



TRIGEMINAL NEURALGIA ASSOCIATION OF CANADA

Summer 2010 Newsletter



Support Group



Eastern Ontario Support Group

The summer months are often challenging for people with TN. Humidity, weather changes, bright sun, rain ... It is a good time to come together and support one another.

If you live in Eastern Ontario, from Kingston to the Quebec border and north to Ottawa, we would love to meet with you.

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 V0N 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>



MARION GUZIK, FOUNDER OF TNAC, RETIRES

Article by Ann Hopkins, Vancouver and Lower Mainland Support Group Coordinator

Marion Guzik, Founder, President and Past President is retiring from the Board of the Trigeminal Neuralgia Association of Canada after more than 14 years of dedicated service.

Marion has had some health problems on top of her TN and now she's 80 she's planning to be a little less busy though she hopes to keep up with her many friends and fellow TN sufferers that she's come to know and value over the years.

I asked Marion to tell me about the early years and how she came to found the TNAC. "My TN started shortly after my husband Walter passed away," said Marion. "In fact, I'd had pain for some time before that but didn't know what it was. Then suddenly it got much worse. I was having dinner with my sisters one night and took a bite of celery. The most excruciating pain hit my face and I couldn't eat or do anything. My doctor

had no idea what was wrong so didn't treat it.

Founding the Lethbridge Group

"Sometime later I went to a presentation being given by a doctor and while I was there a ray of sunshine hit me in the eye and I got another attack," said Marion. "To this day I have no idea what that presentation was about, but the most important thing the doctor said was that he thought I had TN. That's when I got on the internet and came across the Trigeminal Neuralgia Association of the US and we started to correspond.

"I started the Lethbridge group on June 15, 1996. I was fortunate in that a reporter for the Lethbridge Herald interviewed me and asked TN sufferers to contact me. There were 12 people at that initial meeting. We met in my home for a year eventually finding a permanent meeting place at our local Seniors Centre where we meet every second Saturday of the month.

Founding TNAC, Going National and Becoming a Charity

"In 2000 I went to my first TNA conference in Pittsburgh and in 2001 I incorporated TNAC as a provincial non profit society. In 2002 I applied for charitable status for our organization from the Canada Revenue Agency. It was granted in 2003. This was a big step forward. And in 2006 we incorporated as a national non profit society.

"Outreach and communications were always key and I started a web page as well as regular newsletters and a phone help line. Support groups grew up across Canada and I distributed newsletters to around 200 members. Fundraising continues and TNAC has been able to support research by Dr. Honey, a neurosurgeon at Vancouver General Hospital. The reality is that we're a small group but we're growing

and we want to make a difference. Research, support groups and educating doctors and dentists are all vitally important.

TNAC Medical Advisor

"I also got in touch with Dr. Anthony Kauffman to ask him to be the TNAC medical advisor. A member of our group had had an MVD with Dr. Kaufmann in Calgary and I approached him. He's now in Winnipeg as the Director of the Centre for Cranial Nerve Disorders and is very supportive of TNAC. He regularly answers questions in our newsletter and gives presentations to TN groups.

"Dr. Kauffman has spoken in Lethbridge three times as well as other centres like Vancouver, Calgary, Toronto, Ottawa and Edmonton. He first spoke at the Lethbridge public library to a group of about 75 and the meeting was well attended by dentists. He was last in Lethbridge in 2008 and gave a presentation to the medical community and people with TN. At that meeting he presented me with the President's Pin which had come from Claire Patterson, Past President and founder of the TNA-US. The pin has been shared with Presidents of sister organization's of TNA.

Thank You Marion

Marion's contribution has been huge. Founding the association and getting charitable association status were major breakthroughs and involved an enormous amount of hard work, persistence and optimism. And we all know how hard it is getting things done with a condition as unpredictable as TN to contend with. Marion will be much missed but her unflagging spirit and the organization she has created will encourage and inspire us all to continue with her work and to reach out to fellow sufferers throughout Canada. Thanks to

Marion we know we can make a difference. We know we are not alone.

Thoughts from Marion

I asked Marion if there were any thoughts she'd like to leave us with.

"As I write this Ann, tears are falling, as I will miss each and every one of you and I want to thank all of you for your patience, guidance and understanding during the first years of inception. We could not have done the things that have made the TNAC a viable organization without this help. We have accomplished what we had set out to do, which was to get all the people with Trigeminal Neuralgia in Canada together, and to get our charitable organization status from Revenue Canada, form a Non-Profit Society, plus establish independent support groups across Canada, which is not as complete as I had envisioned, but this all takes time. It is now time for someone who is younger and healthier than I, to carry on with the organization and take it to the next level.

"May God bless each and every one of you. I will miss you all and hope that your TN will one day be lost to history. Please feel free to still correspond if you would like to."

If you wish to contact Marion her email address is: mquzik@telus.net and her mailing address is: 1514 Lakemount Blvd., Lethbridge, Alberta T1K 3K4.



Sniff of Local Anesthetic in the Dentist's Chair Could Replace the Needle

ScienceDaily (May 13, 2010) — Modern dentistry has eliminated much of the "ouch!" from getting a shot of local anesthetic. Now a new discovery may replace the needle used to give local anesthetic in the dentist's chair for many

procedures. Scientists are reporting evidence that a common local anesthetic, when administered to the nose as nose drops or a nasal spray, travels through the main nerve in the face and collects in high concentrations in the teeth, jaw, and structures of the mouth.

The discovery could lead to a new generation of intranasal drugs for noninvasive treatment for dental pain, migraine, and other conditions, the scientists suggest in American Chemical Society's bi-monthly journal *Molecular Pharmaceutics*. The article is scheduled for the journal's May-June issue.

William H. Frey II, Ph.D., and colleagues note that drugs administered to the nose travel along nerves and go directly to the brain. One of those nerves is the trigeminal nerve, which brings feelings to the face, nose and mouth. Until now, however, scientists never checked to see whether intranasal drugs passing along that nerve might reach the teeth, gums and other areas of the face and mouth to reduce pain sensations in the face and mouth.

Neil Johnson, working in the labs of Frey and Leah R. Hanson, Ph.D., at Regions Hospital in St. Paul, Minn., found that lidocaine or Xylocaine, sprayed into the noses of laboratory rats, quickly traveled down the trigeminal nerve and collected in their teeth, jaws, and mouths at levels 20 times higher than in the blood or brain. The approach could provide a more effective and targeted method for treating dental pain/anxiety, trigeminal neuralgia (severe facial pain), migraine, and other conditions, the scientists say. Furthermore, these scientists discovered an improved future location to administer anesthetic, the maxillary sinus. The maxillary sinus is a golfball-sized space located underneath each cheek where drug can be sprayed. Delivery into this confined space may be the next generation approach

beyond a nasal spray in providing a more rapid and focused delivery of aesthetic.

Story Source:

Adapted from materials provided by [American Chemical Society](#), via [EurekAlert!](#), a service of AAAS.



Evaluating Alternative Therapies

Searching through the internet you can find a lot of information. Some of it looks to be too good to be true. How do you know when a 'new treatment' or 'natural treatment' is worth your trying or just a touted miracle cure that is not worth the money? Below are some guidelines that you can consider when you read or hear about a new, alternative, or complimentary therapy for TN.

When considering use of alternative and complementary therapies, it is important to balance promotional (often belief based) information provided by sellers of alternative therapies, with objective, evidence-based information.

"How to Spot False Claims" quoted from Federal Trade Commission website.

The product is advertised as a quick and effective cure-all for a wide range of ailments.

The promoters use words like scientific breakthrough, miraculous cure, exclusive product, secret ingredient or ancient remedy.

The promoter claims the government, the medical profession or research scientists have conspired to suppress the product.

The advertisement includes undocumented case(s) [or testimonials] claiming amazing results.

The product is advertised as available from only one source, and payment is required in advance.

The promoter promises a no-risk "money-back guarantee". Be aware that many fly-by-night operators are not around to respond to your request for a refund.

"Tips on evaluating herbal remedies" quoted from the University of Toronto. Faculty of Medicine Health News

- Always tell your physician about any [herbal remedies] being taken
- Use herbal products only for short periods, in moderation.
- Do not use them [herbal remedies] to replace prescribed treatment.
- Purchase [herbal remedies] from established and reputable suppliers. Ask about what you are buying: Are the Latin names of herbs, the quantities and uses listed?
- Do not give children under age two herbal teas.
- Be cautious in using very concentrated oils and teas.



Membership Drive

Are you a member of TNAC? Do you know of someone with TN who is not a member? Does your doctor have other patients with TN who could benefit by being a member of TNAC? If so drop off a copy of this newsletter with your doctor the next time you have an appointment. They may just file it away but who knows. Perhaps they will pass it along and you will be able to reach out to and help

others with TN break out of the isolation and connect to the support and help they need!

Our membership year runs from July 1 – June 30 each year. If you have not renewed your membership for 2010 – 2011 now is the time to do so. A copy of the membership application is included with this newsletter.

Our AGM is Thursday July 22 at 4PM EST. To attend by teleconference please contact Jane at 613.936.6977 for the access number and code.

If you are not sure of your membership status please contact our member chair, Joya Dickson. Joya will let you know if your dues are currently due for renewal or if you are paid through to the end of June in 2011.

Our organization operates on membership dues and the donations of our members. We thank you for supporting TNAC through your continued membership!



Preparing for your appointment By Mayo Clinic staff

Make an appointment with your family doctor or primary care provider if you have symptoms common to trigeminal neuralgia. After your initial appointment, you may be referred to a doctor who specializes in the diagnosis and treatment of conditions that affect the brain and nervous system (neurologist). Here's some information to help you prepare for your appointment and what

to expect from your doctor.

What you can do

Write down any symptoms you've been having, and for how long.

Note the triggers that bring on your attacks of facial pain.

Make a list of your key medical information, including any other conditions for which you're being treated and the names of any medications, vitamins or supplements you're taking.

Take a family member or friend along, if possible. Someone who accompanies you may remember something that you missed or forgot.

Write down questions to ask your doctor. Creating your list of questions in advance can help you make the most of your time with your doctor.

For possible trigeminal neuralgia, some basic questions to ask your doctor include:

- What is the most likely cause of my pain?
- Are there any other possible causes?
- Do I need any diagnostic tests?
- What treatment approach do you recommend?
- If you're recommending medications, what are the possible side effects?
- Am I a candidate for surgery? Why or why not?
- Will I need treatment for the rest of my life?
- How much do you expect my symptoms will improve with treatment?
- Should I see a specialist?

In addition to the questions that you've prepared to ask your doctor, don't hesitate to ask questions during your appointment at any time that you don't understand something.

Your doctor is likely to ask you a number of questions. Being ready to answer them may reserve time to go

over any points you want to spend more time on. Your doctor may ask:

- What are your symptoms?
- Where are your symptoms located?
- Are both sides of your face affected?
- When did you first develop these symptoms?
- Have your symptoms gotten worse over time?
- How often do you experience bouts of facial pain?
- What seems to trigger your facial pain?
- How long does an attack of facial pain typically last?
- How much are these symptoms affecting your quality of life?
- Do you have any other signs or symptoms in addition to facial pain?
- Have you ever had dental surgery or surgery on or near your face, such as sinus surgery?
- Have you had any facial trauma, such as an injury or accident that affected your face?
- Are you currently being treated or have you recently been treated for any other medical conditions?
- What medications are you currently taking, including prescription and over-the-counter drugs as well as vitamins and supplements?
- Have you tried any treatments for your facial pain so far? Has anything helped?

A diagnosis of trigeminal neuralgia is primarily based on a description of your pain, including the:

- Type.** Pain related to trigeminal neuralgia is sudden, shock-like and brief.
- Location.** The parts of your face that are affected will tell your doctor if the trigeminal nerve is involved.
- Triggers.** Trigeminal neuralgia-related pain is typically brought on by light stimulation of the cheeks, such as from eating, talking or even encountering a

cool breeze.

Tests used to confirm the diagnosis may include:

A neurological examination.

Touching and examining parts of your face can help your doctor determine exactly where the pain is occurring and — if you appear to have trigeminal neuralgia — which branches of the trigeminal nerve may be affected.

Magnetic resonance imaging

(MRI). An MRI scan of your head can show if multiple sclerosis is causing trigeminal neuralgia.

Facial pain can be caused by many different disorders, so an accurate diagnosis is important. Your doctor may order additional tests to rule out other conditions.

Trigeminal neuralgia treatment usually starts with medications, and many people require no additional treatment. However, over time, some people with the disorder eventually stop responding to medications, or they experience unpleasant side effects. For those people, injections or surgery provide other trigeminal neuralgia treatments options.

Medications to lessen or block the pain signals sent to your brain are the most common initial treatment for trigeminal neuralgia.

Anticonvulsants. Carbamazepine (Tegretol, Carbatrol) is the drug most commonly prescribed — and with the most demonstrated effectiveness — for trigeminal neuralgia. Other anticonvulsant drugs used to treat trigeminal neuralgia include oxcarbazepine (Trileptal), lamotrigine (Lamictal), phenytoin (Dilantin, Phenytek) and gabapentin (Neurontin). If the anticonvulsant you're using begins to lose effectiveness,

your doctor may increase the dose or switch to another type. Side effects of anticonvulsants may include dizziness, confusion, drowsiness, double vision and nausea. Also, carbamazepine can trigger a serious drug reaction in some people, mainly those of Asian descent, so genetic testing may be recommended before you start carbamazepine.

Antispasmodic agents. Muscle-relaxing agents such as baclofen may be used alone or in combination with carbamazepine or phenytoin. Side effects may include confusion, nausea and drowsiness.

Alcohol injection Alcohol injections provide temporary pain relief by numbing the affected areas of your face. Your doctor will inject alcohol into the part of your face corresponding to the trigeminal nerve branch causing pain. The pain relief isn't permanent, so you may need repeated injections or a different procedure in the future. Side effects may include infections at the injection site, bleeding and damage to nearby nerves.

Surgery The goal of surgery for trigeminal neuralgia is either to stop the blood vessel from compressing the trigeminal nerve or to damage the trigeminal nerve to keep it from malfunctioning. Damaging the nerve often causes temporary or permanent facial numbness, and with any of the surgical procedures, the pain can return months or years later. Surgical options for trigeminal neuralgia include:

Gamma-knife radiosurgery (GKR).

This procedure involves delivering a focused, high dose of radiation to the root of the trigeminal nerve. Because of GKR's effectiveness and safety compared with other surgical

options for trigeminal neuralgia, the procedure is becoming widely used and may be offered earlier than other surgical procedures.

Gamma-knife radiosurgery uses radiation to damage the trigeminal nerve and reduce or eliminate pain. Relief occurs gradually and can take several weeks to begin. GKR is successful in eliminating pain for the majority of people. If pain recurs, the procedure can be repeated. Fewer than 5 percent of people who undergo this procedure experience side effects, which may include lasting loss of facial sensation. The procedure is painless and typically is done without anesthesia.

Microvascular decompression

(MVD). This procedure involves relocating or removing blood vessels that are in contact with the trigeminal root.

During MVD, your doctor makes an incision behind the ear on the side of your pain. Then, through a small hole in your skull, part of your brain is lifted to expose the trigeminal nerve. Any artery in contact with the nerve root is directed away from the nerve, and the surgeon places a pad between the nerve and the artery. If a vein is compressing the nerve, the surgeon typically will remove it. MVD can successfully eliminate or reduce pain most of the time, but pain can recur in some people. While MVD has a high success rate, it also carries risks. There are small chances of decreased hearing, facial weakness, facial numbness, double vision, and even a stroke or death. Most people who have this procedure have no facial numbness afterward.

Note that if no artery or vein appears to be compressing the nerve, your surgeon may sever part of the nerve, instead. This procedure is called a rhizotomy.

Glycerol injection. During this procedure, your doctor inserts a needle through your face and into an opening in the base of your skull. The needle is guided into the trigeminal cistern, a small sac of spinal fluid that surrounds the trigeminal nerve ganglion — where the trigeminal nerve divides into three branches — and part of its root. Images are made to confirm that the needle is in the proper location, and then a small amount of sterile glycerol is injected. After three or four hours, the glycerol damages the trigeminal nerve and blocks pain signals. Initially, this procedure relieves pain in most people. However, some people have a later recurrence of pain, and many experience facial numbness or tingling.

Balloon compression. In balloon compression of the trigeminal nerve, your doctor inserts a hollow needle through your face and into an opening in the base of your skull. Then, a thin, flexible tube (catheter) with a balloon on the end is threaded through the needle. The balloon is inflated with enough pressure to damage the nerve and block pain signals. Balloon compression successfully controls pain in most people, at least for a while. Most people undergoing this procedure experience some facial numbness, and some experience temporary or permanent weakness of the muscles used to chew.

Electric current (radiofrequency

thermal rhizotomy). This procedure selectively destroys nerve fibers associated with pain. While you're sedated, your doctor places a hollow needle through your face and into an opening in your skull. Once the needle is positioned, an electrode is threaded through it to the nerve root. You're then awakened from sedation so that you can indicate when and where you feel tingling from the mild current pulsed through the tip of the electrode. When the neurosurgeon locates the part of the nerve involved in your pain, you are returned to sedation. Then the electrode is heated until it damages the nerve fibers, creating an area of injury (lesion). If your pain isn't eliminated, your doctor may create additional lesions. Almost everyone who undergoes radiofrequency thermal rhizotomy has some facial numbness after the procedure.

Severing the nerve (rhizotomy). A procedure called partial trigeminal rhizotomy involves cutting part of the trigeminal nerve at the base of your brain. Through an incision behind your ear, your doctor makes a quarter-sized hole in your skull to access the nerve. Because it cuts the nerve at its source, your face will be numb permanently.

Living with trigeminal neuralgia can be difficult. The disorder may affect your interaction with friends and family, your productivity at work, and the overall quality of your life.

You may find encouragement and understanding in a support group. Group members often know about the latest treatments and tend to share their own experiences. If you're interested, your doctor may be able to recommend a group in your area or contact TNAC.



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)
613.936.6977
cmusicstudio@cogeco.ca



Trigeminal Neuralgia Association of Canada



Membership Application

NAME: _____

Please Print (Surname, First Name)

ADDRESS: _____

CITY/TOWN _____ PROV _____ P. CODE. _____

Birthdate: _____ Telephone Number _____

Email Address _____

Membership year: July 20 _____ - June 20 _____

Is this a new membership or a renewal?

I would like to become a new member: _____

I would like to renew my membership: _____

Membership Fees: \$ 25.00 Enclosed: _____

Are you interested in starting up a Support Group in your area? ☐ Yes ☐ No

If **yes**, would you like information on how to start a support group? ☐ Yes ☐ No

Are you interested in being a Telephone Contact Person? ☐ Yes ☐ No

Are you interested in attending a Support Group? ☐ Yes ☐ No

If **yes**, can we give your contact information to a support group leader in your area? ☐ Yes ☐ No

Donations:

TNAC exists largely on the support of donations. If you would like to make a donation for yourself or in memory of a loved one please indicate below.

I would like to make a donation to TNAC in the amount of: \$ _____ (all donations are tax deductible)

I would like to make a donation in memory of: (please list name of person): _____

I would like TNAC to acknowledge the donation by sending a note to: (please write name and mailing contact information of family below)

Note: Would you like your name and/or contact information listed in our membership directory? This will be accessible by members only. With your permission we would also list your contact information to others with TN and/or to local support groups in your community. If you would like your name listed for any of the above please sign and date below checking off the boxes for the areas where we may release this information. Note that TNAC does not sell or give out its membership list to any organization.

Name, signature, and date

I, the above signed, give permission for TNAC to list my name and contact information as indicated below left for the purposes indicated below right:

Information to be shared

☐ name

☐ phone

☐ email

☐ street address

Purpose

☐ telephone support (for others to call me)

☐ membership list

☐ support group

☐ you can put my contact information on the
members only section of the web site

Check enclosed in the amount of:

\$ _____ Membership fee

\$ _____ Donation

\$ _____ TOTAL

**Please make checks payable to TNAC and return to:
Trigeminal Neuralgia Association of Canada Membership**

**Joya Dickson
7- 5300 Admiral Way,
Ladner BC V4K 5G6**

