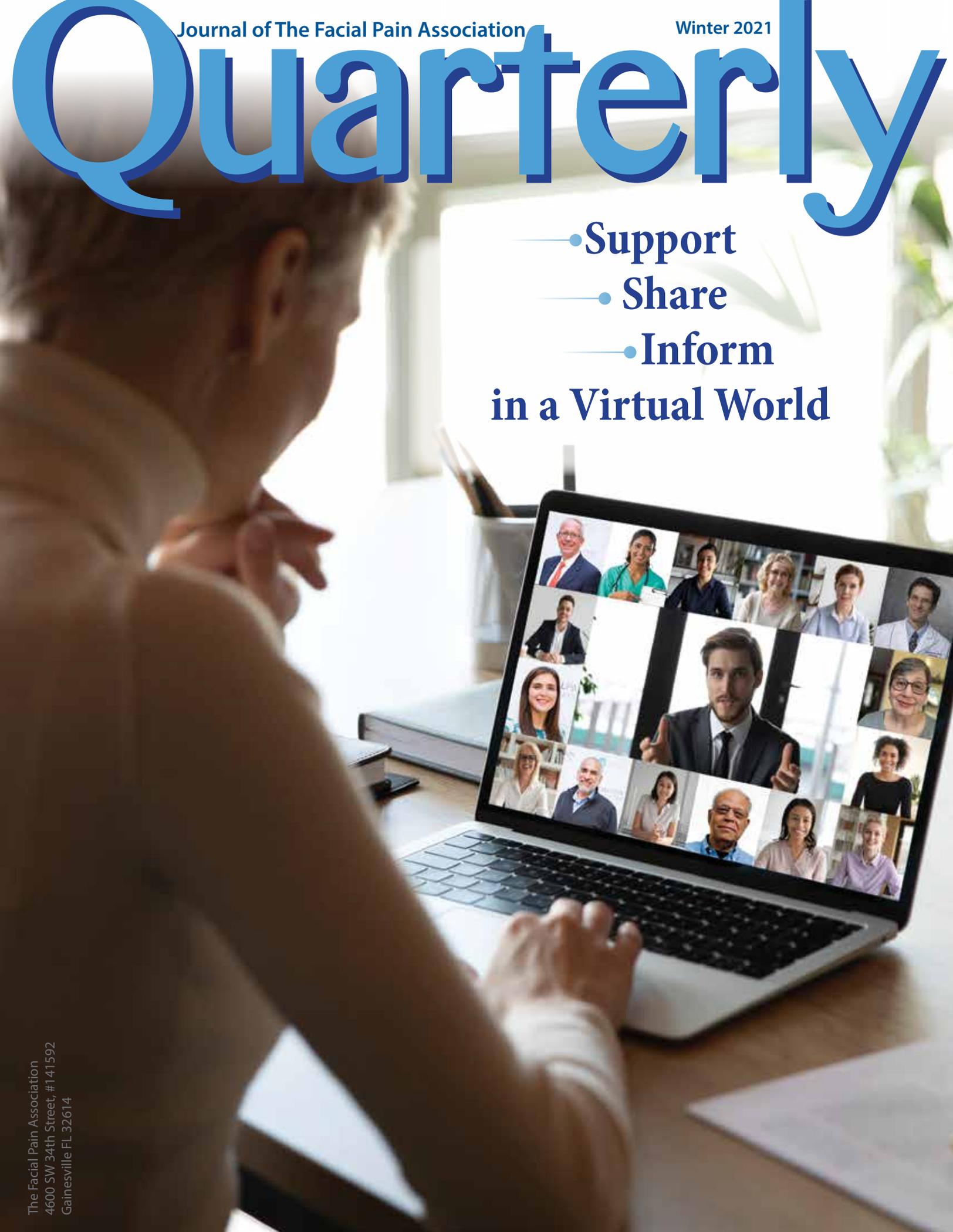


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In this issue many contributors reference the rise of virtual communication. Will this new aspect of life remain after the pandemic is gone? Time will be the judge, but for now, many tools enable all of us to stay connected and continue to receive the services and support we rely on.

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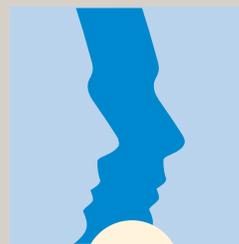
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From the Chairman of the Board

Although this has been a difficult year for nearly everyone, I'm pleased to report that the FPA made great progress toward its mission of providing information and support to those with facial neuropathic pain, their caregivers and the medical community that supports us. And this terrific progress was due to many of you.

There were many FPA achievements this past year, and four that I'd like to highlight. First, the FPA transitioned to become a virtual organization (we started this before Covid hit), which allows us to lower costs and staff the organization with the best talent we can find regardless of their location. Second, a Peer Mentor Corps was created and staffed with 27 volunteers to add another important dimension to the breadth of support we are able to provide. Third, *Facial Pain: A 21st Century Guide For People With Trigeminal Neuropathic Pain* was published. It was three years in the making, and it is likely the most comprehensive book on this topic in the world. Finally, the FPA hosted its first Virtual Conference with close to 1,000 attendees from 47 states and 14 countries. Not only did this event receive outstanding praise from its attendees and participants, it was an incredibly important big, first step in developing our ability to reach more people in our community through this format.

Whew, I feel like I'm riding on the *Little Engine That Could!*

How did all of this happen? Our small staff led by our new CEO, Allison Feldman, deserves most of the credit. They work tirelessly for our community. On top of that, we have ~ 85 volunteers who are members of our Medical Advisory Board, Board of Directors, Support Group leaders,

Peer Mentors, leaders of our Young Patient Committee and others. And last, but certainly not least, we are extremely fortunate to have had more than 1,500 people generously donate to our cause. Without these donations, we'd vanish.

As we enter 2021, we dream about being even more helpful and valuable to those in our community. For example, this past year we cataloged all of our important information assets (e.g., studies, articles, videos) by topic in a manner that allows staff, Support Group Leaders and Peer Mentors to provide you with the resources you need. In 2021, we will launch a new FPA website that will enable you to retrieve some of this vital information directly and be even better at helping you answer your most pressing questions. (But remember, even with an improved website, we want to hear from you directly.)

Those of us with trigeminal neuropathic pain are in an unenviable position. But there are many world-class medical professionals dedicating their lives to helping us, and research is being conducted everyday to find new solutions to our problem. Furthermore, there are many things to try to stop, or at least reduce, the pain.

And always remember that you are not alone. We at the FPA stand ready to help, as do many other members of our community.



David Meyers, Chairman of the Board
The Facial Pain Association



Jeffrey A. Brown, MD

The MAB Corner

The Road Out of Pain

There is a scene in the futuristic movie, "2001- A Space Odyssey" in which one of the voyageurs, long into his spaceship's journey in search of the mysterious planetary origins of a moon-found monolith, watches a birthday greeting from his family on a telelink. The film gives one no insight into the thoughts of a man so isolated on a trip to the unknown upon relating to his family only by a two-dimensional screen. As a young man in 1968 I wondered how anyone could tolerate such an existence.

Now, in 2020, we are all of us presented with such a burden. Many of you, like me, sat at your Thanksgiving table facing the flat plated screen depicting the image of one whom you considered close but could not touch. And just before Thanksgiving the facial pain association presented its first virtual national conference. Unlike every other year for the past 25 years, we were all "faced" with two-dimensional views of three-dimensional speakers. Unlike every other year for the past 25 years we could not pull up alongside one of those speakers to ask the one burning question at the fore of our thoughts. "What can one do for my problem?"

There is an inherent isolation embedded in the nature of zoom, Webex, FaceTime, mobile phone communication, something missing

in the connection-the invisible touch of humanity. Yet, the onset of telecommunication/telemedicine has also allowed a patient a thousand miles distant to learn a diagnosis, be assigned a plan for treatment and conclude with a sense of hope that would hardly have been possible in the era in which in-person travel was required for a doctor's office visit. One is no longer a geographic captive. The journey towards the recovery of good health can now begin with a digitized transmission, almost as if being transported by that spaceship to Jupiter.

When the Pilgrims celebrated their first Thanksgiving, they had already lost half of their friends and colleagues to illness, yet they had the urge to give thanks with a celebration of what provender they could set on their tables. And, yes they invited King Massasoit of the local tribe, the Wampanoag Indians. It did not end well. Massasoit's second son was destined to lead his tribe in the bloodiest of Indian-Settler wars.

History and mythology are often conflated. What is wonderful can become horrible and vice versa.

Why bring out the real story, but to emphasize that the road out of pain is in reality not smooth nor straight, but it is a path that the facial pain organization is here to guide each of you along to a destiny we hope is one of joy and comfort. ■



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2020 FPA Conference Recap



By
Allison Feldman,
Facial Pain Association CEO

On Saturday, November 7th, FPA held our first virtual conference. Close to 1,000 attendees from 47 states and 14 countries participated in a full day of education.

After a welcome from FPA Chairman David Meyers and FPA Medical Advisory Board Chairman Dr. Jeffrey Brown, Dr. Donald Nixdorf and Dr. Michael Lim provided an overview of diagnosis and treatment for neuropathic facial pain. Dr. Brown and Dr. Raymond Sekula then gave a presentation on microvascular decompression surgery.

Next, Dr. Steven Chang and Dr. Ken Casey discussed radiation treatment and other non-surgical treatments. FPA Board member Megan Hamilton moderated an informative discussion about decision-making with Dr. Mark Linskey and Dr. Richard Zimmerman, followed by a presentation of FPA programs and services by FPA CEO Allison Feldman. Dr. Ali Makki and Dr. Julie Pilitsis then gave presentations on pain management. FPA Board members Jeffrey Fogel and Anne Ciemnecki next answered some top questions about medical marijuana for facial pain.

Dr. Gary Stanton followed with a presentation on acupuncture, after which Dr. Leesa Scott-Morrow discussed mental health and coping. The conference was concluded with a moving presentation by FPA Young Patients Committee member, Kenzie Winslow and closing remarks from Dr. Brown and Allison Feldman. Our wonderful moderators for the day were FPA board members Ally Kubik and Anne Ciemnecki.

The post- event survey provided us with valuable data and feedback which will enable us to make future events even more relevant to you. We were pleased to find that:

- **74%** of survey respondents reported that they had not previously attended an FPA conference
- **97%** say the cost of the event was either exactly right or that they got their money's worth and more
- Attendees report an **87%** likely chance they would recommend our conference to a person with facial pain, and an **85%** likely chance they themselves would attend another.

It was also helpful to learn that:

- Top requests for future virtual events include more time for Q&A, time for breaks, small group sessions
- 26% say they will only attend conferences virtually in the future

The comment below tells us how valuable this event was for many of the attendees.

"I just wanted to say that this conference for me personally was life changing. I felt for once not alone. Like there were doctors who understood me, like I shouldn't be afraid to be the expert or to fight for what I need. So really, thank you so much more than I can ever say! I can't thank you enough again!" ■



An uncommonly common: Glossopharyngeal Neuralgia



Written By P.M.Singh, Manpreet Kaur and Anjan Trikha

Reprinted Courtesy of the NIH

Glossopharyngeal neuralgia is a relatively rare condition characterized by severe, paroxysmal episodes of pain localized to the external ear canal, the base of the tongue, the tonsil or the area beneath the angle of the jaw. This pain is often confused with Trigeminal Neuralgia and mistreated. There are various diagnostic and management dilemmas which are herein addressed in this review.

Neuropathic pain is defined as non-nociceptive pain or pain that is not related to activation of pain receptor cells in any part of the body. It is a type of pain caused by a lesion or disease of the somatosensory system. [1]

Glossopharyngeal neuralgia (GPN) is a condition causing throat, ear, and neck pain. The International Association for the Study of Pain (IASP) defines it as sudden, severe, brief, recurrent pain in the anatomical distribution of the glossopharyngeal nerve. [2] Classically, it is described as a

severe transient stabbing pain experienced in the ear, base of the tongue, tonsillar fossa, or beneath the angle of the jaw. However, the location of the pain can have significantly varied distribution and overlap amongst the nerves supplying the face (trigeminal, vagal, facial). [3] The unusual presentations are cardiac arrhythmias associated with pain episodes, fear to eat (which may be the precipitating cause for pain episode), and syncope. [4]

It must be emphasized that GPN is not as uncommon as reported in the literature due to difficulties in diagnosis, unawareness of the disease and more so with increasing number of patients with styalgia (pain due to elongated styloid process). It is often compared with trigeminal neuralgia in presentation and incidence due to significant overlap of symptoms and thus causing a diagnostic dilemma. [3]

Historical Aspects

In 1910, Weisenburg first described GPN as a cause of Tic douloureux when a patient presented to him with lancinating pain of the throat and the ear. [5] In 1921, Harris

“Glossopharyngeal” Continued from page 5

coined the term “glossopharyngeal neuralgia” [6] describing it as a painful syndrome characterized by paroxysms of unilateral and severe lancinating pain in the distribution of the nerve, which may be elicited by stimulation of trigger points in regions of the nerve. The pain may be spontaneous or precipitated by a variety of actions that stimulate the region supplied by the glossopharyngeal nerve namely yawning, coughing, swallowing, and talking. In 1933, Reichert [7] recognized the tympanic branch (Jacobson’s Nerve) of glossopharyngeal nerve as a cause of ear pain in GPN. Wortis et al. (1942) first described GPN in association with cardiac arrest and syncope that are unusual presentations of GPN. [4,7]

Anatomical Aspects

Glossopharyngeal nerve is a mixed cranial nerve with both sensory and motor components. It receives somatic sensory fibers from oropharynx, posterior third of the tongue, Eustachian tube, middle ear, and mastoid. The sensory supply to the middle ear and mastoid passes along the tympanic branch or Jacobson’s nerve. The glossopharyngeal nerve also receives special sensory fibers for taste in the posterior third of the tongue as well as chemoreceptor and baroreceptor afferent inputs from the carotid body and carotid sinuses respectively. [16] The motor component supplies the striated muscle stylopharyngeus and secretomotor parasympathetic fibers to the parotid gland. The other important branch is the carotid sinus nerve (Nerve of Hering) that supplies the carotid body and carotid sinus. It conveys chemoreceptor and stretch baroreceptor information centrally for respiratory, circulatory reflex function and may be responsible for arrhythmogenicity of GPN.

Clinical Presentation

The characteristics of GPN are similar to trigeminal neuralgia with some differences, which must be identified for the correct diagnosis and treatment.

Clusters of unilateral attacks of sharp, stabbing, and shooting pain localized in the throat radiating to the ear or vice versa are characteristic of GPN. The distribution of pain is diagnostic: The pain shoots from the pharynx, tonsil, and posterior tongue base upwards to the eustachian tube and the inner ear or to the mandibular angle [Table 1]. [15]

The pain of GPN is subtle in onset with a mean duration of 30 sec. It is excruciating and can recur after a brief period without pain, but an ache may persist in the same region. [16] Many crises can reoccur over days, weeks, or



months, [17] and usually the attacks occur during the day. Swallowing is the most common trigger factor, and cold liquids seem especially to induce pain. Chewing, talking, sneezing, cleaning the throat, and touching the gums or oral mucosa, even sudden movements of the head, raising the arm on the side of the pain, and the lateral movement of the jaw may also trigger the paroxysms. Several patients found that touching the external auditory canal, the side of the neck, and the skin anterior to the ear triggered the pain on the same side. [18]

The trigger zone is recognized late as compared to trigeminal neuralgia: therefore, it may not be found during initial examination. [19] Some patients can have the pain triggered by sweet, acid, cold or hot food. [20] Other rare features are tinnitus, vomiting, vertigo, swelling, sensation, and involuntary movements. [7] GPN can sometimes be confused with intermedius neuralgia when the only symptom is sensory loss at the ear (Jacobson’s neuralgia). Temporal arthritis can have a similar pain. Asystole, convulsions, and syncope are associated with GPN in many patients described in the literature, and this condition is called vagoglossopharyngeal neuralgia (VN). [7,21] These reactions occur due to the complex anatomical relationship between the intermedius, vagus, and glossopharyngeal nerves leading to difficulties during neurosurgical assessment. [22]

Most of the glossopharyngeal neuralgia is idiopathic, but they may be associated with cerebellopontine angle masses, oropharyngeal tumors, arachnoiditis, stylohyoid ligament ossification, multiple sclerosis, [23] and vascular malformation. [24] GPN can be associated with trigeminal neuralgia [25,26] or be a part of combined hyperactive dysfunction syndrome [27] or be associated with Chiari type I malformation. [28]

Life threatening complications of GPN

Harris et al. (1921)[6] reported that GPN could be associated with cardiac dysrhythmia and instability. This relationship is well-accepted and has been documented by many authors. The various reports and case studies have been compiled and summarized by Ferrante et al. [29] Intense irritability and hyper-stimulation of glossopharyngeal nerve feedback onto the nucleus of the tractus solitaries of the midbrain and via collaterals reach the dorsal motor nucleus of the vagus nerve. This activation of this abnormal loop during severe neuralgic pain would be responsible for heightened vagal response as cardiac dysrhythmia, bradycardia, and hypotension, with cerebral hypoxia, slowing of EEG activity, syncope, and convulsions. Convulsive movements, limb clonus, automatic smacking movements of the lips, and upward turning of the eyes are signs of cerebral hypoxia induced by bradycardia. [10,11,30,31] The cardiovascular phenomenon is seen during the pain attack or immediately following it. Both pharmacotherapy and surgical treatment eliminates these. There is a subset of patients with demonstrable cardiac manifestations without typical neuralgic symptoms who have responded very well to glossopharyngeal nerve avulsion or MVD. Such syndromes have been called non-neuralgic GPN, [32] in recognition of the fact that glossopharyngeal nerve irritability may not always give rise to a pain.



Types

There have been multiple attempts to classify GPN on different basis. The various ways the disease has been classified are:

Anatomical Area Involved [7]

Otitic type – pain in and around the ear. This is commoner form of the two in the anatomical classification. The pain is often described in relation to the ear. The pain can be of any type, ranging from burning, sharp shooting, shock-like, pressure, pinprick, etc.

Oropharyngeal – pain is in and around throat and face region. This form has more varied distribution, and significant overlap may occur with other cranial nerve distribution areas.

The International Headache Society (IHS) Classification of GPN [33]

The basis of classification is that pain occurs as episodic or constant basal pain that persists between the episodes of peaks and troughs of pain. The types proposed by IHS are:

- Classical GPN-episodic pain
- Symptomatic GPN-continuous pain, commoner

Cause-based Classifications

Idiopathic type – No demonstrable lesion is found in these cases. Most often, these are attributed to nerve ganglion compression by vessel or by compression of glossopharyngeal nerve as it exits or enters the brainstem. This is supported by the fact that microvascular decompression (MVD) eliminates GPN symptomatology. Most of the cases belong to this type of GPN.

Secondary type (Symptomatic) – In this, a demonstrable lesion can be found, which includes trauma, neoplasm, infection, vascular malformation, or elongated styloid process [Table 2]. Secondary nature of GPN is suspected when there are neurological deficits, like numbness in the distribution of glossopharyngeal nerve, absence of symptom-free interval in between the attacks, and pain distribution different from glossopharyngeal nerve area. [34]

“Glossopharyngeal” Continued on page 8



Diagnosis

The diagnosis of GPN is strictly clinical as no imaging findings or other testing can reliably link to the syndrome. The first priority is to ascertain the diagnosis of neuralgia and exclude other causes of pain due to inflammation and neoplasia. The description of pain will help. Neuralgic pain is severe, episodic, and lancinating and of short duration, which may be associated with intervening periods of a low-grade dull ache. In contrast, inflammatory or neoplastic pain is more constant, of longer duration, and of deep-seated boring quality. Next, the distribution of the pain has to be mapped out. This is important for two reasons, firstly, there is a need to know if the neuralgic pain is typically glossopharyngeal or it involves the other cranial nerves like the trigeminal nerve or nervus intermedius.

In any pain with typical glossopharyngeal distribution, ascertain its predominant distribution: Tympanic or oropharyngeal. It is important to determine the site of any trigger points; check if the trigger point is in the oropharyngeal area or is in the ear? Is the neuralgic pain precipitated by oral activities e.g. swallowing, talking, yawning, or it is brought about by hearing activities e.g. pain on exposure to loud sounds. Are there any otologic symptoms? By evaluating the patient on above lines, GPN can be differentiated into classical/symptomatic and otitic/non-otitic type.

If the patient does not have pain at that point of time, but anticipates that he would have it later in the day, the trigger

point may be injected with lignocaine 2% or bupivacaine 0.5% to see if it can avert another attack of pain. If the symptoms are primarily otologic, inject lignocaine 2% or bupivacaine 0.5% into the external auditory meatus to see if it abolishes the pain that is present at that time or it will avert a subsequent attack. Lastly, determine whether it is idiopathic type or there is a secondary cause. Differential diagnosis of secondary GPN [Table 2] should be checked for. The most important cause of secondary GPN is Eagle's syndrome due to either an elongated styloid process or calcification of the stylohyoid ligament. In history, look for: trauma, radiation, surgery, inflammation, and demyelination. Pathology related to base of the skull, head and neck, nasopharynx, [35] and teeth [36,37] etc. can be the culprit of secondary GPN.

Investigations

Laboratory testing includes complete blood count, erythrocyte sedimentation rate, anti-nuclear antibody, and automated serum chemistry that are done to rule out occult systemic disease like temporal arteritis, infection, inflammation, and malignancy. Imaging of the brain includes non-contrast MRI, [38] magnetic resonance angiography (MRA), and 3-dimensional computed tomography angiography (3D-CTA), which is useful to rule out nerve compression by a vessel[39] or any tumor or by any other bony structure or signs of demyelination. [40] High resolution MRI and subsequent image processing with 3D constructive interference in steady state (CISS) provides precise diagnosis of potential neurovascular

compression of various cranial nerves (especially vagal, glossopharyngeal, and trigeminal nerves) and hence are the latest promising tools. [41] MRA allows visualization of the anatomical relationship between the nerves and the vessels in supraolivary fossa. Special attention should be paid to the posterior inferior cerebellar artery (PICA), the anterior inferior cerebellar artery (AICA), and their courses as these vessels often course in the supraolivary fossa, which is the site of origin of glossopharyngeal nerve. Three radiological findings are also important for diagnosing GPN as vascular compression syndrome. They are, 1) High-origin PICA, 2) The PICA making upward loop, 3) The PICA coursing and compressing the supraolivary fossa. [42] However, if the offending vessel is AICA, GPN is difficult to diagnose before surgery because of its normal anatomy. [43] In patients suspected of peripheral origin GPN and responding to therapy may not be subjected to an MRI scan.

Imaging of neck is done to rule out the hypo pharynx, larynx, or piriform sinus. Panoramic radiograph should be taken to rule out Eagle's syndrome [44]. An electrocardiogram (ECG) should be done (during pain attack) to rule out associated arrhythmias. [45]

Treatment

Treatment for GPN can be non-surgical or surgical.

Non-Surgical Treatment

Pharmacotherapy for GPN

Pharmacotherapy forms the first line of treatment for GPN. The medications of choice are carbamazepine, gabapentin, and pregabalin although theoretically any membrane stabilizer can be used. [47] In addition, low doses of selective serotonin reuptake inhibitors (SSRI) and vitamin B12 can be used. Baseline complete blood count, blood chemistry, and urinalysis are obtained before initiation of carbamazepine that forms the first line and gabapentin that is reasonable alternative for the treatment of GPN.

The use of NSAIDS is not routinely recommended for treating neuralgic pain. [48] There are isolated reports of neuralgia responsive to NSAIDS and opioids. It is postulated that neuralgia responsive to NSAIDS is more likely to be due to some unknown acute inflammation. Opioids have been used as an adjuvant to the frontline neurogenic agents with limited success. [49] However, these medications have to be titrated to effective levels, and gradual tolerance may develop with their prolonged use. Most often, the disease shows relapsing and remitting pattern, with an acceptable pain relief in around 2 months. These medications can be gradually tapered down to achieve much lower maintenance doses. These remissions can last from months to years. On a relapse, resteping

up of dosages can be tried. If, however, adequate pain relief is not achieved, a different agent can be tried. One must have a lower threshold for stylectomy in bilateral styalgia. A large number of patients with neuropathic pain are currently treated with either two or multiple agents in combination. There are limited studies on pharmacologic and non-pharmacologic treatment combinations, hence an additional benefit by add-on physical therapy or psychological treatments is doubtful. [50] The target of medical therapy should be to achieve pain relief. Leading to minimal affliction of daily activities. The bad prognostic signs are – bilateral, GPN, constant pain, or multiple daily bouts of pain.

The target of medical therapy should be to achieve pain relief.

Glossopharyngeal nerve blocks

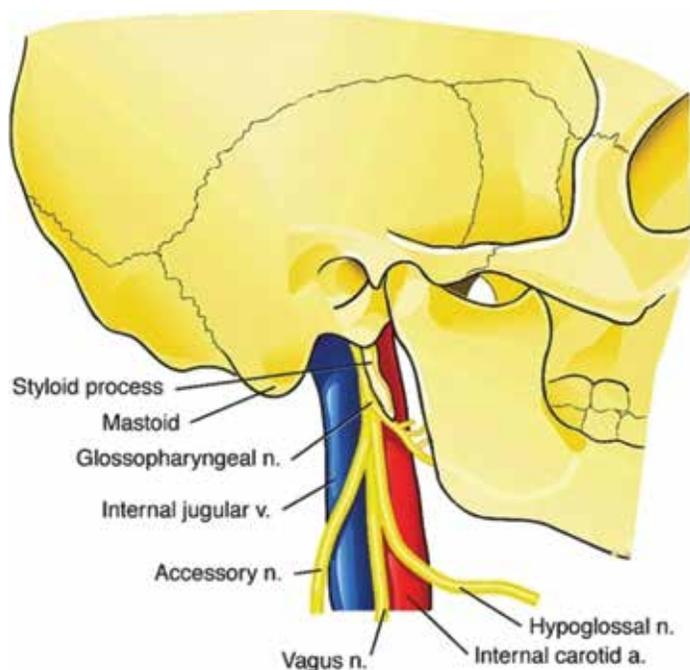
Glossopharyngeal nerve block can be used for the evaluation of atypical facial pain, treatment of GPN, and intractable pain caused by pharyngeal cancer. [51] These nerve blocks are excellent adjunct to the pharmacologic treatment of GPN, ensuring rapid palliation of pain. They can be performed with either non-neurolytic agents (local anesthesia agents) with or without additives (steroid, ketamine, etc.) or with neurolytic agents (phenol, alcohol, glycerol, etc.) LA blocks are used both, diagnostic and therapeutic purposes; thus establishing the diagnosis of GPN. A diagnostic block is given as one of the first interventions to label any lower facial pain simulating GPN as true GPN. Neurolytic agents are safe alternative to more invasive procedures.

The various approaches used to block glossopharyngeal nerve are [52]:

Intra-oral approach: This block is given using a distally bent spinal needle (approximately 25 degrees) up to a depth of 0.5 cm through the mucosa at the lower lateral portion of the posterior tonsillar pillar. [53]

"Glossopharyngeal" Continued on page 10

Extra-oral approach: This block is given at the midpoint of an imaginary line, running from the mastoid process to the angle of the mandible, at a depth of up to 3 cm. The nerve lies immediately below the styloid process at the point [See Illustration]. This technique is simpler to perform and is more comfortable to the patient. [54]



An extra-oral block is preferred for treatment of neuralgia as the intraoral block may spare the tympanic branch of glossopharyngeal nerve. Also, there is an increased likelihood of inadvertent tonsillar artery injection due to decreased dexterity in approaching the site of the block in the posterior part of the mouth in intra-oral approach.

Complications of glossopharyngeal nerve block

Intravascular injection can occur into the carotid artery or into the internal jugular vein. Difficulty in swallowing and hoarseness can result from the glossopharyngeal and vagus (recurrent laryngeal branch) nerve blocks, respectively. Bilateral GPN block can cause bilateral vocal cord paralysis, hence bilateral block is not recommended. The loss of parasympathetic outflow with vagus nerve blockade could cause tachycardia and hypertensive response. [51]

Surgical Therapy

Once the patient becomes refractory or intolerant to medications, surgery is the next treatment option. However, surgical therapy is associated with high morbidity of the patients and is limited to younger patients. These surgical procedures for the lesions may be classified as follows:

1. Peripheral procedures:
 - a. Extra cranial, such as direct surgical neurotomies or percutaneous radiofrequency, thermal rhizotomy [55-57]
 - b. Intracranial, such as direct section of glossopharyngeal and vagal nerves in the cerebello-pontine angle [58,59]
2. Central procedures, such as percutaneous or open trigeminal tractotomy-nucleotomy or Nucleus caudalis DREZ operation

These days, the best-established surgical treatments are MVD of vascular roots [60-62] and rhizotomy of the glossopharyngeal nerve with upper vagal nerve roots. [63] In essential GPN, the primary pathology, being vascular compression of the nerve roots, responds well to MVD. However, in secondary GPN, first address the underlying pathology: Tumor resection, posterior fossa decompression in Chiari malformation, embolization of an arteriovenous malformation, coagulation of choroid plexus overgrowth, stylectomy for Eagle's Syndrome. [34] In secondary GPN, when MVD is not possible, intracranial root section is considered curative and is most widely employed. In the largest case series by Rushton et al. [9] and in smaller series by Taha et al., [59] there were no recurrences after preganglionic section of the ninth and upper tenth nerve roots. However, sectioning of cranial nerve fibers IX-X, open or percutaneous tractotomy-nucleotomy is followed by severe and persistent dysphonia and dysphagia. [55,60,64] This is because all neutral destructive or ablative procedures carry the risk of neuritis, deafferentation pain, and neurovascular injury. [65]

With the refinements of microsurgical and anesthesiological techniques (Brainstem evoked potentials), MVD has proven to be an effective and safe available treatment and should be considered the first line treatment in drug-resistant GPN. [58] In a study by Resnic et al., [66] MVD provided complete pain relief in 76% of the cases and substantial improvement in a further 16%. Sampson et al, [63] found pain relief of more than 10 years by MVD, hence indicating its efficacy and safety even on long term follow-up. MVD should be considered when a patient experiences typical GPN symptoms and has a PICA loop near the glossopharyngeal nerve [42] and especially in patients with isolated symptom of throat pain. [14]

Extracranial neurotomy and percutaneous radiofrequency rhizotomy are restricted to those patients who have failed medical therapy and cannot tolerate an open intracranial procedure. Stylectomy done for elongated styloid process has been promising, once the central causes of GPN have been ruled out[67,68] and associated styloid enlargement is diagnosed.

Recently, various case reports have been published, which have shown beneficial effects of pulsed radiofrequency neurolysis (PRN) and gamma knife surgery (GKS). PRN is a non-destructive neuromodulatory method to treat both, idiopathic and secondary GPN. [69,70] Short pulses of radiofrequency energy, delivered at a constant temperature, procedure central and peripheral neuromodulatory effects. [71,72] In GKS system, an 80 GV dose is stereotactically directed to the isocenter with MR imaging-based target localization and 4-mm collimation. [73,74] It might serve as a potential alternative to other percutaneous techniques and surgical options for patients with secondary GPN. Stereotactic radiosurgery (SRS) with GKS system offers a less-invasive option for patients with GPN. Pollock and Boes have reported the largest series of patients (5 patients), with suspected GPN being treated with SRS directed at the glossopharyngeal and vagus nerves, within the jugular foramen with a failure rate of 40%. [74] The new techniques offer a promising direction that might spare patients from pain and potential morbidity of surgery.

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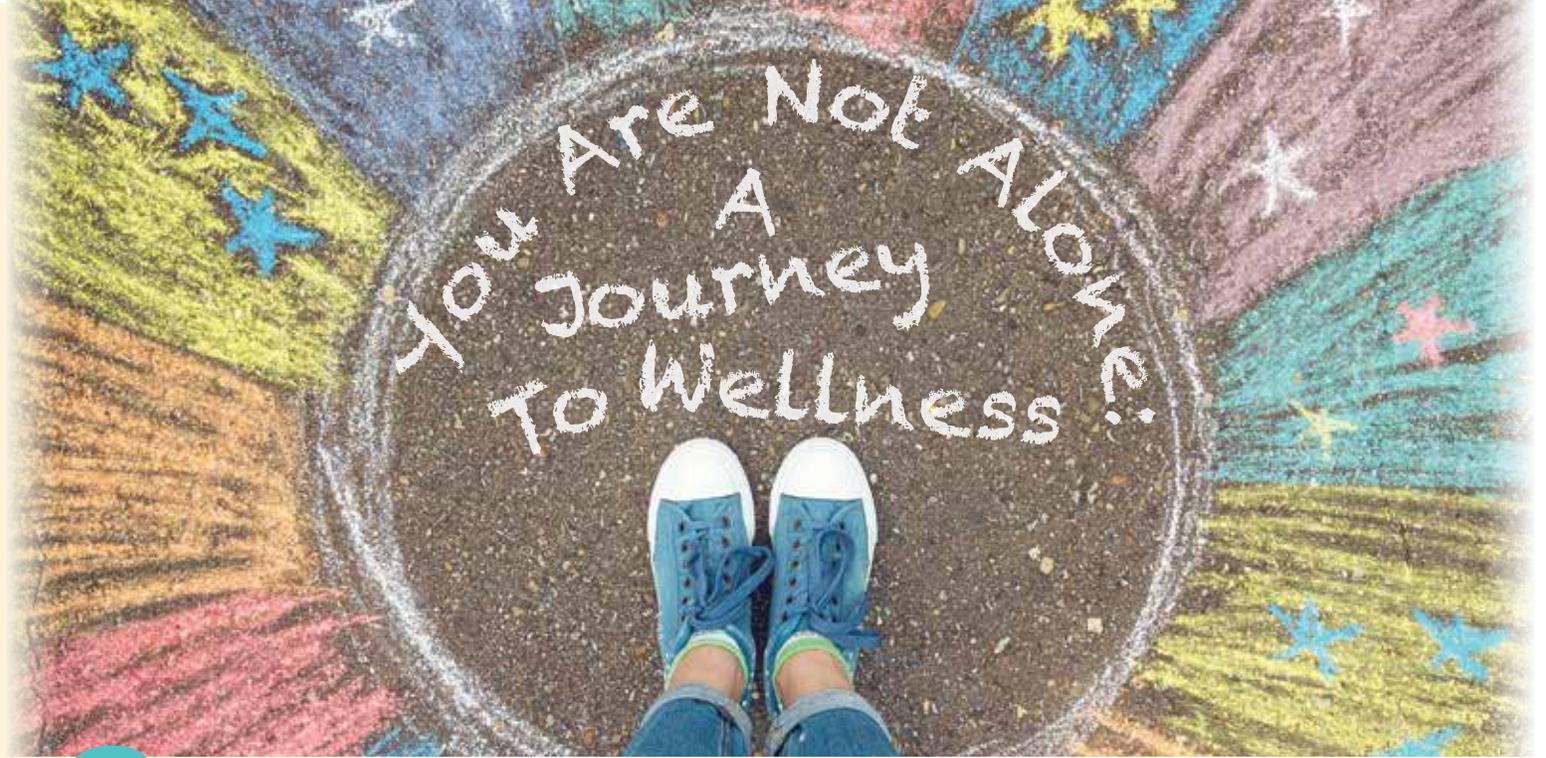
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Functioning through life with facial pain is difficult - we stress over everything. With the persistent worries of remembering medications, what the weather is going to be like, is what I'm going to do or where I'm going to be going to set off a pain attack? And, frankly, it's exhausting - both mentally and physically. With the new year starting, we want to remind everyone that wellness doesn't happen overnight, it's a journey. And we're right alongside you through it.

A Crisis Within a Crisis

Not only do we have chronic pain but we are in the midst of a global pandemic. This pandemic has forced us to stay home for the majority of the year. For many, it's been a time of angst and uncertainty. But, we can acknowledge that it's also been a time for self-reflection and rejuvenation. This

year has allowed us the opportunity to be present with loved ones, to be more conscious of our own health, and to take a moment to breathe. As we begin 2021, let's all remember to take the lessons we've learned in 2020 with us. Remember to take time for yourself daily, to have moments of gratitude, and to reflect.

Functioning But Still Suffering

We are going to school as a student or as a teacher. Our work commute may not be as far as it used to be, but the hours of work are piling up. Doctor visits are no longer in person and instead they're online, but the wait in the drive through of the pharmacy isn't getting any shorter. We are cooking dinner for the family or just barely making it to the table to eat at all. Oh, and don't forget the pain - how could we ever forget that?! We are living in extraordinary times and the chronic pain we have does not make it easy for us, yet we press on. While the rest of the world is getting a small taste of what it's like to be in our world, we've known this sort of life. How do we make the most of our time at home?

We have to get out of a functioning mindset and into a living mindset. This is especially important as we move into 2021. Though the world might not be totally back to normal, we can adapt to our new normal and focus on living our lives to the fullest. So if you're a teacher or a student, create a project on giving back to the community that you poured into during 2020. If you're still working from home, make a conscious effort to clock out at 5 PM, and spend an hour doing something you love like painting or listening to new music. When you're stuck in line at the pharmacy, use the alone time to make a list of things you're grateful for or listen to a new podcast. Whatever it is, start 2021 by focusing on living your life rather than going through the motions. It will lead to a more prosperous 2021!

Acknowledge the Good Days

It can be so easy to dwell on the pain we all feel, especially when it's been nagging you to no end. You've made it through all those other bad days, you are going to make it through this *"Not Alone" Continued on page 14*

“Not Alone” Continued from page 13

one too. If your only goal is to get out of bed for the day; do it and celebrate that accomplishment! You need to run to the store and you know it will cause a flare once you're home; do it and remember to celebrate that you accomplished your goal! Take each day one moment at a time and remember to acknowledge the good days. As we start to acknowledge and appreciate all the things we do on a daily basis in spite of our pain, we can also start to recognize how incredible we are. Don't forget to celebrate yourself!

Take Care Of Yourself

Eat a meal, take your meds, take a nap - these are all simple things that can be easily forgotten in a day. Set alarms so that you are reminded to do them, pick a notification that makes you happy - maybe your favorite TV show's theme song. When you hear the jingle to Friends, you know it's time to take your meds! It's also very important to read a book, take a bath, journal, snuggle with a pet, and unplug from the internet from time to time. All of these things help to relax

and unwind, to forget about the world around us for just the moment and escape to a place of happiness. Finding that happiness can help improve your thoughts and lighten the days that can often become dark. Finding your own slice of happiness will also empower you to speak up for yourself and to acknowledge to others how you're feeling. But, if you do find yourself in a dark day, you need to remember you are not alone and speak up to someone.

You Are Not Alone

It is incredibly important to reach out for support on both your good and your bad days. Trigeminal neuralgia is overwhelming on its own without all the extra stress of our current times. Remember that you can always call a loved one, message a friend, or join one of many virtual support groups. In a support group, we can all relate and you don't even have to leave the comfort of your own home. Though the people in a support group will never fully know your personal experience, we have been through

similar situations and are here to listen and lift one another when you are in need. You can ask questions in a judgement free zone, and it's likely someone there has been wondering or asked the same questions. The most important thing to remember is that you are truly never alone.

Are you looking to connect with other patients on a more private level? We have created both a YPC Facebook community and a private group where you can join discussions and connect with others like you. The Facial Pain Association also has multiple resources from peer mentorship, listings of upcoming support groups, to a library of information at your fingertips.

Useful links

 /tnypc

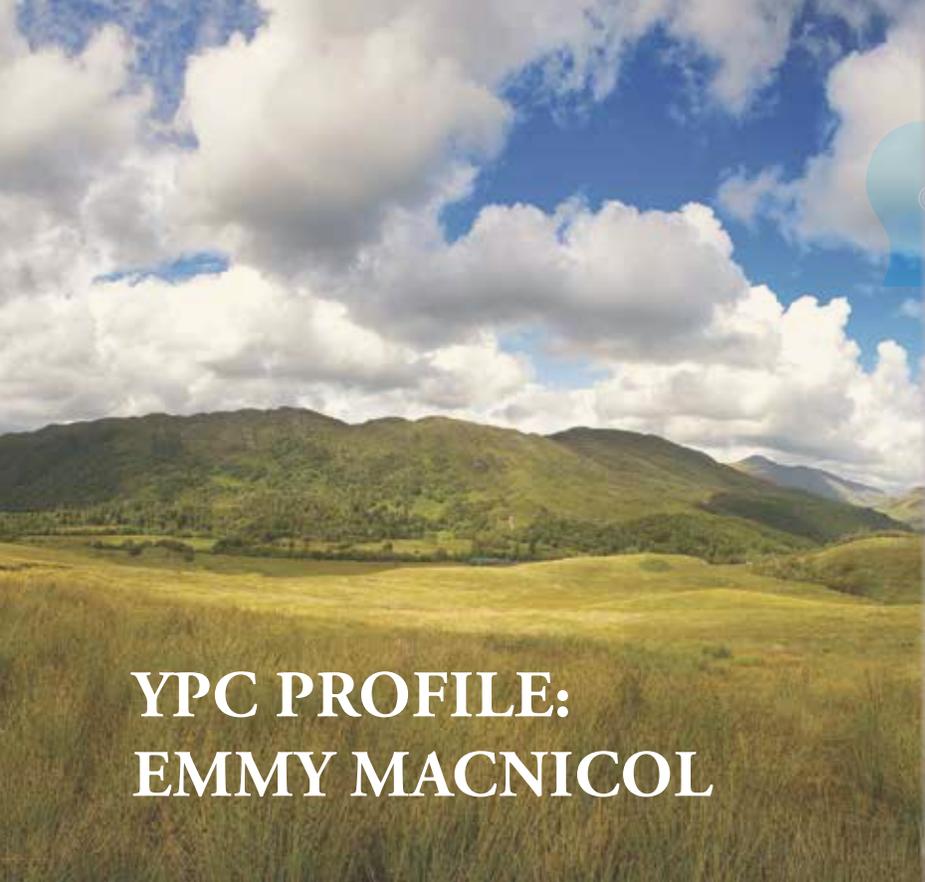
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 /tnaypc

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 www.facepain.org





YPC PROFILE: EMMY MACNICOL



How old are you? I am 29.

Where do you live? Scottish Highlands

When did you first experience neuralgia?

I first experienced Geniculate neuralgia at the age of 12 when playing school hockey, which progressed to include GPN at age 14.

What is/are your diagnosis?

I have a rare form of a genetic condition- Ehlers Danlos Syndrome and Chiari which doctors wonder whether it has caused the compressions resulting in neuralgia. Geniculate neuralgia and vagoglossopharyngeal are the facial pains I battle. Most recently TN started on my other side.

What do you do day to day?

Day to day, I am an undergrad student studying for my degree in cellular biology, with an avid interest in virology and genomics (all pre covid!). I'm just a geek at heart! Aside from studying, being a board member for the YPC is very dear to my heart, and I am truly dedicated to helping the community. I count myself as extremely blessed to be a part of the YPC board and will continue to strive to serve our fellow warriors!

What do you do in your free time?

In my free time, reading is one of my favourite hobbies...I am a true bibliophile! Any book related chat wanted? Come to me. After my stroke, I had to alter my hobbies as I was

an avid clarsach (traditional harp) player, cyclist and walker but now I love puzzles, baking, board games, listening to podcasts and speaking with my friends, wherever they may be in the world (I find the time differences can help when painsomnia hits!). Writing letters to those who are chronically ill and spending time with animals is something I enjoy very much too.

What has TN taught you?

Neuralgia has taught me that "nothing is impossible, for the word itself says I'm possible". It was hard to adapt to this way of life and navigating education whilst being 'different' from my peers, but I learnt to enjoy and value the small things so much more, which gives me a more grateful approach to life. Being bullied through school as a result of being sick taught me the value and power of true friends, those who stood by me are the ones who truly matter. I am blessed to have a non-judgemental personality, living

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life with an invisible illness taught me this quickly. Just because we may look okay, does not mean we are and so I see life through the perspective that everyone has a story. It helped me to forgive my bullies and all the judgemental people I have crossed paths with. Facial pain has taught me invaluable lessons that no school, no level of science could ever teach me.

What non-surgical procedures have you tried?

I have tried an array of non-surgical procedures; medications too many to count, nerve blocks, acupuncture, homeopathy, reflexology, reiki, psychology, tens therapy and radio-frequency lesioning.

Have you had any surgical procedures?

I have had microvascular decompression for vagus and glossopharyngeal nerves in 2016. But the UK has never performed surgery on GN so I'm now deemed palliative without seeing a specialist in the US.

How has your facial pain changed you?

Facial pain has changed me in so many ways. I had to grow up a lot quicker than my peers and learn to advocate for myself at a really young age, but I see this as a valuable achievement. Although I have forgotten what it is like to be truly pain free because I have now lived longer with GN/GPN than I have without, I do not wish my diagnosis never happened for it has made me the person I am today. Because of my journey, my goal in life is to help others and bring a little sparkle. Having facial pain has blessed me with some of the strongest, truest and most powerful friendships. A family of choice. And this is something I would never change for the world. I am eternally grateful for the people I have met and will cherish forever.

What tips do you have for other young patients?

I think that to have facial pain, no matter which type and no matter at what age, can be incredibly tough, isolating and scary. But there is always hope. A positive mindset is vital I believe to journey through life and all that we have to deal with along the way. I am very shy by nature and it has made advocating for myself tough, but you are worthy of being heard and treated with kindness and respect. Please do not beat yourself up for not being where you want to be at any moment in time. Allow yourself to feel and grieve. It *IS* okay to not be sparkly all the time, it is tough and exhausting living with this and every day isn't good, but there is something good in every day. Please reach out if you are struggling. Keep doing the things you enjoy, it doesn't matter how seemingly small. But it is so important to have things you like and that bring you happiness. For me, when my body is malfunctioning, I read because reading allows me to travel to far off distant places and times, to live a thousand lives. Podcasts are a great source of distraction too!

My motto in life is "Have Courage and Be Kind". After my stroke these words mean more than ever. The world is a better place when we treat one another and ourselves with kindness. Navigating pain and illness with courage keeps generating hope, and hope, hope always prevails. You are worthy. You matter. You are strong. Strong beyond measure. You are literally made of stardust and the world needs you. ■



Can I Donate Stock to the Facial Pain Association?

By Brian Beers

Giving stock, instead of cash, as a donation to an organization can greatly benefit both parties. You will find that many charities, hospitals, schools, and other nonprofit organizations will accept stock as a gift or donation.

Key Takeaways

- Many non-profits, such as hospitals, schools, and various other organizations, will accept stock as a gift or donation.
- Giving stock often results in a larger donation to the organization, as the gift is tax-deductible and there are no capital gains taxes to pay.
- If your stock has risen in value since purchase, donating it directly is preferable, but if it's lost value, it may be more advantageous to sell it first and then donate the profits, so the giver can take the tax loss.

Tax Benefits of Donating Stock to Charity

If the stock has increased in value from the time of purchase, the owner can avoid paying the capital gains tax by donating the security to another party. When the security is being donated to a charitable organization, the total amount will still be eligible for a tax deduction. Since taxation is avoided on the stock donation, the giver will be able to make a larger donation.

For example, let's say you were looking to make a \$1,000 donation to a charity. You could either give cash or donate

stock. Let's assume that you bought stock for an original purchase price of \$700, but it is now worth \$1,128.55. To make it simple, let's assume capital gains tax is 30% of the stock's appreciation. Selling the shares for cash would net about \$1,000 after capital gains tax ($1,128.55 - (1,128.55 - 700) * 0.30$).

In this case, it shouldn't matter to your bottom line whether you are donating the entire stock or giving cash, as both choices will cost you \$1,000. However, the charity can receive more benefit from a stock donation, as they will receive a gift valued at \$1,128.55, instead of the \$1,000 in cash.

One thing to note, if you hold the stock for longer than a year before giving it away, then you can deduct the full fair market value of the donated stock. Otherwise, if it was held for less than a year, your deduction is limited to the cost basis.

Meanwhile, if you're holding a stock that is trading for less than you paid for it, it's usually better to sell first before donating the cash to charity. This allows you to take the loss for tax purposes. ■

[Donate to FPA Now](#)

FACIAL PAIN ASSOCIATION SUSTAINER CIRCLE

The Sustainer Circle is an incredible community of monthly givers who help ensure that FPA meets our mission of support, education and advocacy of the facial pain community.

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- **It's Convenient.** No need to write checks and no payments to remember.
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- **How Do I Join?** Visit facepain.org. Decide your gift level, click "DONATE," and start providing ongoing help to the facial pain community!

A monthly gift of \$10, \$20, \$50 or more makes giving easy and often allows you to make a more generous gift to

support of the facial pain community by breaking it down into smaller increments. To join the FPA Sustainers Circle, go to the online giving form and indicate that you want to make a monthly gift and designate the amount.

We gratefully recognize all donors who have joined the Sustainers Circle, having funds directly charged to their credit card or withdrawn from their bank account automatically each month. These donations provide a reliable source of funding that allows us to sustain the initiatives of the Facial Pain Association while spending fewer resources on fundraising.

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



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



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