

Quarterly

NEVER

GIVE

UP

There's Always
Another Path....

Dr. Brown on what to do
when your doctor tells you
there's nothing left to do.

Freedom from the pain of trigeminal neuralgia



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from
FPA National Office

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From the Chairman of the Board

The Facial Pain Association is here to provide information and support to patients and caregivers of all ages. For our members under 40, the FPA's Young Patients Committee was founded in 2011. In 2013, the FPA's Board of Directors invited the President of the YPC to attend and participate in all Board meetings. In 2016, the Board elected young person Allison (Ally) Kubic to be a full voting member of our Board. We are pleased to have Ally on our Board, and this letter is about how our initiative to include young people in the FPA yields benefits to our members of all ages. Progress so far is material and exciting, and there is much more to come.

First, the YPC is an autonomous organization under the FPA. It has its own officers and a Board of Directors. The YPC provides support for young patients and their families, advocates for young facial pain patients, raises awareness about facial pain, engages the face pain community, and it raises funds for programs that benefit young people with facial pain and the FPA as a whole. The YPC has a web page within the FPA's website under "Get To Know FPA" and YPC members are active on Facebook and other social media. Meeting places and times are provided to young people at FPA conferences. Every issue of this Quarterly has an article that is about the unique challenges that young people with facial pain disease are overcoming.

The benefits of our initiative to assist young patients and their families are many and much beyond the direct benefits to the young that we are glad to provide. The young bring energy and ideas to our organization.

They are the raw material for our future, some of them will be our leaders in the future. Now, the old model for many organizations like ours is evolving rapidly into a model that involves a so-far-uncertain mix of physical meetings and internet-based interaction. Our young members are at the forefront of this change. Our mission at the FPA is to be as useful as we can be to all of our members, and we need the input, ideas and skills of our young members to accomplish that mission. OK, I like to think that the scars of age and experience are important too. And a broad range of skills is essential. The FPA will be most useful if we listen to and rely on the skills of all of our members.

The FPA encourages diverse research that we hope will lead to better diagnosis and treatment of facial nerve pain disease. Better medications and surgical methods have already improved life for many patients. The research underway now will take time to yield effective treatments in clinics so we expect it to be useful to all of our current members when they are older than now. Some of the results may be the most useful to our young patients of the future.

We will not rest. The FPA is here to assist patients and caregivers of all ages, and we stay alert to the unique needs of our young members and to the unique skills and perspectives that they bring to our organization.



Jeff Bodington, Chairman of the Board
The Facial Pain Association



Jeffrey A. Brown, MD

What to do when your surgeon says that there is nothing left for him to do

Your face hurts. But, you had your surgery and you are still in pain. You return to your surgeon who tells you there is nothing more that he can do and you should seek out a pain management doctor. You don't want a "management doctor." You want to rid yourself of this scourge. Where do you turn?

First, by reading this article, you have taken the first step in the right direction, because the reason for existence of The Facial Pain Association (FPA) is to provide information to people just like you.

Some guidelines:

Many neurosurgeons are able to perform one operation for facial pain—they are careful to select those patients

who have what they comfortably call "classical trigeminal neuralgia." But, when that one surgery that they offer hasn't "worked," they are helpless to continue to offer you care. First, the medical advisory board of The Facial Pain Association recommends that you seek out a neurosurgeon who is able to offer "multimodality" care. One size does not fit all, but one neurosurgeon, expert in the field, with many options to offer, may fit most.

The care of a patient with "trigeminal neuropathic pain" is a complex and nuanced sub-specialty of medicine and neurosurgery especially. "Classical trigeminal neuralgia" may seem straightforward to treat. It is not.

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QUARTERLY
is published four times per year by
The Facial Pain Association,
408 W. University Avenue, Suite 402
Gainesville FL 32601-3248

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www.facepain.org

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Here is a partial list of neurosurgical treatments currently accepted by the field for trigeminal neuropathic pain: (in historical order or development)

- Peripheral supra or infraorbital nerve section
- Radio frequency thermal rhizotomy.
- Microvascular decompression
- Gamma knife radiosurgery
- Glycerol rhizotomy
- Balloon compression
- Cyberknife radiosurgery
- Motor cortex stimulation
- Peripheral neuromodulation

An important question is "How many of these options is your physician able to offer?" This should be straightforward. More difficult is the question, "Which of these options is appropriate for me?"

The response to the last question is beyond the scope of this brief essay. Let us start with two non-surgical options to consider when your pain reaches an intolerable level.

In the situation where neuropathic facial pain has elevated to the point that it is intolerable and uncontrolled, it is possible for the neurosurgeon or neurologist to arrange

for an intravenous infusion of 1000 mg of the seizure drug, Dilantin (diphenylhydantoin). This is a standard anticonvulsant medication that is rarely used orally to treat neuropathic face pain, but when given as a single occasion loading dose, under careful cardiac monitoring in the the hospital or emergency facility, it can halt the stabs of pain. After the infusion, the goal is to return to a regimen of oral medication to limit the pain- at least until the next treatment step.

Another, more involved, step, used for progressive, constant, burning, dysesthetic pain is to be admitted to an intensive care unit setting that allows continuous cardiac and respiratory monitoring. Under the supervision of an experienced anesthesiologist, a continuous infusion of the anesthetic drug, Ketamine, can be delivered for up to three days. My residency professor called such an admission, a "cool down."

Ketamine is an n-methyl-d-aspartate inhibitory drug that is thought to reduce nociceptive pain. There has been much research over the years, however one recent study, in which healthy individuals were studied with functional MRI, showed that low dose ketamine activates the anterior cingulate cortex, the orbital frontal cortex, the insula. These areas are involved in descending inhibition of pain and functional MRI scans show areas of brain action.



Ketamine can have cardiac and psychotropic side effects, which is why it is recommended that it be administered in an intensive care unit under constant observation and supervision by an anesthesiologist experienced in its use. It is also recommended that to achieve persisting benefit the infusion continue over several days and not as a brief one or two-hour outpatient, office administration.

Now, what if pain persists after MVD?

The necessary first step should be to determine the nature of the pain. Is it neuropathic? Is it similar to the pain present prior to surgery? There is a 3% risk of trigeminal nerve injury during MVD and this may lead to dysesthetic pain as a consequence of the resultant numbness. Repeat MVD is unlikely to be helpful in eliminating the numbness and ablative procedures designed to further injure the nerve may prove harmful and aggravate the pain. Anticonvulsant medication should be used in this case. When a dose level is reached that is both ineffective in relieving pain and causes bothersome side effects of sedation, then neuromodulation might be considered. This could be either using peripheral percutaneously implanted electrodes or by motor cortex stimulation. Details of these procedures will be discussed in an ensuing section.

If the persistent pain is similar in site and nature to the preoperative pain, then a repeat MRI using CISS or FIESTA technique and contrast may be helpful. Often postoperative

studies are difficult to interpret because of the presence of scar tissue and the Teflon used for decompression. Clear persistent or adjacent new compression may be dealt with by a repeat MVD. When that should be performed cannot be decided by protocol, but depends on the severity of the pain. Some residual pain may resolve on its own, in the immediate post-operative period.

Repeat MVD is a simpler technical undertaking for the surgeon in the early postoperative period. It is a difficult undertaking for the patient, however, physically and emotionally. A percutaneous ablative procedure may be more reasonable solution. Balloon compression, thermal rhizotomy or glycerol rhizotomy are feasible alternatives. However, radiosurgery may be more difficult because of the imaging difficulties in targeting the nerve present after the MVD.

This is a brief discussion of a lengthy decision-making tree for what to do if the pain is still present. But, what if the pain is of a new nature?

“MAB Corner”...continued on page 6



Advanced Treatment for Facial Pain

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



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.

Offering a full roster of advanced options for treatment, including:

- Microvascular Decompression
- Stereotactic Radiofrequency Lesion
- Stereotactic Radiosurgery
- Neurostimulation
- Alcohol Rhizolysis

The Facial Pain Program at the Weill Cornell Brain and Spine Center is an innovative program that focuses on the diagnosis and treatment of trigeminal neuralgia, one of the most disabling causes of facial pain. Our team includes top specialists in vascular neurosurgery and pain disorders—internationally recognized experts in the field who have advanced training in the very latest minimally invasive procedures used to treat facial pain. Find out more at weillcornellbrainandspine.org or call 212-746-4684 to make an appointment.



This is the problem of constant, dysesthetic, usually burning pain.

Peripheral neuromodulation is a newcomer to the armamentarium of the neurosurgeon treating trigeminal neuropathic pain. The FDA has not approved it, because the manufacturing entities have not performed a study sufficient for their requirements. In fact very few studies have been undertaken to date to define the incidence of success. The procedure involves percutaneous placement of one or multiple electrodes subcutaneously overlying either the supraorbital branch of the trigeminal nerve at its exiting foramen above the eyebrow- for forehead pain; overlying the infraorbital foramen for cheek, lateral nasal and lower eye pain; along the jawline for lower jaw pain. It is possible, if needed, to place three electrodes at once. An outpatient trial then proceeds to determine efficacy before a "battery" is implanted and the electrodes internalized. The advantage of neuromodulation is that you are provided more personal control over your pain. You can turn the device on or off, up or down, or change the stimulation patterns within limits set by the doctor. Neuromodulation does have the ability to reduce the pain of intermittent stabbing neuropathic pain, but it is primarily used for constant discomfort.

Motor cortex stimulation is also an off-label application of equipment long approved for clinical use, but not for the

specific entity of trigeminal neuropathic pain. Corporate entities have not chosen to study devices with intent to bring them to market. The surgery was introduced twenty-five years ago, yet its benefits are still controversial. It is primarily used for constant, dysesthetic burning facial pain, not stabbing, intermittent pain. Cortical stimulation is done through implanted electrode paddles that are placed by surgery on the brain covering, the dura, over the specific brain cortex, or surface, that leads to facial movement in the area of neuropathic pain. This requires a small "craniotomy," or opening in the skull followed by intraoperative physiological testing to confirm the site for placement. Stimulation is "subthreshold." It is not perceived. Only the pain relief is perceived, and it is mediated through the same neuropathic controlling sites that ketamine has for its effects. Use of the device, within physician set limits, can be within patient control. Physician, re programming of the device is usually needed over time to continue benefit.

It should be obvious, after reading this brief discussion, that the treatment of trigeminal neuropathic pain is not straightforward. However, it can be life changing for the patient and satisfying both for you, as an individual suffering from chronic facial pain, and for the neurosurgeon challenged by the need to return you to being the person you used to be before the onset of this treatable disease entity. ●



A TN WARRIOR FACES MEDICARE PART D

By Ann Ciemnecki

Reprinted from the
Spring 2016 *Quarterly*



On June 18, 2016, I will turn 65. Am I troubled by aging? Not at all! Though retired, I still feel and, I hope, look young. Graying hair, I hide it. Pravara hair color and Coppola Keratin treatments keep my brunette hair shiny and smooth. Wrinkles, I conceal them too. My medicine chest is stocked with Bare Mineral foundation with SPF 18; I use the best moisturizers; and swear by Active Cell Renewal Night Serum. I am not too unhappy that my grandson dubbed me “Didi” instead of grandma, even though, I love being his grandmother. I drive a car that my children envy, a sporty little Mazda Miata MX5 convertible. I own an iPhone 6s and use social media daily. Friend me on Facebook! I am intelligent, tenacious, and fearless. Like most Quarterly readers, I am a TN Warrior! A third generation person with facial pain (my mother and grandmother were warriors too), I survived two MVDs, a Gamma Knife and have taken more drugs than I can name: Trileptal, Baclofen, Cymbalta, Lyrica, Neurontin, Clonazepam, Methadone, Elavil. My pain is under control. What is the big deal about

turning 65? It is just another trip around the sun!

Except when you “Pass Go” on this particular trip, you “collect” Medicare, not \$200. Medicare terrifies me. Not **Medicare Part A** (the hospital insurance) or **Medicare Part B** (the medical insurance)—I am afraid of **Medicare Part D**, the prescription drug coverage. A Medicare Prescription Drug Plan (called a PDP by the alphabet soup-loving bureaucrats) has the potential to come between me and the drugs that control my pain. I worry that Part D will not be as generous as the private prescription drug plan that paid for every drug I needed in every amount prescribed. So, like many TN Warriors, I was determined to understand Medicare Part D and get the drugs I need now and in the future.

The first step was a vocabulary lesson. The PDP that I get for free as part of a retirement benefit is “Express Scripts Medicare.” I can use Express Scripts Medicare or select another PDP. If I select another plan, I will need to

pay for it and I will be automatically disenrolled from Express Scripts. You can only have one PDP at a time.

- All Medicare PDPs have a **network of pharmacies**. In most cases, prescriptions are covered only if they are filled at one of the network pharmacies. And, the network changes periodically. PDPs publish their directory of network pharmacies on their websites or you can request a printed directory. You might want to be sure that your pharmacy is part of the network. You can always switch to a network pharmacy or order prescriptions by mail if a mail order program is available. My pharmacy is in the network. *So far, so good!*
- Next, a **formulary**. A formulary is a list of covered drugs. Before I sign up for Express Scripts, I need to check the formulary. I will check for the drugs I take now and drugs that I may need in the future. The formulary can change too.
- If the *formulary* changes, and payment is denied for a drug, you

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can work with your doctor or prescriber and ask for an **exception**. Usually you can get a short term supply of the denied drug while you are asking for an exception.

- Express Scripts (and all Part D plans) have **drug payment stages**. At any time in your trip around the sun you will find yourself in a drug payment stage. The payment stage that you are in may affect how much you pay for a drug. Pay attention, this gets complicated.

- Yearly deductible stage.** In the yearly deductible stage, you must pay for your covered prescription drugs before your PDP begins to pay its share. Medicare PDPs may not have a deductible of more than \$360 in 2016. My plan has no deductible. This could be a good omen!

- Initial coverage stage.** In the initial coverage stage, the PDP will pay its share of the drug costs and you will pay your share. How much you pay for a drug depends upon which tier the drug is in. There are three tiers. These are the costs for the drugs in each tier and a definition of each tier in Express Scripts.

Cost Per Prescription			
Tier	Drugs in Tier	One Month at Retail Network Pharmacy	Three Months if Mail Ordered
Tier 1	Generic Drugs	\$10	\$5
Tier 2	Preferred Brand Drugs	\$22	\$33
Tier 3	Non-Preferred Brand Drugs	\$44	\$55

Page seven of my Express Scripts Medicare manual says that I will stay in this stage until the total cost of my drugs reaches \$3,310 per year. The total cost of the drug is the cost I pay plus the cost that Express Scripts pays. Under the 2016 Part D Standard Plan Cost-Sharing rules, Medicare beneficiaries pay 25 percent of the costs of covered drugs and their PDP pays 75 percent. While the cost sharing percentages are standard, each PDP negotiates a separate contract with the drug manufacturer, so the actual costs that you, the beneficiary pays, may vary from plan to plan. Three of my drugs are generic. I call Express Scripts to ask which tier my fourth drug is in. It is in tier two.

In a retail pharmacy, I would pay \$624 annually:

3 generic drugs	12 months	\$10 a month	= \$360
+			
1 Tier 2 drug	12 months	\$22 a month	= \$264
I could save \$432 annually if I mail order the drugs:			
3 generic drugs	4 quarters	\$5 a quarter	= \$60
+			
1 Tier 2 drug	4 quarters	\$33 a quarter	= \$132

Remember, I am paying 25 percent of the total cost. The total cost of my drugs in a retail pharmacy is \$624 X 4 = \$2,496. This is comfortably below the \$3,310 maximum. But I may need other drugs, so I continue to investigate the other stages.

Note: Some PDPs have **out-of-pocket maximum costs**. If you reach your **out-of-pocket maximum**, you do not pay anything for your covered drugs for the rest of the year. My annual out-of-pocket maximum is \$1,351.

- The Coverage Gap Stage.** After my total drug costs reach \$3,310, I enter the coverage gap stage, commonly known as the **donut hole**. There is nothing sugary sweet about the coverage gap stage. My Express Scripts Medicare plan is generous. While I am in the coverage gap stage, Express Scripts continues to cover my drug costs at the same cost sharing amount as in the Initial Coverage Stage, (*This is truly good news!*) In many plans, the PDP pays nothing when the insured reaches the coverage gap stage and the full cost of the drug is borne by the beneficiary. I stay in the coverage gap stage until I pay \$4,850 **true out-of-pocket** costs (better known as **TrOOP** by my alphabet soup-loving friends) for Part D drugs. Now I am really confused because my out-of-pocket maximum is \$1,351. So, I call the Express Scripts help line again and learn that out-of-pocket costs and *true* out-of-pocket costs are not the same. Out-of-pocket costs are actually member out-of-pocket costs or what I pay out of my own money for a drug: deductibles, co-payments and anything I might have to pay while wallowing in the donut hole. True out-of-pocket costs also include payments for covered drugs that are made from or by: a Medical or Health Savings Account, a Flexible Spending Account, family members or friends, Qualified State Pharmacy Assistance Programs,

Medicare's Extra Help (low-income subsidy), most charities, drug manufacturers, the Indian Health Service (IHS), or AIDS Drug Assistance Programs.

These additions to the TrOOP help you climb out of the donut hole faster and into the Catastrophic Stage. You move out of the coverage gap stage when you reach either the out-of-pocket maximum or the TrOOP, whichever comes first.

The **Catastrophic Stage** is the final drug payment stage. If you reach this stage, you stay in it until the beginning of the next calendar year when you begin the stages all over again. In my Express Scripts Plan, if I reach my member out of pocket maximum, I do not pay anything for my covered prescription drugs for the remainder of the year. Otherwise,

Medicare Advantage plans are sometimes referred to as Medicare Part C. They are Medicare-approved private health insurance plans. When you join a Medicare Advantage plan, you are still in the Medicare program and must continue paying your Part B premium. Medicare Advantage plans provide all of your hospital and medical insurance. They generally offer additional benefits, such as vision, dental, and hearing, and many include prescription drug coverage. These plans often have networks, which mean you may have to see certain doctors and go to certain hospitals in the plan's network to get care. Pricing, benefits, and rules (like whether you need a referral to see a specialist or can only use doctors or facilities in the network) vary, so it's worthwhile to compare all plans in your area.



I pay \$2.95 for a generic drug and \$7.40 for all other drugs or five percent of the total cost, whichever is greater. The TrOOP of Lyrica, for example is \$1402.04 for a mail-ordered 90-day supply. If I had to pay for Lyrica, it would cost \$70.05 for a ninety-day supply because that is greater than \$7.40.

In summary, I am happy about Express Scripts Medicare. I have no premium or deductible and it seems that my annual drug costs will be \$624 annually if I continue to use the local pharmacy which is part of the network. I could reduce those costs to \$192 annually if I use the mail order service which is potentially more convenient. The plan is actually more generous than the plan I have now. If I move into the coverage gap stage for any reason, my drug costs will be the same as they were in the initial coverage stage.

My advice to my fellow-TN warriors is to shop around. While some costs are fixed by the Medicare program (such as the \$360 maximum deductible), plans offer variations within the fixed costs. Compare two or three plans. Visit websites, get manuals and formularies (either download them or request them), check whether your drugs are covered, in what amounts, and in which tier. Ask what coverage the plan offers while you are in the

Coverage Gap and Catastrophic Stage, and calculate your out-of-pocket costs. Visit www.medicare.gov and click on "Find Health and Drug Plans" for more information. You can also call 1-800-MEDICARE (1-800-633-4227) 24 hours a day, 7 days a week. More free help is available through the **State Health Insurance Program** or **SHIP**. SHIP counselors can help you understand available plans and choices. Also know that if your income is limited, you might be eligible for **Medicare Extra Help**, a program that helps pay for drugs. The Medicare number listed above or the Social Security Office (1-800-772-1213) will help you see if you are qualified for Extra Help. Use the resources available to become an informed consumer. Doing the work or asking for help can assure that you have the drugs you need to eliminate or reduce facial pain.

Just one more piece of advice: even if you don't take many prescriptions now, you should consider joining a Medicare drug plan. If you decide not to join a Medicare drug plan when you're first eligible, and you don't have other drug coverage, and you don't get Extra Help, you'll likely pay a late enrollment penalty if you join a plan later. Generally, you'll pay this penalty for as long as you have Medicare prescription drug coverage from any PDP. ●

Maintaining a Positive Attitude



By Deborah Barrett, PhD,
MSW, LCSW

Part of FPA's mission is to provide information and offer support. In fulfilling this mission we are continually looking for ways of coping with neuropathic facial pain. Until a cure is found, it is important to keep a positive attitude. Facing pain everyday makes this very difficult to do. Sometimes we must reach out to a fellow sufferer of pain to find new ways of coping. One such person is Deborah Barrett, PhD, MSW, LCSW. Dr. Barrett draws from her professional experience and "the empathy that comes from life in the pain trenches." She is a clinical associate professor in the School of Social Work at the University of North Carolina at Chapel Hill, and a psychotherapist in private practice. She has published self-help articles on fibromyalgia and other chronic pains as well as scholarly papers on health and illness, global culture, and public policy. She has written a new book "Paintracking" and shares her knowledge in coping with pain.



Maintaining a Positive Attitude

"Have a positive attitude." How many times have we heard that one? While our emotions can not cause fibromyalgia or chronic fatigue syndrome, they no doubt affect our symptoms. But how can we maintain good thoughts when our bodies feel so lousy? This challenge, of course, does not pertain exclusively to chronic illness, but to any time when things do not go as we wish. But in the case of ongoing illness, seeing the positive presents a continuous struggle.

Yet our moods are not perfectly correlated with our physical state. Most likely we can all recall times that despite much pain or fatigue, we were able to cope and even achieve high spirits. Perhaps the weather was perfect, good friends visited, we just accomplished something or helped somebody, making us feel good about ourselves. Other times, depression seems to take hold even when our physical discomfort is at a manageable level. Why is this? Answering this question is the key to finding optimism.

To me, the vicissitudes of fibromyalgia feel like a swim in the turbulent sea -- sometimes it seems we have fallen and the waves continue to crash on our heads, as we fight to rise, only to be knocked down yet again. But that same ocean sometimes allows us to find a wave we can ride smoothly to the shore.

What can we do when we feel under the waves? How can we find the strength to climb back on top, and the patience to know that we will? Here are ten cognitive exercises I use to maintain the most positive attitude I can:

1. Expect bumps! It is important to acknowledge that we will sometimes feel down. Who wouldn't in our condition? But by expecting rather than dreading down time, such periods become more tolerable. In addition, recognizing that we will have blue periods helps keep them in perspective. We will be able to say to ourselves, "I was depressed before, and got out of it;

this time, too, it will pass." It is easy to forget that before our illness, there were times we felt down. Now these periods are wrapped up in our medical problems; but everyone gets depressed some of the time. After accepting that we will sometimes feel sad, and even experience self pity, we can concentrate on ways to shorten these periods and make them fewer and farther between.

2. Track the changes. Keeping track of moods helps put ups and downs into perspective. During your best times, make a conscious attempt to capture the feeling. Leave notes on your wall attesting to the way you feel. Living with chronic illness easily creates a Jekyll-and-Hyde persona, where your optimistic self and your flare-up self are not sufficiently acquainted. When we feel bad, it becomes quite difficult to imagine that things can be otherwise. Similarly, during times of improvement, it's amazing how quickly we may forget how bad a previous period was, making subsequent flare-ups not only intolerable but shocking. Counting and measuring the duration of the bad times -- as well as the good ones -- can put them into perspective. It may be that over time, our worst occurs about once a month, although it feels much more frequent. This knowledge is empowering, because we can remind ourselves that a bad flare is, for example, our monthly temporary setback, and find ways to ride it out until our baseline returns.

3. Stockpile fun distractions. We all need to keep lists handy of the things that make us happy. One of the cruelties of our condition is that when we need distractions most, we are least equipped to seek them out. For this reason it is important to compile a list of our favorite activities when we are feeling optimistic to be used when we most need them. People with fibromyalgia often describe how even their worst pain can be put on a back burner, so to speak, when they become engrossed in an activity. This is not only a psychological but a physiological response: our brains can only process so much input at once. When we are engrossed in a beautiful movie, talking to a good friend on the phone, or listening to our favorite music while lying on a heating pad or in the bathtub, we can trick our pain



*"Is the glass half empty or half full .
..having a chronic illness creates an
ambiguous construction of reality for us"*

"Positive Attitude" . . . continued on page 12

receptors into leaving us alone! Meanwhile improvements in spirit have an added impact on our entire well-being. Laughter is good medicine; while dwelling on our troubles tends to compound them.

4. Shape your perspective. Is the glass half empty or half full? Perspective determines, quite literally, how we view the world. Having a chronic illness creates an ambiguous construction of reality for us. Am I, for example, a successful cripple or an unsuccessful professional? In American culture, much emphasis is placed on independence, individualism, and achievement. Through this lens, developing a condition that makes us feel more dependent and less productive is likely to be a huge disappointment. Yet as we get older, it becomes more likely that we, or somebody close to us, will experience debilitating problems. People are often forced to adapt to sudden, new conditions by adopting a perspective that accommodates change. Our perspectives are shaped by the comparisons we make and the expectations they create. Consider, for example, the immigrant who had been practicing medicine in his home country, but flees to the US to escape a repressive political regime. Here he works as a janitor; after years of medical study, he has lost a prestigious and rewarding occupation. Yet he is thankful for the opportunity to work and wakes each day driven by hope, perhaps, of a better future for his children. Yet his difficulties are also quite apparent. What keeps his spirits up and makes him thankful rather than bitter? His perspective.

5. Create a new self. If we hang on tightly to the “old self” we were, finding the value of our “new self” becomes increasingly difficult. (We may even exaggerate how fit that person was: “I didn’t need any sleep, I never felt bad, I could do anything!”). This does not mean we should totally discard our previous conception of self; rather, we need to find a way to integrate the two. In other words, we should seek to find in our new bodies new ways to enjoy and experience the things that we had done before. Consider all the aspects of yourself that you like, and the things that you most want to do; then step by step, find ways to achieve as many of these as you can. At the same time, recognize that our expectations must shift so that we can once again meet them.



6. Don’t forget the good stuff. While the physical symptoms of fibromyalgia can feel all-encompassing, there are other parts of our life—our social relationships, passions, family -- that also exist. By focusing on the positive aspects of our life, we become more aware of how many there are: the friends that stuck by us, the things we still enjoy, and the accomplishments we have been able to make, however small, under very different conditions. Because each task now represents a challenge, we should celebrate whatever we manage to accomplish. As we have been told many times, if we shorten the list and pace ourselves whatever we do eventually adds up to something to be very proud of.

7. **“Oy, it could be worse.”** (The Jewish mantra). As comparisons shape our view, it is helpful to find comparisons that will provide a fuller appreciation for what has befallen us. OK, the “eat because children are starving in (fill in the developing country)” did not work for you as a child. But try to think of it this way: Many bad things happen in the world. The odds are that some of them will happen to us. Not because of anything that we have done, but because, as the saying goes, shit happens. It takes only a short view of the evening news to remind ourselves of the horrors occurring every day. So, this is what has happened to us. We too were caught. Let us examine what we have: (a) We know our condition is not terminal, so we need not begin contemplating our pending mortality. (b) As bad as we sometimes feel, our underlying condition is not going to get worse. We have already experienced the worst, and, to our credit, have gotten through it. (c) Although few people achieve permanent remission, many improve significantly. As we understand how our actions and emotions influence our general well-being, we can find ways to partake in more and more activities.

8. **Keep the hope alive!** There is so much room for hope. It has only been since the 1990s that our condition has acquired any legitimacy from the medical community. We are in a far better position than the generations before us who suffered without ever receiving validation. We know much more about the important roles of exercise, medication, stretching, pacing and meditation to bring relief and a sense of control. Furthermore, as medical research increases, it is only a matter of time before better therapies (and perhaps even a cure!) are introduced.

9. **Lean on me!** A single most important predictor of how we do is the support network we create. We certainly appreciate what it means when someone helps us when we feel especially lousy. Make sure that, within your means, you continue to be a good friend to those you care about. We still have lots to give. During a good moment, write to a friend that you are thinking about

her. Help your family and friends find ways to maintain their relationship with you. Invite them to your place to eliminate traveling (and do not worry what your place looks like! They came to see you, not your housecleaning abilities). Try to be open with family members, while at the same time supportive of their needs. Put yourself in their shoes as often as possible -- it can be scary to have someone you love be sick! Also make sure to seek help outside of your immediate circle so as not to drain your closest friends and family. There are now all sorts of support groups, both live and in virtual computer space.

10. **Indulge whenever you can.** We have lots of time to focus on our thoughts. Most people do not have the luxury of taking time to relax and think. OK, we did not ask for these “time outs.” They are demanded by the needs of our bodies. Nevertheless, we have control over how we use this extra time. Instead of dwelling on what our bodies are not doing, give your fantasy full liberty. Turn these rest periods around to be indulgent time. In our mental playground, we can practice dance steps we used to know (for there will be some times we can dance!). We can use the time to think through problems we face and how we want to spend time when we are feeling ready, or we can analyze a movie we recently saw, say prayers, or mentally write a letter to a friend. The article you are now reading is a product of a spell in the middle of the night, when I lay in bed, unable to sleep. After taking steps to make myself more comfortable, I decided to think about what I would write next. I figured that if I fell asleep, great! But if not, I'd have thought through my next article. It was about this point when I, satisfied, went off to dreamland. ●

Managing Your Pain Through the Holidays

By Cindy Ezell, Patient Services for FPA

The holiday season is fast upon us and with this joyful time come many occasions that can often exacerbate neuropathic facial pain. Having neuropathic facial pain myself I have learned over the years that I can predict and therefore prevent several triggers that make the pain worse. I am not saying they will prevent the pain from occurring, but I do follow these commandments and my TN stays under control:

- Being overtired - Get plenty of rest and ask for help from your doctor if you are not sleeping well. Remember, you might need more sleep than average.
- Cold wind - Wear a jacket with a hood or a scarf, even when making a quick trip to the mailbox. Do not let your body and face get cold. This only takes a minute to avoid, but once the pain is triggered it made take hours to become bearable again.
- Stress – Now this is a big trigger and difficult to manage, but it is very important for us to reduce stress. Much of the advice we receive on reducing stress is easier said than done. But, we must try. Say “No,” Feel No Guilt, and Ask for Help! Take time out of your day for **You**. Read, listen to a book-on-tape, watch a movie, take a hot bath, light candles, play relaxing music. Most of all “Do Not Feel



Guilty,” ask your doctor about an antidepressant, it can make a big difference in how you cope.

- Changes in Barometric pressure - not much can be done about this, but it does help knowing that it is temporary and will stabilize.
- Take medications on time!
- Give back and help someone else! Even when you do not think you feel up to it, you will find that you are better off than someone else. Often you can't change the pain, but you can change your emotional response to the pain. Helping others can change your emotional response. Be proactive not reactive! Share the information you have gained.

Neuropathic facial pain is something that must be managed; there is no “Home Depot Quick fix.” But, we have many opportunities to share the information we have gained with each other. Here at FPA we are always looking for information that we can share with you.

We found these tips from the American Pain Foundation to be very helpful in easing neuropathic pain during the holidays and we want to share them with you!

Top Ten Tips: Easing Pain Around the Holidays

It's supposed to be the "most wonderful time of the year," but the rush of the holiday season can leave many people anxiety-ridden. Juggling competing demands, such as work, visiting relatives, parties, cooking and crowded stores and shopping, can be stressful. And stress aggravates many chronic pain conditions and can trigger pain flare ups. It's important to pace yourself and take plenty of deep breaths.

Here are some helpful tips to reduce stress and help ease pain around the holidays:

- 1** Get organized and plan ahead! Make to-do lists and delegate tasks to trusted family and friends, so you won't feel overwhelmed.
- 2** Don't feel pressured to entertain house guests. Tell them to make themselves at home and show them where to find the essentials (e.g., towels, newspapers, beverages and snacks). Surround yourself by people who are supportive of you and will pitch in and help.
- 3** Be true to yourself. As hard as it might be, put your own needs first. If you feel the need to withdraw to another room to rest, do so. Pass on activities that you're only doing out of obligation; instead, concentrate on those that have meaning to you. You'll be able to enjoy the festivities much more as a result.
- 4** Prepare food well in advance or, consider hosting a pot-luck dinner. Order a pie instead of baking it yourself. If you decide you want to chop vegetables or peel potatoes, do it sitting down rather than crouched over the counter.
- 5** Stay on top of your treatment, plan ahead to avoid interruptions in routine care. Don't let your treatment slip over the holidays. Talk with your healthcare providers to find out who you should call over the holidays, so you get help when you need it. Be sure to have enough medications on hand. Many pharmacies are either closed or have limited hours.
- 6** Set expectations. It's difficult to enjoy time with family and friends when you have too many responsibilities and not enough time. Talk openly with loved ones about what activities you think you may or may not be able to handle.
- 7** Pay attention to your mood. The holidays have a way of reminding us of loss and how things could have been. If you have the holiday blues, talk about your feelings with friends and family.
- 8** Keep up with regular sleep schedules, eat healthful meals, exercise within your limits and stay hydrated. If you don't already, consider practicing relaxation techniques, including deep breathing and visualization, to help ease stress.
- 9** Avoid crowded stores. Standing in long lines and fighting against masses of people may worsen your pain. Think about ordering online or through catalogs instead.
- 10** Keep a healthy sense of humor. Not everything has to be perfect.
Don't let the holidays become something you dread because of neuropathic pain. Instead, take steps in prevention where you can. You know how your pain reacts and your limit! Stay within that limit and enjoy the holidays!



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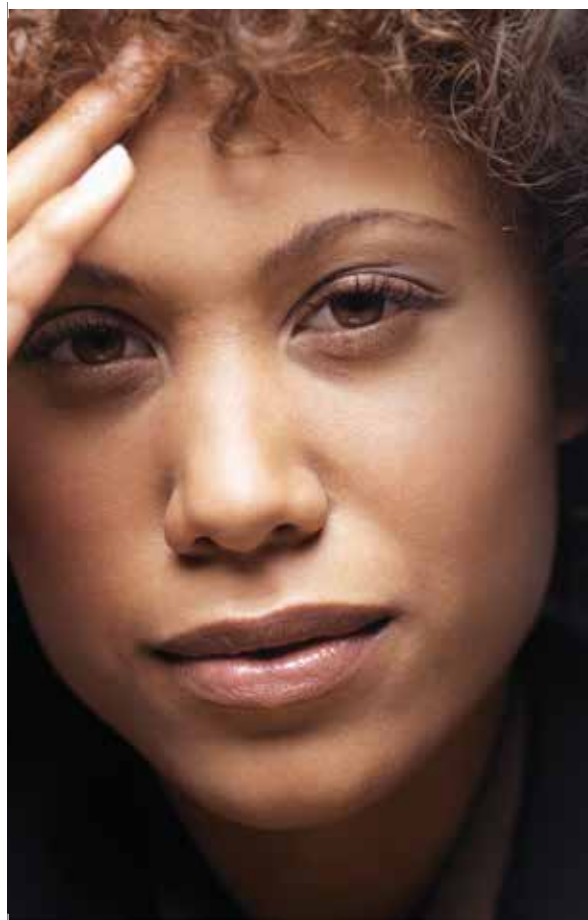
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10 REASONS A YOUNG PATIENT SHOULD ATTEND A FACIAL PAIN ASSOCIATION CONFERENCE



For more information about the YPC [f /tnaypc](https://www.facebook.com/tnaypc)

There are many reasons to consider attending a Facial Pain Conference. For Young Patients specifically, attending a facial pain conference can assist with education, networking, and further understanding. The Young Patients Committee fully appreciates the benefits of attending conferences and the impact they can have on patients. Here is a list of reasons we have gathered:

1 **Developing a Social Network of Patients**

Being part of a community and connecting with others can be extremely empowering for any chronic illness warrior. You get to meet people face-to-face, laugh, hug, and cry, all while in the same room together.

2 **Knowledge is Power**

By attending a conference you hear from the experts. These medical professionals span a variety of disciplines and specialties that are all relevant to facial pain. They cover a variety of different medication and surgical options. Being a young patient with facial pain can present many challenges, but educating yourself will help you get the help you need.

3 **Alternative Treatments**

Not only do you hear about medications and surgical options, but you will also hear from the experts about alternative treatments that might work for your facial pain.

4 **Advocacy**

You can learn how to be a better medical advocate overall – both for yourself and others– during doctor visits, specialist appointments, or procedures. You will learn that advocacy is arguably even more important when you are a young patient in pain.

5 **Meeting Doctors**

At conferences you have the opportunity to meet many different experts in the field. You are able to ask them questions directly and get to know their personalities and understand their approach to treatment. This will help you make a more informed decision when choosing a doctor.

“10 Reasons”...continued on page 18

6 Research and Treatment
Conferences are a great place to get the inside scoop on the latest research and the newest treatment modalities for facial pain. You can hear from the experts and meet patients who have used many different treatment options.

7 You Won't Feel Alone
You are finally in an environment with an entire room full of people who get you. Going to a conference connects you with young patients who truly know what you're going through and it can be eye opening in a way that new medical knowledge

can't be. It's a chance to get out in the world and if something goes wrong, you don't have to explain yourself because we all understand.

8 Already Attended? Invest in Yourself
Already attended a conference? Don't hesitate to invest in yourself and attend another! No two conferences are alike and chances are you will be able to learn new things and connect with new faces each time you go!

9 Reconnect with Friends
We often live far away from

one another, so conferences allow you to reconnect with friends you haven't seen since the last conference and to add to your friendship circle.

10 The YPC Will be There!
The YPC would love to meet you! You can also find out about ways to get involved in the facial pain community. Are you a young patient wanting to attend a conference? The Young Patients Committee offers scholarships to young patients attending the Facial Pain Conference - Keep an eye out for upcoming scholarship opportunities. ●



Young Patient Profile

Name: Jacob Smith

Current age: 19

Where do you live?
Colorado Springs, CO

How old were you when you first experienced facial pain?
I first experienced facial pain when I was 16 after a car accident, after a year of a constant headache, and after sustaining numerous concussions from sports. I started getting sudden ice pick stabbing above my right eye. After another year of doctors and tests and treatments it turned out that I had two small fractures leaking spinal fluid, and had surgery to repair those through my nose. Since then, the facial pain

has gotten much worse and my skull has burst open in three more leaks, suggesting I have high CSF pressure.

How old were you when you were diagnosed?

19. I wasn't told about trigeminal neuralgia until this summer (2017) by a dentist, pain management doctor, headache specialist, and it was mentioned by a neurosurgeon.

What was your diagnosis?

I scheduled to meet with a neurosurgeon that specializes in TN for an official diagnosis of whether it's trigeminal neuropathic pain, TN2 or ATN. In the meantime, I am just managing pain.

What do you do for fun?

I compose and play music all the time, writing new piano pieces every day. I also write orchestral stuff, and I am working on things for marching band right now. I've spent hours and hours every day for the past four years playing/writing music because it's not just an escape but a way to turn all the pain into something beautiful through the music. I guess what that taught me is that there's always something good that can come out of even the most horrible thing.

What has TN taught you?

I can turn my pain into something for other people. I know what it's like to go almost a week without sleeping at all because there's an invisible man with an icepick behind every corner just waiting to jump out and stab you in the face before taking a stun gun to it. And it still terrifies me. And on the bad days when it hits every hour, and you just curl up in a ball and lay there all day drugged out and still in pain. And that makes everything I do more of an accomplishment. I don't see any of that as me being brutally tortured for no reason or think why me anymore. It's what I have, how do I do it? I use it through music. I wouldn't be able to without spending hours playing through sleepless nights or practicing hours a day when I couldn't do anything else, using it as a distraction (before I could actually write stuff). Find something you're passionate about, and channel everything you've got into it.

How has your facial pain changed you?

The pain change me in a couple ways, first by making me mature faster by taking out my entire high school experience and putting me in a situation that was extremely difficult to deal with. It isolated me too: not going to school, not being able to drive or do things I

wanted, no more sports. It did increase my spiritual life greatly though, especially because I was only able to start composing after praying hard during a really bad flare-up one night, asking God that if the pain wouldn't go away, could I at least use it? And boom, I instantly got this full symphony in my head that I actually wrote out and worked on for months before submitting it to an all-state young composers high school competition at CU Boulder. The composition won 1st place. Since then I've been able to write every day and it's made me see pain in a different way. It's still excruciating to say in the least and keeps me up at night and makes me pace around the house waiting for it to hit again. But now I can see the complete opposite of what that is too, and I put it through the piano. I'm locked in a little box and I'm looking outside a window, and outside the box is everything. I see and play, through that little window. And because I can share that music with other people and make them happy, I win.

Have you had any procedures?

Sphenocath

What treatments (non-surgical) have you tried?

Upper cervical C1 adjustments and lymphatic drainage. Medications: carbamazepine, tramadol, and medical marijuana. I rinse my mouth around with a type of alcohol called "Tingala" that numbs up my mouth like novocaine when my teeth are buzzing really bad.

What tips do you have for other young patients?

Keep looking for things you love and try in any possible way you can USE the pain. You can't change the fact that you have TN. Treatments help! But those are the cards you're dealt and if you really want to beat it, find a way to use it. Don't lose hope that it won't go away. ●



FPA Membership

The following individuals joined or renewed their FPA membership between June 2017 – August 2017

JUNE:

Kelley Bergman
Elise Billock-Tropea
Sherry Buhler
Mary Collett
Diana Crites
Roxanne Dickey
William Freeman
Jennifer Highland
Christina Hook
Barbara Humphrey
Anne Iezzi
Peter Miller
Glynn Pellagrino
Kathleen Reid
Julie Smith
Kenneth Turner
Yiwen Xu
Linda Zacarias

Helen Burrows
Christine Calabrese
Michele Cohen
Terry Czigan
Deborah Dahlinger
Denise Doucette
Kim Estrada
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Mary Jones
Kathleen Kempken
Theresa Marston
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Don Pfothenhauer
Suzie Reese
Elza Satterfield
Vicki Scharringhausen
Steve Schwalbe
M. Joanne Schwebach
Ron Sconyers
Nancy Tucker
Rachel White
David Yost
Mildred Zingone

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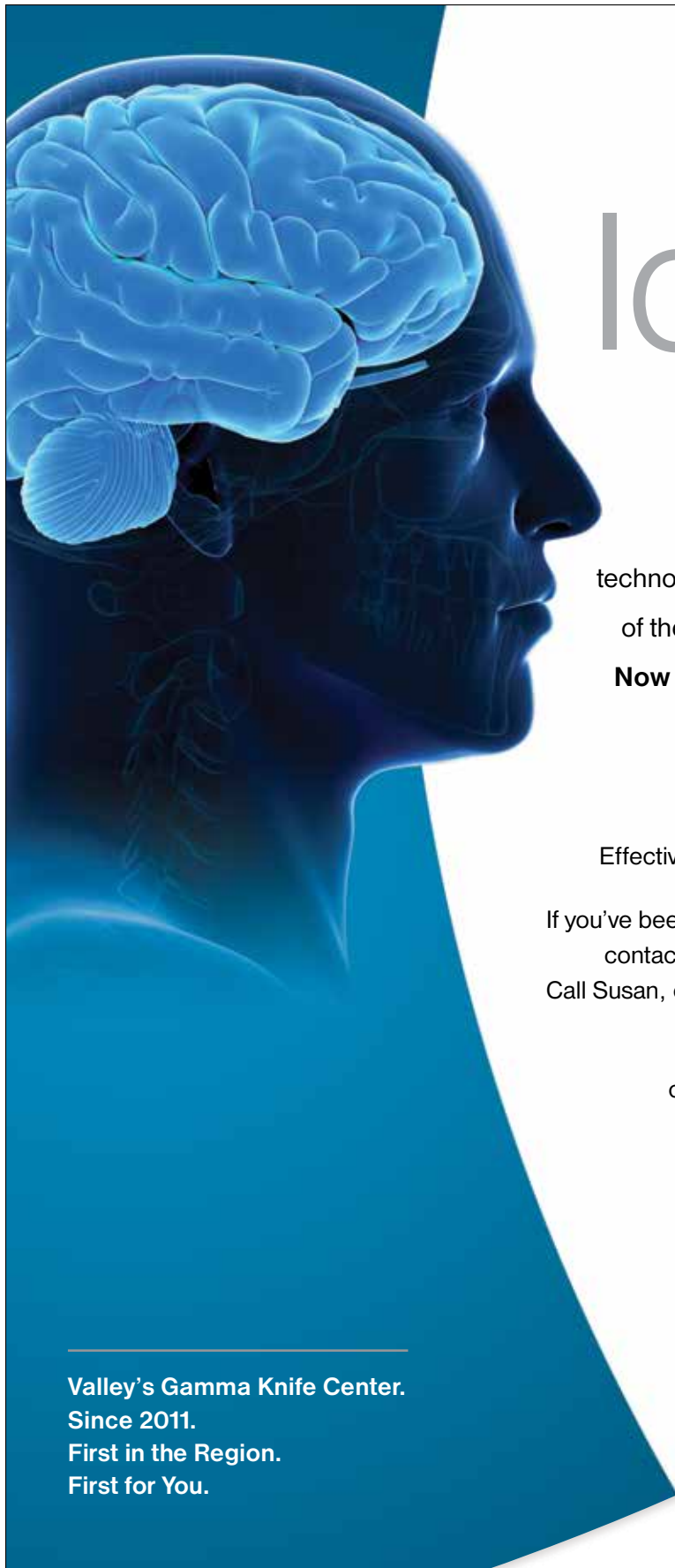
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Dr. Michael Brisman, Dr. Jeffrey Brown and Dr. Alan Mechanic perform all of the different procedures for trigeminal neuralgia, and are leaders in the field of face pain surgery.

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.



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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