Welcome to Stanford’s first FPA Conference

Medical Marijuana for the Treatment of Chronic Pain, page 7
How Can Nutrition and Diet Affect TN, page 10
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For more information and a complete list of conditions treated, visit www.ValleyGammaKnife.com.
Dr. Chang discusses Stanford's spirit of continuous learning, collaboration and innovation.

Two neurosurgeons from Columbia University discuss the use of medical marijuana for the treatment of chronic pain.

Volunteer FPA staffer Pam Neff on the affect of nutrition and diet on TN and chronic pain.

What patients should know about pain relief. Reprinted from Consumer Reports.

IN EVERY Q

From the Chairman of the Board

Describing TN pain.

New Members, Memorial and Honorary Tributes
This Letter brings news about the Facial Pain Association’s mission and research aimed at improving the diagnosis and treatment of trigeminal neuropathic pain.

First, the FPA formed the Facial Pain Research Foundation during 2011 to fund basic research concerning the trigeminal nerve and related pain. Under its charter as a division of the FPA, the FPRF obtained financial support from donors large and small. The FPRF funded research concerning the genetic basis of facial nerve pain, how our brains process pain signals, how medication can be targeted to the trigeminal nerve, how the insulation around nerves may be repaired and other aspects of neuropathic pain. That good work is being done by leading scientists. The FPRF grew well and enough that it made sense to both the FPA and the FPRF to, as of January 2018, spin off the FPRF as an independent non-profit organization. We thank the FPRF for its efforts in making the spin off cordial and constructive, we at the FPA remain enthusiastic fans of the FPRF and we hope for its continued success.

There is more good news. Serving the needs of our young members is essential to the FPA. To that end, we are pleased to have Melissa Anchan join our Board of Directors. Ms. Anchan works for a global bank, was recently active in the FPA’s Young Patients Committee and brings useful business experience to our Board. We are also pleased to have Stephanie Blough representing the YPC at our Board meetings. Ms. Blough is President of the YPC and she also brings healthcare and business experience to our deliberations. We welcome Ms. Anchan and Ms. Blough and we look forward to their thoughts and efforts. The path for young members of our Board was blazed by existing Director Allison Kubik, she brings wisdom and essential perspective. Now adding Ms. Anchan and Ms. Blough is part of our effort to secure the future of the FPA.

The two news items above, about research and our young members, are related. It takes time to undertake basic research and for the results of that research to materialize as better drugs and procedures. So it is our younger members, and those who follow, who are most likely to benefit from research that is underway now. With that in mind, the FPA has a portfolio of programs. Most of our programs help patients now. Those include the information available through fpa-support.org and our office, newsletter, magazine, support groups and conferences. Our program to support research will help patients in the future. We encourage research concerning trigeminal neuropathic pain, we increase awareness of that research through our publications, and we assist researchers who need subjects by making our members aware of such needs.

Since the founding of the FPA in 1990, our regional Support Groups have been useful to many patients and their supporting friends and relatives. SGs are another of the programs the FPA runs to help people now. SG meetings feature speakers who provide useful information as well as an opportunity for patients to meet and confer about managing life outside of a doctor’s office. As I described in the Chairman’s Letter last fall, the internet is enabling new ways of finding information and new ways of interacting with others. The FPA’s website and internet-based forums are busy places these days with thousands of participants. Hundreds of people are logging on to watch the webinars run by Dr. Jeffrey Brown, Chairman of the FPA’s Medical Advisory Board. That is all good, but it also means that our SGs need to evolve. We are working on that and we invite your input. We are starting with our SG Leaders. They are on the front line, they know who attends SG meetings and they see evolution underway. Their input will guide our next steps.

Jeff Bodington, Chairman of the Board
The Facial Pain Association
Welcome to Stanford’s First FPA Conference

Join Patients and Clinical Care Experts at Stanford for the 2018 FPA Regional Conference by Steven Chang, MD

At Stanford, finding solutions for patients with the most complex disorders and continually seeking ways to improve their quality of life, is always at the center of everything we do. We are therefore thrilled to be able to provide patients, physicians, and caregivers, with a unique opportunity to learn more about, and contribute to our expanding knowledge about trigeminal neuralgia, by hosting the 2018 Facial Pain Association’s Regional Conference, this spring.

I have been at Stanford for three decades, and in that time, I’ve gained a deep understanding of the types of struggles patients face, and the many answers they still seek to help alleviate their symptoms and to find a cure for this condition. By bringing together patients, researchers, neurosurgeons, radiologists, psychiatrists, and pain management specialists, under the expert guidance of the Facial Pain Association, the Regional Conference will help us build a strong community of local advocates. Our hope is that this Conference will serve as an important step in enabling this community to learn from, and teach one another, and to bring us one step closer to finding long-term, safe, and minimally-invasive solutions for those suffering from trigeminal neuralgia and chronic facial pain.

My colleagues and I work tirelessly to provide our patients with the most current diagnostic and treatment options, and the latest research findings. I am proud of Stanford’s leadership in innovation and clinical research—two areas that most profoundly advance our abilities to help our patients. One of our greatest accomplishments was the development of the Stanford Cyberknife Radiosurgery Program, which, when first launched was limited to tackling brain tumors. Now, we can apply this technology beyond tumors, to also treat conditions like trigeminal neuralgia. Offering this noninvasive, outpatient treatment provides our patients an alternative to conventional surgery and its associated lengthy inpatient hospitalizations. We have also developed expertise in both microsurgical and radiosurgery approaches for treatment of trigeminal neuralgia, and specialization in microvascular decompression for facial pain. Additionally, current research at Stanford is focused on clinical outcomes for radiosurgery treatment.

“Stanford”…continued on page 4
of trigeminal neuralgia, which we’re hoping will showcase the safety and efficacy of non-invasive approaches. I am excited to be able to share all we’ve learned about these approaches and their effectiveness with patients and colleagues.

At Stanford, we know that patients need more than just clinical treatment, but also an approach that accounts for a person’s emotional and mental well-being. For that reason, we have invited psychiatrists and pain management specialists to join the conference, and to share their knowledge with our community. Those who attend our Trigeminal Neuralgia Support Group for patients and family members, which we launched in 2012, are also encouraged to attend the conference to provide and gain support, by sharing their experiences with others.

Stanford’s spirit of continuous learning, collaboration, and innovation, makes it a perfect setting to host the 2018 Facial Pain Association’s Regional Conference. I am looking forward to welcoming patients and caregivers alike to join me at this important event. My hope is that this gathering will provide an opportunity to further our understanding of trigeminal neuralgia and related neuropathic face pain, and to strengthen our trigeminal neuralgia community. I look forward to seeing you all on March 24, 2018, at the beautiful Stanford campus.
# AGENDA

## MORNING SESSION

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<td>Registration</td>
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<tr>
<td>9:15 AM</td>
<td>Welcome and Introduction</td>
<td>Steven Chang, MD, Faculty Director</td>
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<td>Jeff Bodington, Chairman, FPA Board of Directors</td>
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<td>9:30 AM</td>
<td>Microvascular Decompression for Trigeminal Neuralgia</td>
<td>Steven Chang, MD</td>
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<td>What Can Ablative Procedures Do for My Type of Facial Pain</td>
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<td>Cyberknife Treatment for Trigeminal Neuralgia</td>
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## AFTERNOON SESSION

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<td>Percutaneous Procedures for Trigeminal Neuralgia</td>
<td>Xiang Qian, MD</td>
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<td>2:00 PM</td>
<td>Anxiety, Depression and Coping with the Diagnosis of TN</td>
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<td>Anatomic Nuances of the Trigeminal Nerve with Respect to Radiosurgery</td>
<td>Geoffrey Appelboom, MD, PhD</td>
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<td>3:45 PM</td>
<td>Meta-analysis of MVD in Patients Younger than 65 versus Older than 65</td>
<td>Allen Ho, MD</td>
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<td>4:30 PM</td>
<td>Meet the Experts</td>
<td>All participating conference speakers</td>
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Conference Faculty

Steven D. Chang, MD is the conference Faculty Director and the Robert C. and Jeannette Powell Professor in the Neurosciences at Stanford University.

Geoffrey Appelboom, MD, PhD is Clinical Instructor of Neurosurgery at Stanford. Dr. Appelboom is focused on advancing minimally invasive surgical techniques for diseases of the brain and spine. Dr. Appelboom is a surgeon scientist. He spent 3 years of integrated PhD research at Columbia University Medical Center to study genetic predictors of vascular fragility. Dr. Appelboom’s research efforts include utilization of MR guided technologies such as stereotactic radiosurgery and focused ultrasound.

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

Iris C. Gibbs, MD, FACR is a neuro-oncologist and Professor of Radiation Therapy at the Stanford University Medical Center. Best Doctors in America, Best Doctors (2005-2017).

Allen Ho, MD was born and raised in Irvine, California. He left California to attend Harvard Medical School where he earned his MD in 2014. His research interests include expanding indications for deep brain stimulation and neuro-modulation, technology-driven minimally-invasive approaches to cranial and spinal neurosurgery, and quality improvement initiatives within clinical neurosurgery.

Bret Schneider, MD is Adjunct Professor of Psychology at the Stanford University School of Medicine. He completed postdoctoral fellowships in Advanced Psychiatry and Stereotactic Radiosurgery at Stanford, where he developed advanced brain therapies.

Xiang Qian, MD is Clinical Assistant Professor of Anesthesiology at Stanford and a Pain management specialist.

To register please use the form on page 25 or visit facepain.org
The United States currently faces two crises: the epidemic of opioid abuse and the epidemic of untreated and undertreated chronic pain. Over one third of the American population has some form of acute or chronic pain, and nearly 40% of older adults require treatment for chronic pain. Given the relative lack of effective non-opioid drug therapies for pain, there has been a dramatic increase in opioid prescribing in an effort to treat this enormous number of patients with pain. This effort has unfortunately led to our current epidemic of opioid dependency and abuse, with approximately 2.5 million Americans affected by opioid addiction in 2014. The current crisis that stems from the widespread availability of opioids clearly suggests the need to explore alternative pharmacological options for the millions of Americans afflicted with chronic pain.

Humans have been cultivating marijuana, also known as cannabis, since as early as 12000 BCE, with the first writings documenting its medicinal applications originating from China in 2700 BCE. Various ancient Egyptian texts also describe its use for a variety of ailments including epilepsy and pain. It was largely unknown to Western civilization until 1839 when an Irish physician returned from India with a large quantity of cannabis for study regarding its clinical utility. Throughout the 19th and early 20th centuries marijuana was widely used for the treatment of headaches, tremors and epilepsy, but it slowly fell out of favor as pharmacology and drug development became more sophisticated and synthetic agents became available. A number of political and economic forces led to our current bans on marijuana use including maneuvering by the nylon industry to eliminate competition from marijuana-derived hemp. Despite protests by the American Medical Association and other physician groups, marijuana was declared a Schedule 1 (high abuse potential with no medical use) drug in 1970, though efforts continue for its...
Reclassification as a Schedule 2 (high abuse potential with potential medical use) drug. The classification of cannabis as Schedule 1 has limited its availability for study in clinical trials and for use in treating medical conditions.

Medical marijuana represents a collection of natural and synthetic drugs. The most common form for medical use is the marijuana plant, Cannabis sativa. The cannabis plant contains over 60 active chemicals. Also known as cannabinoids, these chemicals alter the levels of various signaling molecules on neurons in the brain. Two of the most important cannabinoids in naturally-occurring plants are tetrahydrocannabinol (THC) and cannabidiol (CBD). THC is psychoactive, and provides the well-known “high” associated with marijuana. It has also been shown to have anti-seizure, anti-nausea, and appetite stimulation effects. CBD is not psychoactive, but does demonstrate pain relieving effects.

In fact, the World Health Organization (WHO) declared in December 2017 that CBD has little potential for abuse but has promising potential for medicinal use. In recent years, the levels of THC in illicit cannabis plants seized by the FDA have been steadily increasing. This increase has resulted from selective breeding of the plants to increase THC concentrations to provide the user with a more intense high. The plants may be dried and smoked or ingested as an ingredient within any of a number of different foods or drinks. Vaporizers are also an efficient method of inhaling the drug, and there are a number of commercially-available methods for doing that.

Synthetic cannabinoids are medications produced by drug companies, each with its own tailor-made concentration of chemicals. For example, dronabinol and nabilone are FDA-approved formulations with relatively high THC / CBD ratios, and thus are effective for the treatment of nausea, vomiting, and wasting associated with chemotherapy. Meanwhile, there are a number of synthetic cannabinoids in development with lower THC / CBD ratios to enhance their effectiveness as pain relieving medications while limiting their psychological side effects.

In 1996 California legalized the medical use of marijuana for select medical conditions, despite its classification as an illicit drug at a federal level. Patients required certification by a physician that they had one of these medical conditions, and once certified, could receive medical marijuana from any of a number of statewide dispensaries. This model was adopted by several more states over the subsequent two decades. As of December 2016, 28 states and the District of Columbia have legalized medical marijuana in some form increasing its availability to those in need and enabling more robust study of its efficacy. Given its illegal status on a national level, it is illegal to distribute marijuana across state lines, and the money associated with this distribution is not allowed to move within the interstate banking system. These limitations have blunted the expansion of the medical marijuana industry, and limited the interest in the industry by the major pharmaceutical companies.

Consequently, there have only been a handful of clinical trials of medical marijuana for the treatment of pain to date. Five randomized controlled trials investigated inhaled marijuana for chronic neuropathic pain with a total of 178 patients across all studies. Taken together, the data suggest that inhaled marijuana was slightly more effective than gabapentin, a medication in widespread use for the treatment of chronic neuropathic pain. Of the six randomized, controlled clinical trials using the synthetic cannabinoids, five compared one of these drugs to a placebo and found significant gains in pain relief, although sample sizes in each study were fairly small.

As with every pain medication, medical marijuana is associated with some adverse effects, including motor, short term memory, and judgment impairment, as well as paranoia at higher doses. One study looked at the safety of marijuana use for pain over a 1 year study period in about 430 patients and found no difference in severe adverse events over the life of the study. Additionally, while there is some concern for addiction with marijuana use, its propensity for addiction is far lower than opioids, alcohol or tobacco. To date there have been no documented deaths due to overdose from marijuana use. While it is both illegal and ill advised to drive under the influence of marijuana,
studies have found that traffic fatalities have actually decreased in states where medical marijuana was legalized compared to states in which it remains illegal. The exact reason underlying this decrease is unclear but it may be due to decreased use of other psychoactive drugs in the setting of medical marijuana use.

The notion that marijuana is a gateway drug has also been widely disseminated and it is true that medical marijuana laws do increase marijuana use among adults. However, if the theory that marijuana is a gateway drug is true, it would be reasonable to think that opioid abuse and overdose related deaths would increase in states in the years following legalization of medical marijuana. It has actually been found that states with medical marijuana laws demonstrated lower rates of opioid overdose compared with states without these laws and the longer the laws were in place the more robust the effect became. Thus, the data suggest that the adoption of medical marijuana laws appears to have a protective effect in the prevention of opioid overdose deaths, possibly because individuals use marijuana, which does not cause death even at high doses, rather than opioids, which is lethal at high doses.

Given the enormous population of chronic pain patients and limited available drug treatment options, the United States must develop novel, non-opioid drug treatments for pain. It is important to have new drug treatments so that pain can be effectively treated while reducing the potential for opioid abuse. Medical marijuana represents one of these safe and effective non-opioid treatments. Moving forward, it will be important to reclassify cannabis as a Schedule 2 drug to allow for more research and development of this class of medications. The legalization of medical marijuana will then allow the cannabis industry to more fully develop, and once large pharmaceutical companies become invested in its development, the full potential for this medical therapy can be discovered. While medical marijuana may not be the right answer for all patients there is enough existing evidence that its use for pain relief should not remain stigmatized and shunned. Only by providing other viable alternatives that actually treat our patients pain can we begin to tackle the epidemic of opioid prescribing and abuse and better care for the millions of Americans afflicted with chronic pain.
Trigeminal Neuralgia (TN) is a rare and excruciatingly painful disorder that requires many modalities and treatments to calm down the pain associated with a hyper-sensitized trigeminal nerve(s). In addition to medications and surgical options there are complementary and alternative medical approaches that should be in every TN or facial pain sufferer’s toolbox. One tool that I am often asked about as a RN and Patients Support staffer at the FPA concerns nutrition, diet and supplements.

CHRONIC INFLAMMATION AND NERVE PAIN

“Chronic inflammation has been implicated not only in heart disease, but in cancer, arthritis, autoimmune disease and neurologic disorders, including trigeminal neuralgia” as described in the book, “Facing Facial Pain.”* The key word here is CHRONIC. We know that acute inflammation is a necessary and helpful process to fight off foreign invaders and send out healing substances when the body has an infection or injury. The problem occurs when that protection goes overboard and is maintained over a long period of time and becomes damaging to the body and brain.

WHAT IS THE DIFFERENCE BETWEEN A PRO OR ANTI-INFLAMMATORY DIET?

On a basic level, a pro-inflammatory diet consists of processed foods and foods with a high level of omega-6 fatty acids such as corn, safflower, peanut or cottonseed oils. Most people are consuming far too many omega-6 fats compared to omega-3 fats. The ideal ratio of omega-3 to omega-6 fats is 1:1, but the typical Western diet may be between 1:20 and 1:50, the National Institutes of Health (NIH) Office of Dietary Supplements states. Also included are foods with a high glycemic index/load such as baked goods and cereals with refined sugar and white flour that can cause insulin spikes and cause inflammation.
Offering a full roster of advanced options for treatment, including:

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

The Facial Pain Program at the Weill Cornell Brain and Spine Center is an innovative program that focuses on the diagnosis and treatment of trigeminal neuralgia, one of the most disabling causes of facial pain. Our team includes top specialists in vascular neurosurgery and pain disorders—internationally recognized experts in the field who have advanced training in the very latest minimally invasive procedures used to treat facial pain. Find out more at weillcornellbrainandspine.org or call 212-746-4684 to make an appointment.
per serving), nuts, apples, berries, peaches, grapefruit, plums, oranges, prunes, apricots, cherries, and non-starchy vegetables (leafy greens, squash, zucchini, cucumbers, green beans, asparagus, onions, peppers, broccoli, cauliflower, cabbage, celery, mushrooms, lettuce, and spinach, just to name a few.

WHAT ARE “HEALTHY” FATS

“Facing Facial Pain” stresses that a high fat diet using “healthy” fats is needed to build up the myelin sheath that surrounds the nerve that may be damaged due to compression, multiple sclerosis and other challenges such as trauma or autoimmune disorders.

Healthy fats include such foods high in omega-3 fatty acids such as extra virgin olive oil, walnut and coconut oil, avocados, wild caught fish such as salmon, sardines, tuna, halibut and trout. Farmed fish are thought to be inflammatory due to the added artificial fish food. With farmed salmon a dye is used to make the flesh a red color, normally the flesh is white since they do not eat the beneficial and healthy zeaxanthin they would normally find in the wild. Nuts, especially walnuts and flaxseed are also on the healthy fat list.

NOTE: Saturated fats such as fatty cuts of meat are unhealthy and not advised!

Since the body does not produce omega-3 fatty acids, they have to be consumed through dietary sources or supplements. If food sources aren’t enough, you may also want to take a dietary supplement of fish oil or sunflower oil – both of which are rich in omega-3 fatty acids.

THERE ARE 3 BASIC FORMS OF OMEGA-3:

Alpha-linolenic acid (ALA) found in English walnuts and vegetable oils like flaxseed, soybean and olive which the body eventually, but in small quantities, converts to DHA. Alpha-linolenic Acid is not the same as Alpha-lipoic Acid, which is an antioxidant.

Docosahexaenoic acid (DHA) found primarily in fish oil, this is the ultimate form of fatty acid in humans. Most people get far too little of this all-important fatty acid, especially since the conversion of ALA to DHA is slow and minimally yielding. Getting a daily dose of DHA (600 to 1000 mg) from supplements is preferable to reap the health benefits. You have a choice of taking a fish oil supplement or one derived from algae or krill, a shrimp-like crustacean.

Eicosapentaenoic acid (EPA) is also found in fish oil, so it’s absorbed if you’re taking a daily dose of DHA omega-3. Fish oil supplements vary in the amounts and ratios of DHA and EPA they contain. For example, salmon oil naturally contains more DHA than EPA; a supplement derived from algae may only contain DHA. Krill oil contains significant amounts of both EPA and DHA. Read the labels and remember whatever supplement you buy, it must have at least 600 mg of DHA.

Be aware that only about one-third of the oil from fish is rich in EPA and DHA. Many supplements also contain vitamin E or other antioxidants to stabilize the oils and prevent them from becoming rancid. If you choose to buy a fish-oil supplement, check the label carefully to see if it recommends refrigeration to prevent spoiling.

Most brands of fish oil have been proven safe, free of
detectable traces of mercury, and do not contain unsafe levels of PCBs (polychlorinated biphenyls), a toxin and pollutant believed to pose various health threats. To avoid contaminants in an unrefined supplement, it’s best to choose a fish-oil supplement made from small, oily fish like anchovy, sardines or menhaden.

There is no set recommended standard dose of omega-3 fats, but some health organizations recommend a daily dose of 250 to 500 milligrams (mg) of EPA and DHA for a healthy adult. (Examine.com)

ARE GRAINS INFLAMMATORY?

Dr. David Perlmutter, in his book, Grain Brain, discusses what he calls “the truth about wheat, carbs and sugar-your brain’s silent killers”. Again the topic focuses on chronic inflammation as “being at the heart of every disorder”. A study published in (2016) from Columbia University Medical Center found that some people develop a systemic immune reaction and intestinal cell damage after eating wheat, even though tests have established that they do not have celiac disease. The researchers noted that while there are no accurate figures for the number of people affected, it’s estimated that this condition may be more prevalent than celiac disease. However, lead researcher Armin Aledini, Ph.D. has been quoted as saying that the study did not confirm that gluten was the cause. For that reason, the investigators refer to the reaction as non-celiac wheat sensitivity, even though removing wheat from the diet eliminated the symptoms.

The well known alternative practitioner Dr. Andrew Weil comments that in people who do not have celiac disease, grains do not cause inflammation or damage the gut – if they are consumed in whole or cracked form. But when grains are milled into flour, the starch they contain becomes a high-glycemic-load food. That means it rapidly converts to glucose, causing rapid rises in blood sugar that promote the formation of AGEs – advanced glycation end products, and these combinations of sugars and protein are pro-inflammatory.

To find out more, research elimination diets and the difference between food allergies and food intolerance. Changing your diet most likely won’t hurt you (always consult your doctor for your individual needs), and may at the least make you feel better as a whole with more energy and less allergies and sensitivities causing havoc in your body and brain.

CURCUMIN IS NEUROPROTECTIVE AND ANTI-INFLAMMATORY

Curcumin, the principal curcuminoid found in spice turmeric, has recently been studied for its active role in the treatment of various central nervous system disorders. Curcumin demonstrates neuroprotective action. The mechanism of its neuroprotective action is not completely understood.

VITAMIN B12 - THE MOST TALKED ABOUT VITAMIN FOR TN

The cause for trigeminal neuralgia is not clearly understood. Multiple theories have been proposed, and some implicate a low vitamin status with trigeminal neuralgia pain however to date there is no conclusive evidence. Vitamin B12 (cobalamin) is an important water-soluble vitamin. In contrast to other water-soluble vitamins it is not excreted quickly in the urine, but rather accumulates and is stored in the liver, kidney and other body tissues. As a result, vitamin
B12 deficiency may not manifest itself until after 5 or 6 years of a diet supplying inadequate amounts.

Cyanocobalamin has been shown to reduce spinal nerve ligation induced allodynia and tactile allodynia in rats and therefore may have a role in humans. Vitamin B12 functions as a methyl donor and works with folic acid in the synthesis of DNA and red blood cells and is vitally important in maintaining the health of the insulation sheath (myelin sheath) that surrounds nerve cells.

Methylcobalamin has recently been identified as a form of Vitamin B12 that protects against neurological diseases and aging. The liver converts cyanocobalamin into methylcobalamin within the body but larger amounts of methylcobalamin are necessary to correct neurological defects. Mauro showed that high doses of methylcobalamin are needed to regenerate neurons as well as the myelin sheath that protects nerve axons and the peripheral nerves (Mauro GL, Martorana U, Cataldo P, Brancato G, Letizia G (2000) Vitamin B12 in low back pain : a randomised double placebo controlled study. Eur Rev Med Pharmacol Sci 4: 53-58).

Low vitamin B12 levels can have consequences long before anaemia is evident. The normal serum level of vitamin B12 ranges between 106 to 665 pg/ml. Researchers now propose that the current standard norms of vitamin B12 levels are too low. Recent research indicates that B12 deficiency is far more widespread than formerly believed.

The treatment of trigeminal neuralgia can be challenging and in the search for alternatives, vitamin B12 has been found to be a clinically useful pharmacological tool for patients with neuropathic pain.

A study (Low Vitamin B12 Syndrome in Trigeminal Neuralgia. J Pain Relief 1:109. doi: 10.4172/2167-0846.1000109), indicates that patients with trigeminal neuralgia have a low vitamin B12 syndrome, as 23% of patients with trigeminal neuralgia, compared to only 12% of patients with other causes of facial pain had serum vitamin B12 levels less than 200 pg/ml.

These results are markedly abnormal when compared to a cross-sectional, population-based study of 1048 aged subjects in which low serum total vitamin B12 (<205 pg/ml) was observed in only 6.1% population controls [8].

There is no known toxicity from taking additional vitamin B12. Methylcobalamin may even be protective against neurotoxicity by enhancing brain cell methylation.

**B12 SUPPLEMENTATION**

Fortunately, oral supplementation with vitamin B12 is safe, efficient and inexpensive. Most multi-vitamin pills contain 100-200 microgram of the cyanocobalamin form of B12. This must be converted to methylcobalamin before it can be used by the body.

The actual absorption of B12 is also a problem with supplements. Swallowing 500 micrograms of cyanocobalamin can result in absorption of as little as 1.8 microgram so most multivitamins do not provide an adequate daily intake. The best approach is to dissolve a sublingual tablet of methylcobalamin (1000 micrograms) under the tongue every day. That will be sufficient to maintain adequate body stores. Some physicians still maintain that monthly injections of vitamin B12 is required to maintain adequate levels in the elderly and in patients with a diagnosed deficiency.

There is however, no scientific evidence supporting the notion that injections are more effective than sublingual supplementation. (Low Vitamin B12 Syndrome in Trigeminal Neuralgia. J Pain Relief 1:109. doi: 10.4172/2167-0846.1000109).
FOODS THAT TRIGGER PAIN

Another important topic for patients with facial pain is food triggers that will worsen their pain. Foods that are most reported to cause increased pain are saturated fats (think bacon), sugar, alcohol, high gluten, cold or hot foods, caffeine, spicy or sour foods, hard to chew foods, anything acidic and aspartame (think mints or gum).

Food additives may also have an affect your brain health. Aspartame (NutraSweet) is an artificial sweetener in foods such as mints, gum and diet sodas. Although the FDA did studies that showed it would take an extreme amount to cause neurotoxicity in the brain and therefore is safe, some people with TN say that discontinuing its use reduced or eliminated symptoms. The same goes for Sucrolose (Splenda).

You can still have sweetness though with Stevia, a natural and excellent sweetener replacement. Learn to read food labels carefully! Glutamate is an excitotoxin. Sufficient magnesium is needed to block the uptake of glutamate along with antioxidants needed to combat free radicals involved in the oxidative process, which might explain why magnesium supplementation helps some people reduce their neuropathic pain. MSG, monosodium glutamate, is added to many foods and condiments such as soy sauce and is well known for contributing to migraines, which many TN suffers also have.

Avoid foods and nutritional supplements that contain or prompt the body to create glutamate or other excitatory neurochemicals that can enter via the glutamate receptors such as aspartate, aspartame, aspartic acid, cysteine, glutamic acid, glutamine (mostly a problem with children), homocysteine and monosodium glutamate (MSG), (American Nutrition Association, Volume 38, No. 2). Then, if you feel better when restricting glutamates, it’s best to modify/limit the amount of food sources you consume.

FOODS THAT FIGHT PAIN

Dr. Neal Barnard, in his book, “Foods That Fight Pain” (Harmony Books, 1998), says there are some foods that are almost never implicated in pain by anyone. These so-called “pain-safe” foods include brown rice, cooked or dried fruits such as cherries, cranberries, pears and prunes, and cooked vegetables such as artichokes, asparagus, broccoli, chard, collards, lettuce, spinach, beans, squash and sweet potatoes. Dr. Barnard suggests that if you suspect a dietary link to your TN or other facial pain, try sticking only with the pain-safe foods for about two weeks. If the pain eases, then gradually add other foods until pain starts to return. This can help you zero in on particular foods that might be a pain trigger for you. However, since TN goes in and out of spontaneous remission, you may have to try the elimination idea several times.

IN CONCLUSION

Trigeminal neuralgia and neuropathic pain are extremely difficult to treat and the challenge can become overwhelming to patients and doctors. Every single bit of information that could possibly be of help in treating facial pain should be considered. Inflammation has been one of the major culprits contributing to facial pain disorders. Hopefully this discussion of inflammation and how the patient can have more control over their own treatment by using diet, lifestyle changes and supplements can be of value.

There are currently several popular diets that incorporate the principles of decreasing inflammation in the body and brain as mentioned in this article such as the Ketogenic and Paleo diets, the Whole 30, the Mediterranean diet and others that not only use healthy fats and omega 3 but also eliminate most grains and any “fast” starch carbohydrates.

Anecdotal evidence of patients with facial pain shows that these types of diets, although they don’t cure trigeminal neuralgia or neuropathic pain, they do make them feel healthier and better overall.

*Facing Facial Pain is available at the facepain.org online bookstore
125 million people are in pain, spending some $300 billion on pills, pot, procedures, and natural ‘cures’ to find relief, but are they worth it?

In the summer of 2014, Carolyn Slutsky was walking to a friend’s graduation party when she felt a sudden burst of pain. The sensation radiated down her lower back to her right leg and worsened with each step she took. By the time she arrived at the party, she could barely stand. She went to an urgent-care center on the Upper West Side of New York City the next morning, where a doctor injected her with what she described as “some heavy pain medications” and gave her the name of a massage therapist.

The massage therapist “pounded on my back,” Slutsky recalls. “He kept saying, ‘See? Better!’ But it was not better.” She tried over-the-counter pain relievers, which helped for a few weeks until one morning the pain returned with a vengeance. She went to a back specialist who recommended an MRI, which revealed a ruptured spinal disk. The doctor then gave Slutsky a list of physical therapists. The first one passed her off to his students, who did a poor job explaining the exercises. Slutsky quickly abandoned the treatment and started her own quest to find relief. Following the suggestions of friends,

PAIN RELIEF: WHAT YOU NEED TO KNOW

First Published by Consumer Reports, April 28, 2016

DOCTORS, PATIENTS NEED TO

Measuring and managing pain can be extremely difficult for patients and doctors. A patient’s experience of pain is subjective, after all; it’s not something that can be measured with a lab test. If patients don’t talk openly and descriptively about their pain, or their doctors don’t ask the right questions or listen attentively, patients can miss out on treatments that could give them relief. This can limit what they can do and how much they enjoy life, especially if they have chronic pain.

Part of the problem may be that there is a gap between how patients and doctors understand and discuss pain, according to a new survey of 500 pain patients and 275 doctors. Barriers such as a lack of trust and insufficient time can thwart productive discussions. Some highlights from the survey that demonstrate the gap in understanding:

• 60 percent of patients felt strongly that they were able to be open and honest about their pain with their doctor; less than 10 percent of doctors strongly believed their patients were being truthful about their pain.

• Nearly all doctors (97 percent) strongly agreed that they have enough time to discuss pain with
she tried self-help books and acupuncture. Neither worked. Eventually, she picked another physical therapist from her list who turned things around. He recommended a special pillow to help her sit properly and taught her exercises that in time eliminated her pain. “Going through this made me feel fallible,” she says of her experience. “I was in this situation that felt out of control.”

Persistent pain can be as frustrating as it is debilitating. As Slutsky or anyone else with prolonged suffering can tell you, there’s never a convenient time for a spinal injury, a migraine, or an arthritis flare-up. Pain can take over your life with little notice. It can disappear suddenly, then return just when you think you’ve beaten it. In some cases, the cause is clear; in others, it’s a mystery. Yet when your head is pounding, your joints are aching, or your back is sending lightning bolts of agony up your spine, it’s a natural impulse to reach for the first thing you can find that will make the pain go away.

That’s why Americans spend some $300 billion on pain relief treatments and care each year. And then there’s the cost of lost productivity, which according to a 2011 Institute of Medicine report runs about $315 billion annually.

**How the Body Heals Itself**

As we acknowledge the dangers of prescription painkillers, we must also come to terms with a more nuanced understanding of pain itself. It isn’t something to simply get rid of; it’s your body’s way of telling you that something is wrong, often a strong signal to stop what you’re doing and correct course accordingly.

Beyond the immediate warning, pain triggers a cascade of responses from within. Inflammation at the point of injury alerts the body’s immune system to get to work on healing. Other chemicals are then notified and rush in to ward off infection, devour dead cells and tissue, and keep inflammation in check.

For most aches or injuries, pain goes away with treatment and time. When it doesn’t, the situation can get tricky. Doctors may find themselves at a loss, and patients can get caught in a cycle of treatments or succumb to the promise of unproven remedies. Others may handle it with a long-term prescription.

But real pain relief isn’t measured in doses. It’s about listening to what your body is trying to tell you, then patiently addressing the underlying cause. For Carolyn Slutsky, that meant finding the right physical therapist and changing her daily routine. “I try not to lift heavy things,” she says. “I lighten my bag by carrying only what I need. And I get out of bed
putting the weight on my hands rather than my lower back."

If you’re in pain, don’t just mask it or ignore it; do something. We’ve put together a glossary of treatments to help you understand the options. We’ve also looked closely at the best scientific evidence to create a step-by-step treatment guide to the most common causes of pain, including back, joint, neck, and head pain from tension headaches and migraines.

How to Communicate About Pain

It’s difficult to find the right words to describe pain intensity. That’s why getting the right treatment starts with effective communication.

Pain treatment isn’t one size fits all, so doctors often press patients for more details. “Pain is subjective,” says Kathleen Cowling, D.O., director of the residency program at Central Michigan University and an emergency physician at the Covenant Medical Center in Saginaw, Mich. “I can’t measure it like I would blood pressure.” Here’s what to tell your doctor:

**How Intense It Is:** You’ll first be asked to rate your pain, usually on a scale of 0 (no pain) to 10 (the worst you’ve ever had). Otherwise, say that it feels mild, moderate, intense, or the maximum—the worse pain possible.

**What It Feels Like:** Is the pain sharp and stabbing, a dull ache or throbbing? It could be from injuries to muscles, tendons, bones, or ligaments, such as a pulled muscle, a torn tendon, or an inflamed joint. Tingling, burning, pinpricks, or shooting pain that feels like a shock can indicate pinched or damaged nerves.

**It Hurts Where:** Identify where it hurts and pain spreads to other areas. Neck pain that radiates to your left arm could signal a problem with disks that cushion your spinal column.

**What Makes It Better:** If you’ve had pain for a while, explain what methods you’ve used to treat it and whether they worked.

**When It Started:** The last piece of information to give your doctor is about the first time you noticed the pain. Be precise, and describe what you were doing at the time you first noticed it. For example, neck pain that worsens during exercise could be a clogged artery.
Face Pain?

You’re in good hands.

Ramesh P. Babu, MD
Board Certified, Fellowship trained neurological surgeon with 25 years of clinical practice
Trigeminal Neuralgia can be described in many words…but if you had to choose just one, what would it be? The YPC recently shared how we would describe TN in one word and how we plan to overcome TN in 2018. Here is what we said:

Ally's Word: Cruel

If you have ever felt the pain of trigeminal neuralgia, you know that it is cruel and that nobody should ever have to experience this pain. Being diagnosed as a teenager, I thought the torturous pain was just cruel. At times, I thought what did I do to deserve this torture? Why should simple tasks be cruel? Shouldn’t I be able to eat ice cream without ending up on the floor in pain? While the pain I face each day is cruel, I also look at each moment I can do things as a gift. In 2018, I will continue to fight the cruelty of the pain and try to stay positive in the times my pain seems so cruel that I just want to be negative.

Kenzie's Word: Humbling

I use the word humbling to describe TN. As a child who was diagnosed with this disease it took hours of explaining in order for me to understand what was happening to me. I say I often feel humble when referring to TN because when I begin to feel sorry for myself I am reminded that there is someone in the world that has it worse. As I describe to people my pain I tend to diminish what I’m going through because I don’t want to take away from other’s experiences. In 2018, I want to work on this delivery. I often forget that though, yes, someone does have it worse off I still went through debilitating pain every second of the day and am now dealing with the repercussions of pain, medications, and brain surgery. I should feel proud that I woke up every day and faced TN and in 2018 I want to talk about my experiences with confidence, rather than fear of minimizing someone’s own story. Everyone’s story is important, and that goes for mine too.

Nick's Word: Battle

I chose battle because Trigeminal Neuralgia is a constant battle. It’s a constant battle that has many mini battles for some that suffer its battles like going to a family party, taking a shower, or just going to work and school. This battle is horrible and it takes a lot out of all of us but at the end of the day it's a battle we’re all committed to win! In 2018, I want to help others win their TN Battle too!

Ellie’s Word: Ouch!

It comes as no surprise - trigeminal neuralgia hurts! When doctors have told me that “we are running out of options” or that “there is not much more we can do,” that hurts just as much, but in a different way. The thing is, a well-educated patient knows that we are never out of
options. This year, I’m going to do more research on possible medication options, pain management techniques, and continue to explore surgical options. In 2018, I’m going to advocate for myself when I know a treatment plan isn’t working, and walk into appointments with more knowledge than ever!

**Brandi’s Word:** Unrelenting

I describe my facial pain as unrelenting simply because it is always there. My neuropathic facial pain is the result of nerve damage from an oral surgery. Therefore, my pain is constant and persistent. It does not yield, it is an ever present entity in my life and it shows no mercy. I’ve struggled tremendously knowing that there are no clear treatment options for me and that it’s all basically trial and error as the damage progresses.

Coming to terms with my lack of options and consequently, my limitations, has been one of the hardest aspects of adjusting to life with TN. This year, my goal is to be more patient with myself. Specifically, to be more flexible with my expectations of my abilities and also be more forgiving of myself if I can’t do as I once did. Sometimes we all need to go a little easier on ourselves. I figure if I give myself a break, maybe my facial pain will also.

**Chris’s Word:** Torture

I use the word torture to describe my experience with Trigeminal Neuralgia. I would also like to note that I use this word sparingly after a long history of other health issues that stemmed from brain cancer. It took a long time to find a doctor that would actually attempt to treat me, and even then the treatments only lasted a handful of months. After brain cancer and around 17 surgeries, I knew how to fight but did not know if I had it in me. I wished back then that I could trade my TN for the cancer, my TN was so much more painful. I even contemplated ending the pain on my own terms. However, I ended up finding a doctor that was willing to work with me and helped me get the pain under control through surgeries. It was a long and torturous experience, but I wouldn’t change it even if I could.

**Steph’s Word:** Debilitating

No one could stop me from doing anything I set my mind to. I had life in the palm of my hand. Then, I was diagnosed with Trigeminal Neuralgia. Despite my ever growing will to push on, I found TN very debilitating. It stopped me dead in my tracks. Some attacks were short, other times the pain hung around for days, one debilitating strike after another. But, I educated myself and still continue to do so, to take back my life the best I can. To overcome the debilitating pain my TN causes me I take better care of myself, prepare against triggers, and continue to learn new ways to control the pain. For 2018, I have made a promise to myself to continue these new patterns and take my life back so that I can eliminate the word, debilitating, from my TN vocabulary.

**Mandi’s Word:** Lonely

I used the word lonely to describe TN because there are many times living with any chronic illness can be lonely and isolating. Often, I find it easier to hide my pain, live behind a smile, and not share my experiences with TN on a daily basis. Yet, when I do that, I experience the feelings of loneliness and isolation and I feel as though others do not understand my pain and my life with TN. I plan to overcome that in 2018 by sharing more and being honest about how I am feeling. I plan to not answer, “I am ok” when people ask how I am feeling. I plan to talk about my pain and my life more to friends and family. My way to overcome loneliness and isolation is to share more, talk more, and be more present overall. The more open I can be, I believe I will continue to build understanding and support. By not allowing TN to make me feel alone, I will overcome that aspect of TN in 2018!!

The YPC knows that TN is not easy, but we are determined to push through 2018 with hope and tenacity. We hope that however you describe Trigeminal Neuralgia, you will find a way to celebrate life and push forward every day!
Name: Tina Harris
Age: 37
Where do you live? Overland Park, KS
How old were you when you first experienced facial pain? 30
How old were you when you were diagnosed? 36

What was your diagnosis? Initially in my early 30’s it was TMJD, then just Facial Pain. Then after a visit to the ER, in which I couldn’t speak (Dec 10, 2016) and was the worst pain I’d ever experienced. A neurologist diagnosed me with trigeminal neuralgia. Subsequently it was determined that my primary physician had disregarded the TN diagnosis several years ago.

Have you had any procedures? Sphenopalatine Ganglion nerve blocks, Tx360 (similar to the nerve block), Occipital Nerve Blocks. Hypnosis isn’t a procedure, but I tried that.

What do you do for fun? I like taking classes, such as yoga or crafting. I enjoy playing Scrabble or Cards Against Humanity or watching movies, hiking and having dinner with friends. I visited a llama farm nearby which was fun. I enjoy helping people in the TN Facebook groups, also. I used to be a social worker and it gives me joy to help others who are newly diagnosed and trying to navigate.

I also volunteer sometimes. Some of my friends that know about TN will go with me to parties, and are kind enough to understand that I may leave the party early or want to step aside and just be with them, rather than a sea of faces that will require me to talk more.

What has TN taught you? To take advantage of the good days. Try to live them to the fullest. Also I’ve learned to be kind to myself. One day I called my friend and said I just need to hear from you that I can get through today, remind me. So, learning to tell people what I need from them, since they are often clueless.

Describe TN in one word. Evil

How do you plan to overcome TN and your describing word in 2018? I may be losing my job of 15 years, come 2018, so Determination is how I plan to overcome TN as far as not letting it win by taking yet another thing from me in life. I just attained a very high level of certification in medical coding. I am going to work hard to get a job in that field that allows me to work from home. I am quite driven, but so are we all, because survival is wrapped up in that. I would also add that along the way, as we feel like we are surviving, sometimes we have days that we will also “thrive”, too!

My plan to overcome it? My current medication regimen is working well to keep my pain low on most days. On rough days the breakthrough meds help also. If they cease to work well in 2018, I am more than likely going to have Dr. Ken Casey do an MVD on me.

Young Patient Profile

Want to see what else the Young Patients Committee is up to in 2018? Check out these sites and connect with us!

On social media:
www.facebook.com/tnaypc  
www.twitter.com/youngpatients  
www.instagram.com/tnypc

For cool swag:
http://www.cafepress.com/young_patients_committee  
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https://www.etsy.com/shop/TealRibbonCrafts?ref=pr_shop_more
The following individuals joined or renewed their FPA membership between September – November 2017

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- Judy Bedford
- James Blodgett
- Richard Boosinger
- Osvaldo Brusco
- Nancy Bryant
- Robert Chernow
- Bronwyn Cowell
- Marilyn Dixon
- Mary Echelberger
- Allan Enis
- Richard Fishman
- Susan Folchi
- Matthew Gaffney
- Lawrence Goodman
- Suzanne Gregory
- Mary Jo Griffin
- Roger Guernsey
- Mary Hanley
- Doris Harts
- Jane Irving
- Mary Ann Kelly
- Judy Lamont
- Judith Levy
- Cindy Lincoln
- Michael Logan
- Aria Magi
- Barbara Manning
- Dale McKinney
- Patrick Muri
- Robert Musser
- Phyllis Ogof
- Janet O'Neil
- Laurie Rauch
- Peter Rubin
- Pearl Schulsion
- Susan Seltzer
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- Erin Silvert-Noftle
- Ina Slutsky
- David Smalley
- Deann Speltz
- Sandra Sussman
- Gloria Thomas
- Rose Tuozzola
- Ted Tylaska
- Kathleen Warren
- Esther Worthington
- Yifu Zhu

**OCT:**
- Lollie Abramson
- Helen Babyak
- Nellie Barg
- Ann Clayton
- Mary Cox
- Tony Di Bona
- Donald Dillinger
- Tom Evert
- David Glyn
- Cheryl Handren
- Terry Hull
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- Mary Lou Peterson
- Mary Jane Pych
- David Rasp
- Susan Reynolds
- Alison Rosenberg
- Janet Stubbs
- Joyce Tyler
- Susan Zeman

**NOV:**
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FPA’s Memorial Tribute Fund

There are special people in our lives we treasure. Increasingly, FPA supporters are making gifts in honor or in memory of such people. These thoughtful gifts are acknowledged with a special letter of thanks, are tax-deductible, and support FPA’s growing initiatives on behalf of TN patients and families. We are delighted to share recent Memorial Tribute gifts received from Sept. 1 through Nov. 30, 2017:

**In Honor:**

All Facial Pain Sufferers  
Cassandra Estey

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Adele F. Abramson

Dr. John Alksne  
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My daughter, Julie  
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Rebekah Urban  
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Kay E. Kimball

Jane Lawrence  
Justin Ketchel  
Don Smith  
Cynthia Zujkowski

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Grace Timblin  
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FPA patient-physician based conferences present a wide scope of information for those who suffer with neuropathic facial pain including trigeminal neuralgia. We hope to advance your care by connecting you with some of the leading experts in this field. Facial Pain Association conferences provide a unique opportunity for people to learn, connect and share with patients and medical experts.

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

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

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

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