would do so in a very personal way, it would attract readers to the newspaper. And he was right.

All the stories are written by volunteers. The newspaper also shares information about all the research. And it also provides an opportunity for people who want to volunteer and become part of the foundation to do so.

What's the toughest part of your leadership role? What keeps you awake at night?

That's a difficult one. I would say the toughest part is the larger and larger number of people contacting us who are in horrible pain. Who are disabled. Especially those families where children have trigeminal neuralgia. That keeps me up wanting to be certain in my mind that we're providing the support necessary for our scientists.

And also my concern that we are properly saying thank you to all those who are helping us. Sometimes I'll pop up in the middle of the night and think, for instance, did I thank Frank Skoviera for all he's been doing? That keeps me awake.

We're at the point where the research is a reality. It's over the hump. The foundation is happening. It's no longer a question of whether it will happen. The scientists are working, and we're waiting for the babies to be born. I go over and over in my mind, are we providing enough support for them? And are we responding effectively to the people who are in pain and trying to keep their hopes up? Hope is important. This has been called the suicide disease by some. So dealing with those difficult situations sometimes keeps me up as well.

Why didn't this research start many years ago?

I think we were naïve enough to think that the medical professionals – many of the neurosurgeons and neurologists – were going to solve the problem themselves. I think we were also ignorant enough that when they were giving us data – I mean outstanding surgeons, we're not talking about quacks here, who were saying that on a good day they could fix 80 percent of the people who came into their offices – we forgot about the 20 percent, hoping we'd be part of the 80 percent.

"Pasternak"...continued on page 20

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But it became more and more important to look at that 20 percent and those whose pain returned later in spite of the surgery. We needed to also look at those who couldn't have surgery and reacted badly to medications. These are the people who are going on disability, who are in horrible pain. It got to the point where even though in our earliest organization we said that research is an important goal, it wasn't research to find a cure. It was research to better understand the disease, better understand how it affected patients. But it became apparent that we simply had to change, that we had to focus on the cure. It just took us time. I think we believed it was going to happen, but it didn't happen.

At one point, we brought together seven neurosurgeons and neurologists in a room and interviewed them and asked them what they would do if we gave them all the money they needed to cure trigeminal neuralgia, and they didn't have a clue. So we understood that we were speaking to the wrong group. That we really had to speak to the scientists and get to the basic science of what's causing this problem in the nerves and the brain. And that's what we're doing.



How do you respond when someone asks you if the foundation's research projects are really going to find the cure? What do you say to health

professionals who say that there can never be a cure for trigeminal neuralgia and related neuropathic pain?

For the health professionals, I just ask them what planet they live on. In pretty much the last hundred years, it's not much more than that, we've learned how to fly, created the Internet, found a cure for polio. One of our major reasons for starting the foundation was Mike Hirsch's talking about President John F. Kennedy, who said let's put a man on the moon in the next 10 years. Think about it, Merv. If you could put a man on the moon in 10 years you sure as hell ought to be able to fix a nerve in 10 years. That's been one of our driving forces. It's let's get it done. Get the necessary resources together. Be very focused.

***Facial Pain Research Foundation Scientific Consortium**

"Nerve Myelin Repair and Growth," Dr. Lucia Notterpek, University of Florida McKnight Brain Institute

"Cell Replacement Therapy as a Treatment for Injury-Induced Neuropathic Pain," Dr. Allan Basbaum, University of California, San Francisco

"Finding the Genes that Predispose to Trigeminal Neuralgia," Dr. Marshall Devor, Hebrew University of Jerusalem, Israel, Dr. Kim Burchiel, Oregon Health & Science University, Dr. Ze'ev Seltzer, University of Toronto, Dr. Scott Diehl, Consultant, Rutgers University

"Mapping Towards a Cure: Identification of Neurophysiologic Signatures of Trigeminal Neuralgia Pain," Dr. John Neubert, Dr. Mingzhou Ding, Dr. Marcello Febo, Dr. Robert Caudle, Dr. Todd Golde, University of Florida McKnight Brain Institute

"Novel Ways to Deliver Compounds That Can Eliminate the Pain of Trigeminal Neuralgia," Dr. Wolfgang Liedtke, Duke University

Facial Pain Research Foundation International Research Coordinator Dr. Joanna Zakrzewska, UCLH NHS Foundation Trust, London UK ●

Facial Pain Association **REGIONAL** Conference Program Kansas City, Kansas



*We invite you to join
us in Kansas City on
September 16th*

Claude and Jean Aldridge

The Kansas City TN Support Group is privileged to further the education of facial pain patients and their families in the Midwest by hosting a Regional Conference for the National Facial Pain Association. This support group, begun by Claude and Jean Aldridge in 2004, has remained strong and supportive in the Kansas-Missouri metropolitan area since its inception.

Over the past 13 years the Kansas City Support Group membership has remained steady. There are currently over 400 patients on the roster throughout Missouri, Kansas and bordering states, all receive announcements for the bi-monthly meetings. Speakers for the regular meetings have included a host of medical doctors and integrative health practitioners from the Kansas City area, as well as an occasional "super guest" from the Facial Pain Association's Medical Advisory Board.

Meetings allow time for members to share their situation or history with the group. A recent meeting facilitated a live via-FaceTime session with Dr. Ken Casey, neurosurgeon and FPA Medical Advisory Board member. Dr. Casey answered questions about TN and medical procedures. Those present, most of whom had never attended a national or regional conference, were in awe of how approachable, caring and informative a neurosurgeon can be. That patient – doctor interaction is the heart and soul of the Kansas City Support Group and of Facial Pain Association conferences.

It is Kansas City's intention to make available their Heart-of-America location for those of you in the surrounding area who can attend, we hope you will be enlightened and enriched by those professionals whose practice has focused on the devastating illness of neuropathic facial pain.

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Kansas City Regional Conference Presenters



Ramesh Babu, MD

Ramesh Babu has been treating trigeminal neuralgia since 1981. He started in India in National Institute of mental health and neurosciences in Bangalore. He studied under Dr. Richard Rovit who did radio ablative lesions for trigeminal neuralgia and Dr. Peter Jannetta who pioneered microvascular decompression. Dr. Babu also studied under professor Madjid Samii, many consider him the father of skull base surgery and he is a Board member of the FPA.



Jeffrey A. Brown, MD

Jeffrey Brown is a neurosurgeon and Chairman of FPA's Medical Advisory Board. Dr. Brown has published more than 35 articles in peer-reviewed neurosurgery journals on the treatment of chronic pain, especially facial pain, as well as in the areas of spinal, vascular, tumor and trauma neurosurgery. He has been selected as one of America's Top Doctors in the 2003 and 2004 editions of the Castle-Connolly Directory.



Tapan Chaudhuri, MD, FACP

Tapan Chaudhuri is Board Certified in Internal Medicine & Acupuncture. Dr. Chaudhuri integrates scientific knowledge and the experience of modern medicine with the precious wisdom of ancient healing methods.



Henry A. Gremillion, DDS

Henry Gremillion is the dean of the dental school at LSU and a member of the FPA medical advisory board. Dr. Gremillion served for 17 years as the director of the UFCD Parker Mahan Facial Pain Center and its fellowship program in craniomandibular dysfunction. He has been a member of the associate faculty of the L.D. Pankey Institute for Advanced Dental Education and in 2005 he was appointed an associate faculty member at the Dawson Center for Advanced Dental Education. Dr. Gremillion also has served as a consultant for temporomandibular disorders and orofacial pain to the Malcolm Randall Veterans Administration Hospital, the United States Army, Navy, and Air Force, and the American Dental Association's Council on Dental Practice.



Leesa Morrow, PhD

Leesa Morrow maintains a private practice in clinical health psychology treating chronic pain disorders. Dr. Morrow has expertise in the treatment of acute and chronic pain, as well as stress exacerbated systemic illnesses. She uses a variety of treatment modalities including biofeedback, hypnosis and cognitive-behavioral therapy. Dr. Morrow is an invited speaker to various continuing education venues throughout the country, where she presents topics related to TMD pain, Personality and Chronic Pain Behavior, Bruxism, the Management of Difficult Dental Patients, and Bioethics in Dentistry.

Saturday, September 16, 2017

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SUMMERTIME: FUN, SUN, VACATIONS AND TN,

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Summertime. For many, it's a time of fun in the sun, vacations, and memory-making with friends and family. But for many facial pain patients, summertime livin' is anything but easy, as warm weather and outdoor adventure bring with them new challenges. Here are some tips to help you manage pain during the summer and make the most out of your sunny days!

1. **Remember that warm can still mean windy**

For most TN patients, wind is not our friend! Even in warm weather, wind can trigger an attack. Stay prepared and make sure to have a face mask or wrap handy, even on warm days so you can enjoy time outside.

2. **Plan a vacation, staycation and make a bucket list**

Summer is a good opportunity to take time away from your day-to-day routine and relax! Take some time off if you can, catch up on rest, and take care of you. We all know that facial pain can be unpredictable. Make a list of trips you would like to take or things you would like to do — at home or outside. Pick things that you can do both alone or with family and friends so you have multiple options depending on how you feel on any given day. Make these plans at the beginning of the summer so that you can plan ahead and, if your facial pain requires that you need to reschedule, you aren't stressing about it.

3. **Prepare for summer activities by packing accordingly (don't forget sunscreen!)**

Summer is a time for outdoor BBQ's, ice cream, and humidity, none of which is facial pain-friendly for many of us. If you are going to an outdoor BBQ, talk to the host ahead of time and let them know you may need a break from the heat and humidity — this may require that you need to hide inside for half an hour. Ice cream and frozen drinks are also a popular staple during the summer; find an alternative so that you can indulge as well! Aside from obvious health risks, facial pain patients should be especially careful to avoid a sunburn. If applying sunscreen is a no-go, find a lightweight hat with a large brim or at the very least seek out the shade. Along with the sunscreen, pack snacks and beverages that are TN friendly to you. This way you can avoid snacks that you may not be able to enjoy. Don't forget to bring your medications with you as well, so that you are always prepared.

4. **Reach out to family and friends and make sure someone knows about your facial sensitivity**

When you are feeling up for it, reach out to family and friends to go out and grab lunch or lay by the pool. Keeping up with those close to you is an important part of creating normalcy with TN. Let your friends know ahead of time that you won't always be able to go out, but when you can you'll reach out. Pick activities that you know you'll be able to do — like going to dinner or to see a new movie. Also make sure that the people you regularly hang out with know about your facial sensitivity. If you're at a friend's pool party and decide to go in the pool just to cool off, make sure that the others in the pool know not to splash you (the less to the face, the

better). You always want to try and have the best time that you possibly can.

5. **Change up your routine**

Summer is all about enjoying yourself and the nice weather. In the colder months, many people fall into a routine that can become monotonous or boring. Summer is a great time to switch up this routine and make each day different. Making each day different can help keep your summer exciting! If you watch movies one day, try reading a book or baking the next. Remember to allow time to rest too.

6. **Make time for yourself, but do what you can when you can**

It's okay if you're not up for an extended family vacation or all day BBQ's, so don't put too much unnecessary pressure on yourself. Take in the nice weather on your own terms... enjoy a family dinner on the patio, or join your friends for ice cream if you're having an especially good day. It's also okay if you're having a bad moment or attack and just need some alone or quiet time. Ask your host(s) if there is somewhere quiet that you can retreat to if you do plan to spend all day at a function. Sit or lie down for a bit if needed. Try to relax and refresh while doing so, and see how you're feeling from there. Don't overdo it either; do summer your way, zero guilt needed! ●



Name: Rebekah Urban

Current age: 20

Where do you live? Austin, Texas

How old were you when you first experienced facial pain? I was 16.

We thought it was Bell's palsy at first due to the drooping, then maybe

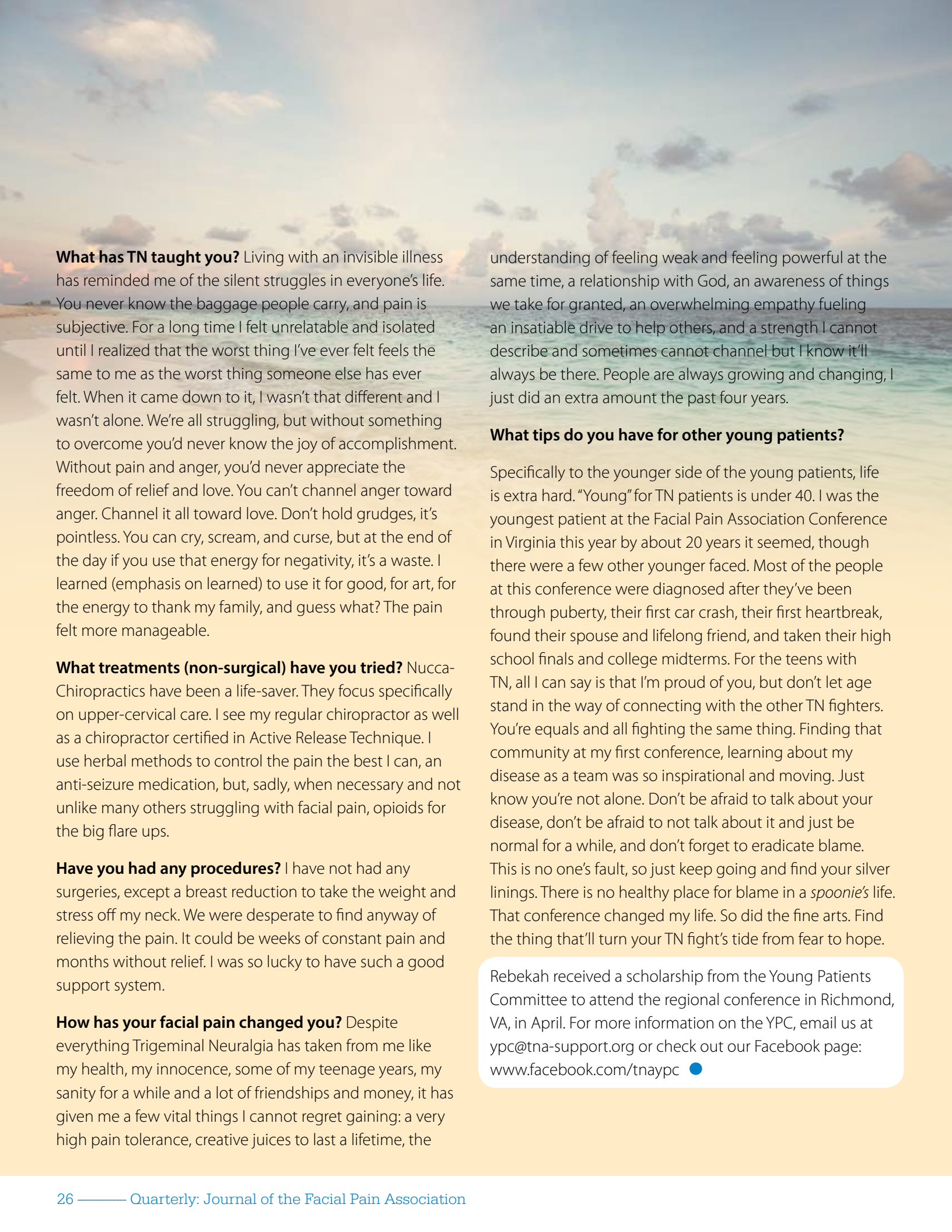
Young Patient Profile

something in my teeth because of the pain, but quickly my entire high school life was on pause.

How old were you when you were diagnosed? I was still 16. Doctors didn't know why I was in pain. A lot of neurologists also wouldn't take me because I was so young. They assumed it was due to multiple sclerosis or a brain tumor, but thanks to my mother being so wonderfully persistent, 21 doctors later we found that the pain was either partially caused or at least intensified by skeletal misalignments and muscle imbalances from an old injury.

What was your diagnosis? I was diagnosed with Bilateral Atypical Trigeminal Neuralgia, then later with severe muscle spasms and a misalignment of the vertebrae around my brain stem.

What do you do for fun? I love to stay active in ways I can, like swing dancing for the music and Krav Maga (a form of self defense) for the stress relief. I mainly stuck to the fine arts like drawing, singing, acting, and dancing. I am as right-brained as they get. I found a very diverse and powerful group of people in the local poetry slams and my university's Fine Arts Department. It takes a toll, but I just can't stay away.



What has TN taught you? Living with an invisible illness has reminded me of the silent struggles in everyone's life. You never know the baggage people carry, and pain is subjective. For a long time I felt unrelatable and isolated until I realized that the worst thing I've ever felt feels the same to me as the worst thing someone else has ever felt. When it came down to it, I wasn't that different and I wasn't alone. We're all struggling, but without something to overcome you'd never know the joy of accomplishment. Without pain and anger, you'd never appreciate the freedom of relief and love. You can't channel anger toward anger. Channel it all toward love. Don't hold grudges, it's pointless. You can cry, scream, and curse, but at the end of the day if you use that energy for negativity, it's a waste. I learned (emphasis on learned) to use it for good, for art, for the energy to thank my family, and guess what? The pain felt more manageable.

What treatments (non-surgical) have you tried? Nucca-Chiropractics have been a life-saver. They focus specifically on upper-cervical care. I see my regular chiropractor as well as a chiropractor certified in Active Release Technique. I use herbal methods to control the pain the best I can, an anti-seizure medication, but, sadly, when necessary and not unlike many others struggling with facial pain, opioids for the big flare ups.

Have you had any procedures? I have not had any surgeries, except a breast reduction to take the weight and stress off my neck. We were desperate to find anyway of relieving the pain. It could be weeks of constant pain and months without relief. I was so lucky to have such a good support system.

How has your facial pain changed you? Despite everything Trigeminal Neuralgia has taken from me like my health, my innocence, some of my teenage years, my sanity for a while and a lot of friendships and money, it has given me a few vital things I cannot regret gaining: a very high pain tolerance, creative juices to last a lifetime, the

understanding of feeling weak and feeling powerful at the same time, a relationship with God, an awareness of things we take for granted, an overwhelming empathy fueling an insatiable drive to help others, and a strength I cannot describe and sometimes cannot channel but I know it'll always be there. People are always growing and changing, I just did an extra amount the past four years.

What tips do you have for other young patients?

Specifically to the younger side of the young patients, life is extra hard. "Young" for TN patients is under 40. I was the youngest patient at the Facial Pain Association Conference in Virginia this year by about 20 years it seemed, though there were a few other younger faced. Most of the people at this conference were diagnosed after they've been through puberty, their first car crash, their first heartbreak, found their spouse and lifelong friend, and taken their high school finals and college midterms. For the teens with TN, all I can say is that I'm proud of you, but don't let age stand in the way of connecting with the other TN fighters. You're equals and all fighting the same thing. Finding that community at my first conference, learning about my disease as a team was so inspirational and moving. Just know you're not alone. Don't be afraid to talk about your disease, don't be afraid to not talk about it and just be normal for a while, and don't forget to eradicate blame. This is no one's fault, so just keep going and find your silver linings. There is no healthy place for blame in a *spoonie's* life. That conference changed my life. So did the fine arts. Find the thing that'll turn your TN fight's tide from fear to hope.

Rebekah received a scholarship from the Young Patients Committee to attend the regional conference in Richmond, VA, in April. For more information on the YPC, email us at ypc@tna-support.org or check out our Facebook page: www.facebook.com/tnaypc ●

FPA Membership

The following individuals joined or renewed their FPA membership between March 2017 – May 2017

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Diane Antonette
Ja Arezzi
Cindy Bennett
Kimberly Bensen
Martha Bertrand
Susan Bruner
Joan Cannelli
Sharon Carrigan
John Collura
Janet Cotugno
Vickie Dance
Walter Daniel
George Downs
Linda Evans
Shera Farnham
Diana Ferris
Cathy Findling
Vickie Guite
Donald Hansen
Kenneth Harvey
Kathleen Hays
BettyAnn Held
Patricia Knight
Billy Leedy
Deborah Lockwood
Annette Ludlam

Patricia Mares-Mischke
Richard Martin
Gayla Merriott
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Susan Ode
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Linda Poland
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Jeannette Rusbosin
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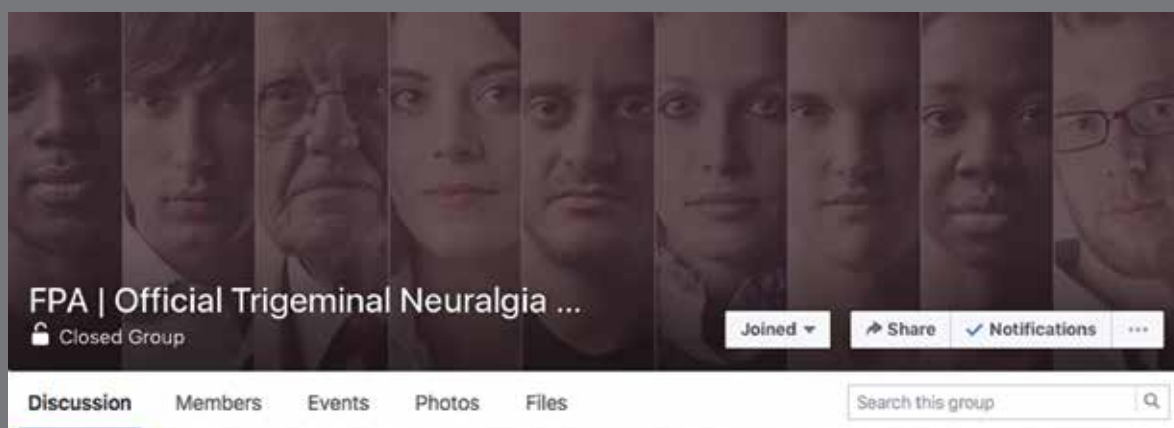
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Annette Washburn
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Faun Danson
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FPA's Memorial Tribute Fund

There are special people in our lives we treasure. Increasingly, FPA supporters are making gifts in honor or in memory of such people. These thoughtful gifts are acknowledged with a special letter of thanks, are tax-deductible, and support FPA's growing initiatives on behalf of TN patients and families. We are delighted to share recent Memorial Tribute gifts received as of May 31, 2017:

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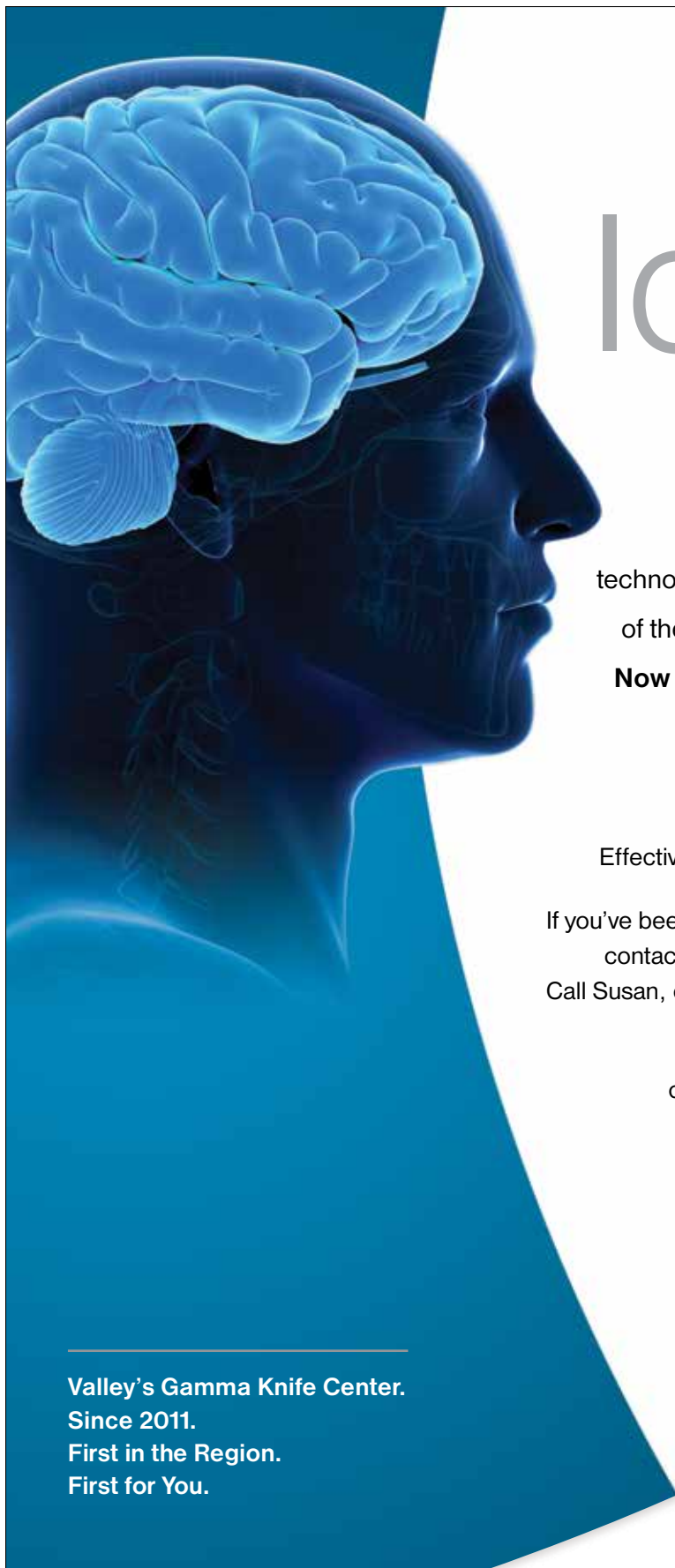
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Jeffrey A. Brown, M.D.

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



Alan Mechanic, M.D.

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



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