Trigeminal Neuralgia Association of Canada

June 2012 Newsletter

Support Group

My friend suffers from fibromyalgia. She went to a support group and came back to say she would never go again! Everyone sat around and talked about how bad they felt, how much they suffered, and how awful life was. She was totally depressed. So she asked my why I do the TN support group and why people keep going to such a depressing thing. I told her the truth. We do share honestly about our struggles and trials but we also laugh, and encourage, and love, and share each other's burdens. TNAC Support groups are not set up to be giant pity parties. They are opportunities to learn about TN, share with those who understand what you are going through, laugh at things unique to the TN journey (that only another 'neuralgian' would laugh at), and to become encouraged and empowered in your TN journey. If you have not yet joined a TN support group please consider attending! If there is not one near you please consider starting one. You will not be sorry!

Eastern Ontario Support Group

Our group consists of people from Kingston through to Cornwall and north to the hills of Gatineau! We are a group of people who enjoy coming together to encourage and support each other along the journey of TN. We swap stories, laugh, and even cry at times. We share news on where we are at in our TN journeys and what paths we have travelled. Most of all we are always open and looking to welcome new members to our group. Our group is open to individuals with TN as well as their friends and family.

For more information and the time place of our next meeting please contact Jane at cmusicstudio@cogeco.ca or by calling 613.936.6977

Vancouver and Lower Mainland Support Group Update

Coordinator: Ann Hopkins

Vancouver & Lower Mainland Group
Meeting Time: 1.00 – 3.30 pm
G.F. Strong Rehab Centre.
Social Sciences Seminar Room 189, Main Floor,
4255 Laurel St.
(Laurel at W. 26th, one block east of Oak)

Friends, family members and supporters are very welcome.

It's a longish walk to the meeting room so if you need a wheelchair give me a call and I'll organize one. Or if you want to have a chat or have questions please make sure you call or email me.To get in touch: contact Ann Hopkins, email: annhopkins@dccnet.com, phone: 1 604 741 0662
4945 Laurel Ave, Sechelt, BC VON 3A2

Lethbridge Support Group

Coordinator Marion Guzik
The Lethbridge Support Group meets every second Saturday of the month at 2:00 p.m. in Rm A, Lethbridge Senior Centre, 500 - 11th Street, S., Lethbridge, AB.
Coordinator: Marion Guzik, past president / founder TNAC email mguzik@telus.net Phone: 403-327-7668

London Support Group

We have a new support group starting in London, ON
Contact Name: Elizabeth Galbraith
Tel: 519.471.3439
energyworksnaturally@bell.net
www.tnsupportlondon.ca

You've Got MAIL!

Money is always a challenge for non profit organizations. TNAC is no different. We rely on memberships and donations to fund the organization. All the work of TNAC is done by volunteers. We have no paid employees. Each we fund research related to trigeminal neuralgia to help find answers and support for those living with this disorder.

In order to save money TNAC will be sending the newsletter out by email to those who have registered an email address with us. This will cut back on our mailing costs. If you prefer to have the newsletter by regular mail please let us know.

We will also be using email and internet to make membership renewals easier. Starting this membership renewal cycle members can renew their TNAC membership ONLINE and also use PAYPAL to pay. Note, this is an OPTION and is not mandatory. If you prefer to mail in a check, that is fine. However for those of you who prefer to do the registration form and payment on line please go to 'join TNAC' on our webpage (www.tnac.org) and follow the steps outlined.

RENEWAL OPTIONS;

1. Regular mail
   - Print the membership renewal from "Join TNAC" at www.tnac.org and mail with a check to the address on the form
2. Online
   - Go to "Join TNAC" at www.tnac.org and follow the steps outlined to do the online membership renewal and pay by paypal
3. Contact our Treasurer and request a membership renewal form mailed to you. Contact is Joya Dickson # 7-5300 Admiral Way, Ladner BC V4K 5G6

PLEASE NOTE THAT MEMBERSHIP IS JULY 1 – JUNE 30TH each year. Therefore membership renewals are due as of July 2012.

Class Notes: Pain to Gain

David Thompson secondary student Yvonne Hao's mother has suffered from a painful condition of the nerves called trigeminal neuralgia for years. The condition causes a stabbing or electric shock-like pain in parts of the face.

It creates so much discomfort it can be difficult to function. Treatments have shown mixed success. Hao's mother worries that one of the treatments—surgery, which involves cutting through the cranium—carries too much risk. Instead, she takes painkillers to deal with the medical problem.

It's not surprising then that when Hao, 14, and two classmates—Narae Kim and Jairah Alindogan—decided to enter the Toshiba ExploraVision science and technology competition, which asked them to think about technology and how it might look 20 years from now, they focused on a better treatment for trigeminal neuralgia. "Usually I do science fairs where you have to make something, but as soon as ExploraVision said something in the future, I thought, well, this means I can go far and try to help my mom," said Hao, a Grade 9 student.

The competition is for kindergarten to Grade 12 students and is open to public, private or home-schooled students in the United States and Canada. Past winners have envisioned technologies ranging from a self-cleaning toilet to a new method of treating diabetes.

The David Thompson team recently learned they won top prize in their region for their 11-page paper on a treatment for trigeminal neuralgia. The win comes with a $10,000 savings bond for each student and a trip to Washington, D.C.

The teenagers worked on the paper last fall. "We had to research. We had a lot of things that we were thinking of, but it wouldn't really work, so we researched a lot about medical stuff. I talked to people who were in the medical field and researched about the history of the disease," Hao said, adding studying about the subject made her realize how difficult the condition was for her mother.

For the competition, the threesome came up with a thermoresponsive hydrogel injection, an effective and minimally invasive operation that delivers medication directly to the painful area. "This starts out as a liquid that flows throughout the affected area and becomes a gel, which coats the nerve endings and reduces or eliminates the pain," explained David Thompson principal Iona Whishaw in an email to the Courier.

The win shocked Hao.

"When [we] got the regional win I was really surprised and shaking, but when they told us we won the nationals, I was too shocked to really have much of a reaction," she said.

David Thompson teacher Danny Borges was thrilled by the news. "I've done this

project before with students, and students tend to think in terms of technology and remote controls and TVs. These students took it and actually used it for something that would actually benefit one of their mothers. I thought it was pretty amazing," he said.

Whishaw said it reflects well on the East Side school. "This is a big deal… it was a beautifully researched paper and I wasn't at all surprised by the regional win and I have to say I wasn't surprised they won the whole thing. This is a pretty big international deal and they were only two winners in Canada."

Hao believes the treatment is realistic in the future. "This one actually seems like it can be done very soon because the technologies are all there—maybe just some minor tweaks in putting it together," she said, adding her mother is also optimistic. "She was really proud and I think she just thinks maybe one day we can actually do this."

Convergence Pharmaceuticals Announces Start of Phase II Study for CNV1014802 for Trigeminal Neuralgia

CAMBRIDGE, England, March 19, 2012 /PRNewswire via COMTEX/ -- Novel sodium channel blocker with excellent pharmacokinetic and safety profile could fill treatment gap for severe pain condition

Convergence Pharmaceuticals Limited ("Convergence"), the company focused on the development of novel and high value analgesic medicines, today announced that the Phase II proof of concept study for CNV1014802 for the treatment of pain associated with trigeminal neuralgia (TN) has started. CNV1014802 is novel small molecule, state-dependent sodium channel blocker that exhibits potency and selectivity against the Nav1.7 sodium channel.

TN is a very severe form of facial pain that is experienced in short bursts or attacks. The International Association for the Study of Pain (IASP) defines TN as sudden, severe, brief, stabbing, recurrent episodes of pain usually on one side of the face and can be provoked by light touch. The pain follows one or more branches of the trigeminal nerve which provides nerve sensation from the mouth, face and the front of the scalp.

TN currently affects approximately 50,000 people in the USA alone. The majority of people affected are over 50 years of age, however many cases have been reported in young adults. TN is more prevalent in women than men, and for most sufferers, the condition is progressive and worsens over time. TN is commonly misdiagnosed and to date there is no guaranteed cure for the condition. Current therapies are centred on sodium channel blockers such as carbamazepine or oxcarbazepine as first-line treatments. However, these agents although providing relief, are often poorly tolerated, and require lengthy dose escalation, resulting in sub-optimal efficacy.

The Phase II trial is a randomised, double-blind, placebo-controlled withdrawal study designed to evaluate the efficacy and safety of orally administered CNV1014802 in patients with TN. The trial will run in six countries and the first results are expected in mid 2013.

Commenting on the announcement Clive Dix, Chief Executive Officer of Convergence Pharmaceuticals, said: "We are delighted to announce the start of this Phase II trial in trigeminal neuralgia, our second clinical trial of CNV1014802, following a Phase II proof of concept study initiated in July 2011 for treating pain associated with lumbosacral radiculopathy (LSR). CNV1014802 has already demonstrated an excellent pharmacokinetic and safety profile in over 160 healthy volunteers in Phase I trials. TN is a very debilitating disorder and we are confident that CNV1014802 will help fill the desperate need for innovative new treatments. We look forward to reporting results in 2013."

Prof Joanna Zakrzewska, Consultant and Facial Pain Unit Lead, Eastman Dental Hospital, UCLH NHS Foundation Trust, said: "It is very exciting to have a potential new drug to use in TN as this rare condition has to date had to rely on use of drugs previously developed for other purposes. Convergence has taken the bold step of testing it in a randomised control trial so that high quality evidence will be forthcoming very quickly. Designing studies for pain conditions where it would be unethical to use a placebo has been a challenge and we hope that this design will enable us to recruit the patients so that we can extend our drug therapies, so desperately needed."

Contacting TNAC

For information on membership or general information:
president@tnac.org
613.936.6977
TNAC, 1602 Walton Street
Cornwall, ON, K6H 1W2
For information on support groups:
support@tnac.org
For information on advocacy:
advocacy@tnac.org
Do you have an article for the newsletter? Do you have a topic you'd like covered? Do you have a drug you'd like profiled? Please let us know.Deadlines for newsletter submissions are:
May 30th
August 30th
Nov. 30th
Feb. 28th

Below is a diagram and description of the Trigeminal Nerve. It is followed by a form you can use to diagram your TN pain when you go to see your doctor. This will help your doctor to understand your pain experience.

Trigeminal nerve

The trigeminal nerve has three branches that conduct sensation from the upper, middle and lower portions of the face, as well as the oral cavity, to the brain.

Upper branch

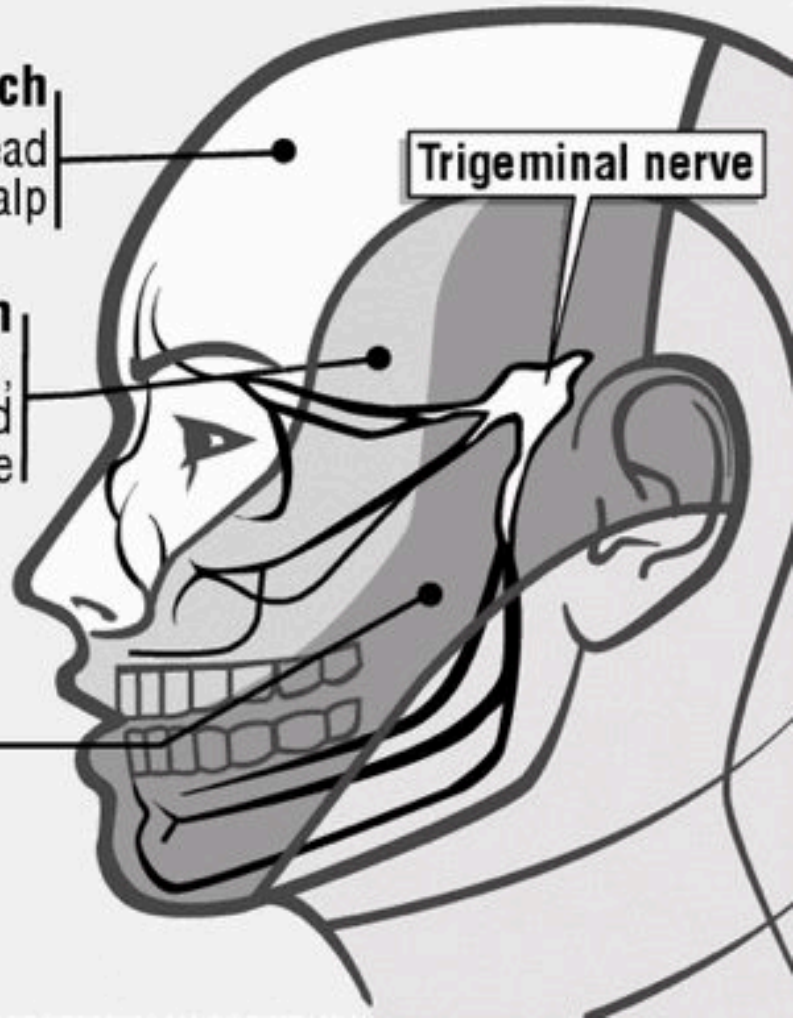
Ophtalmic - eye, eyebrow, forehead and frontal portion of the scalp

Middle branch

Maxillary - upper lip, upper teeth, upper gum, cheek, lower eyelid and side of the nose

Lower branch

Mandibular - Lower lip, lower teeth, lower gum and side of the tongue. Also covers a narrow area that extends from the lower jaw in front of the ear to the side of the head.



DRAW YOUR PAIN PATTERNS FOLLOWING THIS KEY:

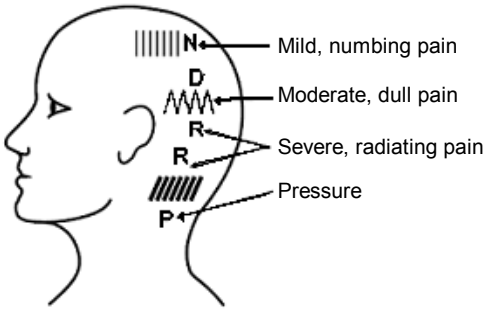
MILD PAIN

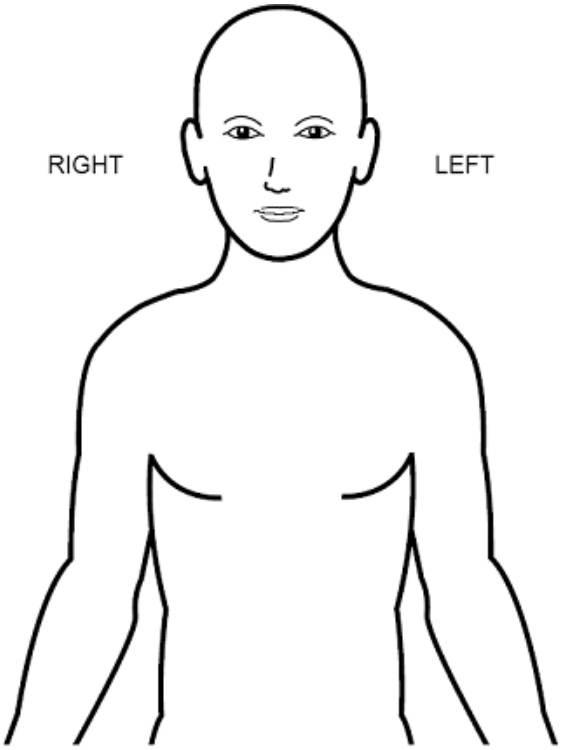
MODERATE PAIN

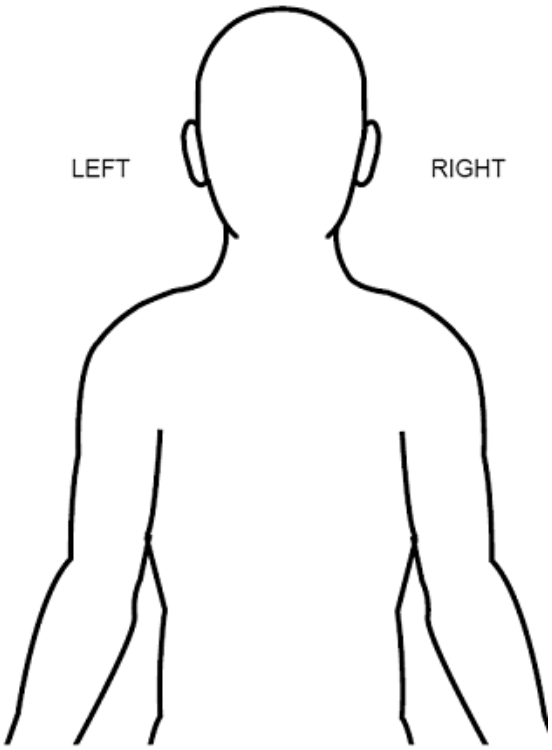
SEVERE PAIN

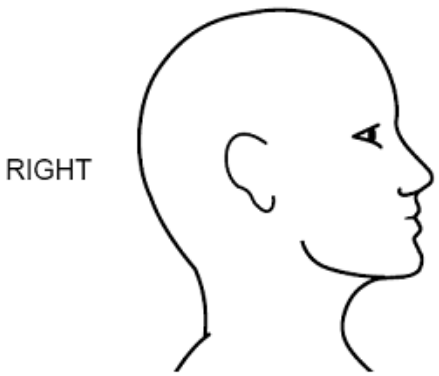
B Burning
D Dull
N Numbing
P Pressure
S Sharp
T Tingling
R Radiating

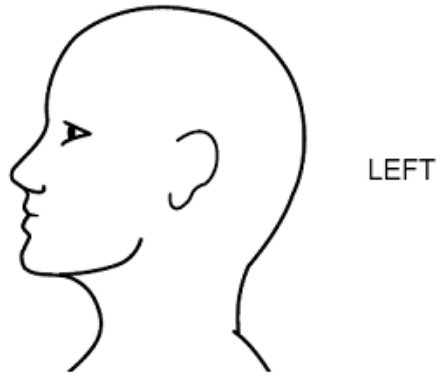
EXAMPLE











Patient Signature _____ Date _____

Wound care co NanoVibronix raises $300,000 from Tegal

Wound care company NanoVibronix Inc. has received a 300,000 strategic investment from Tegal Corporation (Nasdaq: TGAL), a technology investment company. NanoVibronix, based in Nesher near Haifa, is developing its proprietary low-intensity surface acoustic wave (SAW) technology for the treatment of chronic, non-healing wounds.

NanoVibronix cites a report by Global Industry Analysts Inc., which estimates that the global wound care market will reach $22.8 billion by 2017, one-third of which is addressed by advanced wound care products. The market growth is fueled by an aging population and the rapidly increasing incidence of diabetes worldwide.

NanoVibronix has obtained US Food and Drug Administration (FDA) and EU CE Mark clearance for its first product, PainShield MD, for the treatment of tendonitis, muscle pain, and trigeminal neuralgia. The company has also developed a family of disposable ultrasound devices, the UroShield, to treat catheter-associated infection and injury by preventing biofilm formation and decreasing the friction between the catheter and body tissues. This product also has CE Mark certification.

NanoVibronix CEO Dr. Harold Jacob said, “Tegal’s investment and management expertise are critical to accelerating the growth of NanoVibronix.

Tegal president and CEO Thomas Mika said, “Our investment in NanoVibronix expands the Tegal portfolio to new markets and new commercial horizons. NanoVibronix is a technology leader in the application of surface acoustic waves in the treatment of wounds and the prevention of infection in indwelling catheters.”

Published by Globes [online], Israel business news - www.globes-online.com - on November 29, 2011

Trigeminal Neuralgia, Differential Diagnosis

Diagnostic Considerations

Other causes of facial pain than trigeminal neuralgia (TN) are excluded by history, physical examination, and special investigations (when necessary). In symptomatic cases, a persistence of aching can occur between paroxysms, as well as signs of sensory impairment in the trigeminal division. Then, a cause is demonstrated by appropriate investigation.

Migraine, cluster headaches, and atypical face pain

Migraine and cluster headaches may produce severe unilateral pain, but unlike trigeminal neuralgia, these conditions are not triggered by movement or contact with the face nor do they respond promptly to carbamazepine. See Table 1, below.

According to Turp and Gobetti, atypical face pain usually extends beyond the distribution of the fifth cranial nerve, is rarely triggered, and presents with a steady unrelenting discomfort lasting hours to days.[18]

In persistent idiopathic facial pain, psychiatric disturbances are associated with pain that is of vague localization and long duration (usually chronic and daily). In Raeder syndrome (paratrigeminal neuralgia), ophthalmoparesis is present. In current practice, Raeder syndrome is believed to essentially be carotid dissection. Tolosa-Hunt syndrome (ophthalmoplegia) presents with pain of longer duration but that is not triggerable; cranial nerve deficits are observed. Short-lasting, unilateral neuralgiform headache attacks with conjunctival injection and tearing (SUNCT) present with pain of longer duration (2-3 min) and associated prominent autonomic symptoms (eg, lacrimation, rhinorrhea).[19]

Temporomandibular joint pain and dental problems in the evaluation of trigeminal neuralgia.

Glossopharyngeal neuralgia and occipital neuralgia syndromes

Other syndromes with paroxysmal lancinating head pain include the less common glossopharyngeal neuralgia and occipital neuralgia syndromes.

Glossopharyngeal neuralgia causes pain in the tonsillar fossa, posterior pharynx, and ear and may be initiated by coughing, yawning, or swallowing cold liquids. During acute attacks of this condition, which is frequently associated with an underlying pathology, the patient may be unable to speak and tries to avoid moving the lips or tongue. An involuntary startle during an attempt to touch the affected side of the face is diagnostic.

Occipital neuralgia causes pain in the posterior head region. Thus, the distribution easily distinguishes it from trigeminal neuralgia. Confusion arises only if the patient cannot provide a clear history.

Paroxysmal hemicrania syndromes

According to Goadsby and Lipton, similar to trigeminal neuralgia, paroxysmal hemicrania syndromes typically last only seconds, however, the latter syndromes occur in and around 1 eye.[20] Intense unilateral conjunctival injection and lacrimation signal an autonomic component, which further distinguishes paroxysmal hemicrania syndromes. Another feature is that paroxysmal hemicrania syndromes do not respond to carbamazepine.

Secondary vs idiopathic trigeminal neuralgia

Symptomatic or secondary trigeminal neuralgia is a more likely consideration than the idiopathic form when pain is associated with hyperesthesia along the course of the fifth nerve or is observed with other cranial neuropathies. Further, consider secondary trigeminal neuralgia in patients with bilateral sensory loss or weakness of the facial muscles or jaw.

Additional investigation may reveal multiple sclerosis (MS), a tumor in the posterior fossa, or a tumor on the trigeminal nerve.

Acoustic neuromas, cerebral aneurysms, trigeminal neuromas, and meningiomas can produce syndromes similar to idiopathic trigeminal neuralgia. Consider these conditions in patients with onset of pain when younger than 40 years, those with predominant forehead and/or orbit pain (ie, first division of the trigeminal nerve), or those with bilateral facial pain. Also consider granulomatous inflammation (eg, tuberculosis, sarcoidosis, Behçet syndrome, collagen vascular diseases) and other vasculitides, as these may affect the trigeminal nerve and simulate trigeminal neuralgia.

Patients with prominent hemifacial spasm, especially if it is continuous, may have tic convulsif, a condition associated with a dilated and ectatic basilar artery or other vascular malformation compressing the trigeminal nerve.

Brain magnetic resonance imaging (MRI) with and without contrast is critical in diagnosing the secondary causes of trigeminal neuralgia.

Failure to properly assess for secondary trigeminal neuralgia is a major potential pitfall. A careful examination of the cranial nerves and an MRI of the brain, especially in an individual who develops the disorder when younger than 60 years, should protect against missing structural lesions (eg, tumor, cerebral aneurysm, acoustic neuroma).

Trigeminal neuropathy and atypical trigeminal neuralgia

Trigeminal neuropathy is also a consideration in the evaluation of trigeminal neuralgia. This condition presents as a constant, unilateral, often mild facial pain with prominent sensory loss. It is nontriggerable and unremitting, and it may be either symptomatic or idiopathic. By contrast, as previously discussed, idiopathic trigeminal neuralgia presents as episodic, unilateral, lancinating, triggerable, often shocklike facial pain with pain-free intervals.

To further complicate diagnostic matters, the clinician may encounter atypical trigeminal neuralgia, a syndrome that overlaps trigeminal neuralgia and trigeminal neuropathy. This syndrome consists of constant pain that episodically intensifies. According to Burcheil, these patients experience both lancinating triggered pain and a baseline, constant, dull, and throbbing discomfort.[21] The atypical form may occur in up to 5% of people after facial surgery or significant trauma and in 1-5% after the removal of impacted teeth. In the experience of many neurosurgeons, atypical trigeminal neuralgic pain results from lesions or injuries of the trigeminal nerve root distal to the route entry zone but with even greater compression than found in the idiopathic form of trigeminal neuralgia.

In contrast to trigeminal neuropathy, whether typical or atypical, atypical facial pain is distinguished by the extension of discomfort beyond the distribution of the fifth cranial nerve and by the frequent lack of lancinating pain and triggers.

Multiple sclerosis

As discussed in the Clinical section, rarely, multiple sclerosis (MS) presents with trigeminal neuralgia. Consider multiple sclerosis in the diagnostic evaluation of individuals who display other features of this demyelinating disorder.

Herpetic and postherpetic neuralgia

Herpetic and postherpetic neuralgia (PHN) usually affects the first branch of the trigeminal nerve. The diagnosis of postherpetic neuralgia usually requires the outbreak of shingles (herpes zoster) in the forehead or eye. Acute herpetic neuralgia is the norm in shingles, but pain that persists after the lesions have healed is postherpetic neuralgia. The risk of development of postherpetic neuralgia is directly related to patient age.

No laboratory, electrophysiologic, or radiologic testing is routinely indicated for the diagnosis of trigeminal neuralgia (TN), as patients with characteristic history and normal neurologic examination may be treated without further workup.

The diagnosis of facial pain is almost entirely based on the patient's history. In most cases of facial pain, no specific laboratory tests are needed. A blood count and liver function tests are required if therapy with carbamazepine is contemplated. Oxcarbazepine can cause hyponatremia, so the serum sodium should be tested after institution of therapy.

Although rarely indicated, appropriate blood work for rheumatic diseases, such as scleroderma (trigeminal neuropathy is reported in up to 5% of patients with this collagen vascular disease) and systemic lupus erythematosus (SLE), should be undertaken in patients with atypical features of facial pain and a systemic presentation of collagen vascular disease. Appropriate blood work includes a sedimentation rate (ESR), antinuclear antibody titer (ANA), double-stranded DNA, anti-Sm antibody, lupus erythematosus cell preparation, and complete blood cell (CBC) count to look for hematologic abnormalities (eg, hemolytic anemia, leukopenia, thrombocytopenia). Particularly in the case of scleroderma, creatinine kinase and aldolase levels may be elevated with muscle involvement. Antibody titers

to SCL-86 and SCL-70 may also be present.

In cases with suspected metastatic carcinomatosis, cerebrospinal fluid analysis may confirm the diagnosis. When surgical procedures are contemplated, appropriate and routine preoperative laboratory tests are in order.

In patients older than 60 years, the clinician may first choose to assess the response to a therapeutic trial of medication before considering imaging. A clear relief of pain with carbamazepine or another anticonvulsant confirms the diagnosis of idiopathic trigeminal neuralgia.

Imaging studies are indicated, because distinguishing between classic and symptomatic forms of trigeminal neuralgia is not always clear. Approximately 15% of patients with trigeminal neuralgia (any form) have abnormalities on neuroimaging (computed tomography [CT] scanning and/or magnetic resonance imaging [MRI]). The most common findings are cerebello-pontine angle tumors and multiple sclerosis.

Brain magnetic resonance imaging (MRI) with and without contrast helps to distinguish secondary causes of trigeminal neuralgia (TN) from the idiopathic form. This study is imaging modality of choice and indicated in patients presenting with trigeminal neuralgia when younger than 60 years, principally to exclude tumor. For example, MRI can reveal multiple sclerosis plaques and pontine gliomas.[22] Perform an MRI if atypical features are present. See the image below.

Some physicians recommend elective MRI for all patients to exclude an uncommon mass lesion or aberrant vessel compressing the nerve roots. However, in a published practice parameter, the American Academy of Neurology stated that because of inconsistency of studies, there was insufficient evidence to support or refute the usefulness of MRI or a specific MRI technique to identify vascular anomalies.[23] The recommendation was that, for patients with trigeminal neuralgia, routine imaging may be considered to identify symptomatic trigeminal neuralgia, and this was graded as a level C or possibly effective action.

Magnetic resonance angiography (MRA) can be useful in locating a vascular compression; however, the sensitivity remains low.

Newer special techniques such as high-resolution, 3-dimensional (3-D) MRA (eg, posteroinferior cerebellar artery compresses the trigeminal root) and 3-D spoiled gradient-recalled imaging have been under study, but thus far no consensus to recommend them has been reached.[24] Overall, however, magnetic resonance studies on neurovascular conflicts have shown great variability in outcomes and techniques, with sensitivities as low as 52% and specificity as low as 29%. Therefore, this type of imaging still cannot be recommended as reliable.

Trigeminal neuralgia is treated on an outpatient basis, unless neurosurgical intervention is required. Management of this condition must be tailored individually, based on the patient's age and general condition. In the case of symptomatic trigeminal neuralgia, adequate treatment is that of its cause, the details of which are out of the scope of this article.Because most patients incur trigeminal neuralgia when older than 60 years, medical management is the logical initial therapy. Medical therapy is often sufficient and effective, allowing surgical consideration only if pharmacologic treatment fails. Medical therapy alone is adequate treatment for 75% of patients.

Patients may find immediate and satisfying relief with one medication, typically carbamazepine. However, because this disorder may remit spontaneously after 6-12 months, patients may elect to discontinue their medication in the first year following the diagnosis. Most must restart medication in the future. Furthermore, over the years, they may require a second or third drug to control breakthrough episodes and finally may need surgical intervention. Simpler, less invasive procedures are well tolerated but usually provide only short-term relief. At this point, further and perhaps more invasive operations may be required, and with these procedures the risk of the disabling adverse effect of anesthesia dolorosa increases. Thus, treatment can be subdivided into pharmacologic therapy, percutaneous procedures, surgery, and radiation therapy. Adequate pharmacologic trials should always precede the contemplation of a more invasive approach.

TNAC extends their sympathies to the family and friends of Clifford Davies. Clifford passed away on May 4, 2012 at the age of 79 at the Etobicoke General Hospital (Toronto, ON). A retired TTC (Toronto Transit Corp) employee, Clifford knew the battle of living and coping with TN. In lieu of flowers the family requested donations to TNAC. As a result TNAC will be able to enhance their support of research into the causes and treatments of trigeminal neuralgia. We thank Clifford's family for thinking of TNAC and are grateful for the donations in his memory.

TNAC ANNUAL GENERAL MEETING

Thursday June 28, 2012
4:00PM EST
Please email president@tnac.org or call 613.936.6977 for the teleconference phone access number.