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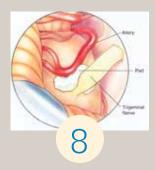
Cover

The feature article of this issue. A comprehensive look at Microvascular Decompression Surgery.

FEATURES



Pam Neff writes about a high school student who wanted to do something to show his support for people with TN, including his Mom.



An in depth review of microvascular decompression surgery (MVD) with Dr. Ken Casey.



The **Virginia Regional Conference** material including Agenda and Faculty list begins on page 20.



The FPA offers up a mini medical dictionary of terms useful to every person with face pain.

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New Members, Memorial and Honorary Tributes



From the Chairman of the Board

The FPA is a 501(c)(3) tax-exempt nonprofit organization that provides people who have facial nerve pain disease, and their caregivers, with information and community that helps them to manage their lives. We have a full-time staff at our office in Gainesville, FL and the outstanding job they do was the subject of this letter last September. This Quarterly letter is about the FPA's Board of Directors. We have three Directors to thank, and we'd like to hear from those of you who have an interest in helping the FPA as a member of our Board.

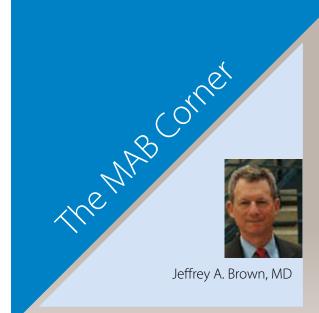
First, we thank and bid goodbye to Thomas Wasdin, Richard Marschner and Jean Raymond. Tom Wasdin was a Director for over 15 years, his wise advice helped steer the FPA forward, his encouragement and support for our staff and other Directors was essential motivation, and he was a seed donor to the FPA's Research Foundation. Rich Marschner was a Director for 10 years, he led several initiates at the FPA, and his keen observations assisted the FPA in running a professional organization. Jean Raymond was a Director for 7 years, she kept us alert to the needs of people with non-classic trigeminal neuralgia, provided useful advice during Board meetings, and she was the FPA's Trustee of our Research Foundation. Tom, Rich and Jean, we thank you for your years of effort, advice and support. We are a better organization thanks to you; we do more for people with facial nerve pain thanks to you. We wish you good health and happiness in the future.

The FPA's Board of Directors is essential to the mission of the FPA. It determines our strategic direction, it monitors the quality of what we do, it is a sounding board for our CEO John Koff, and it ensures that he and his staff have the resources to get the job done. Our Board has four meetings each year, usually two in person and two by telephone/video. Meetings are often scheduled next to FPA conferences so that Directors can attend for their

own benefit and also so they can stay in touch with the needs of those we serve. Each meeting involves reports on various aspects of the organization and then decisions concerning FPA operations and key initiatives. Examples of those initiatives include healthcare professional education to accelerate correct diagnosis and the writing of articles for the Quarterly about diagnosis and treatment by world-recognized experts in facial nerve pain. All of the Directors are volunteers. Each Director serves an initial term of three years. We value transparency, open discussion and dissenting views. We invite the spouses and significant others of Directors to attend meetings and participate too. Being a Director of the FPA is an important job, it makes a positive difference in peoples' lives and making that difference is a joy.

Standing back, identifying new Directors can sometimes take extra work. Although we are fortunate that facial nerve pain is a rare disease, rarity also means that people with the disease, caregivers and potential Directors are thinly dispersed. The next generation of Directors can be hard to spot. All of our Directors' lives have been touched by the disease. We had it, we have it, or it burdens a family member or friend. We see and feel its impact. Each of us has resolved to do something about it. We understand that facial nerve pain can take over one's life and make doing well at work and caring for one's relationships a consuming challenge. After that, if you have bandwidth then the FPA would like to hear from you about joining our Board of Directors. Do call our CEO Joh Koff.

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



The first national meeting of TNA was held at The University of Cincinnati two decades ago. Its purpose was to educate support group leaders on the optimal treatment of trigeminal neuralgia by members of the Medical Advisory Board. Dr. Peter Jannetta had selected the MAB members who attended on the basis of their lifelong commitment to and expertise in the treatment of trigeminal neuralgia. Over the years the national meeting has expanded, as has the MAB. Patients and their caregivers now attend and regional meetings are interspersed between biannual national meetings. Such meetings are held at expense to those attending, those presenting and those organizing it. The advantages are obvious to all who take the time to participate, but the number of patients who can ultimately be reached by each such meeting is limited.

For each of the four hour-long webinars that we have now broadcast live (with

the opportunity to ask questions) in the past half-year, there have been around 250 homes tuned in. By placing the full broadcast on our website for repeated review, countless others around the world have been able to access the expertise and assistance of the MAB.

This is an educational revolution for you and for us.

The web is now filled with information on facial pain from diverse sources scattered round the world. How does one evaluate the accuracy of the information offered? TNA-the facial pain organization hopes that, by the careful selection of members of its board of directors and its medical advisory board and their considered review of the information dispersed through print, web, even telephone this organization can serve as a trusted and respected resource for all who suffer from the intolerable mysteries of facial pain.



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Student Helps Mom Deal With Her TN

By Pam Neff, RN, FPA Patient Services

Michael Brown would appear to be your typical 11th grader, except that Michael is exceptional in his passion, ability to work hard and research for answers, which takes up a lot of normal teenage time. He is also driven to go above and beyond to help his mom and other people with Trigeminal Neuralgia (TN).

On October 25, 2013, Michael's mother, Eileen Brown, underwent mandibular advancement jaw surgery to correct her sleep apnea. Soon after, she began to have extreme pain on the right side of her face, which later spread to the left side. She has a combination of the electric shock attacks and numbness in her chin area. She went through many doctors and medications, as so many sufferers do, and finally said, "I am done". She no longer takes any medications, except an antidepressant, which she says helps her quite a bit, and copes as best as she can with the chronic numbness and the shock-like flare up pains.

"The hardest part about watching my mom having TN is knowing that there is not much that I can really do about it. She's in so much pain, and there's nothing I can do to alleviate that. All I can do is give her some hope, and that's what I wish to do with this research", Michael commented.

Michael, or Mikey as his friends call him, is enrolled in a unique advanced placement program at Coral Springs



High School in South Florida, which is an Advanced Placement research class. This class involves designing, planning and conducting a yearlong research-based investigation to address and research a question of interest to the student. At the end of the year a paper of 4000-5000 words plus a presentation with an oral defense is required, during which the student will answer 3-4 questions from a panel of evaluators. Sounds a lot like a Master's thesis!

The students were asked to focus on a topic that had not been studied or had insufficient data and Michael chose the social issues that affect a person with Trigeminal Neuralgia. He looked at scholarly information and read patient accounts and was able to put together several

"Michael Brown"...continued on page 6

"Michael Brown"...continued from page 5

questions for an online survey. Some of the questions asked how TN affected the ability to perform activities such as attending social functions, or maintaining relationships with family and friends. Working outside the home and performing daily tasks such as talking, eating and exercising were also important parts of the survey.

Michael contacted John Koff, CEO of the Facial Pain Association and asked for help to get the survey out to people with TN that might participate. He received 400 responses in the first hour! He was also touched by the written comments at the end of the survey such as "God bless your mom" and "It is really touching, what you are doing" which meant so much to him. "The support was tremendous". Michael said.

Social changes in a person's life with TN are not often brought to the forefront and addressed. Chronic pain from TN is frequently very isolating and depressing for the individual. Depression and sleep disturbance can conversely render persons more vulnerable to pain and suffering which in turn can inhibit them from enjoying everyday activities. As TN is an "invisible" illness friends and family may think the pain is exaggerated or that it is mismanaged which in turn may strain those relationships. The sudden change from "normal pain" to being entirely

unable to speak because of a flare up can also be perplexing to others.

Also the fear of "triggers" that might cause pain can lead to anxiety and panic attacks that prohibit or discourage the sufferer from going to work or attending social activities. Medications that include anti-seizure drugs can make the person feel "zombie like" and sometimes confine them to bed.

Michael is giving his mother hope. The kind of hope that comes from the recognition and knowledge of how the severe pain, such as is associated with TN, can affect daily life. Knowledge is power and the information from Michael's research will shine forth as an example of how we can do more to help the quality of life for those individuals with TN.

Michael said that "the whole project was so worth it and I am happy that I can make that impact". If he passes both parts of his paper, the methodology and the limitations and conclusions, also including an oral presentation, he will be given an AP Capstone Diploma. We wish you the best Michael! You have a great future ahead!

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Microvascular Decompression: Attacking the Root of the Problem

By Kenneth Casey, MD, member of the FPA Medical Advisory Board

Edited by Anne Ciemnecki





When Dr. Peter Jannetta proposed attacking TN by going inside the skull to insulate the trigeminal nerve with a minicushion, the idea wasn't wholly embraced by the medical world. More than a few fellow neurosurgeons openly questioned the wisdom of risking serious complications and even death when 1) TN is not a fatal condition and 2) other, less risky, and reasonably effective treatments were available.

A lot of patients weren't crazy about having their head opened either. Yet five decades later, the microvascular decompression (MVD) procedure has become widely accepted and many surgeons consider it the patient's best chance at long-term pain relief without numbness.

MVD is the only surgical procedure that addresses the purported cause of most TN. The aim of MVD is to hunt down one or more blood vessels compressing the

trigeminal nerve and to move the two apart by inserting a small pad between them. The aim of other procedures is to alter the pain-transmission ability of the nerve with a surgically-induced injury.

MVD approach

The idea of MVD is to be as nondestructive as possible. However, MVD requires an opening in the skull before the surgeon can try to undo the damage the body is causing itself. If all goes well, the surgeon will get in and out with no lasting problems. This action essentially takes the offending mechanical force - a pulsating blood vessel - out of play. That alone is often enough to stop the pain in its tracks. With the vessel no longer beating on the nerve, the patient wakes up and finds the pain is gone completely.

Other times, moving the vessel out of the way gives some

Numbness sometimes occurs with MVD, but it's not a necessary or intentional effect. In the procedures that injure the nerve, more numbness usually means better and longer-lasting pain relief but that's also more annoying to the patient. So, surgeons try to strike a balance of injury - enough to help but not so much as to be annoying or harmful.

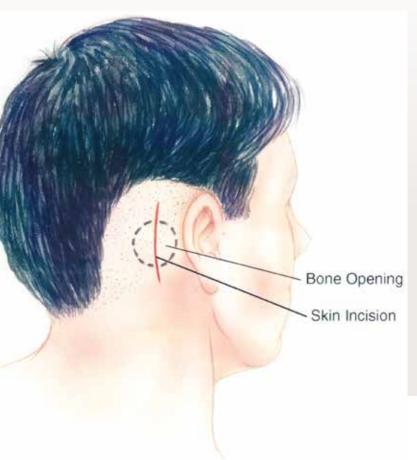
In an MVD, there is no such balancing act: Having numbness doesn't mean better pain relief. In fact, one study found that most patients with excellent relief (defined as no pain and no requirement for medicines) had no postoperative numbness at all.

In the early years of MVD, some surgeons speculated that it wasn't the padding action of this procedure that was stopping the pain. They theorized that the mere action of moving the vessel off the nerve was causing mild injury to

the nerve and stopping pain. Long-term studies have discounted that theory. In fact, it's now believed that irritating the nerve during surgery might be behind the numbness that sometimes occurs. Sometimes vessels can be decompressed easily but other times the surgeon must do some tugging and manipulating to separate a vessel that has adhered to the nerve or wedged itself tightly behind the nerve. When numbness does occur after MVD, it's usually mild and clears up within a few weeks.

improvement at first, but the nerve needs to gradually heal over days or weeks before the pain fully subsides. The longer a person has had TN pain before having an MVD, the less likely it is that pain relief will be immediate.

This sketch shows where surgeons work to move a blood vessel off the trigeminal nerve during a microvascular decompression procedure. Reprinted with permission of the Mayfield Clinic, University of Cincinnati



The MVD procedure

Prior to surgery, patients must be tested and screened to make sure their overall health is good enough to tolerate the stress of major surgery and the two to three hours of general anesthesia that an MVD may require.

Once the patient is asleep, a 1-inch-by-3-inch area of hair is shaved, behind the ear on the side with the pain. Positioning is important at this point. The head is secured in a surgical clamping device to prevent any movement during the procedure. After surgery, this may give patients a feeling of having had bands tightly wrapped around their heads.

With the head in place, the surgeon cuts a half-dollar-sized hole (sometimes smaller) in the skull just behind the ear. The waterproof covering of the brain (the dura) is then opened to expose the brain.

In a microvascular decompression procedure, surgeons enter the skull behind the ear through an opening that's slightly larger than a quarter.

Sketch by David Peace, University of Florida



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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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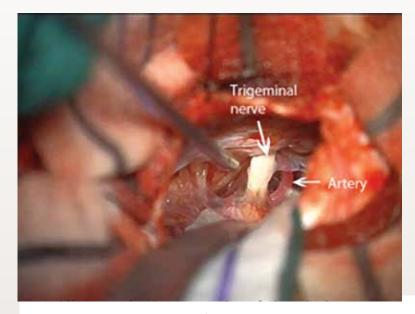
Using an operating microscope, the surgeon works next to the brain to locate the cranial nerves. Technically, this is cranial surgery, not brain surgery, since nothing is being done to the brain itself. The surgeon is looking for the root zone of the trigeminal nerve - the point where it connects to the pons or brainstem. That's the spot where arteries and

veins are most often found to be compressing the nerve. (An artery is a vessel that carries blood from the heart to various parts of the body; a vein carries blood back to the heart.)

Another doctor monitors a device that continually tests the nearby auditory nerve, which lies in the path between the skull opening and the trigeminal nerve. The surgeon must work around the auditory nerve and, if it's irritated too much, hearing damage can result. Monitoring keeps track of whether the auditory nerve is being overly stressed, so the surgeon can take corrective action before damage occurs. This step has greatly reduced the threat of hearing problems. Many surgeons require a hearing test as part of the preoperative screening so that a baseline reading is available to determine whether the MVD affected hearing.

While exploring the trigeminal nerve root through the operating microscope, the surgeon hopes to find one or more offending blood vessels. A pre-surgery MRI sometimes gives surgeons an idea ahead of time where they're likely to find compressing vessels, but not always.

In most cases, the compressing vessel is obvious to the surgeon's eye, but occasionally it's well hidden. In rare cases, vessels have been found growing through the middle of the nerve. And in more than half of MVD surgeries, more than one vessel is compressing the nerve.



These two photos are actual views of what a neurosurgeon sees through the operating microscope during an MVD procedure.

In as many as 10 to 15% of MVD surgeries, surgeons fail to find or recognize any compressing vessels. When that occurs, many surgeons cut some of the sensory nerve fibers to bring relief without troubling numbness. (More on this below.)

Failure to find a compressing vessel means one of two things: either something else is causing the patient's pain or the surgeon simply hasn't been able to locate the troublesome vessel. The better a surgeon's training and experience, the fewer "nothing-found" cases should occur. In the early 2000's, some of the most experienced surgeons reported finding vessel compressions in 99% of the cases – significantly higher than even a decade before.

Some surgeons use a camera device called an endoscope to give a magnified look inside the skull. Some use it in conjunction with the operating microscope; some use it exclusively.

"Microvascular Decompression"...continued from page 11

MVD advances

Improvements are still being made in microvascular decompression surgery. Not only are many more neurosurgeons trained in the procedure, but their growing experience has led to improved techniques, fewer serious complications, less time to complete the surgery, and faster recoveries for patients. All of that is being done with smaller skull openings.

One newer tool being used for MVDs is the endoscope, a device that employs a fiber optic tube that's inserted into the skull opening. It gives a magnified look at the nerves and blood vessels inside. Some surgeons use it instead of the operating microscope, which also lights and magnifies the nerves and vessels but from outside the opening. Others use it in addition to the conventional microscope.

Backers say the endoscope allows the MVD to be done with a smaller opening and doesn't require the cerebellum to be moved. One neurosurgeon who does endoscopic MVDs, says this instrument often gives a better view of

the trigeminal nerve because of better lighting, better magnification, and the endoscope's ability to rotate and to "look around corners." That searching ability enables the surgeon to locate compressing blood vessels that he may have missed with the standard microscope.

Most neurosurgeons aren't yet sold on the tool, though. Some say it gives only an occasional and marginal improvement in view, and it may be slightly more likely to lead to hearing problems. The hearing nerve is not in view when the endoscope advances toward the fifth nerve. With the smaller opening, there's also less room to work, which could be detrimental in case of a complication, others point out. For now, few neurosurgeons are using it. Most of those who are having good success with the microscope say they are reluctant to start on a new learning curve until they're sure the new technology will make a significant difference. Overall, most of the literature endorses the endoscope as an adjunct tool, and the practitioners who report using it solely, do report the operative approach, and intraoperative tools are similar. They also report the operation does not take any longer, compared to standard MVD.

"Microvascular Decompression"...continued on page 13

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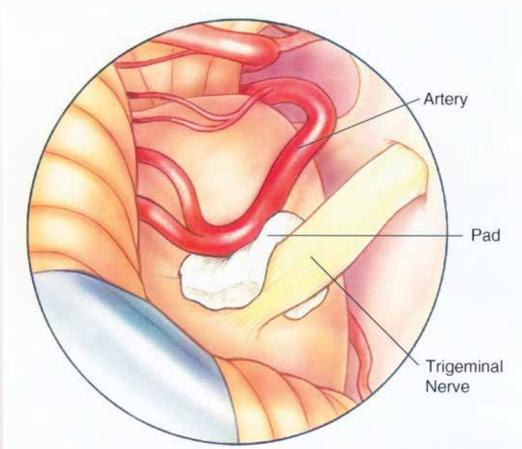
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Surgeons also continue to look for better nerve-cushioning materials to use in MVDs and better ways to apply these materials. Shredded felt is still most commonly used today, although a few surgeons have been trying other materials, such as Gore-Tex. A few other surgeons use implanted neck muscle, which is soft and natural but tends to break down and be absorbed over time.

Besides inserting these materials between vessels and the nerve, surgeons have tried wrapping the insulating material all the way around the nerve. The idea is to keep vessels from bumping the cushion away and to protect the nerve at all angles from any vessels that may get near it in the future.

Other materials such as Dacron felt and Ivalon (a hard sponge) have been used in the past, but these tended to irritate the nerve. Slivers of transplanted muscle, dura, and periosteum (a fibrous connective tissue) also have been tried, but most surgeons do not use them because the body tends to break them down.

Polytetrafluoroethylene surgical felt also occasionally has caused some scarring and adhesions on the trigeminal nerve and there have been a few reports recently about this padding causing abnormal growths (granulomas) (<1%). But at present, this has been found to be the best, least irritating material, and is widely used.

Close-up of how a sponge or pad is inserted between a blood vessel and the trigeminal nerve during a microvascular decompression procedure.

Sketch by David Peace,
University of Florida

Dealing with the vessels.

In two-thirds to three-

quarters of the cases, when a blood vessel is found to be compressing the nerve, that vessel is an artery. It's important to make this distinction because arteries cannot be cut or removed but must be padded off the nerve. Veins, however, can be divided by sealing them off and cutting them out rather than padding them. Blood that had been traveling through the removed veins will find its way back to the heart through other veins. According to neurosurgeon Raymond Sekula, women between the ages of 35 and 52 seem to have a higher prevalence of veins causing their pain than other groups. This was often the case in patients presenting with isolated V2 pain.

The problem with cutting out veins is that, in about a third of the cases, new branches will form and cause a new compression.

To avoid some of the higher pain recurrence in vein cases, some surgeons now pad veins even though they could more easily cut them out. This seems to reduce recurrence rates, and intraoperative complications.

"Microvascular Decompression"...continued from page 13

Patients sometimes ask why surgeons don't just remove all veins found anywhere near the trigeminal nerve. That can't be done because these veins return blood to the heart from the brain, and removing too many of them (or too big a one) could lead to a stroke.

Once the padding is in place or the vein has been eliminated, the surgeon sutures together the dura and covers the skull opening with a variety of techniques. While a thin titanium plate was initially popular, many surgeons now use bone substitutes, finding these materials easy to mold to fit the opening in the patient's skull. It was quite common, when the opening was not repaired, to experience mild but noisome headaches probably resulting from the scarring and the muscle of the upper neck that attaches at the opening appear to reduce the incidence of headaches as a late complaint.

The patient usually spends the first night in an increased care area, with a smaller nurse patient ratio. Most patients are often well enough to go home in one to two days, in part due to improved anesthetic techniques. Pain medicines are used for the first several days, and most physicians continue the pre-operative medical regimen for the nerve pain. In the case of the anti-epileptic drugs (Carbamazepine, Dilantin, Neurontin, etc.) a bit of a taper for each drug is normally done after discharge. Coordination and other neurological tests are done at regular intervals for the first 24 hours. The entire MVD procedure typically takes two to four hours, although the actual repair takes more like 90 minutes. But individual cases can vary, depending on the nerve-vessel anatomy.

Many patients can return to work within two weeks (longer if they have physically demanding jobs) and most say they are completely recovered in about two months.

MVD's role in TN

Neurosurgeons often tell their patients that MVD is a procedure that sounds worse than it is. Improvements in technique, anesthesia, and technology over the past 50 years have greatly reduced the serious risks.

Still, complications such as hearing loss (1%), meningitis (1%), spinal fluid leaks (2%), occur. Death from the procedure remains guite rare (<0.2%)

On the other hand, this is the only procedure that attempts to fix the underlying problem. And it offers a high probability of complete pain relief (sometimes as much as 98%) with the best chance that the pain won't come back.

What it boils down to is weighing the potential risks vs. the potential benefits and carefully selecting patients who are best able to tolerate the surgery.

MVD works best in classic TN-1 and many TN-2 cases; it is especially good to relieve those patients that have sharp, stabbing pain and definite trigger zones. The more the pain gravitates away from that, the lower the success rate.

Atypical or mixed cases are often helped, but the success rates for these are 50 to 65% as compared to 90% and up. What often happens is that the MVD helps the sharp, stabbing component of a person's pain but not the more constant, burning, underlying pain.

MVD is generally not recommended for neuropathic and deafferentation pains (these are caused by injured or disabled nerves, not blood-vessel compressions) and it's usually not helpful for facial pain related to multiple sclerosis. The exception is if a person with MS related pain also happens to have a blood vessel compressing their trigeminal nerve. This sometimes can be seen on an MRI.

General health is now considered more important than chronological age. A healthy 70-year-old is probably a better MVD candidate than a 60-year-old with heart problems. Besides those with heart problems, people who have breathing or lung problems and those with bleeding disorders are poorer risks.

Since the whole idea of an MVD is to find and correct a compressing blood vessel, it's important to make sure of the diagnosis before operating. Facial pains that are not TN and therefore are not being caused by a compressing blood vessel are not going to be helped by MVD.

The arguments for and against MVD

Most surgeons also do not advise MVD initially until medication has been given a fair trial and either has failed or is causing the patient unacceptable side effects.

In the past, MVD was often suggested as an option of last resort - something that one should consider only if in agony or if having debilitating side effects on a handful of medicines. But that's changed, too. Studies have found that MVD success rates seem to start dropping off after people have had their pain for more than seven or eight years.

Some surgeons believe the prime window of opportunity is before irreparable damage is done to the nerve. This can be detected by a careful exam of the nerve function before surgery. They say that younger patients should think about earlier MVDs, even if they're not in severe pain or having troubling side effects from their medicine.

Not all agree with this more aggressive approach. More conservative surgeons say the success rates are still good enough in the long term that it isn't worth the extra risk of subjecting people to MVD any sooner than necessary. Others add that radiosurgery and the through-the-cheek procedures are successful enough and repeatable enough that their lower risk outweighs MVD - at least in older, less healthy patients. They argue that if the less risky procedures fail, only then should MVD be considered - even if the success rates are a bit lower at that point.

One neurosurgeon contends that even a 1 or 2% risk of death or serious complication in MVD is too high for a nonfatal pain condition. He says that is not a trivial figure for a disease with no spontaneous mortality or fixed disability when successful alternatives exist.

On the other hand, pro-MVD surgeons argue that the other procedures have their risks as well - problems such as anesthesia dolorosa, corneal numbness, and severe numbness that are all but eliminated in MVD. And they point to several studies showing that MVD success rates are about 30% lower when MVD follows one of the nerve injuring surgeries.

MVD surgery is routinely covered by insurance but for those without insurance, this is easily the most expensive of the TN procedures. Recent research has disclosed that the cost may represent what most shoppers already know: you get what you pay for. The researchers found the most utilized procedures were also the costliest, though lower cost does not always mean better results. In fact, the researchers found that MVD, the costliest procedure, also had the most quality adjusted life years (QALY) score, as defined as complete freedom of pain, not including facial numbness or a partial reduction in pain symptoms. The late Steven Graff-Radford, DDS, treated TN extensively at the Cedars-Sinai Pain Center in Los Angeles, California, and served on the board of the Trigeminal Neuralgia Association. Dr. Graff-Radford said the most successful surgical procedure has consistently been MVD.

The medical literature is relatively consistent regarding MVD. Microvascular decompression achieves the most sustained pain relief with 90% of patients reporting initial pain relief and over 80% still pain free after 1 year, with 75% after 3 years and 73% after 5 years remaining pain free. In most cases, pain relief is immediate. Once the pressure of the blood vessel is removed, the nerve's fibers are no longer pressed together and signals from the light touch fibers stop jumping onto the pain signaling fibers.

However, in some cases - especially in those who have had pain for a long time - the pain may take a few days or even weeks to resolve.

"Microvascular Decompression"...continued on page 16



What isn't always spelled out in the studies is whether success means no pain or whether it also includes people who are significantly improved but still in some pain. One of the few to try and sort out the pain-free cases from those who are much improved is a prospective, long-term 1996 study of 1,185 patients who underwent MVD surgery at the University of Pittsburgh. That study found that 82% of patients had no pain and 16% had at least a 75% reduction of pain. The remaining 2% either had no relief or only minor improvement.

In a study of MVD patients by patients themselves, the Australia TN support group surveyed 71 Australians, Americans, and Canadians who had undergone MVDs and found that 80% were pain-free immediately after surgery.

Pain recurrence in MVD

As with the other procedures, pain can return after an MVD. When the pain does come back, it tends to come back soon after the surgery. Several studies have found that more than half the people whose pain ultimately recurs after an MVD get it back within the first two years.

Long-term studies have found the MVD pain recurrence rate goes down as time passes. On average, about 6% of MVD patients get recurrence in the first year, 3% a year get it in years two through four, fewer than 2% get pain back in years five through nine, and fewer than 1% get it

in year 10. One recent review noted recurrent symptoms typically occur after a mean of 1.9 pain-free years, with a yearly recurrence risk of 1 to 4%. In addition, refractory and recurrent symptoms can occur after radiosurgery or radiofrequency ablation. After the latter procedure, 21 to 50% of patients have recurrent TN and 15% require retreatment. After radiosurgery, approximately 13 to 22% of patients require repeated treatment for recurrent symptoms.

Counting the initial failures along with those who have pain recurrence, one pain specialist came up with the following prospects for MVD patients: 81% will be pain-free at two years, 76% will be pain-free at five years, and 71% will be pain-free at 10 years.

Initial failures may happen for several reasons, such as the surgeon was unable to find the offending vessel (or vessels), the nerve wasn't sufficiently cushioned, or the patient didn't have TN in the first place.

When pain recurs, it's not because the effects of the MVD wear off. Rather, the most likely reason is that a divided vein sends out new branches and sets up a compression problem all over again. Or it could be that a different blood vessel elongates with age and causes an altogether new compression point. And sometimes these vessels don't cause a new compression but instead push away the implanted cushion from between the nerve and the vessel.

Other possible causes of pain recurrence include adhesions that form to cause new damage to the trigeminal nerve or failures of the implant. (Adhesions are fibrous growths that sometimes occur along with scar tissue around the surgical site and implanted pad. Implants occasionally can be absorbed by the body - one example of failure.)

In the long-term study mentioned above, patients with vein compressions were more likely to have a recurrence of pain. Also, female patients and those who didn't get immediate pain relief from the MVD were slightly more likely to have their pain return.

Although MVDs can be done following other procedures that have failed, the success rates are reportedly lower, but several recent papers did not support that concern. The best MVD results come when MVD is the first procedure.

Repeated MVDs also can be done following a failed MVD. Those success rates also are a bit lower than the first surgery - around 80% compared to the 85 to 95% range for first time patients.

The possible drawbacks

MVD patients can expect to be stiff, have a headache, and have some pain around the incision for the first couple of weeks. Those after-effects are common.

Occasionally, patients experience one or more of the following: blurred or double vision, muffled hearing, an outbreak of cold sores, nausea, dizziness, lack of coordination, fluid in the middle ear, or ringing in the ears. These almost always go away on their own in a matter of days or weeks.

A few other possible complications may require medical treatment. These may include meningitis (an infection of the membranes covering the brain), cerebrospinal fluid leaks, lung difficulties, and wound infections. The modern series reflect low complication rates; infection 1%, fluid leaks 2%, Meningitis, non-bacterial 8%. These also are almost always short-term problems. Among the more serious risks are hearing loss on the surgery side (<1%), brain swelling, intracranial bleeding, stroke, blood clot, facial paralysis, and even death.

Hearing loss is the most likely of the serious complications. The most recent reports estimate hearing loss at 1% or less.

The chance of nonfatal stroke or cranial bleeding is also estimated at about 1%.

As for the chance of dying, that rate remains low at 0.2%. Deaths have occurred due to brain seizures, cranial bleeding, heart attack, stroke, and pulmonary embolism.

Facial numbness occurs in very few patients (0.15%). But this is almost always mild and almost always greatly improves or clears up within a few weeks. Permanent facial numbness in any part of the face occurs but is quite rare.

About 5% of MVD patients report sensations of tingling or crawling in the face, in the first few weeks.

The complications rates are related to the number of procedures performed at an institution- more procedures result in fewer complications. The Medicare report concluded that discharge to home versus a rehabilitation facility is also affected by the number of procedures performed. (more procedures=more discharge to home).

An alternative: partially cutting the nerve

There's one more surgical procedure that's sometimes used, short of completely disconnecting the trigeminal nerve at its roots. It's called a partial root section or partial sensory trigeminal rhizotomy(PSR). This can be confusing, as some centers use that acronym to refer to Percutaneous Sensory Rhizotomy. So, it is important to clarify that with your physician.

The idea of this procedure is to cut just enough trigeminal nerve fibers near where the nerve first exits the brainstem to stop or lessen the pain, while preserving at least some feeling in the face. This was a common surgical treatment for TN from the early 1900s until the 1960s.

Partial root sections are primarily employed today as a backup strategy in cases when an MVD surgeon finds no offending blood vessel to decompress. Rather than do nothing, one option (discussed with the patient beforehand, of course) is to cut some of the nerve fibers near their roots.

A partial root section also may be done if a vessel or vessels are found that cannot be safely moved away from the nerve. That may be the case, for example, when a vessel has grown into the nerve fibers. Another time a partial root section may be done is when pain comes back after a prior surgery and the surgeon goes back in, only to find no new compression or a situation that's unlikely to be helped by a second MVD. And occasionally it's done when all other procedures have failed and the patient is willing to trade the almost certain numbness for pain relief.

In a 1993 report, 70% of 83 patients who underwent this partial cutting of the trigeminal nerve root had no pain or well controlled pain for an average of six years after surgery.

About half of these patients reported mild numbness and 18% had severe

numbness, but the remaining onethird had little or no loss of feeling.

A British comparative study in 2003 of 220 MVD patients and 53 partial-root-section patients found that 89% of the MVD patients were satisfied with their situation five years later, compared to only 72% of the partial-root-section patients.

More than one in five of the partial-root-section patients said they were worse off than five years earlier. The study attributed that dissatisfaction largely to complications, primarily numbness.

As with the through-the-cheek procedures, partial root sections involve a bit of a balancing act. The more nerve fibers that are cut, the greater the chance of lasting pain relief but also the greater the chance of dense and permanent numbness. Lighter cuts may limit numbness but increase the chance that pain will come back.

A few surgeons routinely do partial root sections along with an MVD because they believe it reduces the chance that the pain will recur. Others say that approach needlessly increases the chance of numbness, because there's no way to tell how much is too much.

Because this is an open-skull procedure much like an MVD, a partial root section is an option open only to those healthy enough to undergo major surgery. One surgeon also adds routine nerve bruising in addition to the section but most practicing surgeons do not feel it offers any additional benefit.

FPA Membership

The following individuals joined or renewed their FPA membership between December 2016 – February 2017

DECEMBER:

Jennifer Corbin Richard Cretter Linda Duffin Douglas Foley **Robert Francis** Meredith Hershev Cindi Gallagher Stephen lacovino Darlene King Constance McMurray Elizabeth Morris LeRoy Nelson Linda Petersen Lynn Sallee Franklin Schlegel Megan Sommer William Stern

JANUARY:

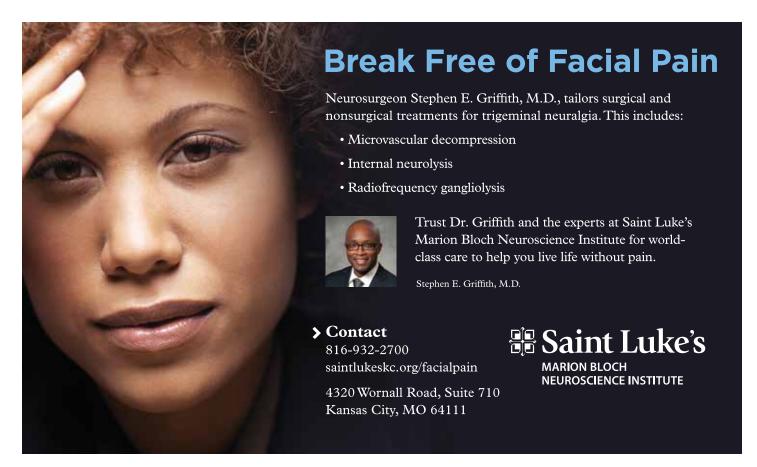
Folashade Adediran William Balthrope Roberta Blumenshine Eugene Bryan Judith Chodil Marlene Clevenger Teresa Cordonnier Eileen Crowley Victor Del Favero Roger Freeman Ellen Heckler Thomas Houle Dwight Jundt Wendy Lyka Richard Motta **Edith Pemberton**

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FEBRUARY:

Marnie Berk Kay Grim

Mary Ann Harrison



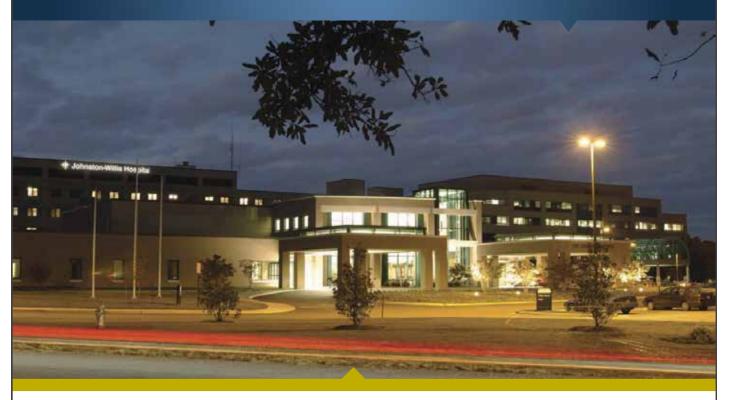


Trigeminal Neuralgia & Chronic Facial Pain Symposium Saturday, May 6, 2017

at Four Points by Sheraton Richmond

7:15 AM	Registration & Continental Breakfast		
8:00 AM	Welcome	K. Singh Sahni, MD, Course Director & Zach McCluskey, CEO, J-W Hospital	
8:15 AM	Multiple Sclerosis and Difficulties of Managing Recurring Facial Pain	Ingrid Paola Loma-Miller, MD	
8:45 AM	Oral and Maxillofacial Surgeon's Perspective of "All that is not Trigeminal Neuralgia"	Jaisri R. Thoppay, DDS, MBA, MS	
9:15 AM	Neurologic Craniofacial Pain Syndromes other than Trigeminal Neuralgia	William Campbell, MD	
10:00 AM	Break		
10:15 AM	MRI: What is the Significance of 3T MRI and What is the Surgeon Looking for?	What Mahati Reddy, MD	
10:30 AM	Trigeminal Neuralgia Treatment Center of VA: 30 Plus Years Experience of Managing Facial Pain with Glycerol Rhizolysis, Gamma Knife and MVD	K. Singh Sahni, MD	
11:15 AM	Patient Panel, their stories and Q/A: Patients having undergone Gamma Knife, MVD and Glycerol Rhizolysis at Johnston Willis Hospital	Moderator: K. Singh Sahni, MD	
12 noon	Buffet lunch served in the Chesapeake Room		
1:00 PM	Non Surgical Medical Management of Different Facial Pain Syndromes	Jason Rosenberg, MD	
1:30 PM	Evolution of Surgical Approaches in the Management of Facial Pain Jeffrey Brown, MD		
2:00 PM	How to Live with Chronic Pain. What are the Options of Patients with Dysestehtic Pain?	Robert White, MD	
2:30 PM	Panel Discussion and Q/A: Attendees will get to ask questions.	All Speakers	
3:00 PM	Break light snacks		
4:00 PM	Optional Tour of the Gamma Knife Center	Alfred Strash, PhD	

PROUD TO HOST PATIENTS AND FAMILIES OF THE REGIONAL CONFERENCE OF FACIAL PAIN IN RICHMOND, VA ON MAY 6, 2017







Johnston-Willis Hospital's Chief of Neurosurgery, K. Singh Sahni, M.D., FAANS, is the founder of the Trigeminal Neuralgia Treatment Center of Virginia. Dr. Sahni has over 30 years of experience in managing facial pain patients medically as well as with Glycerol Rhizolysis, Gamma Knife and Microvascular Decompression. We tailor each patient's treatment according to their age, medical condition and response to prior treatments. At Johnston-Willis Hospital, each patient is treated with compassion and respect. Here, you're not a number.

For more information, please call (804) 320-DOCS (3627). johnstonwillismed.com/service/trigeminal-neuralgia





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Trigeminal Neuralgia & Facial Pain Conference Staff



K. Singh Sahni, MD, FACS is the conference host and Medical Director of Virginia Trigeminal Neuralgia Treatment center. Dr Sahni has 30 years of experience of treating facial pain patients, medically and surgically

including Gamma Knife, Glycerol Rhizolysis and MVD. Dr. Sahni's practice is limited to management of facial pain and cranial surgery and he has been named among the Top Neurosurgeons consistently by Richmond Magazine.



Jeffrey A. Brown, MD 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.



William Campbell, MD is currently in private practice with Neurological Associates, Richmond, Va. Long career in academic and military medicine and medical education, retired Colonel, U.S. Army, Professor

Emeritus, Uniformed Services University. Best Doctors in America, 2009-2015. Author of the 6th and 7th editions of DeJong's The Neurologic Examination, a book which has been in continuous publication longer than any other in American Neurology.



Ingrid Loma-Miller, MD completed a post-doctoral fellowship in adult Multiple Sclerosis at the University of Pittsburgh Medical Center. She is certified by the American Board of Psychiatry and Neurology with Special Competence in Child Neurology. Dr.

Loma-Miller specializes in the diagnosis and treatment of patients with Multiple Sclerosis.



Mahati Reddy, MD is a neuroradiologist at Southern Virginia Regional Medical Center. Dr. Reddy completed her residency at the University of Cincinati and received a fellowship to Emory University Hospital.



Jason Rosenberg, MD is Assistant Professor of Neurology at Johns Hopkins, and focuses his clinical efforts primarily on the treatment of headaches and facial pain disorders. He founded the Johns Hopkins

Headache Center in 2006. A migraine sufferer himself, Dr. Rosenberg is a member of the American Headache Society and the National Headache Foundation. He lectures frequently on the diagnosis and management of headaches to the general public as well as healthcare providers.



Jaisri R. Thoppay, DDS, MBA, MS is Assistant Professor of Oral Medicine and Orofacial Pain at Virginia Commonwealth University School of Dentistry. Dr. Thoppay's expertise includes Temporomandibualr Joint

Disodres, Orofacial Pain, Neuropathic Pain and Burning Mouth Syndrome.



Robert White, MD is a board certified neurologist and completed a fellowship in clinical neurophysiology-EMG at the Mayo Clinic in Rochester, MN. In addition to general neurology, Dr. White's interests

include electromyography and nerve conduction studies, single fiber EMG and diagnosis and treatment of disorders of the neuromuscular system.



Ablative - Removal, separation or cutting of a structure.

Acoustic neuroma - A tumor growing on the acoustic or hearing nerve. This can sometimes cause TN when the nearby tumor pushes a blood vessel onto the trigeminal nerve.

Allodynia - Pain due to a stimulus which does not normally provoke pain.

Anesthesia Dolorosa (AD) A difficult to treat condition that feels like a combination of pain and numbness.

Anticonvulsant - Medication that prevents convulsions or seizures. Prescribed for trigeminal neuralgia

Asymptomatic - No symptoms or complaints.

Atlas - The top-most bone of the spine.

Avulsion -Tearing away of a structure, as in removing or cutting away a section of nerve.

Auditory - Hearing 8th cranial nerve

Bilateral - Occurring on both sides of the body.

Cluster headache - Searing, boring, come-and-go pain in the face or forehead thought to be caused by dilation of the blood vessels in the skull. Sometimes confused with trigeminal neuralgia.

Cluster tic syndrome - Combination of cluster headaches and trigeminal neuralgia.

Compounding - A pharmacy technique in which medications are custom-prepared to meet specific needs of individual customers. Those who offer this service are called "compounding pharmacists."

Cranial nerves-Twelve pairs of nerves that serve various areas and functions of the head. The trigeminal nerve is the 5th cranial nerve.

Craniosacral therapy - Gentle manipulation technique somewhat similar to light massage that's aimed at freeing the flow of cerebrospinal fluid. Some believe impeded flow of this fluid can cause face pain.

Deafferentation pain - Pain that occurs when parts of a nerve are injured to the point where they're disabled. It's usually a constant, burning type of pain.

Demyelination - The process of losing or destroying myelin, the protective sheath around nerve fibers.

Dorsal Root Entry Zone (DREZ) - A surgical procedure done in the neck region to disable the origin of the trigeminal nerve in the upper spine.

Dura - The waterproof covering that surrounds the brain.

Dysesthesia - A numbness or abnormal sensation severe enough that a patient considers it disturbing.

Facial nerve – The 7th cranial nerve that controls most of the muscles in the face.

Familial TN - Tending to occur in more members of a family than expected by chance alone

Gasserian Ganglion - A large ganglion at the root of the trigeminal or fifth cranial nerve, where all three major branches come together.

Geniculate Neuralgia

– Pain deep in the ear. Also referred to as nervus intermedius -part of the facial nerve (cranial nerve VII) located between the motor component of the facial nerve and the vestibulocochlear nerve (cranial nerve VIII).

Glossopharyngeal neuralgia - Similar condition to TN, only this pain is in the throat and neck, 9th & 10th Cranial Nerves.

Herpes zoster - Also known as shingles, this is a viral infection caused by the same virus that causes chickenpox. When it strikes the face, it can cause burning pain.

Hyperalgesia - An increased response to a stimulus which is normally painful.

Hypesthesia - Medical term for numbness.

Idiopathic - Refers to a disease or condition of unknown cause or origin.

Myelin - A white fatty material, composed chiefly of lipids and lipoproteins, that encloses certain axons and nerve fibers

Myofascial pain - Dull, aching muscle pain of uncertain cause. When it occurs in the facial muscles, it's sometimes confused with TN because the pain can be triggered by touching the area.

Nerve block - Use of a drug, chemical or surgery

to stop a nerve signal from getting through to the brain. In the case of TN, these can be used for temporary pain relief or as a way to diagnose the exact nature and location of a pain.

Nervus intermedius - A branch of the geniculate nerve. When compressed by a blood vessel, it can cause pain deep in the ear.

Neurectomy - Surgical removal of a nerve or nerve branch

Neuroma - A tangle of poorly developed nerve endings that resprout following a nerve injury.

Neuromodulation -

Electrical stimulation of a peripheral nerve, the spinal cord, or the brain for relief of pain.

Neuropathic pain - Pain that originates in the nerve, usually due to injury or disease.

Neuropathy - Disturbance of function or pathological change in a nerve causing numbess when it occurs in a sensory nerve.

Neurotransmitter - A

body chemical that's used to transmit nerve impulses from one nerve cell to another. Sodium and calcium are two of the most common.

Nociceptor - A type of nerve receptor that activate when there's a painful stimulus.

Ophthalmic - Area referring to the region of the face around the eyes.

Opioids - Pain-killing agents that originate from the poppy flower and its product opium. Morphine and codeine were two of the earliest. These are sometimes used to treat persistent face pains that haven't responded to other therapies.

Orofacial - Area of the face around the mouth.

Paresthesia - An unusual sensation that may be described as "tingling" or "pins and needles." Often accompanies mild numbness. An abnormal sensation whether spontaneous or evoked. Not unpleasant.

Percutaneous - Passed, done, or effected through the skin.

Peripheral nerves - Nerves outside the brain and spinal cord. In the case of TN, these include the many branches of the trigeminal nerve that serve the teeth, gums and other parts of the face.

Post-herpetic neuralgia -

A type of facial pain caused by damage from the herpes zoster (chicken-pox) virus. Can occur after a bout of shingles.

Radiofrequency - Use of generated heat through an electrode to cause selected damage to tissue.

Radiosurgery - The use of radiation devices to treat diseases and disorders without having to cut into tissue. Two examples of devices used in treating TN

are Gamma Knife, Cyberknife and Linac.

Refractory - Does not respond.

Remyelination - The process of rebuilding lost or damaged myelin, the protective sheath around nerve fibers.

Rhizotomy - A surgery to cut or damage a nerve root so as to interfere with the transmission of pain signals to the brain.

Root entry zone - Section of the trigeminal nerve near the brain stem at which point the myelin covering changes.

Schwann cells - Any of the cells that cover the axons in the peripheral nervous system and form the myelin sheath.

Stereotactic - Guided by X-ray view or similar scanning device. A way for TN surgeons to be guided to precise, three-dimensional locations in the skull and face.

Stimulus - Something causing or regarded as causing a response.

Subjective experience -

Particular to a given person; personal

Tic douloureux - Another name for trigeminal neuralgia. Means "painful spasm" in French.

Trigger - Action performed or area touched which results in pain.



Spring represents a time for new beginnings. The snow has melted. The trees and flowers are starting to bloom. The days are getting longer. And hopefully you've been able to put away that winter coat and get started on some spring cleaning.

In addition to clearing out your closet and changing the batteries in your smoke detectors, it's also a good idea to do some spring cleaning of your TN life. Let's examine many of the ways TN impacts our lives and take stock of possible changes to consider:

> BE HONEST. Are you being real with yourself and others? Are you truthfully communicating with others in your life regarding your pain and your needs? Are you also being honest with your doctor? Sometimes taking a step back and allowing some time for self-reflection and improvement is a much needed thing.

BE HONEST BEKIND

RESEARCH. Take some time to renew your research efforts. There may be a new treatment option that has come along that you might not have been aware of and that might possibly work for you. Or perhaps there is a clinical study being conducted that you fit the criteria for. In short, make sure to find out what's new regarding your facial pain.

SELF-ADVOCACY. Are you advocating for yourself in effective ways? Are you making those around you aware of what you need? Selfadvocacy can be hard,

but it's also vital when dealing with a chronic illness. Unfortunately, those around us can't see the kind of pain we're in and it can be hard to be vulnerable in front of others. But advocating for yourself is the surest way to be happy with how peers, friends, colleagues and/or doctors are treating you.

MEDICATIONS AND SUPPLEMENTS. When

was the last time you thought about your medication regime and how it is working? Are you getting adequate relief or just experiencing side effects? If the latter, how do those side effects impact your quality of life? Are all your medications up to date? If you have expired medications, dispose of them properly. It is also important about where you store your medications. Is that a safe place for children

and pets? Do you have easy access to your meds wherever you are - at home, work, school, etc. Do you take supplements? If so, check in to see how they are working for you and confirm with your doctor or pharmacist they they do not contradict the effectiveness of your medications.

GENERAL HEALTH AND BLOODWORK. What other health concerns need addressing? When is the last time you got a physical and other routine health screenings? Sometimes TN can take over but that doesn't mean that you can ignore the rest of your body.

DIET AND EXERCISE. Are you exercising regularly? Are you doing something once a day to get blood and endorphins moving? If not, this can be a good time to try it out; even just walking around the house can provide a change of scenery and get blood pumping. You may find that the endorphins will make you feel happier! How can diet and healthy eating make a difference? Look at your diet, check nutrition labels, and make note of what you are eating and how it impacts your pain.

JOURNALING. Are you keeping track of your pain? Monitoring your symptoms and triggers can be helpful to your medical team, and to you so you can learn what sort of habits you may need to adjust. Also keeping track of your feelings and experiences can be helpful when you need to reflect. Factors to consider? The length and intensity of your pain. Where were you and what were you doing when it started and stopped? What was the weather like? What had you eaten or drank? How was your stress level? Were you well-rested or lacking sleep?

DO SOME SPRING
CLEANING OF YOUR
SUPPORT NETWORK
AND SOCIAL MEDIA.

Take a moment to reflect: are you getting what you need from your friends and family? Are there any naysayers who you need to block out of your life - online or in person? If so, remove their posts from your newsfeed or minimize your contact. Save yourself the stress! On the flip side, have any friends offered to help you with things, no matter how small? If so, take them up on their offer - they want to show support in the ways they

know how.

CHECK IN WITH YOUR
TN SUPPORT NETWORK.

Have you connected with others who are also battling facial pain? Share your story and offer words of encouragement to those newly diagnosed - we all needed to be lifted up when beginning this journey, so pay it forward and make someone else's struggles a little easier.

BE KIND. Having trigeminal neuralgia can be exhausting so you need to make sure that you are being kind to yourself. When was the last time you did something for YOU? Take a day or even a few hours to pamper yourself; a long bath or even just curling up and reading a book. It's important to recharge your batteries often and nourish your soul.

ROME WAS NOT BUILT IN A DAY,
THE GARDEN DOESN'T GROW
ALL AT ONCE, AND THAT CLOSET

CERTAINLY DOESN'T CLEAN ITSELF.

Similarly, taking steps to a healthier and happier you will not happen overnight. But start somewhere. Pick one thing you can try to change or improve and give it a shot - it might just help.

Young Patient Profile



Name: Amy Tomasulo

Current age: 39

Where do you live? Chicago, IL

How old were you when you first experienced facial pain? 23 years old

How old were you when you were diagnosed? 23 years old

What was your diagnosis? Trigeminal Neuralgia

What do you do for fun? Hove spending time with my husband (Pat) and my dog (Penelope), eating good food (mostly dessert!) and watching movies or TV with Penelope in my lap. We try not to make big plans, because they often fall apart. If and when I feel well enough to see friends, I enjoy visiting with them. I also volunteer for the Facial Pain Research Foundation. My husband Pat and I are coming up on our 3rd annual Laugh Your Face Off! comedy fundraiser to help find a cure for this awful pain for all of us! I also contribute to the FPRF by writing their Mini-Newsletter (when I am able).

What has TN taught you? It's taught me that I am so much stronger than I ever knew I was, and most importantly, that I can make a difference. I always knew I wanted to do something meaningful with my life, I just hadn't figured out my "life plan." I guess it took getting TN and living with it for a while to realize it was in me all along. Funny how these things work.

What treatments (non-surgical) have you tried? I've tried every medication conceivable used to treat TN, as well as different treatments for TMD. I've tried chiropractic care, myofascial release massage, acupuncture, lidocaine patches, topical creams, biofeedback therapy, injections, a nasal application of sphenopalatine ganglion block. I even spent 30 days at the Mayo Clinic's chronic pain rehabilitation program.

Have you had any procedures? Yes, a failed MVD.

How has your facial pain changed you? I appreciate EVERYTHING I get to do now. My TN pain has been with me every single day for 16 years. It's not ALL day, every day, but I get attacks every day. So when I get an opportunity to walk my dog, go out to dinner, or have a conversation without an attack, I appreciate every single moment!

What tips do you have for other young patients? Do your research! Be absolutely certain you are seeing the right doctor(s) for YOU. In my experience, there are a lot of fantastic doctors out there, and just as many

that simply don't understand this disease. Be informed! Be your biggest advocate! Utilize the FPA- let them help! Also, know that you're not alone- you should NEVER have to feel that way. I think a support system is crucial. When I was first diagnosed, I desperately could have used support from others in my situation, but I wasn't aware of any support groupsnow they are everywhere. Whether it is in person or online, get involved in a positive group. Know exactly how to rely on friends and loved ones. This is difficult for them, too. Deep down, many of them want to help, but they may not fully understand the pain we have. Sometimes they just need to know exactly what they can do. Laugh every day! Even if it's just for a minute, laughter can be the best medicine. If we don't continue to laugh in life, this disease is going to win. Please don't let that happen. And believe me, I know sometimes laughing hurts, but it's worth it! Know that you can make a difference too! It took me far too long to realize my potential. Instead of running away from the disease, try running toward it. It feels amazing to know you're helping, whether it's by spreading awareness, fundraising to find a cure, or volunteering in another way. Every little bit helps- you might just be the difference in us finding a cure.

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 February 28, 2017:

In Honor:

All Facial Pain Suffers Raymond McCord Linda Smith

My mother Karin Koff

My son Carolyn Bell

The Philadelphia Support Group Leaders
Michael Logan

Melissa Anchan Lauren Dukes

Kimberly Armstrong
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Dr. Scott Ballinger Diane Ramey

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Mary White Joe Garner

EVERYONE'S JOURNEY WITH FACIAL PAIN IS UNIQUE.

THAT'S WHY EVERYONE **NEEDS A NURSE** NAVIGATOR.





Meet Kelly LoPresti, RN, and Susan Visco, RN, **Nurse Navigators**

The Valley Hospital Gamma Knife Center Paramus, New Jersey

LET OUR **NURSE NAVIGATORS GUIDE YOUR** TRIGEMINAL NEURALGIA **JOURNEY**

If you have questions about Gamma Knife treatment for trigeminal neuralgia or wish to discuss a consultation, contact Susan at 201-634-5677 or by email at svisco@valleyhealth.com.

www.ValleyGammaKnife.com

The road to successfully treating trigeminal neuralgia can be a long one, especially if you've relied on medications for years with modest to little success. It's time to take a different road: outpatient, incisionless radiosurgery at The Valley Hospital's Gamma Knife Center in Paramus, New Jersey.

And to help you down that road are Valley's highly experienced Nurse Navigators - Susan Visco, RN, and Kelly LoPresti, RN.

Susan and Kelly literally meet their patients at the door, ready to take them through each step of their treatment journey.

From a patient's first phone call through treatment and follow-up, Susan and Kelly are personally invested in each patient's care and accessible to patients at any time.

Susan and Kelly have helped hundreds of gamma knife patients receive the treatment they need for trigeminal neuralgia and other conditions.



World Class Trigeminal Neuralgia Facial Pain Program

The New York Area's Experts



Michael H. Brisman, M.D.



Jeffrey A. Brown, M.D.



Alan Mechanic, M.D.

Dr. Michael Brisman, Dr. Jeffrey Brown and Dr. Alan Mechanic perform all of the different procedures for trigeminal neuralgia, and are leaders in the field of face pain surgery.

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

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

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



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