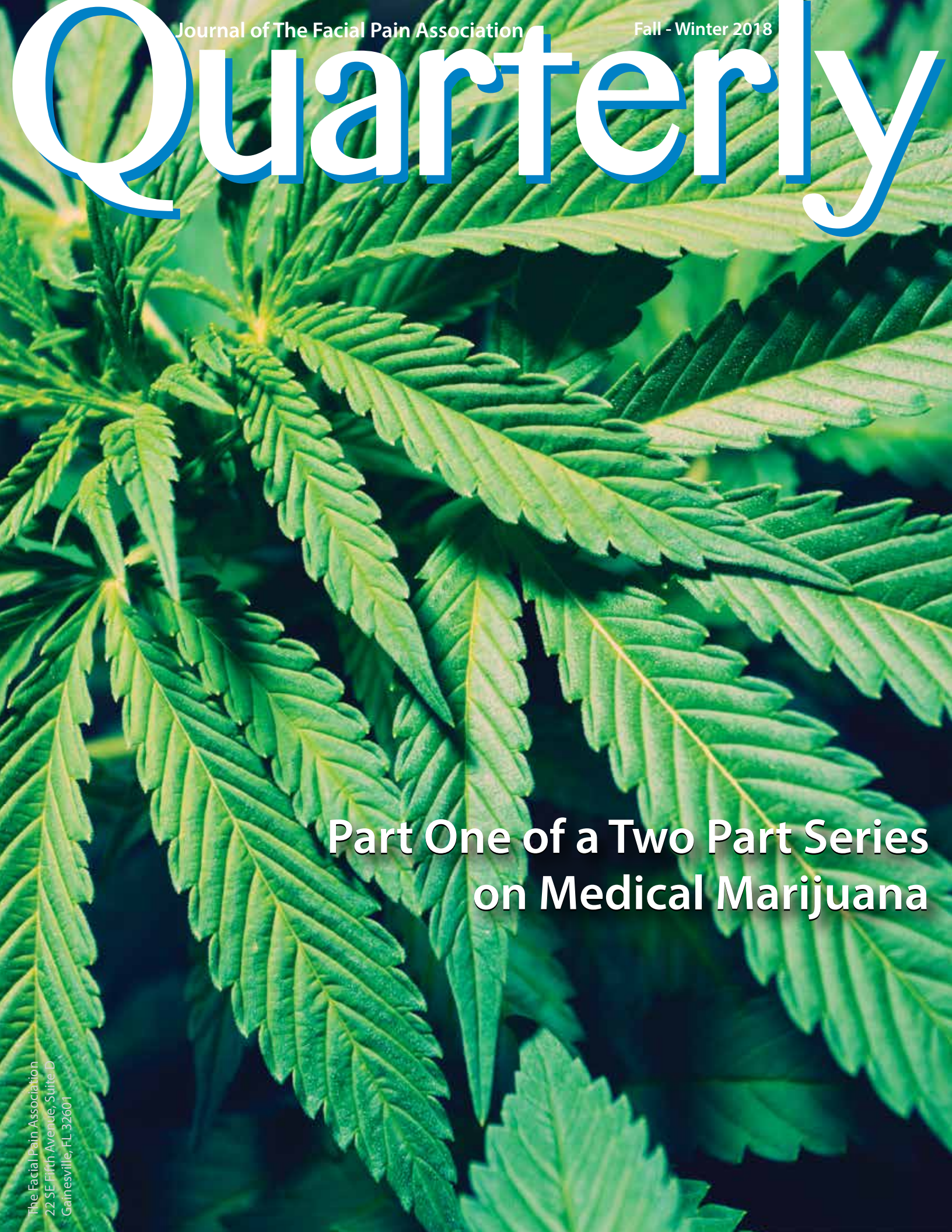
Journal of The Facial Pain Association

Fall - Winter 2018

Quarterly



Part One of a Two Part Series on Medical Marijuana

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FACIALPAIN ASSOCIATION

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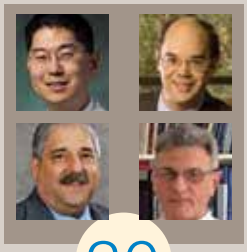
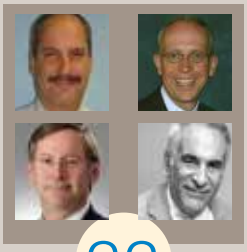
Wishing you the gift of good cheer in the new year from all of us at the Facial Pain Association

IN THIS EDITION OF THE Q





Q FEATURES

FACIALPAIN ASSOCIATION

From the Chairman of the Board

Much is underway at the FPA. One of the joys of my volunteer role as Chairman is reporting to you about the progress the FPA is making in its effort to provide information and community to those with and affected by trigeminal neuropathic pain. In this Letter, the FPA welcomes impressive new talent to our staff and Board of Directors.

First, an internal consulting analysis of the FPA and similar organizations led to our decision to add a development position to the FPA staff. Our CEO John Koff undertook a search, considered hundreds of inquiries, and we are pleased that Ms. Amy Turner has joined the FPA as Director of Development. Ms. Turner joins the FPA after 10 years at the American Red Cross. At our meeting in September, the FPA Board was impressed by her skills, her knowledge and her initial plans for development and the outreach that it involves. We welcome Ms. Turner and are excited about the strength that she adds to our staff and to the future of the FPA.

Our Board of Directors provides strategic direction and quality control to the FPA. We seek to maintain a mix of skills, experience and perspectives. We value transparency, open discussion and dissenting views. Directors are volunteers who serve one or more three-year terms. For many reasons, we need new Directors from time to time and I am pleased that we added four new Directors during 2018. We appreciate the interest of and welcome Jeffrey Fogel, MD, David Meyers, John Temple and Eric Wertheim to our Board.

Dr. Fogel retired as a pediatrician and is active in the Fort Washington Fire Company. Mr. Meyers has decades of experience as a chief executive officer and management consultant. Mr. Temple has decades of experience in finance and investment banking. Mr. Wertheim is a practicing lawyer who is also active in a volunteer fire department. All four have personal experience with TN. More about each of these new Directors appears in following pages of this Quarterly. We are both humbled and thrilled to have them join our Board.

The internal consulting analysis mentioned above began during 2017. We looked within the FPA (Staff, Support Group Leaders, Board), looked at similar organizations (four), and we identified seven key objectives. FPA Business Model: Ensure a sustainable business model. Internet Engagement: Drive traffic toward FPA sites, counter wrong and harmful postings. Promote FPA information, programs and conferences. Physical Conferences: Increase backlog of sponsoring venues. Membership: Increase the value of membership and supporting the FPA. Director Recruitment: Increase visibility of potential candidates. Inspire candidates to help us. Support Groups: Experiment with methods of promoting and supporting physical, video and telephone-based support groups.

Hiring our Director of Development and deepening our Board of Directors move the FPA toward accomplishing those seven objectives. Another effort underway involves our internet-related objectives and Facebook in particular. Directors Anne Ciemnecki, Ally Kubik, Melissa Anchan and YPC President Stephanie Blough are posting in an effort to make the FPA's Facebook pages more useful. To date, all of the number of posts, number of page likes, number of unique users seeing our content and the average number of people who clicked on a post have increased 100% to over 800%. Those results demonstrate the importance of outreach and managing our internet platforms.

We will not rest. The FPA is devoted to helping those with trigeminal neuropathic pain to manage and improve their lives. Do contact our office in Gainesville if there is more that we can do.

Jeff Bodington, Chairman of the Board
The Facial Pain Association

THE FIRST IN A TWO PART SERIES

A Summary of Research on Medical Marijuana for Neuropathic Facial Pain

By Anne B. Ciemnecki

Literature reviews are important sources of information in evidence-based medicine (EBM). They highlight key findings, find contradictions in the published research, and provide an analysis of the approaches that researchers use. This literature review is a summary of research on the use of marijuana for relief of neuropathic facial pain.

Medical marijuana is the whole, unprocessed marijuana plant or the chemicals contained within it to alleviate the symptoms of certain conditions or diseases. The plant is comprised of over 100 chemicals, or cannabinoids. Each has different effects on the body. The first main chemical is tetrahydrocannabinol, or THC. This is the psychoactive compound in marijuana, i.e., the element that produces the high. The second is cannabidiol, or CBD. This substance does not produce any

"Cannabis". . .continued on page 4

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psychoactive effects. Medical marijuana has a higher CBD content, so users do not feel the euphoria associated with recreational marijuana. Recreational marijuana usually has more THC content than the medicinal variety, as this is what provides users with a "high."

Summary of Findings

Medical marijuana shows promise for relief of chronic, neuropathic pain though the amount of relief varies from study-to-study. Overall, studies show that it offers low to moderate pain relief. Some studies show considerable pain relief, while others show none at all. Medical marijuana relieved pain no matter where in the body the pain occurred. However, there has not been a study that focused specifically on orofacial pain.

Scientists believe that medical marijuana can address allodynia, abnormal pain from normal sensations such as light touch, slight temperature changes, or gentle brushing of the skin. Endocannabinoids are neurotransmitters which send signals through the brain. These signals are important for many functions in the human body including those involving mood, pain, and inflammation. Endocannabinoids could be early players in bringing on allodynia. Using medicines to regulate the endocannabinoid system could be a breakthrough in treating neuropathic pain that is untreatable with commercially available pain killers.

Studies suggest that patients try other treatments with higher levels of evidence before turning to medical marijuana. A pharmaceutical study classified cannabinoids as 4th level treatment behind other medications such as anti-epileptic drugs, tricyclic antidepressants, topical lidocaine, selective serotonin-norepinephrine reuptake inhibitors, and even opioid analgesics. Most studies believe patients should use cannabinoids along with other treatments. Only one study suggested that patients use cannabinoids as an alternative to conventional medications.

How is medical marijuana administered and dosed?

Whole-plant cannabis is smoked or vaped, extracts are oromucosal sprays, and synthetics are taken orally in pill form.

The therapeutic range of cannabinoids is small; often small doses are sufficient for clinically significant pain reduction. A 2014 study compared two doses of cannabis (medium dose, 3.5 percent THC, to low dose, 1.3 percent THC) to see if the pain relief from the low dose was enough to recommend using lower doses to avoid side effects. It was. Another study injected capsaicin, an irritant that produces a burning sensation, in healthy volunteers and tested the efficacy of different doses of THC as a therapy. Low dose cigarettes (two percent THC) had no analgesic value, while high dose (eight percent) cigarettes were associated with reports of increased pain. The medium dose of cannabis cigarettes (four percent) produced significant analgesia. A third study compared 3.5 and 7 percent cigarettes and found that each had a ceiling effect. A ceiling effect means that once the therapeutic limit of a drug is reached, increases in dose may produce side effects but no further benefits. In this study, researchers discovered adverse effects on memory with the 7 percent dose .

To achieve full effect on pain reduction, patients may need to repeat doses of medical marijuana more often than doses of other medications. In a small study of patients with allodynia and hyperalgesia, abnormally increased sensitivity to pain, authors analyzed pain reports three hours and eight hours after taking medication. Those in the study drug group reported less pain three hours after taking their drug than those who had the placebo drug. Eight hours after intake of the drug, the reported pain differences between groups were less marked.

What else is known about side effects or adverse events?

Cannabis, the plant, and cannabinoids, natural occurring compounds in the plant, do not always significantly improve pain, but consistently improve sleep and quality of life.

Both non-serious and severe side effects were higher in patients using medical marijuana than patients in placebo groups. (Note that placebos are usually medications conventionally used for neuropathic pain, not sugar pills.) Patients in the marijuana groups reported dizziness most often. Other common side effects include dry mouth, nausea, disorientation, euphoria, confusion, sedation, and increased heart rate, which may increase the chance of heart attack in people who are already at risk. Severe side effects were dyspnea, pneumonia, pleural effusion, lower respiratory tract infection and pulmonary embolism; vomiting, diarrhea, gastroenteritis, abdominal pain, constipation, duodenal ulcer; and convulsions. Regular smoking of marijuana is associated with breathing problems such as cough and increased risk of lung

"Cannabis". . .continued on page 5

"Comparison". . .continued from page 4

infections. Gastrointestinal adverse effects occurred more often when the medicines were taken orally rather than inhaled. Many authors noted that the medications used to treat chronic pain are have some of the same side effects. Medical marijuana and placebos did not differ in terms of safety during the study period. Cannabinoids are well-tolerated by patients and tolerance to their beneficial effects does not develop.

Continuous long-term use of cannabis is associated with harmful effects on bone mineral density, leading to an increased risk of bone fractures. This concerning for people who may need neurosurgery. Neurosurgeons must take extra care with instruments in these patients.

Why is more research needed?

A cannabinoid meta-analysis does not always distinguish between types of cannabinoids used or their route, dose, or duration of administration. Contrast this with a meta-analysis of a specific drug which only includes studies that use specific doses and routes of administration. Everyone knows, for example, what researchers mean by 600 mg. of oxcarbazepine taken daily by mouth.

How cannabinoids should be taken, their optimal doses, and which type of cannabinoids would be effective with fewest side effects are still questions to be answered. The evidence for using cannabinoids specifically for orofacial pain is absent. We need high quality studies that specifically address orofacial pain conditions.

Methodology: How I Did This Literature Review

The first step in any literature review is to pose a question. I used the PICO mnemonic to formulate my question. PICO stands for patient, intervention, comparison, outcome. My question is, "Do patients with neuropathic facial pain (the "P") who use marijuana (the "I") get pain relief (the "O")?" I did not specify a comparison for this review.

I used the PubMed data base for my searches. PubMed (pubmed.gov) is a free, easy to use search engine developed and maintained by the National Center for Biotechnology Information at the National Library of Medicine (NLM). PubMed includes more than 28 million citations for biomedical literature from MEDLINE, the NLM's journal citation data base. PubMed also includes life science journals and online books. PubMed is to MEDLINE as Google is to the World Wide Web.

The next step is to select search terms. At the suggestion of Dr. Jeffrey Brown, chair of the Facial Pain Association's Medical Advisory Board, I searched for cannabinoids and neuralgia. I did not limit my search to just facial pain because I did not think I would find enough published studies that focused only on facial pain. In fact, I found just two. PubMed uses MeSH, or the Medical Subject Heading. Though MeSH is quite complicated, I think of MeSH as the NLM's thesaurus. Using MeSH, a search for cannabinoids will also search for cannabis and marijuana. Searching for neuralgia will also search for neuropathic pain and neuropathy. So, I am confident that I did not miss any important research by not searching for enough terms.

I was not sure how many articles I would find, so I did a broad search going back ten years. It yielded 155 articles. I knew I could not review that many. I narrowed my search to the past five years. That yielded 62 articles, still too many for me to read. I decided that I would

only look at articles published in the past three years. That search yielded 45 articles. I went back to my PICO model and narrowed my search even further by dropping articles that focused on just multiple sclerosis, cancer pain or other unrelated conditions. I also dropped animal, not human, studies. Eventually, I had just 19 articles that fit my PICO strategy. Dr. Brown sent me another that I did not see in PubMed and, of course, I included that one too. Twenty was a manageable number for me. In the end, two of the twenty articles were not available to me on PubMed or on Elsevier, a data base of medical articles to which I have access. I used a published summary for one of the two missing articles but did not have enough information to include the other.

The included journal articles came from around the world, including Australia, Brazil, Canada, China, Germany, Israel. Italy, Spain, the United Kingdom, and the United States. Most of the articles, thirteen, were systematic reviews, the strongest form of medical evidence. Three of those also had meta-analyses. Another three were meta-analyses alone. There was one random control trial and one case control study. (See the Dr. Google side bar for definitions of these research methodologies.) Finally, I read a profound editorial.

About the Author

I am a public-policy health researcher. I retired from one of the world's most prestigious research organizations after 30 years of designing and implementing experiments of public programs and processes. But I have no clinical training or experience. That limits my ability to review the articles all of which were written by professionals with medical training and/or clinical experience. The pharmaceutical research articles were the hardest for me to understand. I have made my best effort to bring you a reader friendly, not-too-technical summary of the most current, peer-reviewed research on marijuana and neuropathic pain. If you learn something of interest, bring it to a trusted doctor. EBM combines relevant research with clinical expertise and patient values to optimize clinical outcomes and quality of life. Research alone is not enough.

Below, I briefly discuss each article in order of publication beginning with the most recent. Feel free to find the full articles on PubMed.

Is Dr. Google Giving You Good Advice?

If you wanted to learn more about a treatment for neuropathic facial pain, or if there is not a nearby provider who you trust, you may have visited Dr. Google. Dr. Google stockpiles oodles of information; and, he can deliver it in the blink of an eye. But, he has no filters. It is up to you, your caregivers, and trusted providers to decide which of the myriad remedies Dr. Google presents will resolve your pain. Medicine? Meditating? Marijuana? How do you know?

You can begin by asking yourself if Dr. Google's solution is rooted in evidence-based medicine (EBM). EBM helps patients and providers decide the best treatment by relying on well-designed and well-conducted research. EBM takes evidence one step further by combining relevant research with clinical expertise and patient values. The goal of EBM is to optimize clinical outcomes and quality of life.

Use the PICO framework to determine if research is relevant. PICO is a technique used in evidence-based medicine to frame and answer a question. I used the PICO framework to develop the literature search strategy for the efficacy of medical marijuana for treating neuropathic pain. PICO stands for:

P – population **C** – comparison

I – intervention **O** – outcome

The population was people with neuropathic pain, specifically, neuropathic facial pain. The intervention was use of cannabinoids. I did not specify a comparison, but I could have compared use of cannabinoids with anticonvulsants or with complementary or alternative medicines. The outcome was pain relief.

Understand that only the strongest types of research can yield strong recommendations. Systematic reviews, meta-analyses, and randomized controlled trials can yield strong recommendations. Weaker types of research such as case-control studies and case reports can

Articles

Australia. Case control study.

"Effect of Cannabis use in People with Chronic Non-cancer Pain Prescribed Opioids: Findings From a 4-Year Prospective Cohort Study." 2018. Gabrielle Campbell, PhD. et. al. extracted data from an Australian national cohort study, the Pain and Opioids IN Treatment, or POINT, to find 1,500 people aged 18 or over who were taking prescribed opiates for longer than six weeks. They used community pharmacies to recruit these people into their study and followed them for four years via telephone interviews and self-administered questionnaires. The recruitment rate into the study was high and the response rates to the annual interviews were good. Of the 1,873 eligible for the study, 1,514 completed the baseline interview. At each follow-up wave, the authors interviewed at least 80 percent of the original participants. Australia decriminalized medical marijuana in October 2016, six months from the end of the follow-up period. Thus, most of the marijuana used by study participants was illegal. Cannabis use was common among participants. At the beginning of the study, 649 people ever used cannabis for

yield only weak recommendations. As you hear about a new treatment, ask from which of the following types of research the evidence comes:

Systematic Review: a complete, exhaustive summary of current literature. It uses systematic methods to collect existing data, critically appraise research studies, and synthesize studies. When done properly, systematic reviews are the strongest form of medical evidence.

Meta-Analysis: a statistical analysis that pools data from separate but similar experiments conducted by different, and usually independent, researchers. It uses the pooled data to test the effectiveness of the results.

Randomized Controlled Trial: an experiment whose participants are randomly assigned into experimental or control groups and followed over time for the outcomes of interest.

Case Control Study: a study that starts with the identification of individuals with a particular health outcome (case) and a group of individuals without the outcome (control). The exposure to a potential risk factor is compared between cases and controls. If the exposure is more common among cases than controls, it may be a risk factor for the outcome under investigation.

Case Report/Case Series: A report on one or more participants with a particular outcome. No control group is involved.

Dr. Google has information but no clinical expertise. If you learn about a treatment of interest, bring it up to a doctor you trust can treat your facial pain. Your doctor can use his or her clinical skills and experience to assess your health status and diagnosis and the risks and benefits of potential treatments for you.

Trust your gut. You have unique preferences, concerns and expectations. You must incorporate these values into your treatment decisions. You have to be comfortable with a treatment.

By combining research, clinical expertise, and your values, you can use EBM to obtain the best medical treatment and quality of life for yourself.

"Cannabis". . .continued from page 7

any reason and 237 ever used it for pain relief. At year four, 295 used it for pain relief. Interestingly, 723 would have if they had access to it. The authors found no evidence that cannabis use improved patient outcomes. Cannabis did not help patients reduce or stop taking their prescribed opiates. It did not reduce pain for those who used it or help users with activities such as working or sleeping. Those who used cannabis had greater pain to begin with than those who did not and were less able to manage their pain levels. This suggests to me that they turned to cannabis when other remedies did not work, and we do not know what their pain levels would have been if they did not use cannabis. This study was nicely designed and implemented, but case control studies yield weak evidence.

Australia. Meta-Analysis.

"Plant-Based Cannabinoids for the Treatment of Chronic Neuropathic Pain." 2018. Sherelle L. Casey, a PhD. Scholar and pain researcher conducted a meta-analysis. She reports that cannabis and its extracts have some value or efficacy in treating chronic neuropathic pain this efficacy is modest compared to placebos. Cannabis, the plant, and cannabinoids, natural occurring compounds in the plant, do not always significantly improve pain, but consistently improve sleep and how much pain interferes with life activities. Cannabinoids are well-tolerated by patients and tolerance to their beneficial effects does not develop. A higher proportion of patients respond better to longer term treatment, suggesting that cannabinoids may offer a safer alternative than some current treatments. A cannabinoid meta-analysis does not always distinguish between types of cannabinoids used or their route, dose, or duration of administration. This information is necessary to determine most effective use of any treatment and is missing in this meta-analysis.

Germany. Meta-Analysis.

"Cannabinoids in Pain Medicine." 2018. Matthias Karst M.D., Ph.D. conducted a systematic review of studies in German. A translation of the summary was available. Normally, I would not include just a summary in a literature review, but the conclusion was salient, and I did not want to overlook it. Karst reports that cannabinoids modulate pain and inflammation. Randomized, controlled studies of several types of chronic pain found both low-to-moderate and sometimes large pain relief. People with chronic neuropathic pain and stress symptoms seem to particularly benefit. The therapeutic range of cannabinoids is small; often small doses are sufficient for clinically significant effects. Available data show good long-term efficacy and tolerability. However, there is little systematic long-term experience from clinical studies.

Germany. Meta-Analysis.

"Cannabis-based Medicines for Chronic Neuropathic Pain in Adults." 2018. Martin Mücke, a specialist in palliative care, and his colleagues studied 16 clinical trials involving 1,750 people. The trials compared different cannabis-based medicines. They rated the quality of the evidence from studies using four levels: very low, low, moderate, or high. Very low-quality evidence means that results are uncertain. High-quality evidence implies high confidence in the results. They did not give high-quality ratings to any study.

They found that more people dropped out due to side effects with cannabis-based medicines than with placebo (moderate-quality). Cannabis-based medicines pooled together were better than placebo for substantial and moderate pain relief (low to moderate quality). Cannabis-based medicines were better than placebo in reducing pain intensity, sleep problems and psychological distress (very low to moderate quality). There was no difference between all cannabis-based medicines and placebo in improving health-related quality of life, stopping the medication because it was not effective, and in the frequency of serious side effects. More people in these studies reported sleepiness, dizziness and confusion with cannabis-based medicine than with placebo (low quality). Herbal cannabis was the same as the placebo in reducing pain or causing side effects that resulted in participants dropping out of the study (very low quality).

This review highlights the importance of knowing the quality of the research results you are reading. On the surface, the results from cannabis-based medicine studies sound very promising. Look deeper into the research to see that these results were mostly from low to very low-quality studies. You cannot rely on low quality research results.

Canada. Systematic Review and Meta-Analysis.

"Selective Cannabinoids for Chronic Neuropathic Pain: A Systematic Review and Meta-analysis." 2017. Meng and his colleagues wanted to determine the analgesic efficacy and safety of selective cannabinoids compared to conventional treatments or placebo for chronic neuropathic pain. They reviewed eleven randomized controlled trials including 1,219 patients. Like Mücke et. al., these researchers reported variability of study quality. There was also variability in

the cause of the neuropathic pain and the dose of the cannabinoids. Patients who received cannabinoids reported a significant, but clinically small, reduction in pain scores compared with control group patients. Using cannabinoids was also associated with improvements in quality of life and sleep with no major adverse effects. There was no significant difference in pain reduction of cannabinoids on various locations of the pain. Selective cannabinoids may have a role as a co-analgesic therapy for neuropathic pain that does not respond to other treatments. They concluded that well-designed, large, randomized studies are needed to better evaluate specific dosage, duration of intervention, and the effect on physical and psychologic function.

Israel. Systematic Review and Meta-Analysis.

"Efficacy of Cannabis-Based Medicines for Pain Management: A Systematic Review and Meta-Analysis of Randomized Controlled Trials." 2017. For this comprehensive systematic review, Aviram looked at 43 English language, randomized design studies with a total of 2,437 patients. Twenty-four of these studies (1,334 patients) were included in the meta-analysis. Note that some of these patients had acute or post-operative pain while others had non-neuropathic cancer pain. The outcome variable was pain intensity as measured by the McGill Pain Questionnaire. This study is unique in its discussion of adverse events.

The majority of the studies did not show that cannabis-based medicines had an effect on pain intensity. Some of the studies, however, showed clinically significant reductions in neuropathic pain. The authors concluded that cannabis-based medicines showed limited evidence in the reduction of chronic, neuropathic pain. The most prominent adverse effects of cannabis-based medicines were related to the central nervous and the gastrointestinal systems. Gastrointestinal adverse effects occurred more often when the medicines were taken orally rather than inhaled. The total amount of adverse effects in the meta-analysis suggests that cannabis cannot be taken lightly, and the physician should discuss the possibility of adverse events with patients. Due to the high rates of central nervous system adverse events, specifically dizziness, drowsiness, and vision impairments, users need to be cautious about driving and using heavy machinery.

Italy. Systematic Review.

"Systematic Review of Safeness and Therapeutic Efficacy of Cannabis in Patients with Multiple Sclerosis, Neuropathic Pain, and in Oncological Patients Treated with Chemotherapy." 2017. Laura Amato, an epidemiologist, and her colleagues at the Lazio Regional Health Service in Rome, looked at the benefits and harms of cannabis treatment for three groups of adults: patients with multiple sclerosis, patients with chronic neuropathic pain, and adults with cancer receiving chemotherapy. This article was in Italian. I read a translation. Altogether, they looked at forty-one, mostly European, trials published between 1975 and 2015. Twelve of the studies were of people with neuropathic pain. In these 12 studies, cannabis had a small effect on pain reduction, but the statistical confidence is low, and the results are not conclusive. In all three groups, patients had many adverse events. None of the studies assessed the development of abuse or dependence. Amato concluded that more, larger, higher quality studies are needed.

"Cannabis". . .continued on page 10

"Cannabis". . .continued from page 9

United States. Systematic Review.

"Proposition 64, Cannabis Legalization, and the California Secession Movement: Why Should Neurosurgeons Care?" 2017. Tobias Mattei, a neurosurgeon, raises three concerns for neurosurgeons and those who might need neurosurgery. (1) Continuous long-term use of cannabis is associated with harmful effects on bone mineral density, leading to an increased risk of bone fractures. Neurosurgeons should be aware of increased risks of osteoporotic compression fractures in cannabis users and of the possible need for more careful screening before instrumentation in such patients. (2) Cannabis is the second most commonly identified drug in blood samples of drivers involved in automobile accidents. The risk of road crashes after recent cannabis use is increased more than 2.4 times. Cannabis consumption leads to a significant impairment of driving skills by increasing lane weaving and decreasing mean distance between vehicles. There is significant long-term impairment of abilities extending several weeks after drug cessation. This makes us all less safe on our roads. (3) Employers and professional societies may be unable to discriminate against individuals on the basis of their free exercise of a lawful activity even if this activity leads to increased risks of accidents, mistakes and undesirable adverse outcomes. The user could be your neurosurgeon, anesthesiologist, or operating room nurse.

Italy. Systematic Review.

"Allodynia Lowering Induced by Cannabinoids and Endocannabinoids (ALICE)." 2017. Luongo and his colleagues looked at more than 80 pharmacological research studies about allodynia. Many of the theories about how allodynia occurs point to nerve damage or malfunction. The endocannabinoid system is a biochemical communication system in the human body which plays a crucial role in regulating physiology, mood, and everyday experience. Endocannabinoids could be involved in both neuronal and non-neuronal mechanisms responsible for allodynia. The pharmacological manipulation of the endocannabinoid system could represent a new target in the management of neuropathic pain that is untreatable with the commercially available pain killers. The advantage of endocannabinoid-based is targeting neurons, astroglia and microglia that are the early players in causing allodynia.

United States. Systematic Review.

"An Update on the Pharmacologic Management and Treatment of Neuropathic pain." 2017. Wright and Rizzolo, physician assistants, describe neuropathic pain, its presentation, causes, diagnosis and treatment. They note that traditional drugs provide only modest pain relief and discuss opioids and cannabinoids as controversial options. Opioids are recommended as third-line treatments due to concerns for potential abuse, diversion, misuse, and overdose. Cannabinoids are available in several routes of administration, including oral and intramucosal, and may play a role in treating central neuropathic pain, though more research is needed. Similar to opioids, cannabinoids raise concerns for abuse, misuse, and psychosis, especially in patients with a premorbid psychiatric history.

United States. Systematic Review.

"Evidence for the Use of "Medical Marijuana" in Psychiatric and Neurologic Disorders. 2017." Noel looked at twenty-three randomized, clinical trials about the therapeutic use of phytocannabinoids for psychiatric and neurologic disorders. He did not look at studies of synthetic cannabinoids or commercially available products such as dronabinol, nabilone, or nabiximols. He selected studies of patients with dementia, multiple sclerosis, Parkinson disease, Huntington disease, schizophrenia, social anxiety disorder, depression, tobacco use disorder, and neuropathic pain. Below are the results of the three studies focusing on neuropathic pain.

One of the first high-quality trials that evaluated medical marijuana in patients with mixed types of neuropathic pain was a randomized, double-blind, placebo-controlled crossover study that included thirty-eight patients. (Wilsey 2008) The study compared cannabis cigarettes (3.5 percent and 7 percent THC) versus placebo cigarettes. All 3 groups had similar pain intensity scale prior to treatment. The procedure consisted of three 6-hour experimental sessions. Each experimental session was spaced out by at least 3 days to allow for the metabolism of residual cannabinoids. Versus placebo, cannabis cigarettes significantly reduced pain and there was a ceiling effect of both the 3.5 and 7 percent cigarettes over time. Authors saw acute cognitive effects on memory with the high-dose cannabis cigarettes.

Another study (Ware 2010) was a randomized, double-blind, placebo-controlled crossover study that included 23 adults with chronic neuropathic pain secondary to trauma or surgery. The study compared various strengths of cannabis (0 [placebo], 2.5, 6.0, and 9.4 percent THC) smoked in a pipe 3 times a day for 5 days, separated by a 9-day washout in the treatment of neuropathic pain. There was a significant difference between the placebo and 9.4 percent THC on average daily pain. Patients using 9.4 percent THC also reported improved ability to fall asleep and more drowsiness than those using the placebo. There were no differences in mood or quality of life between various THC doses and placebo. Most common adverse effects included cough, headache, numbness, dry mouth, dizziness, and burning sensation in the areas of the pain.

The third study was a randomized, double-blind, placebo-controlled, crossover study (Wilsey 2013) that included 39 patients with mixed neuropathic pain. The study compared vaporized cannabis at varying THC strengths during 3 study visits: 0 percent (placebo), 1.29 percent (low dose), and 3.53 percent (medium dose). Patients were allowed to self-titrate dose (8-12 puffs per visit). The authors calculated number needed to treat for 30 percent pain reduction for the various strengths of cannabis. The number needed to treat is an aggregate measure of clinical benefit that stands for the number of patients who would need to be treated to prevent 1 more adverse event. Results showed that the number needed to treat was 3.2 for low-dose THC versus placebo and 2.9 for medium-dose versus placebo. Notably, the number needed to treat for 50 percent pain reduction for first-line medications ranges from 3.6 (tricyclic antidepressants) to 7.7 (pregabalin).

Noel concludes that while there seems to be strongest evidence for the use of medical marijuana in patients with multiple sclerosis or neuropathic pain (versus psychiatric disorders), clinicians must weigh risks and benefits in their patients and should ensure that patients have tried other treatment modalities with higher levels of evidence.

China. Systematic Review.

'Clinical Practice Guidelines for the Management of Neuropathic Pain: A Systematic Review." 2016. Deng and his colleagues, all anesthesiologists, reviewed sixteen clinical practice guidelines (CPGs) for neuropathic pain. The guidelines, all developed between 2004 and 2016, came from around the world. Thirteen CPGs were developed using an evidence-based approach, and three were produced by consensus panels. While Deng's main focus was to analyze the development and presentation of the CPGs, they noted that their pharmacological recommendations were consistent. The consensus is that cannabinoids are 4th level treatment behind other drugs such as anti-epileptic drugs, tricyclic antidepressants, topical lidocaine, and selective serotonin-norepinephrine reuptake inhibitors, and opioid analgesics.

Spain. Systematic Review.

"Cannabinoids and Autoimmune Diseases: A Systematic Review." 2016. Katchan's research focused on the dosing and side effects of cannabinoids in patients with neuropathic pain. For a systematic review, Katchan and her colleagues selected 18 randomized control trials.

There were 28 patients with hyperalgesia and allodynia in one trial. Authors analyzed the pain patients reported three hours and eight hours after taking medication. Those in the study drug group reported less pain three hours after taking their drug than those who had the placebo drug. Eight hours after intake of the drug, the reported pain differences between groups were less marked.

In two different trials, patients with HIV peripheral neuropathy in cannabinoid therapy showed reduction in the pain (46–52 percent) compared to the placebo groups (18–24 percent). This type of pain is notoriously resistant to usual treatments for neuropathic pain, which emphasizes the importance of these studies.

Another study injected capsaicin in healthy volunteers and tested the efficacy of different doses of THC as a therapy.

"Cannabis". . .continued on page 12

"Cannabis". . .continued from page 11

Low dose cigarettes (two percent THC) had no analgesic value, while high dose (eight percent) cigarettes were associated with reports of an increase in pain. On the other hand, the medium dose of cannabis cigarettes (four percent) produced significant analgesia.

A randomized double-blind placebo-controlled trial published in 2014 compared medium dose (3.53 percent THC) to low dose (1.29 percent) cannabis, to see if the analgesia was sufficient in the low doses. If yes, the low dose could be used to avoid side effects. Both doses had statistically significant reductions in pain (30 percent) compared to placebo.

Katchan also cited the same 2010 Ware study that Noel did. (see above)

All those studies showed that modulating the cannabinoid system can help patients with neuropathic pain, not only by relieving their pain, but also by improving their sleeping skills.

Patients in cannabinoid therapy had twice the incidence of severe adverse events than control group. They experienced respiratory, gastrointestinal, and nervous system disorders most often. Severe side effects were: dyspnea, pneumonia, pleural effusion, lower respiratory tract infection and pulmonary embolism; vomiting, diarrhea, gastroenteritis, abdominal pain, constipation, duodenal ulcer; relapse of multiple sclerosis, and convulsions. The incidence rate of non-serious adverse events was significantly higher among subjects assigned to cannabinoid therapy than among controls, dizziness being the most frequent.

She concludes that further studies are needed to determine how cannabinoids should be taken, their optimal doses, and which type of cannabinoids would be effective with fewest side effects.

Germany. Systematic Review. Meta-Analysis.

"Efficacy, Tolerability and Safety of Cannabinoids for Chronic Neuropathic Pain: A Systematic Review of Randomized Controlled Studies." 2016. Petzke F, an anesthesiologist, and his colleagues were concerned that recent systematic reviews came to difference conclusions about the efficacy, tolerability and safety of cannabinoids for treatment of chronic neuropathic pain. They did their own review of 15 randomized controlled trials with 1,619 participants. Study durations ranged between 2 and 15 weeks. Ten studies used a plant-derived oromucosal spray with tetrahydrocannabinol/cannabidiol, three used a synthetic cannabinoid (two with nabilone and one with dronabinol) and two studies used medicinal cannabis.

Cannabinoids were better than placebos in reducing average pain intensity. There were no differences between cannabinoids and placebos in improving health-related quality of life, and in how often patients had serious adverse events. Patients treated with cannabinoids dropped out more often due to adverse events such as central nervous system and psychiatric side effects. Cannabinoids were marginally superior to placebos in terms of efficacy and inferior in terms of tolerability. Cannabinoids and placebos did not differ in terms of safety during the study period. Short-term and intermediate-term therapy with cannabinoids may be used in patients with chronic neuropathic pain after failure of first-line and second-line therapies.

United States. Systematic Review.

"Medical Marijuana for Treatment of Chronic Pain and Other Medical and Psychiatric Problems: A Clinical Review." 2015. As of March 2015, 23 states and the District of Columbia had medical marijuana laws in place. Hill, a substance abuse specialist, wanted physicians to know both the scientific rationale and the practical implications for medical marijuana laws. He reviewed 28 randomized clinical trials of cannabinoids not approved by the US Food

and Drug Administration. He found high quality evidence for the use of marijuana for chronic pain, neuropathic pain, and muscle spasms due to multiple sclerosis. He based this finding on six chronic pain trials that included 325 patients, six neuropathic pain trials that included 396 patients, and twelve multiple sclerosis trials that included 1,600 patients. He recommends that physicians educate patients about medical marijuana to ensure that it is used appropriately and that patients benefit from its use. Common side effects include dizziness, dry mouth, nausea, disorientation, euphoria, confusion, and sedation. It causes an increase in heart rate, which may increase the chance of heart attack in people who are already at risk. Regular smoking of marijuana is associated with breathing problems such as cough and increased risk of lung infections. It can also be addicting and can interfere with work, school, and relationships. Marijuana can be used in diverse ways. It can be smoked, mixed into foods, and brewed as tea. Dosing of marijuana is not straightforward and depends on the patient, the preparation, and the way the drug is used.

Brazil. Systematic Review.

"Cannabinoids in Neurology - Brazilian Academy of Neurology." 2015.

This summary is from a translation of the Brucki et. al. article, written in Portuguese. It is the Brazilian Academy of Neurology's position on the use of cannabidiol and other cannabis derivatives for neurological conditions. It is based on scientific evidence. In a discussion of cannabinoids for headache the authors note that some pathologies related to head pain, such as in orofacial neuropathic pain (trigeminal neuralgia, burning mouth syndrome and persistent orofacial pain) respond to the use of cannabinoids. They say cannabinoids are simple, easy, cheap and rational drugs compared to expensive, toxic and costly conventional treatments. Cannabinoids may be an option for pain that does respond to other treatments. More research is needed to support systematic use. The academy does not approve of recreational cannabis.

United Kingdom. Randomized Control Trial.

"A Multicentre, Open-label, Follow-on Study to Assess the Long-term Maintenance of Effect, Tolerance and Safety of THC/CBD Oromucosal Spray in the Management of Neuropathic Pain." 2015. This article was not available. I am reporting based on a PubMed summary. Hoggart and colleagues looked at the long-term efficacy of THC/CBD oromucosal spray in a 38-week study. In total, 380 patients, some with diabetes and some with allodynia received THC/CBD in addition to their current medication. Neuropathic pain severity was the primary efficacy measure, rated on a scale of 0-10. They also examined safety and tolerability. In total, 234 patients completed the study. Pain measures over time dropped from a mean of 6.9 points to a mean of 4.2 points. The proportion of patients who reported at least a clinically relevant 30 percent improvement in pain continued to increase with time. Patients also reported better sleep. The spray was well tolerated, and patients did not try to increase their dose. There were no new safety concerns. THC/CBD spray was beneficial for the majority of patients with allodynia or diabetic neuropathic pain. I cannot tell from the summary how people with diabetes and allodynia differed in their response. Also, patients knew if they were getting the medication or a placebo. That can seriously bias results and is a flaw in this study.

United States. Systematic Review.

"The Effectiveness of Cannabinoids in the Management of Chronic Nonmalignant Neuropathic Pain: A Systematic Review." 2015. Boychuk, a dentist, and his colleagues conducted a systematic review of 13 studies with 771 participants to assess the effectiveness of cannabis extracts and cannabinoids in the management of chronic nonmalignant neuropathic pain. They were most interested in pain reduction and adverse side effects. They reviewed three types of cannabis trials: whole plant, extracts, and synthetic. Whole-plant cannabis is smoked or vaped, extracts are in oromucosal sprays, and synthetics are taken orally in pill form. In the whole plant studies, researchers found statistically significant reductions in pain in the cannabis group compared to placebo. One of the studies customized doses to the patients' needs, balancing pain relief with unpleasant side effects. In another, the pain relief was significant only for patients taking the highest dose (9.4 percent THC) compared to other doses and placebo. Yet another researcher showed that low and medium doses (1.3 and 3.5 percent) of vaped cannabis were equally effective in reducing pain than placebo. In the extract studies researchers compared treatment with each of two active drugs (THC:CBD or CBD alone). Each of these therapies showed a significant reduction in pain and improved sleep. A third study of extracts had the same results and longer follow up showed that the relief was maintained for a full year without toxicity or increasing the dose. In contrast, a fourth study showed no difference in pain reduction and a fifth was equivocal. All of the synthetic

"Cannabis". . .continued on page 14

"Cannabis". . .continued from page 13

drugs tests showed significant pain relief.

As for adverse effects, in the whole-plant studies, 3.5 percent THC was well tolerated, and side effects were minimal. Patients who smoked or vaped their cannabis reported sedation, anxiety, confusion, disorientation, and dizziness most often, but no one withdrew from the study because of the side effects. Another study added hunger to the side effects and noted that those using 7 percent THC had impaired cognition and those using 3.5 percent THC experienced impaired learning and memory. In the study that customized the dose by allowing patients to select a dose that balanced pain relief and side effects, there were study dropouts. Side effects reported in this study included difficulty concentrating, fatigue, sleepiness, sedation, increased sleep duration, and dry mouth. Even in the high dose study, patients rarely reported feeling high or euphoric. Patients who used the oromucosal sprays, experienced dry mouth, mouth ulcers, sore throats and a distorted sense of taste along with dizziness and fatigue. In studies of synthetics, patients added head ache to the list of aforementioned side effects.

In conclusion, cannabinoids offer significant pain reduction without significant side effects in either the short or long term. Many of the conventional medications used to treat chronic pain are of limited value and have the same side effects as cannabinoids. Cannabinoids should be considered at least an effective adjunct if not an alternative medication for chronic neuropathic pain. Newer delivery methods such as oromucosal sprays provide more consistent blood levels of the drug than smoking. In addition to reducing pain, cannabinoids can improve sleep, appetite, nausea and anxiety. More studies are needed to test the duration of treatment, and method of drug delivery.

Canada. Editorial.

"Are Cannabinoids Effective for Orofacial Pain States?" 2015. Barry Sessle is the editor-in-chief of the Journal of Orofacial Pain and Headache. He wrote an editorial review of the Boychuk article. He noted that the main focus of the research on cannabinoids for relief of neuropathic pain has not been for orofacial pain. He considers the evidence for using cannabinoids specifically for orofacial pain quite limited. He emphasized the need for high quality studies at specifically orofacial pain conditions. ■

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Dear Reader

When I was first diagnosed with Atypical Trigeminal Neuralgia (ATN) I was relieved. For years I had been suffering with a variety of progressively painful symptoms and **no one was able to tell me what it was**. It started in my teeth and gums – numbness, tingling, throbbing. Dental and sinus issues were ruled out.

When I had surgery to remove and replace 3 herniated discs in my neck, I thought for sure that would also ease these other strange sensations. Within a year, however, I found myself in the ER with excruciating pain on the left side of my face, under my eye and in both temples. My primary care physician finally sent me to a neurologist who, after a series of tests, **diagnosed me with atypical trigeminal neuralgia and atypical migraines.**


Me having a Sphenopalatine Ganglion Block

I began to scour the internet looking for as much information as I could find. I began to question the TN diagnosis because the symptoms are so varied and could be associated with an array of other conditions (and up to that point I had been "diagnosed" with several). I came across a blog post on the Facial Pain Association (FPA) website related to ATN, with an excerpt from Striking Back: The Trigeminal Neuralgia and Face Pain Handbook by George Weigel and Kenneth F. Casey, M.D.

Reading this helped me to better understand that **ATN is a complicated diagnosis** and perplexing even to medical professionals. Each person's journey is different and treatment options vary widely. **The resources available to me on the FPA website were invaluable.** The website offers access to online webinars, a quarterly journal, a national network of support groups, regional conference programs -- just to name a few.

In order to continue providing this wealth of information, the **Facial Pain Association needs your *HELP***. The FPA is a patient-funded organization that relies solely on the generosity of its community to continue providing meaningful support.

Please consider making a tax-deductible year-end donation by mailing your contribution in the envelope provided by **December 31st.** You can also make an online gift at facepain.org, call us at (800) 923-3608 or donate through PayPal using **paypal.me/facepain**.

EVERY GIFT HELPS, regardless of size.

So, thank you in advance for your support! We look forward to an exciting new year and the opportunity to continue providing valuable resources and a network of support for the entire FPA community.

Sincerely,

Amy Turner
Director of Development

PS
I hope we can count on your support for the Year End Appeal.
John Koff, CEO

Jeffrey A. Brown, MD

The MAB Corner

PERCUTANEOUS STEREOTACTIC TRIGEMINAL NERVE BALLOON COMPRESSION RHIZOTOMY

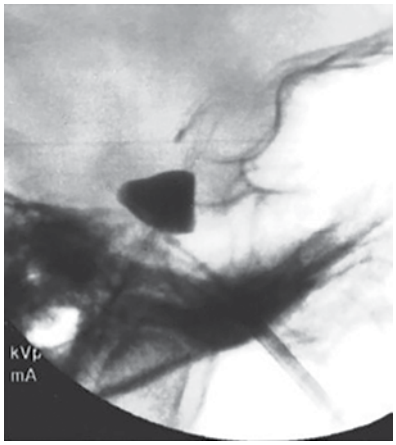
Balloon compression for trigeminal neuralgia is a simple and effective outpatient treatment for trigeminal neuralgia. It is one of the ablative options that injures the trigeminal nerve in a very specific way.

Who is a candidate for it?

If your pain consists predominantly of paresthesias, it is a consideration. What are paresthesias? These are paroxysmal sensations that can be described with a variety of words. These include a spatial category: jumping, flashing or shooting; a punctate category: pricking, boring, drilling, stabbing or lancinating; an incisive category: sharp, cutting or lacerating.

How does balloon compression work?

A balloon is temporarily inserted through a needle placed through the cheek and is inflated under X-ray guidance. It squeezes the trigeminal nerve root against the skull base for a selected time period at a measured pressure. The balloon only injures the insulation that individually surrounds thousands of wires within the cable that makes up the trigeminal nerve. By injuring this insulation, the ability of the nerve to conduct electricity is affected. Thus, it turns off the switch that allows the short-circuit upstream in the nerve to occur. It is this short circuit that leads to the electrical sensations you as the patient feel. Interesting, these injured nerve fibers do not conduct pain sensation. They conduct the sensations of light touch that trigger the painful short circuit. Fibers in the nerve that conduct pain



sensation are actually preserved.

How effective is it?

More than 90% of procedures will eliminate the pain of trigeminal neuralgia in properly selected candidates.

What are the side effects?

By injuring the trigeminal nerve, an element of numbness is introduced. 92% of patients say that this numbness is only mild. Numbness is in fact not an absence of sensation. It is another form of sensation called a dysesthesia. If severe enough it can be interpreted as burning, scalding, searing, tingling, itching, stinging, cool, cold, even freezing. Such sensations result from significant nerve injury, which must be avoided. Fortunately, these are rare occurrences. The likelihood of such complications occurring is dependent on the art and experience of the surgeon.

One other side effect often seen is temporary weakness of the chewing muscles on the same side as the surgery. This can lead to temporary aching pain in the jaw joint. Such a pain is treatable with Tylenol and this weakness resolves over the course of several weeks. The trigeminal nerve has a branch that gives motor function to these muscles.

What is the experience of undergoing balloon compression like? The procedure takes only one hour to complete. It is done while you are asleep and you return home within another few hours with only a band aide to cover the needle entry site.

How long is the pain relief?

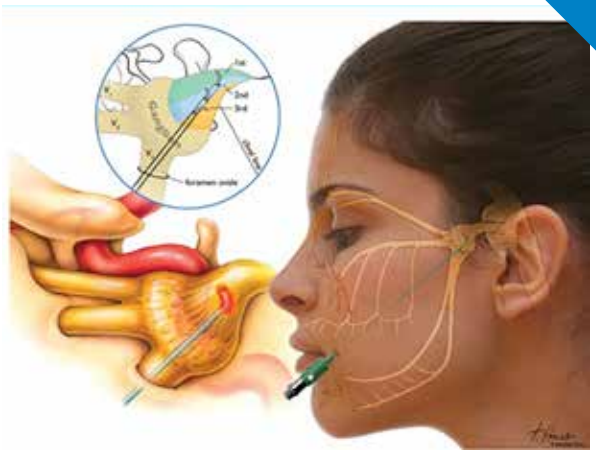
Because the nerve insulation can heal, the pain can recur when that happens. Such recurrence is expected, because the planned injury is a mild one. Mild numbness is well tolerated. Severe numbness is not, so a recurrence rate of 30 to 50% within 3 to 5 years is expected. When the pain recurs the compression can be repeated.

Balloon compression is especially indicated for those patients with stabbing pain in the region of the eyes. This is because the small fibers that do not have insulation mediate what is called the corneal reflex and thus their function is preserved. This is the reflex that protects your eye from scratches that can affect over time ones vision.

The needle used to guide entry of the balloon catheter is larger then the one used to inject glycerol or to place the radio frequency electrode. Perhaps because of this, the placement of it is done using three specialized Xray images that provide precise guidance to the surgeon.

In summary, when balloon compression is done by an experienced neurosurgeon, it is a simple and effective means of ablative treatment for the terrible pain of trigeminal neuralgia.

Harry Van Loveren, MD



RADIOFREQUENCY RHIZOTOMY

Percutaneous radiofrequency rhizotomy (PSR) produces a controlled injury to the trigeminal nerve and is therefore able to trade numbness for relief of tic pain. It does so by temperature monitored heating of trigeminal nerve fibers. The extent of numbness can vary but, in general, the amount of numbness is proportional to the duration of relief. Too much numbness can also be a problem because it can cause uncomfortable sensations. Numbness is not the absence of sensation. Instead, it is the presence of another sensation as anyone who has had Novocain at their dentist knows.

PSR can limit numbness to a specific part of the face, especially if the pain originates in the lower face, jaw or tongue. It is probably the only procedure that can reliably limit numbness to that part of the face. This is helpful because the more widespread the numbness, the harder it can be to tolerate. Numbness of the upper face that includes the surface of the eye (the cornea), V1 creates the risk of eye irritation or even corneal scarring with loss of vision. Absolute control of the lesion is not possible, however and sometimes one gets more numbness than planned in spite of the surgeon's best efforts. PSR can cause numbness in all three trigeminal divisions if necessary but once the ophthalmic division is to be included, I tend to favor the balloon compression procedure because it offers at least some protection of the corneal reflex. For some reason, corneal reflex nerve fibers seem to be less vulnerable to the pressure of the balloon than to the heat of the radiofrequency electrode.

Let's take a look at how the PSR is actually done:

Patients are briefly anesthetized with an intravenous medication. An entry point for the needle electrode is selected in the cheek an inch to the side of the corner of the mouth. Trajectory guidance points can be marked on the face to help the surgeon set the proper angle of approach with the needle. The needle is passed to the floor of the skull to an opening called the foramen ovale where one of the three divisions of the trigeminal nerve enters the skull. An X-ray taken at the proper angle during surgery will show it. The needle is then passed through the foramen and positioned in a dip in the skull base called Meckel's cave. This is where the tip will lie amongst the nerve fibers of the trigeminal root and Gasserian ganglion. A ganglion is a swelling in the nerve that serves as a relay center for sensation on the face to the brain. This is all done with the patient briefly anesthetized. The sharp inner needle used for insertion is then exchanged for a radiofrequency electrode. Patients are allowed to awaken to the point of sleepy but effective communication. Current is passed through the electrode to cause small shocks in the face, hopefully without triggering a tic attack. This allows the surgeon to maneuver the electrode to the right location where stimulation is felt in the trigeminal division where the patient normally gets tic pains. Once properly localized, the patient is again lightly anesthetized and the electrode's radiofrequency current turned up to the point that it causes the nerve fibers to heat up. At 50º centigrade nerve conduction temporarily stops. At 60º the proteins in the nerve fibers start to coagulate and part of the nerve is injured. Between lesions, the patient is allowed to awaken so that the location and degree of numbness can be tested until it is exactly what the surgeon wants for that specific patient.

"Rhizotomy". . .continued on page 18

"Rhizotomy"...continued from page 17

The majority of patients are happy with the results, willing to exchange their tic pain for their mild new numbness. Over time there is some diminishment of the numbness and some accommodation to it. Like putting on a new pair of shoes, the new sensation is stronger at first, but the brain starts to see it as the "new norm" over time. That's why when I ask my patient if their face feels numb shortly after the procedure they say of course it does as if chastising me for a question for which the answer is obvious. Months later if I ask the same patient if their face is numb, they reach up and feel it to check if the sensation is still altered. Not so obvious any more. If the numbness wears off too much, the pain will come back. Recurrence in spite of continued numbness is well known and one of the mysteries of the disease. It is presumed that this represents some intensification or progression of the disease, which must be within the nerve.

PSR can be repeated for recurrence, but each repeat procedure carries the need for more numbness and therefore the increased risk of troublesome numbness. PSR is one of the oldest and yet still one of the best procedures to relieve tic pain. It is an outpatient procedure with an acceptably low risk profile and can be a very good option for patients with medical reasons to avoid open surgery. ■

Managing Your Pain Through 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 according to the American Pain Foundation.

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! ■

INTRODUCING THE NEW MEMBERS OF THE MEDICAL ADVISORY BOARD OF THE FACIAL PAIN ASSOCIATION

Michael Lim, MD

Director of Brain Tumor Immunotherapy
Professor of Neurosurgery
Johns Hopkins School of Medicine

Dr. Lim's surgical interest is in the treatment of primary and metastatic brain tumors as well as pituitary and skull base tumors. He also has an interest in surgical treatments of trigeminal neuralgia. He utilizes the most advanced techniques in neurosurgery including image guided surgery, microsurgery, minimally invasive techniques, and endoscopic surgery.

Dr. Lim also possesses expertise in radiosurgery. He is the Director of the Spine Radiosurgery program. In addition to treating spinal tumors, he is an expert in the treatment of brain tumors, arteriovenous malformations, and trigeminal neuralgia with radiosurgery.

In October 2016, Dr. Lim was recognized for outstanding patient care, earning a Service Excellence Award from HealthNetwork Foundation. The awards are presented annually to 10 physicians who have demonstrated extremely high levels of integrity and compassionate care. Dr. Lim was nominated by former grateful patients.

Summary of Expertise: Arteriovenous Malformations (AVM), Brain Cancer, Brain Tumors, Glioblastoma, Metastatic Brain Tumors, Neurosurgery, Neurosurgical Oncology, Radiosurgery, Skull Base Surgery, Skull Base Tumors, Trigeminal Neuralgia, Von Hippel-Lindau (VHL).

Research Interests: Brain Tumor Vaccines; Brain Metastases; Trigeminal Neuralgia; Spine Radiosurgery

Steven D. Chang, MD

Neurosurgeon, Aneurysm neurosurgeon, Cerebrovascular neurosurgeon, Pituitary tumors neurosurgeon, Stereotactic neurosurgeon, Neuro-oncologist
Stanford University School of Medicine
Robert C. and Jeannette Powell Neurosciences Professor and, by courtesy, of Otolaryngology-Head and Neck Surgery.

Dr. Chang is a Professor and Vice Chairman of Strategic Development and Innovation in the Department of Neurosurgery at Stanford. He is also the inaugural holder of the Robert C. And Jeannette Powell Professorship in the Neurosciences at Stanford University School of Medicine. His clinical work and research focuses on the treatment of brain tumors and cerebrovascular disease.

After receiving his Medical Degree and completing his Neurosurgery residency training at Stanford University, Dr. Chang joined Stanford's Department of Neurosurgery in 2000. He was named full professor in 2008, and that same year was appointed as the Powell Professor in the Neurosciences. Dr. Chang has a national and international reputation as an expert in both microsurgery and radiosurgery for treatment of brain, spine, and skull base tumors, and is the Co-Director of the Surgical Neuro-Oncology Program. His radiosurgery practice focuses on the use of the Cyberknife to treat neoplasms of the brain and spine. He was instrumental in the rapid growth of the Stanford Cyberknife Radiosurgery Program and is currently Co-Director of this program.

Dr. Chang also specializes in the treatment arteriovenous malformations and cavernous malformations of the brain

and spine, and surgical treatment of intracranial aneurysms. A fellowship trained cerebrovascular neurosurgeon, Dr. Chang specializes in multi-modality therapy for these vascular lesions. He is also an expert in both microsurgery and radiosurgery for treatment of trigeminal neuralgia.

Dr. Chang's research focuses on clinical outcomes for radiosurgery of brain and spine tumors. His lab has active research projects involving genetic analysis of arteriovenous malformation patients. He is the Director of the Stanford Neurogenetics Oncology Program and the Director of the Stanford Neuromolecular Innovations Program. He is the author or co-author of more than 300 peer-reviewed publications and book chapters.

Gary D. Klasser, DMD, Cert. Orofacial Pain

Associate Professor in the Division of Diagnostic Sciences at Louisiana State University, School of Dentistry

Dr. Klasser obtained his dental degree from the University of Manitoba (Canada) in 1980. Over the next 22 years, he enjoyed the practice of general dentistry from both a public health and private practice perspective until he returned to graduate studies in 2002.

In 2004, he completed his training and graduated from the University of Kentucky with a Certificate in Orofacial Pain. In 2005, he completed a fellowship in Oral Medicine/Oral Oncology at the University of Illinois at Chicago (UIC). From 2005 – 2011, he was an Assistant Professor and Director of the Oral Medicine/Orofacial Pain clinic at the College of Dentistry in the University of Illinois at Chicago.

Dr. Klasser has published in a number of peer reviewed journals and has contributed chapters to various textbooks while serving as an editorial reviewer for a number journals. He is also co-editor for the next edition of the American Academy of Orofacial Pain book entitled: Orofacial Pain: Guidelines for Assessment, Diagnosis, and Management.

Marc Sindou, MD and DSc

Professor Emeritus at the University of Lyon, France.

Dr. Sindou received his PhD degree on "Electrophysiological generators of the cerebral cortex in Humans" and his MD degree on "Dorsal Root Entry Zone as a target for pain surgery", in the seventies. After his neurosurgical training, he benefited from two Fellowships, first in Micro-neurosurgery in Kantonspital in Zurich with Pr. Gazi Yasargil, then for Functional Neurosurgery in MGH and Harvard University in Boston with Pr. William Sweet.

Medical activity in Lyon was then directed to: 1) Functional Neurosurgery of Pain, Spasticity, Epilepsy and Trigeminal Neuralgia; 2) Microsurgery of Meningiomas and Skull Base Tumors, Aneurysms and Neuro-Vascular Compression Syndromes; 3) Neurophysiology applied to Neurosurgery. Surgical activity, together with his superb team and pupils, amounted at twenty-five thousands surgeries over a forty-year period of time. Medical and scientific experience has been published in 548 articles, 35 book chapters and six books, and also through 171 invited-comments or editorials in International Journals. He was honoured by 32 Visiting-Professorships. He mainly introduced the concept of Surgery in the DREZ for Pain and Spasticity in 1974.

He was a Founding member of the International Association for the Study of Pain (1976), the President of the World Society for Stereotactic and Functional Neurosurgery (1997-2001), a Vice-president of the European Association of Neurosurgical Societies (1999-2003), a European Teacher in the EANS Training Committee (1985-2014), the President of the French Speaking Society (2007-2010).

He delivered 280 invited-lectures in 54 different foreign countries. Among many international distinctions, he was awarded the European Lecture in 2007, the Spiegel and Wycis Medal in 2009, the Award of the Ten Masters in Neurosurgery by the World Federation of Neurosurgical Societies in 2009. ■

Meet the New Members of the Board of Directors for the Facial Pain Association

JEFFREY FOGEL, MD

Jeff is a retired physician and current TN patient. Before his retirement Jeff was a board certified Pediatrician, a fellow of the American Academy of Pediatrics and in private practice for 30 years in the Philadelphia area. He was also a contributing author to a number of medical publications and lead investigator on several research projects on pediatric health issues.

Dr. Jeff is an expert on medical marijuana and helped craft the Pennsylvania legislation legalizing the use of MM in the state. He is also a Support Group Leader for the Philadelphia FPA Support Group and the outreach coordinator. He and his wife Jean live in Ambler PA. They have been married for 37 years and have 2 adult sons.

In addition to medicine and family, his other passion is being an active volunteer firefighter with the Fort Washington Fire Company for over 25 years.

DAVID MEYERS

David is retired as CEO of Microbahn International, a leading provider of antimicrobial technology and odor control solutions to companies around the globe. He has extensive experience conducting business in Asia, Europe and Latin America

David is a TN patient, has undergone a successful MVD procedure and has been avid and generous supporter of the FPA for many years.

JOHN TEMPLE

John is President of Cambridge International Partners, a boutique investment bank that provides M&A advisory services to the global investment management industry.

John joined Cambridge as a partner in 1995 and became President in 2011. He was previously a

principal with Allegiance Capital, a GE Capital affiliated investment partnership focused on

leveraged buyouts in financial services.

John holds Bachelor of Arts and Master of Arts degrees from Trinity Hall College, Cambridge University. He is also a current TN patient, actively managing his pain.

ERIC WERTHEIM

Eric was appointed to the FPA Board of Directors this past September. He is a husband, a father, a successful attorney and a TN patient. Here is Eric in his own words.

I graduated from S.U.N.Y. Binghamton (now known as Binghamton University) with a Bachelor of Arts degree in 1980.

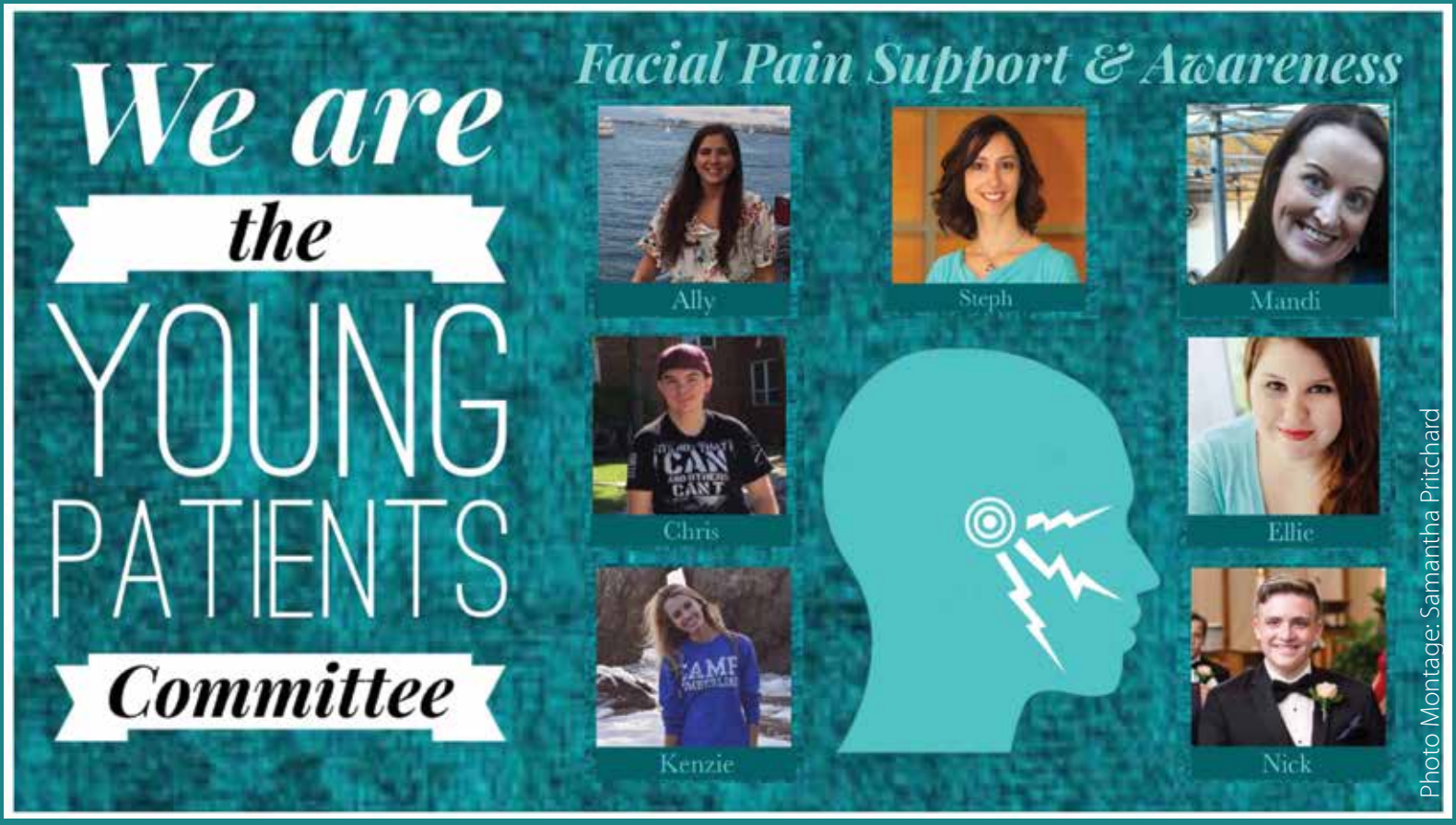
I graduated from Fordham University School of Law, where I was a member and editor of the Law Review, in 1987.

I began my legal career in 1987 as the first law clerk to the Honorable Kenneth Conboy of the United States District Court for the Southern District of New York. Following my clerkship, I spent my formative years in private practice as a litigation associate with Patterson Belknap Webb & Tyler, one of the leading litigation firms in the United States.

I am a certified emergency medical technician, and have been a member of my town's volunteer first aid squad for twelve years. I have served as an officer and a member of the board of trustees of the squad.

For about seven years, I, along with my two children, raised money for the fight against multiple sclerosis by riding in the New York City MS Bike Tour.

Although I have no official role, I assist my wife in her longstanding role as co-chair of our community's "Green Team." ■



7 REASONS WHY TN PATIENTS ARE PRETTY AWESOME!

"Out of suffering have emerged the strongest souls; the most massive characters are seared with scars."—Kahlil Gibran

WHAT'S IN A NAME

Trigeminal Neuralgia itself is far from awesome. It is excruciatingly painful and can be very hard to live with on a daily basis. As TN warriors, we know that makes us strong and unique individuals that have a lot to offer the world! Here are just a few of the many reasons that TN patients are awesome…

1 We can predict the weather with quite some accuracy!

Some TN patients have a great sense of shifts in barometric pressure, or looming storms. We can tell you when it's hot, humid, damp, or cold just by how our face feels! This can be very useful during outdoor events and gatherings!

2 We know how to rock scarves and face masks like no other!

TN patients are well versed in wearing scarves and face masks to protect from cold and wind – or anything that can trigger a flare! No, we are not going to rob a bank, we are just trying to get our frozen goods from the cold aisle in the grocery store! We are used to the looks and stares, and could care less because we know how to cover our face and rock a scarf with grace and style!

3 We are Pain Warriors with a superhuman pain tolerance (we make pretty good actors too!)

TN patients know what pain feels like and we know how to tolerate it because we have no choice. We learn to function with pain and find ways to live life despite the shocks and burning we feel. We are great actors and we know how to keep pushing forward! We are like superheroes, fighting an internal battle every day!

4 We know how to build community and connect with others.

TN patients, along with their friends, family, and supporters know the true definition of community and how to come together for support. There is a strong community both online and in person of TN patients that provide love and support to one another. By sharing stories and experiences, we have built a strong community and made some great friends along the way!

5 We know how to speak up and advocate for ourselves!

Most TN patients know how to be an advocate for themselves, both personally and medically. For most, getting a diagnosis of Trigeminal Neuralgia is not an easy road, and often comes with confusion and misdiagnosed illness along the way. TN patients learn how to speak for themselves to find the right treatment plan and doctors. We sometimes know more than the physicians do about our condition and we speak up as we need to! If you are a doctor treating us, just know we have researched, we have a voice, and we are prepared!

6 We know the value of time.

TN patients spend a lot of time sitting in doctors and specialists offices. We spend time at home, in pain, unable to participate in life sometimes. We recognize the minutes we lose sitting in waiting rooms, driving to appointments, and lying in bed feeling too much pain to move. But that means we also recognize the minutes we feel well, and we appreciate them immensely! TN warriors understand how precious time is and we don't want to waste it when we are able to participate and enjoy life!

7 We have Gratitude!

TN Warriors understand what it means to be truly, deeply grateful. We are grateful for the doctors and nurses that help us. We are grateful for the moments we spend with family and friends doing ordinary things. We are grateful for the Internet that allows us to stay connected on the bad days, when we are housebound. We are grateful for anyone that shows patience and compassion at times when our pain means we are struggling. We are grateful for the friends who take the time to love and care for us despite the times we need to cancel or break plans. We are grateful to be breathing.

The list doesn't stop here! Connect with us and many other awesome TN patients in our private Facebook group: Official Trigeminal Neuralgia Support Group: Young Patients and by visiting the following sites. ■

More information about the YPC can be found at

/tnaypc

/youngpatients

/tnypc

Young Patient Profile

Mollie Dyer

1. How old are you?

I'm 16.

2. Where do you live?

I'm from the UK, just outside London.

3. When did you first experience trigeminal neuralgia?

I was 14 when it first happened.

4. What is your diagnosis?

I have trigeminal neuralgia.

5. What do you do in your free time?

I love to bake and knit. Also to hang out with my friends and family.

6. What has TN taught you?

It has helped me learn who my real friends are. And how to be productive and prove to people I'm more than my diagnosis.

7. What non-surgical procedures have you tried?

I've had an occipital nerve block, which was unsuccessful.

8. Have you had any surgical procedures?

I haven't had surgery yet, but I'm meeting a neurosurgeon and consultant at my next appointment.

9. How has your facial pain changed you?

I've become very determined. I won't let it [TN] stop me doing anything.

10. What tips do you have for other young patients?

You can't control the pain, when it's bad it's bad. But you can control your outlook on life. If you have a positive attitude it makes life a lot easier to deal with.

11. How are you raising awareness for TN?

I'm doing an assembly in a couple of months and throwing an ABBA benefit concert in March to raise money. I'm going to throw a concert in March. It's very early in the planning stages but it's to raise money for the TNA. My friends and family are going to sing the songs from Mamma Mia and we'll charge an entrance price to raise the funds. I'm trying to contact a few people, like the Universal Records Company, to ask about performing rights and also a TV doctor in the UK who also had TN. It's in the very early days but everyone is very excited about it! ■

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 from June 2018– October 2018

In Honor:

Dr. John Alksne
Linda Perdue

Cindy Bennett
Claude and Jean Aldridge

Catherine Costello
Janet L. O'Neil

Beth DeBaugh
Amy Turner

David Julian and Heather Howard
Marcy Kulakow
Skyler Lewis
Michael Saracco
Steven Saracco

Karl Kroeppler
Vincent Rinehart

Gaynelle Lentz
Nicole Lentz

Jo Marie Margiotta
Giovina Margiotta

Kelley Pollard
Douglas Weeks

Dr. Abhay Sanan
Linda Faye

Kevin Schroeder
Sherry Schroeder
Pat Yendra

Madeline Swist
Mary Krell

Tiffanie Tagner
Cathy Kimball

TN Sufferers of Detroit and SE Michigan
Genevieve Lenda

Kathleen Warren
Claude and Jean Aldridge

Nicole Wiemer
Karen Griffin

Memorial Tributes:

Gladys Addison
Cynthia Johnson Hall

Grant Carlson
Priscilla L. Carlson

Arlene DeFrances
Tony Longo

Bessie Elledge
Loretta Lockett

Ann Geishecker
Paul Geishecker

Lewis and Mary Green
Delores G. Williams

Viola (Vl) Rose Szoke Hill
Ken Bozick, *Washington Navy Yard*
Sandye Aldridge Dunlap
Alison McCrary

Ray Lambrecht
Mallory MacIsaac

David D Murdoch
Daniel N Murdoch, David D. Murdoch Trust

Michael O'Brien, Statesman
Miles Varghese

Harvey Parker
Jane Packer Gerber

Gary Redwine
Mark Kashmanian, RAMS

Pat Robb
Jim Zook

Rossi
Maya Edmondson

Caroline Scarlett
Laura Hillis

Douglas P. Tongue
Marjorie M. Tongue

Judy Watson
Linda Branch
Scott Pieratt

FPA Membership

The following individuals joined or renewed their FPA membership between June 2018– October 2018

JUNE

Catherine Casey
Trudy Derryberry
Kathleen Dettman
Mark Epp
Estela Gonzalez
Kathleen Hays
Donald Hoblit
Gail Ivey
Edith Jones
Josie Katz
Patricia Mares-Mischke
Catherine McCarthy
James Phillips
Marge Rahn
Kimberly Rios
Dale Rounsaville
Madeline Sanders
Ruth Scott
Kathy Wargo
Maria Whiston

JULY

Maria Becerra
Darlene Daniels
Pennie Dee
Cheryl Dillard
Cheryl Dillard
Bonnie Dobbins
Carrie Du Bois
Cynthia Freitag
Anthony Garcia
Vickie Guite
Steffany Haertsch
Christine Hall
Susan Kaesemeyer
Pam Kleim
Isabella LaGrego
Kathleen Lopes
Jeff Loveland
William Lynch
Lynne Martin
Maria Martinuzzi
Carolyn Moore
Tracey O'Neill
MiYona Pagni
Ali Patz
Linda Perdue
Robert Stephenson
Maureen Stone
Noubar Vanlian

AUGUST

Stacie Abraham
Pam Adams
Domingo Algorri
Mary Argeris
Albert Auster
Beth Berger
A. Bryson
Karen Burrow
Douglas Caldwell
Lucy Childs
Betty Jane (BJ) Coghan
Roberta Collins
Dolores Cornejo
Nancy Darrah
Natalie De Pena
Virginia Dickinson
Delbert Donelson
Raymond Dunne
Charles Everts
Stacey Ferguson
Sandra Fletcher
Patricia Foggin
Joyce Forcke
Andreina Goldberg
Carol Granger
June Haberbusch
Valerie Haynes
Robert Hirsch
David Huang
Teri Huntington
Karin Jawitz
Sherry Jones
Ronald Jutzy
R. A. Kather
Hannah Keller
Conrad Kerwath
Walter Kirschkel
Dorothy Kresconko
Faith Laning
Sally Lapiduss
Joseph Leonard
Carole Lilja
Sheila Luellen
Anthony Marshall-Smith
Stacey Mason
Larry Matthews
William McDowell
Jane Meyer
Cheryl Micheli
Craig Miller
Rebecca Miller
Susan Mitchell
James Moore
Charles Muchnick
Maureen Niese
Shirley Olsen
Alice Paxton
E. Madonna Peachey
Elaine Perkins Lipps
Pamela Powell
Dixie Richards

Thomas Samide
Sheila Shuford
Gail Sinwell
Russell Sjaarda
Elizabeth Smith
Nancy Snyder
Gayle Springer
Cheryl Stibel
John Temple
Connie Thomas
Raghavendra Tikot
Marjorie Tongue
Miorky Torres
Robert Wassall
Linda Weseloh
Joe Woodruff
Jane Xiques

SEPTEMBER

Joseph Apicella
Charles Beaudoin
Anthony Bilangino
Paulette Chandler
Joe Christian
Dorinda D'Agostino
Anneka Davis
Arthur Emery
Andrew Encisco
Edward Fenton
Jennifer Garvin
Mary Goelz
Anne Goetzman
Charles Hester
Tracey Houston
Amy Langione
Bernard Lieberman
Denise Maire
Selma Martin
Merle McCartney
Janice McConahy
Carol Moss
Donna Penaluna
Eleanor Pourron
Laurie Rauch
Ashley Rizzuto
Carolyn Ruby
Joseph Scheuchenzuber
Mona Schorow
Dana Strothman
Brenda Sturgeon
Lawrence Walton
Mary Waltuck
Jennifer Wilson
Mary Woodson

OCTOBER

Cheryl Beech
Richard Blackshere
Geri Brodie
Elizabeth Brown
Regina Brusky
Tammy Burns
Eldon Christians
Linda Cooper
James Cosson
Tracey Cox
Debbie Culligan
Donna Dixon
Conni Dowgiert
Daniel Eachus
Nicole Evans
Susan Ewald
Thomas Fenstermacher
Melissa Fogle
Diane Harrison
John Jonkman
Gwen Lias-Baskett
Reba Little
Maria Monteleone
Charlcie Montgomery
Jeffrey Norwood
Mollie Osgood
Mary Jane Pych
Dorothy Rainwater
Lynn Ruppe
Vicki Scharringhausen
Frances Sciuto
Ron Sconyers
Richard Spahn
Mary Stec
Ellie Stone
Gregory Stoner
Tracy Tata
Gloria Thomas

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 facial pain surgery.

Dr. Brisman has served as Chief of Neurosurgery at NYU Winthrop Hospital, Mineola, NY, and is Co-Medical Director of the Long Island Gamma Knife® Center at South Nassau Communities Hospital in Oceanside, NY.

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

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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Brain & Spine Surgery

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