Trigeminal Neuralgia Association of Canada

Fall 2010 Newsletter

Support Group

Eastern Ontario Support Group

Call us the little group that grew. From three people who met in 2007 there were fourteen at our last meeting! Our group proves that persevering despite a small start can result in a strong and flourishing support group. But perhaps more important is the friendships that are growing from within this group. Meeting as a support group is nice but knowing you have people you can email, call, and facebook with who care about you and are there for you when you need them is a great thing indeed! These are the friendships that are being created out of the Eastern Ontario Support Group.

If you live in Eastern Ontario, from Kingston to the Quebec border and north to Ottawa, we would love to meet with you. We are always open to and welcome new people to our group. We hope to meet again in late November or early December.

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.

Face Book and TNAC

TNAC now has a Face Book page called Trigeminal Neuralgia Canada. It's an international page as "friends" come from all over. It seems that TN does not respect international boundaries. People post all kinds of interesting things and it's also a place where people can say they're having a bad day and receive messages of support from fellow sufferers. It's also a place to ask questions, make suggestions, exchange information and hang out with other people who have TN. To become a friend just Google Face Book and Trigeminal Neuralgia Canada or click on:

http://www.facebook.com/profile.php?id=100000379484216

TN and Cymbalta

At the recent Eastern Ontario Support group meeting one of the members shared about a change in his medication and the positive response he had. He had been on the usual routine for TN including anit convulsants. Recently a course of anti depressants had been added. This past spring he had a consultation with a new physician who noted that an anti depressant called Cymbalta was noted to work both as an anti depressant and also to impact the working of the nervous system similar to the anti convulsants this individual was taking. So rather then taking two medications why not try one in the form of cymbalta.

Why not indeed?

For this particular individual it worked! Within a short time he had a significant improvement in his TN and control of TN symptoms and, at the same time, a significant decrease in the side effects of medication. Though cymbalta may not be the answer for everyone with TN we wanted to share this information for your consideration. Research has been done with this medication in regards to diabetic neuropathic pain. Often a medication that works for diabetic neuropathy will also work for TN.

Below is the province of Ontario's report on the research done on Cymbalta and neuropathic pain. An online search for information on Cymalta and TN did not reveal anything conclusive. There were success stories and stories that were not as successful. But we do believe that knowledge is power so we share this information with you to increase your knowledge about TN and a possible medication to treat it.

Committee to Evaluate Drugs (CED)
Duloxetine (for diabetic peripheral neuropathic pain)
Product:
DULOXETINE (Cymbalta®) 30mg, 60mg capsules
Class of drugs:
Serotonin and norepinephrine reuptake inhibitor (SNRI)
Indication:
Treatment of diabetic peripheral neuropathic pain
Manufacturer: Eli Lilly Canada Inc.
The CED recommended that duloxetine (Cymbalta) be funded for the treatment of diabetic peripheral neuropathic pain through the Exceptional Access Program according to specific criteria.
The CED noted that duloxetine Cymbalta) has been shown to reduce pain and improve quality of life in the treatment of diabetic peripheral neuropathic pain. However, there is no evidence that duloxetine (Cymbalta) is as or more effective than lower cost alternatives.

Based on the CED's recommendation, the Executive Officer decided to fund duloxetine (Cymbalta) through the Exceptional Access Program according to specific criteria. Funding available through the Ontario Public Drug Programs via the Exceptional Access Program.

Highlights of Recommendation:

♦ Duloxetine (Cymbalta) is indicated for the treatment of diabetic peripheral neuropathic pain (nerve pain in the arms and legs experienced by some patients with diabetes) as well as for the treatment of depression. This review is specific to its use in the management of neuropathic pain in patients with diabetes.

♦ The Committee evaluated three studies comparing the effects of duloxetine (Cymbalta) to placebo in adult patients with diabetic peripheral neuropathic pain. Compared with placebo, patients treated with duloxetine (Cymbalta) reported reductions in pain and improvements in their quality of life.

♦ There are no comparison studies between duloxetine (Cymbalta) and other treatments for diabetic peripheral neuropathic pain; therefore, its efficacy relative to alternative therapies is unknown.

♦ Available studies for duloxetine (Cymbalta) in the treatment of diabetic peripheral neuropathic pain were short in duration (12 weeks). The long-term safety of this drug is uncertain.

♦ Common side effects reported with duloxetine include nausea, dizziness, fatigue and sleepiness.

♦ At the recommended dose of 60mg daily, duloxetine (Cymbalta) costs $3.56 per day. It is more expensive than alternative treatments such as amitriptyline, carbamazepine, and opioid analgesics that are listed on the Formulary. Duloxetine (Cymbalta) is similar in cost to gabapentin, a neuropathic pain treatment funded through the Exceptional Access Program.

♦ **Overall, the Committee acknowledged that duloxetine (Cymbalta) has been shown to reduce pain and improve quality of life in the treatment of diabetic peripheral neuropathic pain compared with placebo. However, there is no evidence that duloxetine (Cymbalta) is as or more effective than lower cost alternatives listed on the Formulary. Furthermore, the long-term safety of this drug has not been established. As such, the Committee recommended that funding be considered through the Exceptional Access Program according to specific criteria.**

Background:

Diabetic neuropathy is a nerve disorder caused by poor blood sugar control in patients with daibetes. Diabetic peripheral neuropathy is the most common type of diabetic neuropathy. Symptoms of diabetic peripheral neuropathy include pain, numbness and tingling in the toes, feet, legs, hands, and arms.

The goal of treating diabetic peripheral neuropathy is to primarily relieve discomfort. The first step is to bring blood sugar levels under control. Drug treatments may be prescribed for the relief of pain, burning, or tingling. Analgesics, antidepressants, and anticonvulsant medications are commonly used for the management of diabetic peripheral neuropathic pain. Many of thesetreatments are listed on the Ontario Drug Benefit Formulary. Funding for other therapies, such as gabapentin and pregabalin, are considered through the Exceptional Access Program.

Detailed Discussion:

♦ The Committee reviewed three double-blind randomized controlled studies evaluating

the efficacy and safety of duloxetine (Cymbalta) for diabetic peripheral neuropathic pain. The studies were 12 weeks in duration and compared duloxetine (Cymbalta) with placeboin a total of 1,139 patients.

♦ The studies reported that duloxetine (Cymbalta), at doses of 60mg daily and 60mg twice daily, was effective in reducing pain, as measured by a reduction in 24-hour average pain scores. Improvements in quality of life measures were also observed in patients who were treated with duloxetine (Cymbalta) compared with placebo.

♦ Duloxetine (Cymbalta) 60mg twice daily was not shown to be significantly better in pain control than the 60mg once daily dose, and the 60mg twice daily dose was associated with more adverse events.

♦ Because direct comparison studies between duloxetine (Cymbalta) and alternative neuropathic pain treatments are not available, its efficacy versus other agents isunknown.

♦ The most common side effects with duloxetine (Cymbalta) reported in the studieswere sleepiness and nausea.

♦ There are no randomized controlled studies evaluating the long-term safety of duloxetine(Cymbalta). Given that diabetic peripheral neuropathic pain is a chronic condition, the Committee was concerned about the lack of long-term safety data. It was noted that the Food and Drug Administration in the United States recently updated warnings on the risk of hyponatremia (low blood sodium levels), bleeding, and urinary hesitancy/retention associated with the use of duloxetine (Cymbalta).

♦ At the recommended dose of 60mg daily, duloxetine (Cymbalta) costs $3.56 per day. It is more expensive than alternative treatments such as amitriptyline, carbamazepine, and opioid analgesics that are listed on the Formulary. Duloxetine (Cymbalta) is similar in cost to gabapentin, which is funded through the ExceptionalAccess Program.

♦ The Committee acknowledged that diabetic peripheral neuropathic pain may sometimes be difficult to treat and that having more treatment options would be valuable in patients who do not respond to standard therapies.

♦ Overall, the Committee noted that duloxetine (Cymbalta) has been shown to reduce pain and improve quality of life in the treatment of diabetic peripheral neuropathic pain compared with placebo. However, there is no evidence that duloxetine (Cymbalta) is more effective than lower cost alternatives listed on the Formulary. Furthermore, the long-term safety of this drug has not been established. As such, the Committee recommended that funding be considered through the Exceptional Access Program. The CED recommended that funding for duloxetine (Cymbalta) be considered through the Exceptional Access Program (EAP) according to the following clinical criteria:

– Patients with diabetic peripheral neuropathic pain (receiving insulin and/or oral hypoglycemic agents) who have failed an adequate trial of tricyclic antidepressant and an adequate trial of gabapentin.

– The dose of duloxetine (Cymbalta) is limited to a maximum of 60mg daily. (http://www.cadth.ca/index.php/en/cdr/recommendations)

The Canadian Expert Drug Advisory Committee (CEDAC) recommended that duloxetine (Cymbalta) be listed for the treatment of neuropathic pain in diabetic patients who are unresponsive to two adequate courses of less costly alternative agents such as a tricyclic antidepressant agent or an anticonvulsant agent. The

dose of duloxetine (Cymbalta) should be limited to a maximum of 60mg daily.

Ministry of Health and Long-Term Care Ontario Public Drug Programs
For more information, please contact:
Ministry of Health and Long-Term Care
Ontario Public Drug Programs
Hepburn Block, 9th Floor
80 Grosvenor Street, Queen's Park
Toronto, Ontario M7A 1R3
or click:
(http://www.health.gov.on.ca/english/providers/program/drugs/ced_rec_table.html)
EAP Criteria: CEDAC Recommendation:

Dear TN Support Group: some food for thought on supplements from someone who used to work with Dr. Jennetta, the surgeon who pioneered MVD surgery for TN. Wishing you all freedom from pain. Regards Ann

Treating Trigeminal Neuralgia

Question: Is there any way to treat painful swelling of the facial nerves (trigeminal neuralgia)?

Dr. Blaylock's Answer:

When I was a medical student and later as a resident, I had a great interest in this condition, and I worked with Dr. Peter Jennetta, an expert in trigeminal neuralgia surgery. While a number of surgical treatments are available, Jennetta's has been the most successful. Yet, I found natural remedies helped a number of my patients.

A combination of curcumin and quercetin (500 mg each), mixed with extra-virgin olive oil and taken three times a day, reduces the inflammation of the nerve and promotes healing.

Magnesium citrate/malate (500 mg twice a day) reduces the pain, blocks excitotoxicity (which triggers the pain), and allows the nerve to heal. Phosphotidylcholine, which makes up a large part of the fatty insulation of the nerve, promotes healing as well.

The B vitamins, especially B-1, B-6, B-12, folate, and niacinamide, also promote nerve healing and improve nerve function. It is critical to avoid all excitotoxins in foods — MSG, hydrolyzed proteins, caseinates, carrageenan, autolyzed yeast, etc. Avoiding caffeine and other stimulants is also important.

Other nutrients that reduce trigeminal hyperactivity include carnosine, acetyl-L carnitine and Silymarin.

NOTE: The above is taken from an online blog related to TN.

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National Pain Association Definitions of Trigeminal Neuralgia

To avoid confusion when discussing trigeminal neuralgia, it is important to understand the words your health care provider is using and what they mean when he or she is talking about facial pain. Below are several definitions that have been and are still used to describe people with trigeminal neuralgia and facial pain:

Atypical Trigeminal Neuralgia

Atypical TN is a term often used to describe pain that does not have the characteristics

associated with classic or typical TN. Patients who have atypical TN often have pain that may be continuous and may be described as dull, aching, or throbbing.

Atypical facial pain is a confusing term and should never be used to describe patients with trigeminal neuralgia or trigeminal neuropathic pain. Strictly speaking, AFP is classified as a “somatiform pain disorder”; this is a psychological diagnosis that should be confirmed by a skilled pain psychologist. Patients with the diagnosis of AFP have no identifiable underlying physical cause for the pain. The pain is usually constant, described as aching or burning, and often affects both sides of the face (this is almost never the case in patients with trigeminal neuralgia). The pain frequently involves areas of the head, face, and neck that are outside the sensory territories that are supplied by the trigeminal nerve. It is important to correctly identify patients with AFP since the treatment for this is strictly medical. Surgical procedures are not indicated for atypical facial pain.

In order to simplify and clarify the diagnosis of the trigeminal neuralgia and eliminate some of the confusion produced by difference in terminology, Dr. Kim Burchiel (Professor and Chairman, Department of Neurological Surgery, Oregon Health Sciences University, Portland, OR) has proposed a new classification scheme for the diagnosis of facial pain. This scheme is based on the underlying causes of the pain and has implications for treatment:

- **Trigeminal neuralgia, type 1**, (TN1): facial pain of spontaneous onset with greater than 50% of pain limited to the duration of an episode of pain (temporary pain).
- **Trigeminal neuralgia, type 2**, (TN2): facial pain of spontaneous onset with greater than 50% as a constant pain.
- **Trigeminal neuropathic pain, (TNP)**: facial pain resulting from unintentional injury to the trigeminal system from facial trauma, oral surgery, ear, nose and throat (ENT) surgery, root injury from posterior fossa or skull base surgery, stroke, etc.
- **Trigeminal deafferentation pain, (TDP)**: facial pain in a region of trigeminal numbness resulting from intentional injury to the trigeminal system from procedures that are typically performed for treatment of trigeminal neuralgia (eg. neurectomy, gangliolysis, rhizotomy, radiosurgery, nucleotomy, tractotomy, or other denervating procedures)
- **Symptomatic trigeminal neuralgia, (STN)**: pain resulting from multiple sclerosis.
- **Secondary trigeminal neuralgia**: pain resulting from anatomical abnormalities that affect the trigeminal nerve such as tumors, aneurysms, etc.
- **Postherpetic neuralgia, (PHN)**: pain resulting from trigeminal Herpes zoster outbreak.

Atypical facial pain, (AFP): pain predominantly having a psychological rather than a physiological origin.

Trigeminal Neuropathic Pain

This is a pain condition that happens after an injury to one or more branches of the trigeminal nerve. Trigeminal neuropathic pain curs as a result of nerve injury following dental procedures (tooth extractions, root canals, etc), facial fractures, nerve injury from sinus surgery, etc. This condition is NOT the same as trigeminal neuralgia. This pain is usually continuous and generally is of a burning quality. Many patients with TNP have documented loss of sensation on the face or forehead. It is important to make this distinction, since the surgical procedures that are effective in trigeminal neuralgia, are almost never helpful for TNP, and not uncommonly can make this condition worse.

Fast Facts

- Approximately four or five in 100,000 people will develop trigeminal neuralgia each year
- The average onset of TN is usually between 50 and 70 years of age
- Trigeminal neuralgia almost always affects one side of the face
- Approximately 1% of patients with multiple sclerosis develop trigeminal neuralgia.

Myths and Misconceptions

Myth: All facial pain is trigeminal neuralgia.

Truth: There are actually many causes of facial pain that have nothing to do with TN. Disorders that affect the eye, eye socket, nose, sinuses, teeth, temporomandibular joint, gums, tongue, inside of the mouth, and ear can ALL produce facial pain. However, the pain symptoms that occur with these problems are usually significantly different from those caused by TN. Also, all of these other conditions usually have other findings that help to differentiate them from TN. However, it is true that the symptoms caused by many of these conditions do overlap somewhat and it is therefore of the utmost important that you provide your doctor with as detailed and accurate description of your pain as possible.

Myth: Microvascular decompression is not indicated in patients over 65 years of age.

Truth: The fact is, there is evidence in the medical literature to suggest that MVD is just as safe and effective for patients over the age of 65 as for patients younger than 65 years of age. Elderly patients who are otherwise in excellent health should not be denied consideration for MVD simply based on age alone.

Myth: There is no risk to stereotactic radiosurgery (gamma knife).

Truth: Although stereotactic radiosurgery is in fact a non-invasive treatment, it must be remembered that it is still a destructive procedure, whose goal is to damage the trigeminal nerve using radiation. The fact is that any procedure that damages the nerve can produce sensory loss on the face and occasionally bothersome sensations known as

dysesthesias. The these problems are more commonly associated with the use of higher doses of radiation. Unfortunately, higher doses of radiation are also associated with better outcomes in terms of pain relief.

Myth: All patients with trigeminal neuralgia have classic symptoms.
Truth: Many patient with trigeminal neuralgia do not in fact have typical symptoms. Also, for patients who have had TN for many years, the symptoms tend to become less typical as time goes by.

Myth: Even patients whose pain goes away, need to stay on medications indefinitely.
Truth: This is not necessarily the case. Trigeminal neuralgia is often characterized by periods of spontaneous remission. For some patients, these periods may last many years. There is no absolute way to manage medications for patients with TN. Therefore, it is essential that you have excellent communication with your doctor and nurse in order to monitor the medications. When you are prescribed a medication, you must take it regularly for it to be effective. Once you have been pain free for perhaps 6 -12 weeks, it may be possible to reduce the medication or even taper off of it completely without the pain returning. However, this should be done in consultation with your doctor. You should not abruptly stop the medications since doing so can cause serious side effects with certain medications.

Contacting TNAC

Want to know how to reach us? We can be reached by using the following email addresses:

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 (and we have a volunteer who does this for our newsletter according to your requests!)? Please let us know.Deadlines for newsletter submissions are:
May 30th
August 30th
Nov. 30th
Feb. 28th

If you would be interested in helping out on the board, or if you have something for a future newsletter, please contact:

Jane (president)
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