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Page 38: Sneak Preview at the FPA San Diego National Conference Speakers and Topics

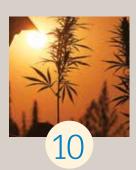
IN THIS EDITION OF THE Q



An Introduction to Part II of our series on medical marijuana.



Medical Marijuana: Past, Present and Future



The current legal status of medical marijuana in the United States.



Pharmacology and Cannabis



Trigeminal Neuralgia and Cannabis



Three people with neuropathic face pain describe their experience with medical marijuana.

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Professional Members, Memorial and Honorary Tributes



From the Chairman of the Board

Much is underway at the FPA and this *Letter* provides several important updates.

First, we are pleased to welcome Ms. Megan Hamilton as a Director of the FPA. Megan is the mother of a teen with trigeminal neuropathic pain and she is the founder of TNKids and TNKidsRock that are devoted to care of pediatric patients. The Board of Directors values transparency, open discussion and dissenting views. Megan brings new ideas and perspectives to deliberations and we welcome her commitment to and energy for our cause.

The FPA will hold its 11th National Conference at UC San Diego on November 2 and 3, 2019. The agenda is packed with speakers who are experts in diagnosing and treating TN, there will be opportunities for one-on-one discussions with them during lunch and other breaks, and there is no substitute for actually meeting with others who have TN. This conference is an essential part of the FPA's mission to provide information and community to people, and to the families and friends of people, with TN. You can register by calling the FPA office at 800-923-3608 or online at facepain.org.

The FPA began at a kitchen table, members joined, received a newsletter by mail and many participated in physical Support Group meetings. That worked well for a while, but that has become the old model and it's gone. The internet has changed, and continues to change, how people find information and community. The FPA now has a very functional website, we provide a lot of information by email, and we are active in social

media forums including Facebook. In an effort to find what works best on Facebook, FPA Directors Anne Ciemnecki, Megan Hamilton, Melissa Anchan, Ally Kubik, and YPC President Stephanie Blough have been posting on the FPA's Facebook page (https://www.facebook.com/facialpainassociation). Their daily posts include TN-related topics in the news, research findings, FPA resources, questions for our followers, and an occasional laugh. Their efforts, which began last August, stimulated a 600% increase in user postings, increased the number of followers by about 20%, and increased donations to the FPA through Facebook's Network for Good by about 150%. We encourage you to log-on, engage and tell us how we can best support and provide resources to you. We're working on it.

We are pleased with the progress described above, but there is still no substitute for getting together. What is the right mix of Facebook interaction and physical Support Group and conference meetings? What is the best linkage between virtual and real forums? How do we manage inaccurate information posted on internet forums? How do we add the most value? How do we inspire people to help and support the FPA's efforts? None of those questions have clear or stationary answers.

Mark your calendar for October 7, International Trigeminal Neuralgia Day. The FPA is developing several programs to raise awareness of TN and you can follow our plans by logging on to the Facebook link provided above.

Jeff Bodington, Chairman of the Board

The Facial Pain Association



FPA Board Member, Jeffrey Fogel, MD Introduces the Second in a Two Part Series About Medical Marijuana



Dr. Jeffrey Fogel is a pediatrician who was diagnosed with Trigeminal Neuralgia in 2008. He has had 2 MVD's. After 30 years in private Pediatric practice in the Philadelphia suburbs, he had to stop practicing medicine in 2013 due to TN. He was active in the passage of Act 16 (2016), which legalized medical marijuana in the Commonwealth of Pennsylvania. He is a Support

Group Leader for the Philadelphia area FPA Support Group and the outreach coordinator. He has also been a Board Member of the Facial Pain Association for the past year.

This issue of the Quarterly is the second in a two-part series on medical marijuana (MM). In the previous issue, FPA Board member Anne Ciemnecki provided an excellent review of MM research to date. This issue of the Q, however, is somewhat unique. It is the first time that an entire issue has been devoted to a single topic. The reason is simple: the use of MM is not just about trigeminal neuralgia (TN) patients. It is a much broader issue addressing the

estimated 100 million Americans who are in chronic daily pain from many different causes. In fact, it is estimated that 10% of the world's population suffers from chronic pain.

Although patients with TN may have different symptoms, the one constant is pain. Currently, the predominant pain management treatment for TN is opioid medications. Unfortunately, use of those medications has led to an opioid overdose epidemic. In 2017,

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QUARTERLY

is published four times per year by The Facial Pain Association, 22 SE Fifth Avenue, Suite D Gainesville, FL 32601

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www.facepain.org

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there were over 47,000 opioid overdose deaths in the United States. That translates to more than 130 Americans dying every day from opioid overdoses.

Limiting opioid prescriptions is certainly one step in solving the crisis. But the pain is real and still present, so new alternatives must be made available for pain management. The intent of this issue of the Q is not to imply that MM is the only choice for pain relief. Rather, it is to offer information about MM, and hopefully break down barriers to marijuana's use for medicinal effects. MM needs to be an option available for management of TN patients' pain, along with the other current surgical, pharmaceutical, and complementary medicine options. The articles in this issue of the Q are limited to MM and its effects on pain control. Usage for other indications, or legalized marijuana for recreational use, are beyond the scope of both this publication and the Facial Pain Association.

The feature article in this issue provides a historical perspective on marijuana use in the United States, and highlights its efficacy and safety. The second article reviews the current status of MM in the United States, as well as internationally, and provides information on various states' MM programs.

Thomas Donia, a Registered Pharmacist at a Pennsylvania Medical Marijuana dispensary, in his article on page 15, reviews the specific types of marijuana. This includes the individual components, and which products work best for pain. His article helps anyone who may be considering MM by removing some of the guesswork in terms of what preparation might work best for them. He also gives an overview of the different delivery methods, highlighting the advantages and disadvantages of each.

The article by Dr. Andrew Medvedovsky, a Board Certified Neurologist and Pain Medicine Specialist, discusses his experiences with recommending MM to patients with neuropathic facial pain. He details what he would typically advise TN patients when they come to see him for the first time.

The last article highlights the stories of 3 individual patients with TN and their experiences, both positive and negative, with using MM to help manage their pain.

Like so many other issues of the day, MM has become highly politicized. It is not, however, a Democrat or Republican issue. It is not a conservative or liberal issue. It is a human condition issue.

Medical Marijuana is a treatment that could potentially help hundreds of thousands of people who are living with daily pain. To deny them the opportunity to potentially obtain relief from a drug that is effective and has a proven record of being safer than any of the current pain relief medication options is simply wrong.

Medical Marijuana: Past, Present and Future

By Jeffrey Fogel, MD

Marijuana in general, and medical marijuana (MM) in particular, has undergone a long and tortuous legal and regulatory path in the United States. To fully understand marijuana's current status, it is essential to understand the drug's history. Only then can the stigma and misperceptions against MM be understood. In this article, we will explore the history of marijuana, it's current status, and look at the potential future for MM.

PAST:

Any discussion on the medical use of cannabis would be incomplete without first discussing its history for use in pain and how cannabis went from being the most widely prescribed product in the U.S. to a Federally-controlled substance. The medical use of cannabis actually dates back to ancient China. Shen Nung, considered the Father of Chinese medicine, reportedly described the medicinal effects of cannabis in approximately 2700 B.C., about the same time he discovered the healing effects of ginseng

and ephedra. The earliest written effects of cannabis date back to the Chinese in the 15th century B.C. In ancient Egypt, cannabis was used for painful eyes (glaucoma) and inflammation, and cannabis pollen was found on the mummy of Ramesses II.

In 1611 A.D. the Jamestown settlers brought cannabis to the US from England. Entries in George Washington's diary indicate he grew hemp at Mount Vernon from 1745 to 1775, and, according to his agricultural ledgers, he was growing high THC strains of hemp to study their medicinal value. In 1850 cannabis was added to the US Pharmacopeia as treatment for a host of ailments including neuralgia, alcoholism, opiate addiction, convulsive disorders and gout pain. By 1918, US pharmaceutical companies were growing 60,000 pounds of cannabis annually to support widespread medical use. It was legally prescribed by physicians and dispensed by pharmacies. Both Eli Lilly and Parke-Davis pharmaceutical companies marketed standardized cannabis extracts for use as an analgesic, antispasmodic and sedative.

Regulation of cannabis use in the U.S. began in 1930 when Harry J. Anslinger, the nephew of the Secretary of Treasury Andrew Mellon, was appointed the Commissioner of the Federal Bureau of Narcotics. Anslinger became the Father of Cannabis prohibition, claiming it caused violence, insanity and pushed people toward horrendous acts of criminality. In 1933 cannabis became the subject of a propaganda campaign in all twenty-eight of William Randolph Hearst's newspapers, where it was claimed that marijuana caused "addiction, madness and overt sexuality." Coincidentally, 1936 was the same year the film "Reefer Madness" was released under its original name "Tell Your Children."

The 10th amendment of the Constitution states that "the powers not delegated to the Federal Government by the Constitution, nor prohibited by it to the states, are reserved to the states." For that reason, the Federal Government had no authority to regulate medicines, only the states could do so. To get around that issue, the Marijuana Tax Act of 1937 was enacted as the way to legislate marijuana. This Act required physicians and pharmacists to register with federal authorities and pay an annual tax, with penalties imposed for violations as high as \$5,000 per incident. At this point prescribing or dispensing medical cannabis was no longer worth the financial risk, and medical use declined rapidly. At the time, the American Medical Association (AMA) was against the Marijuana Tax Act, claiming that passage of the bill would deprive US citizens the benefits of a drug of "substantial value" and that "it is not a medical addiction that is involved."

Due to the difficulty in legally obtaining marijuana for medical use, in 1941 cannabis was removed from the U.S. Pharmacopeia, the compendium of drug information in the United States. By default, therefore, marijuana was no longer considered an accepted medical product.

Cannabis possession was eventually criminalized in 1951 under the Boggs Act, which imposed 2 to 5 year sentences for first offenses for trafficking or possession, and in 1956 cannabis was added to the Narcotics Control Act. Under this Act, first-offense possession led to a 2 to 10 year minimum prison sentence and fines up to \$20,000.

In 1969, the U.S. Supreme Court held the Marijuana Tax Act unconstitutional. As a result, Congress passed the Controlled Substances Act in 1970. This Act created five schedules which were intended to categorize drugs based upon its acceptable medical uses and the abuse or dependency potential. Schedule I drugs have a high potential for abuse and can create severe psychological and/or physical dependence. Progressing through the drug schedules - Schedules II through V - the abuse potential declines. Schedule V drugs, such as cough medicines with codeine, represent the lowest potential for abuse.

Marijuana was temporarily placed in Schedule I until a final categorization could be determined. To make that determination, the Controlled Substances Act of 1970 established the National Commission on Marijuana and Drug Abuse to study, among other subjects, cannabis

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abuse in the U.S. This commission was also known as the Shafer Commission after its chairman, Raymond P. Shafer. The commission's report was entitled "Marihuana, A Signal of Misunderstanding." Its recommendation, as presented to Congress, was that there be a decriminalization of simple possession, with Shafer stating:

The criminal law is too harsh a tool to apply to personal possession even in the effort to discourage use. It implies an overwhelming indictment of the behavior which we believe is not appropriate. The actual and potential harm of use of the drug is not great enough to justify intrusion by the criminal law into private behavior, a step which our society takes only with the greatest reluctance.

The Commission's report also acknowledged that, decades earlier, "the absence of adequate understanding of the effects of the drug" combined with "lurid accounts of 'marijuana atrocities' greatly affected public opinion."

Further, the Commission concluded that "there is little proven danger of physical or psychological harm from the experimental or intermittent use of the natural preparations of cannabis."

The Commission found that cannabis was not physically addictive, nor a gateway drug, nor proven harmful in any physical or psychological way. They recommended rescheduling marijuana and abolishing all criminal penalties for the private use and possession of marijuana. Even though then President Richard Nixon had appointed 9 of the 13 members of the Schafer Commission, he rejected their findings.

Since marijuana had only been placed in Schedule I pending the results of the Shafer Commission report, once Nixon rejected the report, marijuana stayed in Schedule I. As a result, the intended temporary placement of marijuana in Schedule I became a permanent fixture to this date.

So even though the only thing that marijuana and heroin have in common is the same DEA Schedule, over time in people's minds marijuana's abuse potential became erroneously linked with that of heroin, since they are both listed together in the same Schedule.

It is also important to note that the classification of drugs in each category was done by lawyers in the Department of Justice, not by physicians. Criminal penalties and regulatory provisions were linked to the drug-classification system. It was the Attorney General who made the decisions on whether each substance has an "actual or relative potential for abuse," whether there is "scientific evidence of its pharmacological effect," what the state of current scientific knowledge was, whether it involves any risk to the public

health, and what its "psychic and physiological dependence liability" may be.

To highlight just how medically inconsistent the classification system is, PCP, or "Angel Dust" which is known to be addictive and hallucinogenic, is listed in Schedule II, in a manner similar to that of opioids. PCP was initially made in 1926 and brought to market as an anesthetic medication in the 1950s. Its use in humans was disallowed in the United States in 1965 due to the high rates of side effects such as delusions, severe anxiety, and agitation. Its use in animals was disallowed in 1978. Today, small amounts continue to be manufactured for research purposes only.

To summarize, PCP, a drug whose use is discontinued in humans and animals, and is only manufactured for research purposes (the nationwide manufacturing quota for 2014 was 19 grams) is still technically allowed to be legally prescribed by physicians, while marijuana remains in the category of illegal drugs with no currently accepted medical use and is erroneously considered to have a high potential for abuse.

PRESENT:

As mentioned previously, eighty years ago the AMA was against restrictions on marijuana use. They currently advocate for clinical studies to be performed but, since it is not legal on the federal level to possess marijuana, no National Institutes of Health grant funding or pharmaceutical research can be performed. Therefore, any studies of its efficacy have had to come from abroad, much of it from Israel. As per Dr. Sanjay Gupta of CNN, "Israel is the marijuana research capital of the world."

The AMA is a lobbying and political organization, not a scientific one. As per AMA Past-President Dr. Cecil Wilson: "What the AMA does, and does best, is in the advocacy arena. And all doctors benefit from this." But not all doctors belong to the AMA. Currently, only about 15% of practicing US doctors are members. In 2011, an online survey found that 77% of physicians say the AMA does not represent their views and only 11% said the AMA's stance reflects their beliefs.

It is ironic that 80 years after lobbying for the status quo to keep marijuana available, the AMA is again lobbying for the status quo but on the opposite side of the issue. The AMA is reactionary, not visionary. As per Dr. Tenery, who once headed the AMA's ethics council: "The AMA is a bit like a tanker crossing the Atlantic. It takes a long time for it to change course."

The Institute of Medicine (IOM), unlike the AMA, is a



scientific organization. Its purpose is to provide national advice on issues relating to biomedical science, medicine, and health, and its mission is to serve as adviser to the nation to improve health. The IOM conducted a rigorous scientific review in 1999 and found, "the accumulated data indicate a potential therapeutic value for cannabinoid drugs, particularly for symptoms such as pain relief, control of nausea and vomiting, and appetite stimulation."

The American Academy of Neurology (AAN), the world's largest association of neurologists and neuroscience professionals, is dedicated to promoting the highest quality patient-centered care for people with diseases of the brain and nervous system. In 2014 the AAN tasked a panel to look at the existing scientific literature as it relates to medical use of marijuana. Their analysis of two high quality studies determined that there is strong evidence (the highest level of evidence-based medicine) that marijuana does have a medical benefit in lessening the central pain in patients with multiple sclerosis (MS). While their official position statement calls for more research and a Schedule change from I to II, it also states, "recent evidence based guidelines by the AAN provided support for the use of specific oral forms of cannabis to improve some symptoms in patients with multiple sclerosis."

Since it is classified as Schedule I along with heroin, many people assume it has the same addictive potential or, in the very least, is a gateway drug to other illegal drugs. Again, the IOM report, as well as others, are clear that marijuana usage does not cause a progression to opioid narcotics. However, opioid medications utilize the same receptors in the brain as heroin, so when opioids become more difficult or expensive to obtain, those patients do progress directly to heroin. In fact, in 2014 Gary Tennis, Secretary of the

Pennsylvania Department of Drug and Alcohol Programs testified to the House Appropriations Committee that: "We know that prescription opioid abuse has been escalating dramatically and evidence is increasingly showing that the recent increase in heroin use is directly related to the prescription opioid abuse epidemic; individuals addicted to prescription opioids are transitioning to heroin use." He further stated that, "among a sample of misusers of prescription drugs who used heroin, 82% started with prescription drugs before transitioning to heroin."

The National Institute on Drug Abuse (NIDA) research also shows that abuse of opioids too often opens the door to heroin abuse and addiction. So while marijuana is not a gateway drug, opioids bypass the gate completely on the way to heroin. In a direct correlation, the Federal Substance Abuse and Mental Health Services Association (SAMHSA) reports that, as opioid abuse has increased, there has been a doubling of the number of heroin users between 2007 and 2012. Opioid dependency and heroin abuse therefore go hand in hand.

Prescription opioid abuse is the fastest growing drug problem in the United States, with the CDC reporting almost 50,000 overdose deaths from prescription opioids in 2017 alone, that number accounting for over 2/3rds of the total number of drug overdose deaths for that year. For comparison, the number of opioid overdose deaths just five years earlier was 16,000. To truly understand the magnitude of the problem, 130 Americans are dying each day from opioid overdoses.

Another claim against medical use of marijuana is that it could lead to increased crime. Robert Morris, an associate professor of criminology at the University of Texas at Dallas,

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analyzed the eleven states that legalized medical cannabis from 1990 to 2006 and "found no evidence of increases in any of the FBI Part I crimes."

Lastly, can one overdose from marijuana? In contrast to opioids, marijuana has an incredibly high safety margin. In fact, there has never been a fatal marijuana overdose. It has been calculated that a person would have to consume 1,500 pounds of marijuana in 15 minutes to get a lethal dose. While there has been a reported increase in E.R. visits related to marijuana in Colorado, recreational use is permitted in that state. Many of the E.R. visits resulted from unintended consumption of marijuana infused edibles. Those E.R. visits, however, are generally related to side effects (palpitations, euphoria, sleepiness, etc.) not overdose, and resolve within a few hours without any treatment.

FUTURE:

Several other issues need to be addressed as regards the potential future legalization of medical marijuana.

First, how can something be prescribed if we do not have sound studies on dosing? Acetaminophen ("Tylenol") has, for decades, been used by millions of children for pain and fever control. Yet since it's approval in 1977, dosing has not been "studied" in infants under 6 months. Even for children under 2 years of age, the FDA states, "it is important to understand that there is no dosing amount specified for children younger than 2 years of age."

Similarly, for opioids such as OxyContin, the FDA package insert states:

It is critical to initiate the dosing regimen for each patient individually, taking into account the patient's prior opioid and non-opioid analgesic treatment. Care should be taken to use low initial doses of OxyContin in patients who are not already opioid-tolerant. Once therapy is initiated, pain relief and other opioid effects should be frequently assessed. Patients should be titrated to adequate effect (generally mild or no pain with the regular use of no more than two doses of supplemental analgesia per 24 hours). Patients who experience breakthrough pain may require dosage adjustment or rescue medication.

These are examples, therefore, that there is no clear cut dosing guidelines for some currently approved pain medications, so the lack of the same for medical marijuana should not be used as justification for not permitting its use. Likewise, it is sometimes claimed that medical marijuana cannot be used because it is not fully understood how it works. Again, a similar situation occurs for OxyContin, where the prescribing information

states, "the precise mechanism of the analgesic action is unknown."

Secondly, what, if any, will be the societal costs of legalizing medical marijuana? To answer that we need to analyze the costs of our current status. In Pennsylvania alone, the opioid death rate over the past 2 decades has increased from 2.7 to 15.4 per thousand residents, with almost 2,000 Pennsylvanians dying annually. Since there are hundreds more substance abuse treatment admissions, ER visits and nonmedical uses of opioids for each overdose death, the societal and economic costs of opioid addiction are staggering. It takes more than 5 years of treatment to reach stability of opioid recovery.

Research has shown a 25 percent reduction in opiate overdose deaths in those states that have legalized medical marijuana. One would expect that along with the decreased death rate, the costs of opioid related incarcerations, medical care, and rehabilitation treatment expenses should decline in a likewise fashion. In 2018, the NIH estimated that substance abuse costs in the United States totaled \$600 billion annually. Any measure to decrease the scope of the problem could have profound national financial impact as well as individual health benefits.

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Medical Marijuana Current Status

By Jeffrey Fogel, MD

This article will highlight the current federal law concerning marijuana, detail the states that do have MM programs, and also look at the status of medical marijuana internationally.

Federal Law

In the United States, the Controlled Substances Act (CSA) of 1970 makes it illegal on a federal level to use or possess marijuana for any purpose. Under the CSA, cannabis is classified in Schedule I which therefore prohibits even medical use of the drug. At the state level, however, policies regarding the medical and recreational use of cannabis vary greatly, and in many states conflict significantly with federal law.

The Department of Justice in 2013 issued the Cole Memorandum during Barack Obama's presidency. That memorandum governed the federal prosecution of offenses related to marijuana. The memo stated that given its limited resources, the Justice Department would not enforce the federal prohibition of marijuana in states that "legalized marijuana in some form and ... implemented strong and effective regulatory and enforcement s ystems to control the cultivation, distribution, sale, and possession of marijuana." President Donald Trump's Attorney General Jeff Sessions rescinded the Cole Memorandum in January 2018.

The Rohrabacher–Farr amendment is legislation that was first introduced by U.S. Rep. Maurice Hinchey in 2001, prohibiting the Justice Department from spending funds to interfere with the implementation of state medical cannabis laws. Specifically, it prohibits the federal prosecution of any individuals who are in compliance with state MM laws. It passed the House after six previously

failed attempts, finally becoming law in December 2014. The passage of the amendment was the first time Congress had voted to protect medical cannabis patients. Unfortunately, the amendment does not change the legal status of cannabis and must be renewed each fiscal year in order to remain in effect.

Of course, the other way around this issue would be for the U.S. Drug Enforcement Agency (DEA) to reclassify marijuana from a Schedule I to a Schedule II medication. Following two petitions in August, 2018, the DEA once again passed on its chance to reschedule marijuana and decided to keep cannabis as a Schedule I drug.

State Regulations

The accompanying Table #1 indicates the current status of the legalization of medical marijuana within the United States. Be advised that while the information listed is accurate as of the date of publication, it is continually changing. Each year more states legislate MM use and the ones that already have programs are modifying their indications for use, method of administration, reciprocity rules, and many other facets of their individual programs. For the most up to date info, consult the health department website for the specific state.

Currently, 35 states, the District of Columbia and 4 out of 5 U.S. territories have legalized the use of medical marijuana for pain control. Those states encompass over 70% of the U.S. population. Several states (AK, CA, CO, ME, MA, MI, NV, OR, VT and WA) have legalized the recreational use of marijuana. For those states, registration for medical marijuana is often optional. Registration, however, in some cases allows a larger amount of marijuana to be possessed

and/or grown without violating state laws. Reciprocity is the process by which a MM patient who is registered in one state is permitted to obtain product in a different state. However, reciprocity is not permitted if someone comes from a legalized recreational marijuana state but is not registered for the MM program in that state. Those states that permit reciprocity are listed in the last column.

In the states that have legalized MM in the US, there is a patchwork of varying indications and disease states for which its use is permitted. Since, in most cases, the list was generated by legislators and not physicians, there is little consistency between states. Further, while some states have a very narrow limited focus, others have taken a much less restrictive approach. The chart only includes the indications that are of importance to TN patients. While many states use the generic criteria of chronic or severe pain, only 3 states (CT, PA, and WV) specify central neuropathic pain, and only one (CT), specifically mentions facial pain. On the other hand, Oklahoma and the District of Columbia do not list any indications, leaving it totally up to the physician. Chronic pain is an important inclusion criterion since the American Journal of Managed Care in February, 2019 found that chronic pain accounted for 62% of all patient reported qualifying conditions under which patients sought MM.

Since TN pain is of neuropathic origin, using the more specific criteria makes it easier for a TN patient to have the indication necessary to get qualified for that state's MM program. Additionally, while many TN patients have chronic daily pain, others have acute pain attacks between which they may be totally symptom free. So it might be more difficult for that type of TN patient to qualify in a state like Utah, for example, that lists its indication as "pain that is not adequately managed".

Illinois, in their list of debilitating conditions, does not list either chronic pain or neuropathic disease. However, in August, 2018 they created an opioid alternative pilot program. This program permits MM use for any patient who has a medical condition for which an opioid has been or could be prescribed. That would have to be the indication for MM treatment of a patient with TN in Illinois. The certification must be renewed every 90 days.

As indicated in Table 1, on page 13, one state (Virginia) and three U.S. territories have recently passed MM legislation within the past 6 months. At the time of this publication, they are in the process of writing regulations. Typically, it takes 1-2 years from the time MM legislation is passed until a MM program can become operational.

Virginia currently only permits the oil to be possessed (not purchased) using the affirmative defense. Affirmative defense defeats or mitigates the legal consequences of the defendant's otherwise unlawful conduct. While it is not legal, technically, to possess the oils, a patient or their caregiver would be able to present their registration if they were stopped by law enforcement or in a court of law as their defense for possession of the oil. In late 2019 there will be 5 pharmaceutical processing facilities where approved Virginia residents may actually purchase MM.

Lastly, voters in Wisconsin during the last election in the fall of 2018 passed non binding referendums in favor of MM. Medical cannabis questions received between 67% and 89% of the vote in the 11 counties and two cities where they appeared. Legislation is currently being considered and the current governor is in favor of a MM program for Wisconsin residents.

The list of states either approving medical marijuana programs or decriminalizing marijuana possession continues to grow. That trend follows public opinion. A Quinnipiac University survey from March, 2019 found that nationally 63% are on board with ending marijuana prohibition but an even greater supermajority of 94% support medical marijuana usage. A New England Journal of Medicine study from 6 years ago found that 76% of doctors at that time were in favor of marijuana for medicinal purposes. A more recent Medscape survey from May, 2018 found that 80% of healthcare providers feel that medical marijuana should be legalized nationwide.

There are 15 states that currently do not permit medical marijuana. There are two main reasons for these states to resist the current legalization trend. The first is that they are primarily Republican states which means they take a more conservative approach to medical marijuana. Therefore they are more likely to side with the Federal government's view of it being illegal.

The second, and probably bigger reason, is the lack of an initiative and referendum (I&R) process in most of those 15 states. The I&R processes are two ways that allow residents within a state to vote on a piece of legislation. An initiative allows citizens within a state to propose a statute or constitutional amendment, while a referendum allows citizens to refer a statute passed by a state's legislature to the ballot so voters can enact or repeal the measure. Therefore, without congressional lawmakers in those non I&R states introducing MM legislation, the residents have no direct recourse to get a law enacted.

Travel

Since marijuana is still illegal on the Federal level, travelling with it across state lines is technically not permitted. This applies even if flying from one state with medical marijuana laws to another permitting its use. TSA agents are Federal employees and therefore must abide by current Federal law. When asked about patients with a valid state card who bring medical marijuana onboard a commercial aircraft, the TSA's response is as follows;

"Although TSA has no regulations addressing possession and transportation of marijuana, possessing marijuana in any detectable amount is a crime under Federal law. Further, it is a crime under the laws of many States to possess or transport marijuana. In the course of screening passengers and their belongings for prohibited items (weapons, explosives and other objects that may pose a risk to aviation security), Transportation Security Officers (TSOs) sometimes discover marijuana or other items that are illegal under State and Federal laws. When this occurs, TSA's standard operating procedures require TSOs to report evidence of potential crimes to law enforcement authorities. It is up to the responding law enforcement officer, not our TSOs, to evaluate the circumstances and decide whether to arrest a passenger or confiscate the illegal item. TSOs must contact a law enforcement officer when marijuana is discovered because (1) possessing marijuana is a crime under Federal law, and (2) TSOs cannot make an independent determination as to whether a passenger's documentation is sufficient to authorize possession of marijuana under State law. Law enforcement officers must be contacted even if a passenger is carrying a State-issued cannabis card or other documentation indicating that the marijuana is for medical purposes."

In addition, drug sniffing dogs may pick up the scent of Medical Marijuana in either checked or carry on baggage, even if it is only the oil that is being transported. Dogs sense of smell is between 10,000 and 100,000 more acute than ours, so they can detect even minute quantities. Recently, however, search dogs in the US are starting to be trained to ignore marijuana as it's becoming legal in more and more states.

The same difficulty may arise when traveling internationally, as each country has their own regulations on the importing or exporting of marijuana for personal use. Not only do the majority of Americans currently support the legalization of MM, there is also an increasing global acceptance of it. It is hoped that within the next 5 years that many of the barriers to travelling with MM will be overcome.

What about CBD oil?

Since CBD oil is sold online, isn't it legal in all 50 states? The short answer is no. Some states have laws that limit THC content, for the purpose of allowing access to products that are rich in cannabidiol (CBD), a non-psychoactive component of cannabis. Cannabidiol is considered by the DEA to be a Schedule I controlled substance under federal law, just like marijuana itself. Further, these products are not required to meet any safety, quality, consistency, or labeling standards. Buyer beware! The DEA recently reaffirmed it's position here:

"Media attention has focused on a derivate of marijuana that many refer to as 'Charlotte's Web' or 'CBD oil.' At present, this material is being illegally produced and marketed in the United States in violation of two federal laws: The Controlled Substances Act (CSA) and the Federal Food, Drug, and Cosmetic Act (FDCA). Because it is illicitly produced by clandestine manufacturers, its actual content is uncertain and will vary depending on the source of the material. However, it is generally believed that the material is an extract of a variety of the marijuana plant that has a very high ratio of cannabidiol (CBD) to tetrahydrocannabinols (THC). Because this extract is a derivative of marijuana, it falls within the definition of marijuana under federal law. Accordingly, it is a Schedule I controlled substance under the CSA.

"As with all controlled substances, it is illegal under the CSA to produce or distribute 'Charlotte's Web'/CBD oil (or any other marijuana derivative) except by persons who are registered with DEA to do so.

"It is important to correct a misconception that some have about the effect of the Agricultural Act of 2014 (which some refer to as the 'farm bill') on the legal status of 'Charlotte's Web'/CBD oil. Section 7606 of the Agricultural Act of 2014 authorizes institutions of higher education (e.g., universities) and state Departments of Agriculture to grow and cultivate 'industrial hemp' (defined under the Act as marijuana with a THC content of 0.3 percent or less) for agricultural research purposes where permitted under state law. However, the Agricultural Act of 2014 does not permit such entities, or anyone else, to produce non-FDA-approved drug products made from cannabis."

Although the Drug Enforcement Administration considers CBD oil a Schedule I drug, it has so far not taken action to shut down these online retail sellers. Additionally, cannabinoids alone do not effectively treat pain; they need to be combined with THC for their synergistic effects to work. None of the currently commercially available CBD oils have any appreciable concentration of THC.

National MM Table 1

STATE	INDICATION	LINK	NOTES
Arizona	Severe and chronic pain	www.azdhs.gov/licensing/medical-marijuana/index.php	Reciprocity: Visitors may not buy it from an Az dispensary
Arkansas	Chronic or debilitating disease causng intractable pain	www.healthy.arkansas.gov/programs-services/topics/medical-marijuana	Reciprocity: Yes
California	Chronic pain	www.cdph.ca.gov/Programs/CHSI/Pages/Medial-Marijuana-Identification-Card. aspx	Reciprocity: No
Colorado	Severe pain	www.colorado.gov/cdphe/medicalmarijuana	Reciprocity: No
Connecticut	Neuropathic facial pain	portal.ct.gov/DCP/Medical-Marijuana-Program/Medical-Marijuana-Program	Reciprocity: No
Delaware	Severe debillitating pain	dhss.delaware.gov/dhss/dph/hsp/medmarhome.html	Reciprocity: No
Florida	Chronic nonmalignant pain	www.floridahealth.gov/programs-and-services/office-of-medical-marijuana-use/index.html	Reciprocity: No
Hawaii	Chronic or debillitating disease causing severe pain	health.hawaii.gov/medicalcannabis/	Reciprocity: Yes
Illinois	Alternative to opioid treatment	dph.illinois.gov/topics-services/prevention-wellness/medical-cannabis	Reciprocity: No
lowa	Pain without adequate result or with intolerable side effects.	https://idph.iowa.gov/cbd/For-Patients-and-Caregivers	Reciprocity: No
Louisiana	Intractable pain	ldh.la.gov/index.cfm/page/2892	Reciprocity: No
Maine	Chronic intractable pain	www.maine.gov/dhhs/mecdc/public-health-systems/mmm/index.shtml	Reciprocity: Yes
Maryland	Chronic or severe pain	mmcc.maryland.gov/Pages/home.aspx	Reciprocity: No
Massachusetts	Intractable pain	www.mass.gov/medical-use-of-marijuana-program	Reciprocity: No
Michigan	Chronic or severe pain	www.michigan.gov/lara/0,4601,7-154-79571_79575,00.html	Reciprocity: Yes
Minnesota	Intractable pain	www.health.state.mn.us/topics/cannabis	Reciprocity: No
Missouri	Severe or persistent pain; neuropathy	https://health.mo.gov/safety/medical-marijuana/index.php	Available by Jan. 2020
Montana	Chronic or severe pain	dphhs.mt.gov/marijuana	Reciprocity: No
Nevada	Severe pain	dpbh.nv.gov/Reg/Medical_Marijuana/	Reciprocity: Yes
New Hampshire	Moderate to severe chronic pain	www.dhhs.nh.gov/oos/tcp/index.htm	Reciprocity: Yes
New Jersey	Chronic pain	www.nj.gov/health/medicalmarijuana/	Reciprocity: No
New Mexico	Severe chronic pain	nmhealth.org/about/mcp/svcs/	Reciprocity: No
New York	Chronic or severe pain, also opioid replacement	www.health.ny.gov/regulations/medical_marijuana/	Reciprocity: No
North Dakota	Severe debilitating pain	www.ndhealth.gov/mm/	Reciprocity: No
Ohio	Chronic, severe, or intractable pain	medicalmarijuana.ohio.gov/	Reciprocity: Negotiating with other states
Oklahoma	No list; condition determined by physician	omma.ok.gov/	Reciprocity: Yes
Oregon	Severe pain	www.oregon.gov/OHA/PH/DiseasesConditions/ChronicDisease/ MedicalMarijuanaProgram/pages/index.aspx	Reciprocity: No
Pennsylvania	Severe chronic or intractable pain of neuropathic origin	www.pa.gov/guides/pennsylvania-medical-marijuana-program/	Reciprocity: No
Rhode Island	Severe, debilitating, chronic pain	www.health.ri.gov/healthcare/medicalmarijuana/index.php	Reciprocity: Yes
Utah	Pain that is not adequately managed	https://health.utah.gov/medical-cannabis	Available by June 2020
Vermont	Severe, chronic pain	medicalmarijuana.vermont.gov/	Reciprocity: No
Virginia	No list; condition determined by physician	https://www.license.dhp.virginia.gov/apply/	Available late 2019; currently only oils
Washington	Intractable pain	www.doh.wa.gov/YouandYourFamily/Marijuana/MedicalMarijuana	Reciprocity: No
Washington, D.C.	No list; condition determined by physician	dchealth.dc.gov/service/medical-marijuana-and-integrative-therapy	Reciprocity: limited to only 16 other states
West Virginia	Severe chronic or intractable pain of neuropathic origin	dhhr.wv.gov/bph/Pages/Medical-Cannabis-Program.aspx	Reciprocity: No

"Medical Marijuana: Current Status"...continued on page 14

International

Table #2 lists the countries that have any type of regulation on MM. In many cases, foreign countries do not have a specific list of conditions for which MM is permitted to be used. Rather, it is often left up to the practitioner. It is also important to note that these regulations apply to the citizens of those countries. Only Jamaica specifically addresses the fact that tourists with a valid prescription may apply to purchase small amounts.

Currently, four countries have legalized recreational marijuana: Canada, Georgia, South Africa, and Uruguay. Uruguay, however, specifically indicates that buying cannabis is prohibited for foreigners. Many other countries have either decriminalized marijuana possession or have kept it illegal but often unenforced. Again, those regulations are for the citizens of those countries, and do not necessarily offer any protections for tourists, even those carrying a valid prescription for MM from another country. On the other hand, some Asian and Middle Eastern countries punish possession of even small amounts with imprisonment for several years. For example, as per the US State Department, the penalty for drug trafficking (in or out of the country) in Saudi Arabia is death, and Saudi officials make no exceptions. Customs inspections at ports of entry are thorough. The U.S. Embassy is unable to obtain leniency for a U.S. citizen convicted of drug offenses. This patchwork

of legalities between countries presents the same obstacles experienced by travelers within the United States. The difference, however, is that obtaining legal representation may be more difficult, and there may also be a potential language barrier. In summary, therefore, no one can make any recommendation for patients with valid MM cards to travel either within the United States or between any other countries.

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International MM Table 2

COUNTRY	Comments
Argentina	Medical consumption accepted but not legislated
Australia	Qualifying conditions vary by state
Bermuda	Condition determined by Physician
Canada	Condition determined by Physician
Cayman Islands	Chronic pain, cancer, anxiety
Chile	Condition determined by Physician
Colombia	Condition determined by Physician
Croatia	Cancer, AIDS, multiple sclerosis and childhood epilepsy
Cyprus	Chronic pain, cancer, AIDS, rheumatism, neuropathy and glaucoma, Tourette's, Crohn's disease
Czech Republic	Condition determined by Physician
Denmark	Cancer pain and/or nausea, Multiple sclerosis
Finland	Condition determined by Specialist Physicians only
Georgia	Legal for all uses
Germany	Seriously ill (not defined), cancer pain, chronic pain, multiple sclerosis
Greece	Muscle spasms, chronic pain, PTSD, epilepsy and cancer
Israel	Cancer, Parkinson's, multiple sclerosis, Crohn's disease, chronic pain and PTSD
Italy	Cancer, chronic pain, multiple sclerosis
Jamaica	Tourists with a prescription for medical marijuana may apply to purchase small amounts

COUNTRY	Comments
Luxembourg	Cancer, multiple sclerosis, neurodegenerative diseases
Malta	No conditions specified
Netherlands	Multiple sclerosis, cancer, AIDS, chronic neurogenic pain, Tourette syndrome
New Zealand	Chronic pain, terminal illnesses
North Macedonia	Cancer, epilepsy, AIDS, multiple sclerosis
Norway	Condition determined by Physician
Peru	Severe epilepsy
Poland	Chronic pain, multiple sclerosis, epilepsy, cancer nausea/vomiting
Portugal	Any condition for which other treatments are ineffective
San Marino	Pain due to multiple sclerosis and bone marrow conditions
South Africa	Chronic pain and spasticity of multiple sclerosis
Sri Lanka	As determined by Ayurvedic practitioners
Switzerland	Serious or terminal illnesses
Thailand	Glaucoma, epilepsy, chronic pain and the side effects of chemotherapy.
United Kingdom	Severe epilepsy, chemotherapy related nausea and multiple sclerosis
Uruguay	Legal for all uses
Vanuatu	Diabetes
Zimbabwe	Condition determined by Physician

Pharmacology of Cannabis:



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Cannabis Pharmacist specializing in children with autism and seizure disorders.



Overview:

Medical cannabis has provided a safe and effective alternative for thousands of chronic pain sufferers since its re-emergence as an acceptable medication in many of the US States. Unfortunately, overcoming the stigma of cannabis as a drug of abuse in our culture continues to hinder its widespread acceptance. This article will discuss the use of medical cannabis for severe intractable pain, the dose forms and strengths available, factors to consider when choosing medical cannabis products, and the anecdotal evidence to date on the efficacy experienced by patients suffering from severe chronic pain.

Pharmacology of Cannabis:

In 1990 a senior investigator at the National Institute of Health named Miles Herkenham discovered cannabinoid receptors in the human brain, which were locations that THC, the psychoactive component of cannabis, attached and exerted its effect. Two years later Dr. Raphael Mechoulam, an Israeli chemist often described as the father of cannabis research, identified a neurotransmitter that also bound to these receptors. This is the first known endogenous (made by the human brain) cannabinoid or "endocannabinoid". They named this chemical anandamide after the Sanskrit word 'Ananda' which translates to 'eternal bliss'. Similar to our natural opioids, called endorphins, anandamide can be released by the brain during vigorous exercise and may also play a role in the euphoric feeling that joggers refer to as a runner's high.

It is now known that there are two cannabinoid receptors in the human body. CB1 receptors are concentrated in the brain and are believed to be responsible for the psychoactive effects of cannabis. CB2 receptors are found throughout the body, and are believed to play a role in the modulation of both pain and inflammation.

The main cannabinoids we currently discuss from a medical perspective are cannabidiol (CBD) and delta-9-tetrahydrocannabinol (THC). Many others are currently being studied, but THC and CBD have the most research to date and are the two cannabinoids most prevalent in medical cannabis products.

THC is the psychoactive cannabinoid, binds mainly to the CB1 receptor in the brain, and is responsible for the cannabis 'high'. THC may decrease pain signaling and is known to increase anxiety at higher doses. CBD is not psychoactive and binds mainly to the CB2 receptor. CBD is believed to be the most important cannabinoid for pain and inflammation. CBD may also compete with THC for binding at the CB1 receptor, thus decreasing THC-induced anxiety. It is important to note that CBD when used alone has not been proven to be as effective as CBD in combination with THC. In fact, most of the patients I have counseled have expressed dissatisfaction with the efficacy of over-the-counter CBD products for severe pain. This may be attributable to what is known as the "entourage effect" of cannabis, which we will cover later.

There are 2 main species of cannabis plants, cannabis indica and cannabis sativa, from which all medical cannabis products are derived. From these 2 species researchers



have identified over 460 chemical compounds, of which 80 are known cannabinoids that can bind to the CB1 and/or CB2 receptors and each may exert slightly different effects on the body. For example, in about 80% of the population indica strains produce a tired and relaxing effect, while sativa strains can create a more heightened sense of alertness. There are numerous genetic variations (hybrid strains) resulting from the cross-pollination of these strains that produce different effects from the 2 dominant strains.

Although there is limited research on the effects of cannabis, preliminary evidence suggest cannabis reduces nausea and vomiting during chemotherapy, improves appetite, and reduces chronic pain and muscle spasms.

The most common adverse effects are the psychoactivity that we attribute to being "high", which is dose and concentration dependent, dizziness, tiredness, and at high doses vomiting and hallucinations. The stigma of using cannabis and getting 'high' are the two most important factors many of my elderly patients admit as hindering or delaying them from enrolling in a medical cannabis program.

The Entourage Effect of Cannabis:

In addition to THC and CBD, over 250 flavonoids (phytonutrients) and terpenes have been identified across various cannabis strains and are believed to be the reason why each genetic variation of plant yields slightly different effects on the human body. They are also the likely reason that whole-plant extracts are more effective than any single molecule like CBD or THC alone. This combination effect supports what researchers have termed as the "entourage effect" of cannabinoids, meaning together they are more effective than any single cannabinoid when used alone.

The entourage effect also explains why patients who have

tried hemp-based over-the-counter CBD products with no positive outcome go on to experience pain relief from a high CBD/low THC combination medical product. Even small amounts of THC in a ratio of 10:1 CBD to THC seem to have greater pain-relieving effects than CBD alone in these patients.

Terpenes, which are produced by a variety of plants and insects, are also known to contribute to the varying effects of different cannabis strains. Many of the terpenes isolated from cannabis are now being studied for their anti-inflammatory, anti-anxiety and anti-tumor effects. Experienced patients seek out strains that express high levels of specific terpenes that they have found to be beneficial. An entire article can be written on the effects of cannabis terpenes in different disease states, and I counsel patients to keep a journal of the strains they use and their positive or negative experiences. A strain that a patient finds beneficial can often be matched with a strain expressing a similar terpene profile.

Picking the Best Route and Dose Form:

Cannabis may be consumed via inhalation, oral, sublingual and topical routes of administration. Products for inhalation usually consist of dry flower (bud), vaping oils, and physical oil concentrates. Oral dose forms consist mainly of capsules, tinctures and oral solutions. The availability of edible forms of cannabis vary from state to state. For topical administration there are lotions and creams that do not provide systemic absorption and can be used topically throughout the day without psychoactive effects, as well as transdermal patches which will cross into the bloodstream and behave as if the medication was inhaled or swallowed.

Inhalation:

When inhaled, the effects of cannabis may be felt within minutes and usually peak within 20 to 30 minutes. Once peak absorption from the lungs is reached the effects of inhaled cannabis usually last about 3 to 4 hours. The rapid onset of action, ability to re-dose in 30 minutes if necessary, and relatively short duration of action makes inhalation the best option to use for sudden pain onset. We typically counsel our patients to use very small amounts of vaporization and wait at least 20 minutes before deciding if they require an additional dose. This helps the patient titrate the dose up to a level where they are experiencing optimal pain relief while balancing the psychoactivity to an acceptable level. Using products that are balanced or skewed heavier in CBD help to minimize the psychoactive

effects of THC and tend to be more effective for pain management than THC alone for most of our TN patients.

Another benefit of inhalation is the freedom to use different strains of cannabis at different times of the day. Cannabis sativa strains can provide a more alert, awake and creative daytime experience while providing pain relief, whereas cannabis indica strains are preferred at night as they are likely to cause heavy sedation and are responsible for the "couch-lock" effect that many describe.

Vaping is inhaling cannabis oil heated until the oil turns to a mist, which can be harsh on the lungs for some patients. Anyone with a pre-existing lung condition such as COPD or asthma should avoid vaping.

Oral:

Oral consumption of cannabis is also effective but may take time to titrate up to the optimal dose. Cannabis oils are absorbed from the GI tract slowly and erratically and can take anywhere from 45 minutes to 3 hours before the full effects are realized. When taken orally THC passes through the liver in what is termed as first-pass metabolism and is converted to 11-hydroxy THC. This form of THC can be more psychoactive and its effects may last as long as 8 hours. Again, choosing products higher in CBD will help minimize the psychoactive effects. We always suggest patients try the highest ratio CBD:THC products first, then move to more balanced 1:1 CBD:THC products over time. Slowly titrating to the optimal dose takes time and patience. We also caution against doubling up doses of oral cannabis, or dose again within a few hours. It is better to wait at least 4 to 5 hours before deciding to increase the dose. This will avoid over-consumption of cannabis. If too much is taken, the effects (and side effects) will last about 8 hours. Patients with known GI motility or malabsorption syndromes should speak to their certifying physician about the use of oral cannabis dose forms.

Sublingual:

Sublingual dose forms of cannabis are meant for use under the tongue to provide rapid relief for patients who cannot or do not wish to inhale. The sublingual route also bypasses the first-pass metabolism of THC/CBD, and is a good alternative for patients with known GI motility or absorption issues. In order for a drug to rapidly absorb through the oral mucosa the product should be an alcohol-based tincture. By definition a tincture is "an alcohol-based extract". Since oil is not readily or completely absorbed through the oral mucosa, the onset of effects of these products may behave more like a capsule. i.e., the patient

may not feel the full effects for 1 to 3 hours after using the product.

Topical and Transdermal:

Topical creams and lotions are available in varying ratios of CBD:THC, and some THC only products are also available. Topical CBD:THC creams are not absorbed into the bloodstream, and only exert a local effect.

There are several transdermal patches available in varying ratios of CBD:THC as well as just THC transdermal patches. Transdermal patches, unlike creams and lotions, are absorbed into the bloodstream but the process is very slow and hard to titrate to the most effective dose. Unfortunately, transdermal dose forms are the only option available for patients who cannot inhale or consume cannabis orally.

Drug Interactions:

Just like any other pharmaceutical product that is metabolized by the liver, CBD and THC are susceptible to interacting with other medications, and these interaction can go in both directions. i.e., CBD and THC can increase or decrease the effectiveness of other medications, and other medications may increase or decrease the effectiveness of CBD and THC. The most notable interactions occur between CBD and some drugs used to treat epilepsy, as well as blood-thinners and some chemotherapy drugs. THC has fewer known interactions, but can have an additive effect with other drugs that cause sedation.

In order to avoid any untoward interactions we ask each patient to provide a detailed list of all medications to review for potential interactions, and remind them to let us know if they make any changes to their medication regimen.

Experience to Date:

I have personally counseled well over 5,000 patients since the inception of the Pennsylvania Medical Marijuana program in February of 2018. By far, the vast majority of the patients I have seen are certified for use because of severe chronic pain syndromes. At least 3 dozen of my patients suffer from TN. They have all been through the pharmaceutical menu of choices for pain management from opioids, to seizure medications, to products for diabetic neuropathy, to antidepressants and back again. Some patients have "cocktails" of products that keep the pain manageable, while others seemingly never get meaningful pain relief.

"Cannabis"...continued on page 18

"Cannabis"...continued from page 17

The good news to share is that there is now an alternative that has provided varying levels of relief to all but one of my TN patients, and I haven't given up on that patient yet. Every patient is an individual and I start every patient with high CBD/low THC products, and then progress up in the THC concentration until we achieve optimal pain relief with minimal side effects or psychoactivity.

I prefer patients use oral solutions, but understand the severity of TN pain onset and respect any patient's desire to vape if they are in a crisis, provided they do not have a pre-existing pulmonary condition. Almost all of my patients will use oral solutions daily, and only vape if the pain is triggered and they are in crisis.

What I have found is that there is no magic formula for TN pain relief. Every patient responds to cannabis differently, but eventually responds positively once we slowly titrate up to the effective dose. The trade-off is always between pain relief and psychoactivity. Getting my elderly patients over the "Reefer Madness" stigma is often more challenging than the disease itself.

First Visit:

On a first visit to a medical cannabis dispensary patients should expect a bit of paperwork. We ask each new patient to provide us a comprehensive medical background, a complete list of medications, and an overview of any previous cannabis experience.

We will schedule at least 15 minutes for each new patient to review their medical history, to establish goals for the patient, and to educate the patient on safe and effective cannabis use.

The first thing I do is quietly observe a patient's ambulatory status. Are they using a cane, a walker? Are they safe on their feet? This will help me decide if a patient is at risk of falling with or without cannabis, and if cannabis use could increase the fall risk.

Next I identify any pre-existing pulmonary or gastrointestinal issues that could prohibit the use of either inhaled or oral dose forms. This helps guide product selection and counseling.

I then look at allergies. Allergies can be an issue with certain products. For example, some topical products may contain methyl salicylate. Patients with an aspirin allergy may experience a cross-reaction to other salicylate compounds. As a side note, I have never had a patient with an allergic reaction to cannabis, but I have had patients who had allergic reactions to inert additives.

The discussion will then move to medications. If a patient is on any medications for epilepsy that have known interactions with CBD I will insist a neurologist check blood levels before starting a CBD-containing product, and then 6 weeks after the initiation of therapy or after any dosage changes. This is to ensure there are no drug interactions that could impact an underlying seizure disorder. If a patient is on blood-thinners such as warfarin, I will ask that the patient's physician do a blood test to check the INR (coagulation time) at least monthly. The same goes for drugs used in organ transplants such as tacrolimus. Having blood levels checked frequently during the initiation of cannabis therapy is critical to a successful, interaction-free therapy.

Finally, we will discuss the goals of therapy and go into as much detail about cannabis as necessary. For example, if the patient chooses not to inhale I skip over any details concerning inhalation.

Once we reach an agreement, I will hand-write a treatment plan that includes product, dosage and instructions to titrate, and the patient is then able to make their purchase.

I ask all patients to keep a detailed log of the products used, doses used and their experiences to date (good and bad). I find this extremely helpful during follow-up visits to guide patients along to other products and concentrations. I encourage all of my patients to keep me informed of their progress, and to reach out if there are any questions, concerns or issues. The goal is to get the patient to the most optimal dose, with minimal adverse reactions.

Conclusion:

In summary, cannabis has been successfully used throughout human history to treat a variety of ailments. When used appropriately in the proper doses and ratios, cannabis is both a safe and effective option for the treatment of severe chronic pain syndromes including trigeminal neuralgia. The largest hurdle to overcome in the initiation of cannabis therapy is often the stigma of cannabis as a drug of abuse. As a Consulting Pharmacist I have personally witnessed how cannabis can be used to replace opioids in pain management, and provide patients a relatively safe and effective alternative to addictive medications and their significant side-effect profiles. I urge anyone who suffers with a pain management issue and lives in a state with a MM program to research their medical cannabis options. It may be another tool to help combat severe chronic pain, and it may change your life for the better.



We hope you'll read David Meyers' story. Join David and his wife, Jody, in supporting the FPA.



David Meyers was looking forward to celebrating his 25th wedding anniversary in London with his wife Jody following a business trip to Spain. The former President and CEO of Microban International, a leading company of antimicrobial products, was struck with excruciating pain during that business trip. They were forced to instead head back to the States where, thanks to a particularly astute primary care physician, he was quickly diagnosed with trigeminal neuralgia. The average time it takes to get a diagnosis is often a year or more. He was lucky.

He learned that he had a rare condition and, although he has tremendous respect for his primary care physician and his neurologist was trying to do his best, neither of his doctors had experience treating someone with his condition.

So, David quickly set out to educate himself and soon learned of Dr. Raymond Sekula, a neurosurgeon with extensive experience in the treatment of TN. During that process he also learned of the Facial Pain Association -- Dr. Sekula is an esteemed member of the FPA Medical Advisory Board.

He ordered some books from the FPA; learned what he could from the web site and attended a regional conference in Richmond Virginia.

David believes that "The regional conference was incredibly eye opening. I learned about the various drugs, and the surgical and non-surgical procedures used to treat my condition, and I had the opportunity to speak with many of the country's leading physicians who treat facial pain. And it was tremendously heartening to learn that there was a community to help me through this setback."

After many years managing the pain through medications, and at a point where the medications no longer seemed to provide much relief, he contacted Dr. Raymond Sekula, a neurosurgeon with extensive experience performing Microvascular Decompression (MVD) surgeries.

MVD is an invasive procedure that relieves abnormal compression of the cranial nerve and offers a good chance of a long-term solution to patients who have certain physiological characteristics. David had a successful MVD procedure and has been pain free for over five years.

David and his wife Jody have stayed involved with the FPA and help fund facial pain research at a major research hospital. They have also recently made a five-year financial pledge to the FPA.

In 2018 David joined the FPA board and says,

"Jody and I can't imagine donating our money and time to anything more worthwhile than helping people with facial pain.

We know first-hand the pain that the patient endures and the stress that the patient's family and other caregivers encounter, so we know that we're working on something that is extremely worthwhile.

And we know that the FPA could do so much more for patients and caregivers with additional resources."

Please join David and Jody by contributing to the Facial Pain Association, allowing us to continue our mission to educate, advocate and raise awareness for people battling TN and neuropathic face pain. Remember that all donations of \$50 or more entitle you to FPA membership.

Please contact us at (800) 923-3608 or info@tna-support.org with any questions.

With thanks,

Amy Turner

Director of Development

Trigeminal Neuralgia and Cannabis



Andrew Medvedovsky, MD

Dr. Andrew Medvedovsky is a New Jersey licensed Physician. A native of Brooklyn, NY, he is the founder and director of New Jersey Alternative Medicine. Dr. Medvedovsky completed his residency at Virginia Commonwealth University and is double board certified as a neurologist as well as a pain medicine specialist. He has

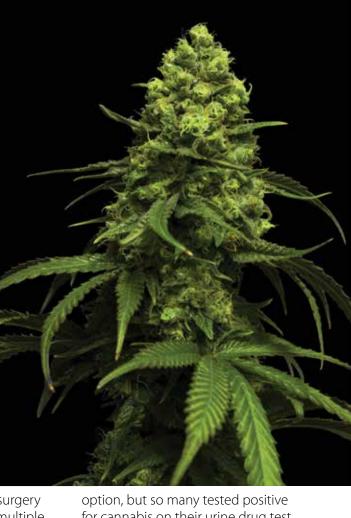
been in practice for 6 years post fellowship, and has a wealth of experience treating patients with Trigeminal Neuralgia and other neuropathic conditions.

Dr. Medvedovsky was at the forefront of the opioid epidemic, seeing the need for safer alternatives to prescription painkillers. He recognized the therapeutic benefits of medical cannabis as an adjunct for treating a variety of chronic debilitating conditions. Since 2014, Dr. Medvedovsky has been dedicated to educating the community and healthcare professionals about the benefits of cannabis.

In this article I would like to share with the readers of this Journal my experience as a pain management specialist. While I will primarily focus on the benefits of Medical Marijuana (MM) for the treatment of facial pain disorders. I will also touch on other modalities that are available as treatment options for this extremely debilitating and rare disorder. For the sake of simplicity, I will use the term "Facial Pain Disorders (FPD)" as an all-inclusive category for patients diagnosed with Classic Trigeminal Neuralgia (TN) and Atypical Trigeminal Neuralgia (ATN). Unfortunately for many patients suffering with FPD, the available treatment options often fail to provide adequate pain relief or improve their quality of life, and often cause adverse side effects.

My first experience with a facial pain patient came during my Neurology Residency at Virginia Commonwealth University. One of my fellow residents was suffering with an intractable case of atypical facial pain, had

undergone decompression surgery without relief and relied on multiple medications to function and control the pain. Unfortunately, the severity of her disease and the medication side effects compromised her ability to work and function. After graduating Neurology Residency, I decided to pursue a fellowship in Interventional Pain and was trained by a renowned expert in the area of neuromodulation. During my fellowship year I had the opportunity to treat patients who had the most intractable and debilitating cases of facial pain. These patients had completely exhausted all options including medications, peripheral nerve stimulation and surgeries. Unfortunately, medical marijuana was not a treatment option that was ever discussed or available during my training. My cannabis education actually started in Turnersville, NJ where I started my post training career as a pain specialist in an outpatient pain practice. Not only did patients ask me if cannabis was an



option, but so many tested positive for cannabis on their urine drug test, that this topic inevitably came up. In July 2015, shortly after Medical Marijuana became more widely available in New Jersey, I decided to start recommending cannabis to my established patients. The outcomes were profound and I knew then that MM was going to change my approach to treating patients with chronic pain conditions.

Patients referred to a pain specialist for management of intractable facial pain are not the "Success Stories" of medications, ablative procedures or decompression surgeries. Most patients that I've evaluated over the years have been through extensive diagnostic neurological workups, medication trials, and many have had surgical procedures. These patients come from all walks of life, ages, and backgrounds. Until cannabis became available, the treatment options in my tool box were limited to a few interventions (such as

greater occipital nerve blocks and cervical medial branch rhizotomy), peripheral nerve stimulation, and opioid medications. The greater occipital nerve block is a simple procedure that I have had some degree of success with. It is done in the office using 1-2cc of a local anesthetic injected into the base of the scalp and repeated several times per year as needed. A different option is a cervical medial branch rhizotomy which is a more advanced procedure and is performed with x-ray guidance in a surgical center. The logic behind targeting the upper cervical and occipital nerves is that there is an area in the brainstem where the upper cervical and trigeminal nerves have a connection and share a common pathway. These procedures are selected on a case by case basis depending on the patient's profile and pain distribution.

A third procedure option is peripheral nerve stimulation (PNS). To those unfamiliar with what peripheral nerve stimulation is, think of it as a

pacemaker for a specific nerve. This is a procedure in which an electrode is placed under the skin in close proximity to a nerve, connected to a small battery like a pacemaker and delivers electrical impulses to provide pain relief in the specific area that the nerve covers. This procedure is an option for patients suffering with FPD in the V1 (above orbit) and V2 (maxilla) regions. This procedure has risks involved including infection, electrode migration, and device failure. I've only had one successful patient undergo this procedure due to very limited insurance coverage and procedure risks.

Finally, for patients who have not had success with the standard neurosurgical treatments for FPD, and are either not candidates for, or failed the above mentioned procedures, opioids had been the only remaining treatment option. The side effects, dependency and abuse potential of opioids are well documented. If you live in a state where Medical Marijuana is legal, then you may ask

when is it appropriate to consider this option for FPD? Odds are you will not find a clear answer since many doctors are still on the fence about cannabis due to the limited available research, federal regulations and their own lack of familiarity and knowledge. I have had much experience treating patients with cannabis and seeing the profound benefits it has had. It has given many patients another chance at living a quality life.

As background, cannabis is a natural plant that has been used for thousands of years. In order to truly appreciate and understand the potential benefits of cannabis, we must rid ourselves of all the misconceptions, stigmas and fears. Although marijuana was legal and widely used prior to the 1930's, the recent discovery and understanding of the endocannabinoid system has shed light on the true medicinal benefits of cannabis. There are different cannabis strains and formulations that provide patients the ability to select the most appropriate

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Weill Cornell Medicine Brain & Spine Center



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

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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.

"TN and Cannabis"...continued from page 21

type for their specific medical needs. For example, one strain may provide sedative properties, which would be optimal to help with insomnia, while another may be more uplifting and energizing, ideal for daytime use to help manage pain, depression, and fatigue.

Besides the well-known painrelieving properties of THC and CBD that patients desire, cannabis may help manage insomnia, anxiety, migraine headaches, and other painrelated issues. Having uncontrolled anxiety and insomnia will ultimately exacerbate pain which then leads to a vicious pain cycle. It makes sense when patients improve their sleep patterns and reduce anxiety levels that their pain control will improve as well. Cannabis provides a solution for managing multiple problems, including reducing the risk of drug interactions, side effects, and dependency to opioids and benzodiazepines like Xanax.

Medical cannabis is grown in a controlled environment with specific strains genetically created to provide specific medicinal benefits. It is tested and dispensed to patients from one of the approved dispensaries. Most patients are nervous when making their first trip to the dispensary, but soon find that it's a very clean, professional and modern facility that more resembles an Apple Store than a dark back alley hidden store. Only patients and registered caregivers are allowed to enter the dispensary with proof of ID and Medical Marijuana card. The staff, also known as "Budtenders", are friendly and well educated, and they are there to advise and educate patients on selecting the appropriate strain and products.

New patients that I see often have a preconceived notion that smoking is the only option as well as a fear of being "high". Both of these facts

are misconceptions and with some education, most patients can be made to feel at ease. I actually discourage patients from smoking and recommend healthier methods of medicating including vaporization, sublingual formulations and oils. Patients often use a combination of methods and product types for their needs. For example, someone who suffers with chronic persistent pain may find benefit with ingesting cannabis as an edible or an oil, while using a vaporizer to inhale cannabis for breakthrough pain episodes due to the quick onset of relief. Patients need to be educated on proper usage of cannabis and dosing. I advise cannabis-naïve patients against using cannabis edibles due to the unpredictable absorption which makes accurate dosing more difficult initially. I recommend to start low and go slow. Optimum is the dose where the symptoms are well managed without unwanted side effects. Additionally, due to the availability of so many different products, it is not that difficult to find a preparation that works for pain relief without giving the patient the psychoactive "high".

Are there any down sides to cannabis? While you may be convinced that cannabis has potential benefits, there are several challenges as well. Cannabis is still illegal at the federal level: therefore, it will not be covered by insurance and patients have to pay out of pocket. In addition, there are no clear guidelines on dosing and which strains work best to treat specific conditions. In addition, laws vary by state in terms of what specific diseases are treatable with MM. The wide variety of cannabis strains, forms, and delivery methods makes cannabis treatment both an art and a science. In the same way that there is no one opioid that works for everyone, there is no consensus on which particular strain is best for which condition and how specific patients will respond

to a particular strain. My overall experience with patients has been very positive, but it does take some initial trial and error to find the right strain, dose, and delivery method. I recommend patients who are new to MM to start with higher CBD strains to avoid unpleasant psychoactive effects associated with high THC strains. Since a significant number of facial pain disorder patients have some degree of insomnia, I often advise first trying cannabis at night to improve sleep and be comfortable in case there are any unpleasant, self-limited side effects. Frequency of dosing depends on the individual patient needs, method of delivery and lifestyle. If someone needs to drive or operate machinery, they should not medicate for at least 4-6 hours before driving, and longer if using edible forms.

Often patients will have many questions, concerns and fears associated with starting cannabis treatment. The fear of the "high" and the stigma quickly disappear as patients begin to feel better, have more pain free days, enjoy more meals, sleep better nights, feel less depressed, socialize and engage with family and friends, and reduce other pain medications. For those patients for whom it works, they are able to return to their favorite activities and feel like they have a second chance at life. Since I finished my fellowship in 2013, I've treated FPD patients with all types of different medications, injections and implantable stimulators. I can honestly say that no single modality has offered patients as much relief, benefit and safety profile as Medical Marijuana. I encourage patients suffering with facial pain to become educated about cannabis, put the fears and misconceptions behind and discuss this option with a physician who is knowledgeable with this treatment option.

Patient Profiles

The following is the story of 3 patients who have Facial Pain Disorders and have experienced uniquely different histories until they began treatment with Medical Marijuana. This is not to say that everyone will have the same results, but it does offer insight into another treatment option for those patients with TN who are not achieving success with their current management plan. While MM is certainly not a panacea for everyone, those who do benefit from it often view it as a life changing treatment.





Rachel

My name is Rachel and I would like to share my 20-year journey with TN and the treatments I have received. I was initially diagnosed at age 30, shortly after giving birth to my

second daughter. My symptoms began as tooth pain which I thought might be due to a cavity. I saw my dentist and he saw no evidence of a cavity, but did think that it could be due to an issue with my molar. He removed the tooth but the symptoms progressed with significant sensitivity to both heat and cold.

Fortunately for me I did not experience the common occurrence of several years of pain and multiple procedures before I was diagnosed. Although the diagnosis was made relatively quickly by the dentist, the manner in which he did it still haunts me to this day. He told me that I had the "suicide disease" and showed me a picture from an old medical textbook of a man with TN who had shot himself in the face and lived. He followed that up with "this is what you have, best of luck to you, and go see a neurologist"

Obviously, that's not the way anyone should receive the diagnosis. So I went to a neurologist who confirmed that I had TN and started me on Neurontin which successfully treated the symptoms for a few months. However, the shocking pain inside my mouth and on my face returned,

and other anti-epileptics were tried. For the next 2 years, it became increasingly difficult to care for my children due to the pain and the side effects of the medical cocktails prescribed for the pain which included Baclofen, opioids, and Benzodiazepines. It was too painful for me to work, so I had to quit my job as a teacher. The toll that it was taking on my life and my family prompted me to have the Gamma Knife procedure performed. Fortunately, I was instantly better and able to gradually wean off all medications.

I was pain free for a period of 7 years after the Gamma Knife, but then the pain recurred, although of different intensity and with different triggers. The recurrence of pain but with different manifestations made me feel like the same person, but just with a different haircut. Based on the success of the first Gamma Knife, I had a second one performed. I was fortunate to not have any side effects from either Gamma Knife procedure. The second one was also successful, except the pain relief period only lasted 4 years.

When the pain returned I was told that I was not a candidate for a third Gamma Knife surgery. I began seeing a pain management specialist who started occipital nerve block injections which helped for a few 6 month stretches. When the effectiveness of the injections dissipated, I was started on several pain medications, including Percocet twice daily.

It was difficult to function while living in a fog from the opioid. So 18 months ago I began using Medical Marijuana.

Although I still experience pain on a daily basis, I only take the MM about 3 times/week. Over the past year I have gained experience with different strains as well as formulation types. I have found that the topical products help the facial spasms, but unfortunately I need to be in not too much pain in order for me to be able to tolerate the massaging in of the product on the affected area.

The strains with higher CBD along with sativa have allowed me to be very functional during the day. I typically take it in lozenge form with hot tea or coffee. Unlike with the Percocet, my mind is 100% clear and I do not experience any psychotropic effect. I feel like I just had a 15-minute catnap and awoke with a refreshed, calm feeling.

At night time, however, I have more of an issue with spasms and inability to sleep, so I vape the flower. I find that I only need one or two inhalations to have the desired effect of pain relief and ability to sleep. I have had absolutely no adverse side effects from MM except maybe sometimes eating too much candy.

Contrary to the Percocet, I do not have to treat any side effects which is so common with the opioids. I have found MM to be the least invasive way to treat my TN pain.

Since I have always been willing to try anything for pain relief, I had no reservations about trying MM. I was initially somewhat anxious about my ability to function but that, in fact, has not been an issue. I am a private person, and have not shared with many others that I use MM. Out of an abundance of caution, I do not drive after dosing, but I find it ironic that people on legally prescribed opioids are behind the wheel each and every day. My children were raised in the "DARE" era and were not especially approving of my marijuana usage, but they now have their mom back and that is all that matters.

I never wanted TN to be an important part of my life but unfortunately it has been. I've missed out on a lot of life moments that I can't get back. The disease has left unintentional scars on my loved ones. Now that I feel I have my life back, I am not missing out on any activities. I don't know if MM will still be as effective for me in 20 years, but for now I feel that I am Rachel who has TN rather than a TN patient whose name happens to be Rachel. TN is a part of my life, but now medical cannabis helps me control it.



Christina

My name is Christina and I am a 35 year old Registered Nurse. I began having TN symptoms at age 9. It began as bad headaches and pain that would begin at my left ear and

radiate across my face. I was initially diagnosed as having migraines, although my mother thought it was psychosomatic and took me to psychologists and psychiatrists. It wasn't until age 14 that I was diagnosed with TN. The TN pain was so unbearable I couldn't always eat, talk on the phone, or do anything a normal 14 yr old kid could do. I was initially started on Darvocet for the pain. It made me feel good and it was the way I was able to feel normal around my friends. Unfortunately, that was the doorway to addiction and I became fully addicted within 6 months.

From that point on my life followed the usual course of an addict. I used Percocet, OxyContin, morphine, Fentanyl patches, etc. Basically anything I could get my hands on. If I couldn't get enough from my doctor, I got it off the street. I was lying, stealing, and dropped out of high school at age 17. I was young, I was hungry for normal and I clung to the first thing that gave it to me.

The prescription meds ended up not being enough so that by the time I was 20, I was addicted to heroin since it was stronger, cheaper and easier to get. I was on heroin for a year until I realized where my life was going and that if I didn't get off it I was going to be a scourge to society and be found dead in a gutter somewhere. All the people I hung out with are now either dead or in jail or still using.

I decided to get off heroin and get into a treatment program. I was then on and off Suboxone for 8 years. When I discovered cannabis, however, it changed my life. I was finally able to get off the Suboxone maintenance therapy. I felt like a hypocrite -- I knew I was a drug addict but I needed it for the real pain I was experiencing.

To manage my pain now I vape for the occasional breakthrough pain, although I generally only need to regularly take 1 cannabis lozenge each morning. It does not make me feel high and I am focused and able to work in the hospital.

I used to be anxious over when my next pain episode would occur but the MM has alleviated that anxiety.

My employer is aware that I take medical marijuana and is okay with it, but I was initially fearful that I would be fired for using MM. In fact, I did stop taking the MM when I

applied for the job, for fear that I would not have even been considered for the position.

The major drawback that I have with the MM program is the expense of the product since it is not covered by insurance. For some, it is easier to continue with the opioid pills that are covered by insurance instead of having to figure out if they'll have enough money to pay the electric bill due to the cost of the medical marijuana. Thankfully, I was able to overcome that barrier, but many of the people who were in the same place as me are unable to afford it and have continued down that path of self destruction.

My last dose of heroin was 13 years ago. I've been off the Suboxone for 4 years. When I take stock of my life and see how I went from a street junkie to a business owner and mother of 4 who will soon be receiving her degree as a Psychiatric Nurse Practitioner, I realize just how far I've come. Life has never been better for me. So I share my story in hope of preventing others from going through the suffering that I've endured.

Janice

My name is Janice J. and I am 36 years old. I was diagnosed with TN 3 years ago despite all the doctors telling me I was too young to have TN. Well, in fact, I wasn't.

My symptoms began as many others, with dental symptoms. I was fortunate to have just graduated from dental assistant school, so when I saw my dentist complaining of maxillary tooth discomfort and the x ray was negative, he referred me to a specialist. However, the next day, I went to the ER due to increased pain (it felt like freezing cold water dripping down my face) and the ER physician diagnosed me with TN. Like other people newly diagnosed, I was confused and didn't really understand the diagnosis and also felt that many of the doctors didn't understand me either. I was started on the usual treatment medications but the pain wasn't being controlled so I went to see a pain management doctor.

The pain management doctor wanted to start me on opioids as a first line treatment but I was unwilling to get started with those meds. Ultimately, however, I did start on OxyContin which helped for a while but then it's effectiveness wore off. I got to the point where I was taking up to 35 pills of all sorts per day to treat both the symptoms as well as the side effects of the medications. All the doctors kept saying "we understand that you don't

"Patient Profile". . . continued on page 26

Face Pain?



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"Patient Profile"...continued from page 25



want to take more medicines, but here's 2 more". I was becoming profoundly depressed looking at how my life was at such a relatively young age. The whole point of going to school and graduating was to plan a life, get married and have children. The TN treatments put a stop to that.

Although the pain management doctor discussed medical marijuana at the first visit, I was hesitant because I wanted to work but didn't want to feel discriminated against at work because I was taking marijuana. However, as the pain increased and I was no longer able to work, my reservations about cannabis dissipated, so I figured I might as well take advantage of it. I decided to try medical cannabis because I realized that all the chemicals in the pills were not for me and I preferred a more natural product instead. And I'm glad I made that decision.

I currently dose about 1-2 times/day and it helps the pain that I experience on a daily basis. More importantly, I am down to taking only 12 pills/day now.

I feel as though eventually I may not need any of the medications other than medical cannabis.

The downside of medical cannabis, however, is the expense of the product since it is not covered by insurance.

Medical marijuana has certainly helped get my life back from the stress, depression, and poor health that I was dealing with before. Now when I look at my return to performing all the daily life activities I was unable to do when I was on all those other medications, I never want to go back to the time before I began medical marijuana. However, as medical marijuana is relatively new for me, I am still in the learning phase of which product and administration route works best.

I have come to realize that all of us with TN are connected, but our stories are different. I hope my story provides other TN patients with hope and a pathway to improved health.







New Facial Pain Association Board Member, Megan Hamilton

Megan is a proud TN Mama to her daughter, KatieRose. KatieRose was diagnosed with Trigeminal Neuralgia at 11 years old, and Geniculate Neuralgia soon after. Megan was her primary support and advocate through diagnosis, treatment, medications, 5 neurosurgeon interviews, and two MVDs. KatieRose recently celebrated 5 years TN & GN pain free.

Through that journey, Megan, along with other awesome TN Mamas she met along the way, began an online support group for caregivers of pediatric TN patients. The group serves the families of more than 100 kids in 7 countries at last count. She also started the online resource TNKidsRock.com to make basic information more readily available for these families.

In the greater TN community Megan has worked for greater TN Awareness, taking part in annual TN Awareness Day activities, and being interviewed along with her daughter for both print and television news. She has also taken part in fund raising activities for the Facial Pain Research Foundation.

Outside of her work within the TN Community, Megan brings education and experience in Human Resources, 13 years of experience as a homeschooling mom, and as a travel blogger at Wandertoes.com. Megan lives in the northern Virginia area with her ever-supportive husband, Scott, and her two fantabulous daughters, KatieRose and Lydia.



Receiving a diagnosis of trigeminal neuralgia (TN) or other painful cranial nerve disorders can be devastating. The Young Patients Committee (YPC) is a dedicated board of people under the age of forty that have been diagnosed with TN and other facial neuralgias.

We all have a facial pain journey. These are ours.



Ellie

When I was eight years old, I would get awful headaches on the right side of my face. I was ultimately diagnosed with

migraines, as I had a family history of them, and was told to take an anti-inflammatory. Fast forward five years, I woke up one night with excruciating pain in my jaw; the same side that I had migraines. My mom took me to the dentist, who found nothing wrong. We saw another dentist, an orthodontist, a pediatrician, a chiropractor, and a pediatric neurologist, who ultimately gave me my official diagnosis. Turns out I never had migraines after all; the pain that I had experienced was related to trigeminal neuralgia, and it took this severe attack at thirteen years old to receive a diagnosis. The doctor went to his bookshelf, pulled out an old textbook and flipped through the pages. I had never seen a doctor diagnose me from an old medical book before! He prescribed an anti-seizure medication, and it helped - for a while.

Every few months the medication would stop working, and the neurologist would alter my medications. I then

developed pain in my ears and throat, and the pain spread to the left side of my face as well. This led to my diagnosis of bilateral trigeminal neuralgia, geniculate neuralgia, and glossopharyngeal neuralgia. I eventually developed an allergic reaction to most of the frontline medications, and maxed out my dosage of Gabapentin. In 2015, I attended the FPA's conference in New York City, and it transformed (and saved) my life. I no longer felt alone, and I learned that I had treatment options! I had been told by my neurologist that I would outgrow TN, and learned that is not the case. This conference led me to pursue bilateral microvascular decompression surgeries (MVD) from Dr. Mark Linskey, which required me to travel across the country from New York to California for treatment. Hey, at least it is close to Disneyland!

Through my diagnoses, I have learned that there are some things that I can't control, but there are many things that I can. I can control my attitude, how I respond to difficult situations, and how I can use these negative experiences to put good into the world.



Mandi

Nine years ago I went to lunch with some colleagues at work, and when I returned to my office I had one of the

worst toothaches I have ever felt. I immediately left work and went to the dentist. After tests and x-rays, he could not find anything wrong with the tooth. However, throughout that week, the intense toothache continued to occur. After several dentist appointments and doctor visits that week, I was told I could possibly have trigeminal neuralgia. I was referred to a neurologist and that is where my TN story really begins. The neurologist put me on Neurontin right away and suggested an MRI of my brain. My MRI showed lesions on my brain. I was experiencing a lot of pain along with other symptoms, including tinnitus and very blurred vision, so I spent a day at the Medical College of Wisconsin with various doctors, including a neuro-ophthalmologist. It was during that visit that Lyme was suggested as a possible cause of my trigeminal neuralgia and other symptoms. I was referred to another specialist and tested for Lyme which immediately came back positive. Since then, I have been treating both Lyme and trigeminal neuralgia.

Over the last nine years, I have been referred to Mayo Clinic twice, but have never made the commitment to go. I have also consulted with several surgeons about various options, but ultimately I am not a candidate for surgery due to the cause and type of TN I have. I take up to 22 pills daily; a combination of medicine and supplements. I have tried most of the typical anti-seizure medications and currently find the most success with Topamax and Lexapro as a combination. I also eat gluten, dairy, and sugar free which has had an impact on managing my pain levels overall. I have found an amazing support network of other TN patients, and I do whatever I can to raise awareness and funding for a cure. In addition to my work on the Young Patients Committee, I work on the Laugh Your Face Off fundraiser in Chicago, and persuade many building managers in both Chicago and Milwaukee to light up teal every year for TN Awareness Day.

My advice to any TN patient would be to find ways to get your power back. I cannot control TN, but I can keep fighting to help others, to bring awareness, and hope for a cure or better treatment. My support network is very important to me, and I rely on other TN patients to help me cope and understand on those really bad days. Find your tribe and then find the small ways that you can fight back against TN. Be a Warrior! I may have TN but I refuse to let it have me!



Rachel

At the age of 15, I started having stabbing ear pain. After several rounds of antibiotics for a suspected ear infection,

this pain spread to my face. Many specialists and two nerve blocks later, I had a glycerol rhizotomy to confirm a diagnosis of trigeminal neuralgia. I was then scheduled for my first MVD at the beginning of my senior year of high school. Pain started to appear on the other side of my face, so I underwent another MVD after my high school graduation. I started college trying to continue with a "normal" life, but the pain worsened. My neurosurgeon at that point recommended opioids, which I did not and could not accept as an answer. I decided to travel to consult another neurosurgeon. After some tests, I was scheduled for a third MVD (and then I convinced my surgeon to do a fourth MVD on the other side two weeks later). The pain was better, but not completely resolved. I continued on with college, studying biology. I eventually elected to try Gamma Knife on one side, and this led to severe numbness, itching, and tingling sensations.

Currently, I manage the TN pain with medications, and have since developed chronic migraines. I am attending Louisiana State University School of Medicine (with a full tuition waiver)! I am loving every second of school, and I cannot wait to show empathy and compassion to my own patients in the future – maybe working as a neurologist! My greatest achievement will be to have that "MD" after my name in 2022.

My best advice to a TN patient would be to not let this condition define you. There have been many days where I cannot get out of bed, or I am constantly thinking about when the next pain attack will hit. I have learned that I should not let it control what I do. I should not let it be the center-stage of my mind. I am trying to accept that I may carry this illness with me for the rest of my life, but I am not going to let it be a barrier to my success. I am going to turn this disadvantage into an advantage. I am going to turn this tragedy into triumph.



Chris

Trigeminal neuralgia is a very strange battle because it can simultaneously bring the worst and best of life. In my

case, even after beating brain cancer, TN brought me to the darkest of times. The pain was so severe and unrelenting that each new day seemed to be torture. Upon finally meeting my neurosurgeon and having bilateral MVDs, I was once again able to live pain-free while also having

the knowledge and wisdom that the experience gave me. Additionally, it was through my battles that I was able to meet my trigeminal neuralgia family; people that understand the physical, mental, and emotional battles that one goes through when coping with TN. While TN came very close to ending my life in the beginning, I can't even begin to imagine how my life would be had I not been diagnosed.



Nick

I was diagnosed with trigeminal neuralgia at the age of eleven, although I had experienced symptoms as early as

eight years old. When we received the diagnosis, we were actually very familiar with TN as my father is a TN patient, too. I experienced initial pain in my lower left jaw. My mother, who has been my biggest advocate since day one, decided to see if there were any other families going through this. What she found through Facebook was a network of people (and later a group of friends) who would provide constant support throughout my TN journey.

Once we found a doctor who would actually treat children, I was put on various medications and none of them seemed to be working. Unfortunately, they never would. I had two unsuccessful Radiofrequency Ablations performed in January and February of 2014 at the University of Chicago.

With no where else to turn , my mom and I decided to meet with Dr. Mark Linskey at the University of California Irvine (UCI) that following July. In October of 2014, Dr. Linskey performed an MVD on my left side, which remains successful to this day. Unfortunately, the pain returned the following October, but this time on my right side. The choice was clear on what to do next. Four months later, Dr. Linkskey performed another successful MVD on my right side. I have been pain-free ever since.

My advice to other TN patients is to stay active in any way you can and to create a network of people that will support you through this process.



Kenzie

I was diagnosed with TN1 at eleven years old. I first felt the pain when I was playing softball. My dad was the coach

and he thought I was hit in the face with the ball. This one embarrassing moment sent me down a path of emergency dentists, emergency room visits, and some not-so-helpful doctors. Right before my twelfth birthday, an emergency dentist handed me a sticky note with the words "trigeminal neuralgia" on it and said, "God bless you." Daunting as a sticky note from a doctor is, at least we had some answers.

I spent the next five years trying every treatment imaginable: countless medicine cocktails, steroid packs, acrylic mouth pieces, and injections. Everything was temporary, every period of remission just a minute of relief. But, that's something we're all familiar with - the relief of sixty seconds of no feeling. I was lost and alone until I found a girl in Canada who knew what I was going through. And suddenly that relief wasn't sixty seconds at a time. It came whenever we got the chance to talk to one another. She helped me get through a very lonely time in my life.

We eventually met Dr. Mark Linskey, who told me he could fix me. In March of 2014 I had MVD surgery at UCI and have been pain-free since then. Not only did Dr. Linskey save my life, but he brought me to a group of kids who also knew what I was going through. As terrible as this pain is, it's brought me into a community that is filled with so much compassion that I wouldn't change a thing.





Steph

As far back as I can remember, I had a sharp pain that would come and go in front of my left ear. I never said anything to anyone because I thought it was

something that happened to everyone. Now fast forward to my mid-twenties. I still had the sharp pain in front of my ear from time to time. However, when I would get out of the shower I would get debilitating pain that dropped me to the floor and made me sick. At this point I brought it up to my family doctor. With the symptoms I described and an instant pained reaction when he touched my face, I was repeatedly diagnosed with chronic sinusitis due to allergies.

It was a total of five years I had this diagnosis. One December, I was on antibiotics the entire month with no relief. I made myself an appointment with an ear, nose and throat (ENT) doctor. I lucked out with that doctor because within the first 5 minutes of our conversation, he told me he was sure of what I had and was sending me to a neurologist. A few weeks later, I met that neurologist and he agreed with the diagnosis of left-sided trigeminal neuralgia. He immediately started me on medications to ease the pain. I began receiving nerve blocks every eight weeks. They were a great help. With the success of those blocks, my neurologist referred me to a neurosurgeon to have a rhizotomy performed. I'm both happy and thankful

to say that surgery was also successful and I have been med-free and mostly pain-free for the past five years.

My TN has taught me so much about myself. It has shown me how resilient I can be and that I need to make time for myself. Even when I felt like I was, I was never alone. I know that others don't always have a strong support group, so I have dedicated my efforts to being part of the Facial Pain Association (FPA) so that I can share support to others and be an advocate for something the world doesn't know much about.

My advice to others with facial pain would be to not let it stop you. Take moments to regroup when you need them, but never stop doing what you love. Look out for others. Build a strong tribe to surround yourself with and talk with them often. Rejoice in the small accomplishments and good days. Most of all, never give up.

Are you looking for a place to find your tribe? Visit the Official Trigeminal Neuralgia Support Group: Young Patients on Facebook to be connected with young patients in a supportive, positive setting.

Now, we want to hear your story! "Like" the Young Patients Committee (YPC) TNA The Facial Pain Association on Facebook, Instagram, or Twitter, and check out some opportunities to share your journey with others. You never know who you will inspire!



"All I would like to say is that I am so blessed and grateful to God for bringing me to this doctor." Mark

"I feel positive, energized and happy. I know that God put Dr. Robinson in my path so he could help me and be able to have a second chance to live without pain. " Teri

"I honestly don't know what would've happened without Dr. Robinson." Juanita



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"Tributes"...continued on page 34

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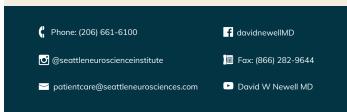
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— L.W.

"Getting to talk to other patients about how they cope with facial pain made a bigger impact on me than I expected."

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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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