Trigeminal Neuralgia Association of Canada

Winter 2011 Newsletter

Support Group

Eastern Ontario Support Group

Calling all Easterners … well Eastern Ontario'ners that is! We will be meeting next March 20th 2011 in Brockville, ON. And in May we will celebrate the fourth anniversary of this 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. 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.

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.

Treasurer's Note

Have you sent in a

membership renewal to TNAC or a donation and not received a receipt? Are you wondering if your letter was lost in the mail? Are you thinking we do not appreciate your donation?

Please do NOT panic and for sure do not think that we do not appreciate your donations. Receipts will be sent out as soon as our treasurer returns from vacation!

Thank you for your patience!

Chronic Pain Linked to Old Memories

Scientists have found that a key source of chronic pain appears to be an old memory trace stuck in the prefrontal cortex. With new understanding of the pain source, Vania Apkarian, professor of physiology, and of anesthesiology, at Northwestern University's Feinberg School of Medicine (USA), has identified a drug that controls persistent nerve pain by targeting the part of the brain that experiences the emotional suffering of pain. The drug is D-Cycloserine, which has been used to treat phobic behaviour over the past decade.

In animal studies, D-Cycloserine appeared to significantly diminish the emotional suffering from pain as well as reduce the sensitivity of the formerly injured site. It also controlled nerve pain resulting from chemotherapy, noted Apkarian, who is a member of the Robert H. Lurie Comprehensive Cancer Center at Northwestern University. The drug has long-term benefits. Animals appeared to be pain free 30 days after the last dose of a 30-day regime of D-Cycloserine. "In some ways, you can think of chronic pain as the inability to turn off the memory of the pain," Apkarian said. "What's exciting is that we now may be relieving what has clinically been the most difficult to treat - the suffering or the emotional component of pain."

Scientists have always tried to understand pain from the viewpoint of sensation, Apkarian said. "To control it, they tried to stop the sensory input to the brain. "We are saying there's a cognitive memory and emotional component in the brain that seems abnormal. Easing that may have a bigger effect on suffering." Chronic pain is not caused by a single mechanism, Apkarian noted.

Sensory abnormalities in people with chronic pain probably drive this memory abnormality.

One of Apkarian's studies with rats tried to separately measure their emotional suffering and their physical pain after being treated with the drug (The rats had chronic pain from a healed limb injury). The results indicated the animals' emotional suffering decreased much more than their physical pain. While the physical pain appeared to be reduced 30 per cent – their emotional suffering completely disappeared. Based on the animal results, the next step will be to test the drug in clinical trials, Apkarian said. "When we do this in a clinical trial, we expect people to say I still have the pain, but it's not bothering me anymore," Apkarian said. "We think they will have a physical awareness of the pain, but its emotional consequences will have decreased." He said the drug potentially may lower the amount of standard analgesics people have to use.

In Apkarian's previous study, published in late 2006, he revealed that chronic back pain appears in a different part of the brain than the discomfort of burning your finger, for

example. With functional MRI, he found that chronic back pain shows up in the prefrontal cortex. By contrast, the acute sensory pain of the burned finger appears in the sensory part of the thalamus. Apkarian also found that the longer a person has been suffering from chronic pain, the more activity in the prefrontal cortex. He was able to predict the years of their suffering from the MRI.

"It's cumulative memory," he explained. "I can predict with 90 per cent accuracy how many years they have been living in that pain without even asking them the question." The study will be published online in Pain: The Journal of the International Association for the Study of Pain .

http://www.scientistlive.com/17863/chronic-pain-linked-to-old-memories.html

Surgery stops screaming pain of trigeminal neuralgia

Written by
Peggy O'Farrell
pofarrell@enquirer.com

Carol Hemker's pain started in 2001. A last-resort procedure performed this month by a local neurosurgeon ended it. The pain, caused by trigeminal neuralgia, came in waves that could last for weeks, always on the right side of her face. Trigeminal neuralgia is an inflammation of the trigeminal nerve, which controls muscle movement and feeling in the face. In the United States it affects about 1 in 25,000 people.

She compared the pain to a lightning strike. "All I could do was hold my face and scream," said Hemker, 70. "If you've ever seen someone being Tasered, I imagine t hey're feeling what I felt then, where they just drop to the ground and scream." The pain can be disabling. Some patients say it's so severe they've considered suicide. Anything can trigger an attack, even just talking.

Medications kept Hemker's pain at bay - mostly - for a few years.

But in 2008, the attacks returned - and more frequently.

Hemker and her husband, Bob, live in Kimball, Neb. They traveled to Denver, Colo., to work with a neurosurgeon there. Hemker underwent four procedures between 2008 and 2009, including one in which a tiny sponge was implanted to lift an artery that was pressing against the trigeminal nerve and three that partially damaged the nerve in an effort to block the pain.

Each worked for a while, but the attacks always returned.

Finally, the surgeon they'd been working with told them there was nothing else he could do.

"Since then, it's been a period of desperation," Hemker said. "I've just felt so hopeless."

It's been frustrating as well for her husband. The couple will celebrate their 51st anniversary in March.

"All you can do is watch," he said. "It's miserable not being able to help." She had another attack over Thanksgiving - the worst ever, she said.

A nurse at the emergency room near their home told Hemker to keep looking for a solution.

"She said there's someone in this country that could help us," Hemker said. They searched online for centers that specialize in trigeminal neuralgia treatment, and found four - the University of Cincinnati, the Mayo Clinic in Rochester, Minn., the University of Utah and the University of Texas.

A friend in a support group for people with trigeminal neuralgia told her to contact

John Tew, the clinical director of the UC Neuroscience Institute and a neurosurgeon with the Mayfield Clinic in Avondale. Tew is recognized as a national leader in treating trigeminal neuralgia.

They wrote doctors at all four centers; Tew wrote back first. He agreed to take her case, and the couple drove 1,100 miles to see him.

Because of the randomness of her attacks, travel is difficult, Bob Hemker said. They worried that the flight itself, or just the stress of being in a crowded airport, could trigger an attack.

“You’re afraid to travel. You’re afraid to do much of anything,” he said.

On Feb. 4, Tew performed a sensory rhizotomy, or the surgical severing of the part of the trigeminal nerve that carries pain signals. The part of the nerve that controls muscle movements - for chewing, for example - was spared.

He made a small opening in the back of her skull, then surgically severed the nerve near where it enters the brain. The surgery is irreversible, and the right side of Hemker’s face is now completely numb. Previous procedures had left her with sensation only under her eye and nose but even with that limited sensation, the pain was unbearable during her attacks.

The day before the surgery Tew performed a nerve block - first to make sure that severing the nerve would actually work, but also to make sure Hemker could live with the facial numbness.

Only about 1 percent of patients who need surgery for trigeminal neuralgia end up getting the irreversible procedure. “You wouldn’t do this on somebody unless all the less dramatic procedures had failed,” he said.

Hemker, who was taking four anti-seizure medications to help prevent the attacks, said she can live with numb.

“The pain is gone,” she said. “Praise be to God.”

Tew said their persistence paid off. “You have to let people know there’s always hope,” he said. “There is always hope.”

NICO NEURALGIA-INDUCING CAVITATIONAL OSTEONECROSIS

Dental Disorders

Description Neuralgia-inducing Cavitational Osteonecrosis described in medical literature since 1976, is known under a number of names including, Ratner bone cavities, alveolar cavitational osteopathosis, Roberts bone cavity, trigger point bone cavity, interference field, and most commonly, NICO. In NICO, it is claimed that small areas of bone in the upper or lower jaw become infected or inflamed and die, producing neuralgia-like pain. Most often, no sign of inflammation appears on x-ray. NICO is said to appear after tooth extraction, jaw surgery, endodontic therapy or crown preparation and is speculated to be the result of a long-standing low-grade infection.

Symptoms The pain felt is constant and is often burning and cramping, much like atypical facial pain symptoms. Usually there are trigger points immediately over the areas of infected jawbone that will produce pain when pressed. NICO can cause "referred pain" in that the neuralgia-like symptoms are "referred" to other parts of the face, intraoral cavity and head.

Possible Causes Some cases of NICO appear to be caused or aggravated by infection. Others speculate that minor trauma from extractions, root canal and other dental

procedures are common initiators of NICO but believe this only happens in people already susceptible because of a pre-existing blood clotting disorder. Some believe that NICO can develop when blood vessels are injured in the area, resulting in poor circulation which in turn can lead to bone death.

Diagnosis It is difficult to diagnose this problem as the pain symptoms often are similar to other conditions such as Myofascial Pain Disorder (MPD), Temporal Mandibular Joint (TMJ) problems, atypical facial pain, trigeminal neuralgia, phantom toothache, or headache. X-rays of the jawbone most often appear normal. However, a bone biopsy of the affected area can show positive signs of jawbone inflammation.

Treatment The only treatment for NICO is jawbone curettage, in which the jawbone is opened, the infected area drilled out, and the bone biopsied to confirm the presence of inflammation or infection. Often the bone cavity is packed with antibiotics such as teramyacin. A course of antibiotic treatment may be prescribed. Jawbone curettage is not currently done routinely, and it is too early to say whether or not it will ever become generally accepted.

Discussion NICO is not generally accepted as a cause of Trigeminal Neuralgia by most medical and dental professionals. It is possible that NICO is involved in some cases of facial neuralgia [1], especially atypical facial pain. One long-term study (of nearly 5 years) has reported considerably or totally reduced pain in 74% of facial neuralgia patients who had jawbone curettage. However, the pain returned for about 30% of these patients of whom most had been diagnosed with either TN or atypical facial pain [-2].

In dental circles, there appears to be two distinct "schools of thought" on NICO. Some medical and dental professionals consider NICO a controversial diagnosis. Not only do they not consider it a possible cause of trigeminal neuralgia or other facial neuralgias, they doubt the condition exists as a disorder. They point to data suggesting bone cavitations are found routinely in cadaver jawbones, casting doubt on the theory that bone cavities cause facial neuralgias.

Another group of dentists believe NICO is the culprit in many facial pain syndromes and that these painful conditions can be cured by jawbone curettage (scraping and removing infected tissue). They point to studies that show a high success rate for jawbone curettage. Some dentists in this group believe that root canals and mercury fillings are partly responsible for NICO.

Trigeminal Neuralgia Association of Canada - Beyond Boundaries

My name is Edith Nyborg Schuetze, I am Danish and live in Denmark. Here is my story, on how I was saved last minute by a phone call from Ann Hopkins of the Trigeminal Neuralgia Association of Canada (TNAC).

I was at the end of my wits, due to suffering from undiagnosed and untreated trigeminal neuralgia for 14 years, from a compressed nerve in my brain AND from a jawbone injury at the same time, when I was unexpectedly rescued by a phone call from Ann Hopkins of TNCA. I knew that my days were numbered, if I did not find the answers quickly. And so I prayed

intensely to have the answers revealed. A few minutes later I was prompted to go on the internet and send a short S.O.S message to a number of clinics and associations, who knew something about facial pain. Then I forgot everything about the message, as I was preoccupied with the pain. Next morning I received a phone call from Ann Hopkins, TNAC, who had received my e-mail from xxx. Ann knew my situation, and that I had difficulty handling and focusing my attention due to pain. She stayed on the phone with me, long enough to make sure I had gotten the necessary information on neuralgia meds down on paper, so that I could ask my doctor for Tegretrol.

Today, nearly two years later, I am now beyond brain surgery, which successfully moved the compressing blood vessels off my trigeminal nerve in my brain. Further, I am scheduled for CT-scans and medical exams, in order to have stem cell transplant performed on my jawbone injury by a group of surgeons in Spain, who have successfully regenerated 3 other cases of end stage craniofacial damage, including nerve damage. All 3 patients have fully recovered and resumed their occupation within one year of surgery. And so I can expect to be totally well in a year, or in less than a year.

Without Ann Hopkins call May 2009, this healing would have never happened. I am eternally grateful to the wonderful woman xxx, who founded this organization, and to it's ambassador, Ann Hopkins, for being supportive from I was diagnosed till I was well beyond brain surgery. Your work has been life-saving! I am eternally grateful and indebted to you for your support.
Edith

Help Needed

TNAC is looking for help. In our next newsletter we will have a call for nominations to the board. We would like to encourage you to consider helping TNAC though becoming a board member.

What does this require?

Honestly, the time commitment is minimal. We are looking for people willing to answer emails requesting information on TN or make phone calls to people who have been recently diagnosed and are looking for information or support. I can tell you that the time we spend corresponding with people impacted by TN across Canada is some of the most precious time we spend in our lives. It is incredibly fulfilling to be able to help others.

We are also looking for people to help with the newsletter. This does not mean taking it over and doing the whole thing. We are looking for people who would commit to find one or two articles per edition. People who would like to start new support groups. People who just want to help others across Canada with TN.

For more information please contact any member of TNAC!

WEBSITE REVISED

Have you been to www.tnac.org lately? If not check it out! The TNAC website was recently revised. The site and information has been updated. We hope you will find the information clear, easy to find, and useful. We will also be setting up a paypal account for donations and/or membership renewals.

If you would like to submit a story for the TNAC site please forward to president@tnac.org

Atypical Trigeminal Neuralgia

By Joanna Karpasea-Jones

Created 03/12/2011 - 09:10

Atypical trigeminal neuralgia (ATN), otherwise known as type 2 trigeminal neuralgia, is a rare form of trigeminal neuralgia. Around 4-5 people per 100,000 have trigeminal neuralgia and a small subset of those have ATN.

It is a disorder of the fifth cranial nerve (trigeminal nerve), where the nerve becomes inflamed and/or demyelinates.

What are the Symptoms of ATN?

ATN is less painful than its more common counterpart, trigeminal neuralgia, but the pain is more constant. Patients may experience a persistent headache that lasts for days at a time and keeps re-occurring. This may be mistaken for a migraine. They will have pain in the trigeminal nerve, sometimes in all of the nerve branches and may have pain around their ears, jaws, nose, eyes and scalp. Pain can be felt as a mild ache, a crushing pressure sensation or a sharp stabbing sensation.

Unlike ordinary trigeminal neuralgia, the atypical type affects people of all ages. Trigeminal neuralgia is more common in those over 40.

What Causes ATN?

ATN can be caused by vascular compression and this is the most common cause of the disease. If the pain is constant, rather than coming and going, it may be a sign of a tumor compressing the nerve, in which case further investigations need to be carried out. If the pain is intermittent, this is not the case.

It can also be caused by trauma, either by an accident or more commonly, a surgical procedure. It can occur after dental surgery. Sometimes it occurs as part of the aging process.

If an infection or long-term inflammatory condition has been present, this can, over time, damage the trigeminal nerve and result in ATN.

Medical Treatments for ATN

ATN is difficult to treat. The conventional medical treatments are either: 1. Use of high dose anti-inflammatory painkillers during a bout. 2. Use of anti-depressants or the anti-convulsant, Gabapentin, to shut down abnormal nerve function. It is thought after a long period of use that the nerve may regenerate normally. There is limited evidence that this type of treatment actually works, particularly for non-epileptic drugs. 3. Surgery. A glycerol injection can be given through the cheek and through the opening to the base of the skull where the three branches of the trigeminal nerve come together. The glycerol damages the insulation of trigeminal nerve fibers to stop pain sensations being transmitted. This is done under sedation. 4. Stereotactic Radiosurgery – this involves firing radiation beams at the trigeminal nerve. This causes a lesion to develop over the nerve (over a period of several months). This lesion stops the nerve from transmitting pain signals. 5. Microvascular Decompression – this is very invasive and involves the patient being put under general anesthetic. The surgeon then makes a small cut behind the ear, through which he puts a microscope. He then moves the vessels away from the nerve and places a cushion between the two. Although this is the most complicated of procedures, it is also the most effective.

Sources: Aust Fam Physician. 2005 Aug;34(8):641-5

Peripheral Nerve Stimulation

The Center for Peripheral Nerve Surgery Department of Neurological Surgery"...because there is always hope" Peripheral nerve stimulation is a technique in which electrodes are placed along the course of peripheral nerves to control pain. These devices are an extremely safe, efficient, and effective way to ameliorate a variety of severe neuropathic pain conditions. Once the electrodes are in place, they are turned on to administer a weak electrical current to the nerve. The patient experiences this as a pleasant tingling sensation. By stimulating nonpainful sensory pathway, the electrical current tricks the brain into turning off (or significantly attenuating) the painful signals. In this manner, pain relief occurs. In general, most patients are then able to reduce or discontinue altogether their pain medications. Nerve stimulation is performed in a two-step process. First there is a temporary trial electrode. This is left in place for a week or so, so that the patient may determine if peripheral nerve stimulation is helpful. The electrode is connected to an external power supply that the patient controls. In the event that the stimulator does not help, it is removed. If it does help, the temporary electrode is replaced with a permanent electrode that is then connected to an internal battery pack, similar to a pacemaker battery. Once in place, the patient may then resume normal activities of daily living, including swimming, exercise, and work. Most peripheral nerve stimulation procedures are performed as an outpatient basis with a local anesthetic. Significant postoperative pain and complications are rare, but can occur. Each of the following conditions may be treated with peripheral nerve stimulation: Complex Regional Pain Syndrome Diabetic Peripheral Neuropathy Ilioinguinal Neuralgia Intercostal Neuralgia Lateral Femoral Cutaneous Neuropathy (Meralgia Paresthetica) Low Back Pain Neck Pain Occipital Neuralgia Pain Following Hernia Surgery Painful Nerve Injuries Painful Peripheral Neuropathies Peripheral Vascular Disease Neuropathy Postamputation (Stump) Pain Postherpetic Neuralgia Postthoracotomy Syndrome Trigeminal Neuralgia Trigeminal Neuropathic Pain

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

Thank you!