



Trigeminal Neuralgia Association of Canada

Winter 2009 Newsletter



Support Group



Eastern Ontario Support Group

The snowbirds flew the coop!

The Eastern Ontario support group is now meeting regularly. It is great to be making friends and seeing new faces at our meetings. At our last meeting we discovered that all but 2 of our group were heading south for part of the winter so we decided to postpone our winter meeting until spring. We anticipate meeting again in April.

If you live in Eastern Ontario, from Kingston east to the Quebec border and north to Ottawa, we would love to meet with you. Currently we are meeting in Ottawa but are considering meeting in Brockville area for our next meeting.

For more information contact Jane at cmusicstudio@coqeco.ca or by calling 613.936.6977

Vancouver and Lower Mainland Support Group Update

Coordinator: Ann Hopkins

Vancouver and Lower Mainland Support Group Meeting
Saturday February 28 2009
Time 1 pm to 3.30 pm
Place: Social Services Seminar Room
189

G.F. Strong Rehab Centre
4255 Laurel St. (Laurel at West 26th - one block east of Oak)
Coordinator: Ann Hopkins, 604 741 0662 or annhopkins@dccnet.com
Please call for further information ... or to have a chat.

Lethbridge Support Group Coordinator Marion Guzik

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. Our next scheduled meeting is February 14th. 2009 and then March 14th.

Happy Valentines Day to you All.

A hearty welcome to Maxine and Linda who have joined our group. Linda informed us that she has sent away for the new drug Trignotab. We will be anxiously awaiting to hear what she says about it.

Ask Dr. Kaufmann

Dr. Kaufmann is the medical advisor of TNAC. If you have questions about TN and/or TN interventions send them to "Ask Dr. Kaufmann" This edition we did have 2 questions however they arrived just before the newsletter 'went to print' and Dr. Kaufmann was not available to respond so look for this section in our next newsletter!

Thank you for submitting your questions! Please send questions to: president@tnac.org or 613.936.6977



What did you say?? Update

Well it has been over 2 years since I started on the journey to better hearing.

I recently returned for a repeat hearing test. It showed that all is stable which pretty much confirms that the hearing loss was a result of the MVD. However it is good news in that the loss remains mild to moderate.

With my ongoing battle with Anesthesia Dolorosa I do continue to struggle to wear the hearing aid to the extent that I should. My audiologist has been supportive but I am simply not able to wear an aid 8 – 12 hours a day, 7 days a week. I cope by carrying a case for the hearing aid with me at all times. If I am having a 'bad' day I will take the aid out. That way I always start off the day optimistic and give it my best try. However the on / off is catching up to me in that I find the hearing aid not to be helping too much.

In my recent consult with the ENT he said 'there has to be a solution out there' and wrote a note to the audiologist to go looking. Well it turns out there is another option.



Siemens makes something called the Vibe hearing aid. This aid sits in the crest of the ear. It is not a behind the ear so will not push on my glasses or into my head which triggers TN pain. It is not an in the canal aid so will not push on the Eustachian tube and therefore put pressure on my jaw causing AD pain. Yes there is a small tube that goes into the Eustachian tube but ...

I considered trying this hearing aid and requested a sample to look at from the company. They contacted me and agreed to send one to my audiologist which I picked up today. It is bright orange! It is also larger than I thought. Feels a bit strange but after 2 ½ hours is not triggering TN or AD so far. I am going to wear it for the next 3 days and let my audiologist know. She mentioned that she may ask me to try the 'dummy aid' for a month before she orders one because I do not qualify for the \$500 assisted devices deductible for another year. We both want to be sure this is going to work if I am going to pay for the whole cost. However if it does work I would rather have a year without additional pain. So at present I'm not sure what I will do or how it will all work out but wanted to share information on this new style of aid with our readers. If you have TN and need a hearing aid you may want to have a look at this style.

For more information go to:
<http://www.siemens-hearing.com/hearing-aids/vibe/>

If anyone has been told they need a hearing aid and would like to chat I can be reached at 613.936.6977 or cmusicstudio@cogeco.ca

Jane

PS I have been wearing the Vibe 'dummy' for 3 days now with no TN or AD problems ... hmmm ... could there be a solution??? I hope so!

A 'Star Trekky' procedure nobody knows about

The Gamma Knife delivers a pinpointed dose of radiation to treat tumours and painful disorders - but it's being underused

HAYLEY MICK

Days before an appointment to have 201 radioactive beams shot into his brain, Canadian actor Gordon Pinsent was gripped with a familiar sort of dread. He had dealt with it before: mostly before stepping onstage or shooting commenced on films such as *Away from Her* and *The Shipping News*.

So, in order to get himself through the hospital doors, he relied on a trick he has used to combat stage fright throughout his long acting career.

"I said, this time I'm going to look forward to the experience," recalled Mr. Pinsent, 78, about a month after he was treated at Toronto Western Hospital for trigeminal neuralgia, a neuropathic disorder that causes episodes of intense pain in the eyes, scalp and face.

Now Mr. Pinsent is grateful for the Gamma Knife, a medical device that treats certain tumours and pain conditions without the slicing involved in regular brain surgery. The treatment trained 201 gamma beams at a millimetre-sized area of Mr. Pinsent's brain.

Gordon Pinsent learned of the possible cure for trigeminal neuralgia not in a doctor's office, but at a writers' conference. (*JENNIFER ROBERTS FOR THE GLOBE AND MAIL*)

The process was painless, fast and allowed him to leave the hospital the

same day. "It felt a bit Star Trekky," he said.

Toronto Western appreciates its high-profile patient and hopes he will generate exposure for the device. Even though the Gamma Knife cost \$7-million and is one of only three in Canada, it's being underused.

"It's such a unique way of treating disorders," said Mojgan Hodaie, co-director of the Gamma Knife program at the Krembil Neuroscience Centre at Toronto Western.

Because the Gamma Knife delivers single doses of radiation therapy to a targeted area of the brain with such precision, surrounding normal tissue receives minimum radiation. Since the mid-1980s, Gamma Knife radiosurgery has proven effective for patients with benign or malignant brain tumours, some vascular malformations and chronic pain conditions.

But until six years ago, Canadians seeking the treatment had to travel to the United States, where there are now more than 100 Gamma Knife centres. Health Sciences Centre Winnipeg got Canada's first Gamma Knife in 2003, followed by the University of Sherbrooke in 2004 and Toronto Western in 2005.

Today as many as 500 patients a year are treated at the Joey and Toby Tanenbaum Family Gamma Knife Centre in Toronto. But the device is only in operation two days a week. In Winnipeg, the machine also runs two days a week, for a total of about 250 patients a year.

"We could do another 50 to 100 patients, and we probably at that point would be very busy, but we have enough staff to do it," said Michael West, co-director of the Winnipeg Centre for Gamma Knife Surgery, which

takes patients from throughout Western Canada and Northern Ontario.



Although both centres have the capacity to treat more patients, both Dr. West and Dr. Hodaie say that because many health professionals and the public aren't aware of the Gamma Knife or all of its applications, patients who could be eligible for treatment aren't being referred.

Mr. Pinsent, who lives in Toronto and struggled with his pain condition for nine years, hadn't heard of the Gamma Knife until he attended a writers' conference in Nova Scotia. There he met a doctor from Toronto who said the Gamma Knife might fix his pain problem.

He had other options, including a needle to the face, which can be effective but often leaves permanent numbness in the cheek.

On Oct. 14, Mr. Pinsent was fitted with a specialized metal helmet that created a stationary and exact target for the gamma rays. He lay down, placing his head into a dome-like cap with 201 holes that helped focus the gamma beams. For about 90 minutes, the 201 rays were focused on one spot, killing the cells.

Mr. Pinsent recited Shakespeare during the procedure. He went home that afternoon.

Dr. Hodaie says in typical trigeminal neuralgia cases, it takes between three and eight weeks for the full effect of the treatment to work and the pain to go away. The pain is erased in about 70 per cent of patients, she said.

"My feeling is that this is an extraordinary piece of technology," Mr. Pinsent said. "And the doctor and so on, they were all terrific."

From Toronto Globe and Mail

Toronto Western Hospital

"The Toronto Western Hospital division of neurosurgery has an active research and clinical program for the treatment of trigeminal neuralgia and other facial pain conditions. TWH also hosts the only Gamma Knife Center in Ontario, which offers a non-invasive method of treatment of trigeminal neuralgia. A variety of procedures are performed, including microvascular decompression, rhizotomy, Gamma Knife radiosurgery as well as deep brain stimulation for pain. Please contact Dr. Mojgan Hodaie, Division of Neurosurgery, Toronto Western Hospital at 416-603-6441 for further information."

Submitted by Dr. M. Hodaie



Medical Tax Deductions

Just a reminder to claim your medical expenses when you do your income tax. This includes:

- Prescriptions
- Hearing aid batteries
- Attendant care for the disabled -up to two-thirds of earned income with no maximum;
- Full-time attendant care for individuals with severe and prolonged mental or

physical infirmities, no maximum;

- Reasonable travel expenses incurred to obtain medical services outside of the vicinity of an individual's home, to the extent these have not been reimbursed by a provincial health plan, or other source.

More information can be found on the CRA web site or last year's winter edition of the newsletter still online in the members section.



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

To reach our past president
treasurer@tnac.org



A LOOK AT TN FROM A RELATIVE'S VIEWPOINT

TN is an all-in-the-family affair.

Relatives may not have the sharp stabs themselves, but they struggle to understand the pain and share the frustration over how to stop the attacks.

Sharon McEver Cargill of Atlanta -- whose aunt, Mary Lou McEver of Jacksonville, Ala., has had TN for 10 years -- wrote the following piece to describe TN as a relative sees it.

Do you have a relative with trigeminal neuralgia? I do. My aunt.

She has always been unique in her independent ways, but recently her behavior has been really strange.

When driving in the summer, she won't turn on the air conditioning. If I drive, she will sit in the back seat.

She won't go to family gatherings. She has become a recluse.

She won't leave her house on a windy day. If she does, she wears a silly rain hat and pulls it down over her face. In an air-conditioned room, she keeps a tissue over her face.

She may be laughing, then suddenly, she turns her back and moans.

She insists on meals at a specific time, explaining that her medication demands it. Then, she usually stops eating after a couple of bites.

Her speech is slurred, she mumbles and sometimes staggers and stares. Her handwriting has always been poor, but now it is impossible to read.

She doesn't use make-up on one side of her face, and her teeth are neglected as well.

When we ask her about her pain, she describes it as being like: "an ice pick chipping the teeth... ants nibbling in her nose... razor blades slashing her

cheek... fire-red poker branding her face... electric-shock sparks in her cheek... needles pricking her eye... and lightning bolts splitting through her head."

This is trigeminal neuralgia. Neurosurgeons say it is the most excruciating pain known to man.

As a relative, you may want to know if it is inherited. Probably not, although some doctors say the structure of the blood vessels and nervous system can be gene-related.

How can relatives help?

- Understand that the pain is devastating.
- Do not allow your relative to be embarrassed or isolated by attacks.
- Know there is relief and help your relative find it.
- Help your relative find a TN support group to better understand the disorder and to be with others who understand.
- Obtain literature.
- Contact TNAC
- Go to a support group

Taken from TNA Alert



Drugstore
By Pat R. TNAC member

Neurontin--gabapentin

Classification: Anti-convulsant

Uses: Neurontin came out in the 1990's, primarily used as a medication to treat seizures. It works by increasing the body's production of GABA, a chemical that decreases or turns off the firing of nerves. Neurontin is sometimes

used alone or in combination with other medications to treat nerve pain. It has been used to treat trigeminal neuralgia, post-herpetic neuralgia, various neuropathies (ex. diabetic neuropathy) and for the more burning, constant types of face pain. The downside of gabapentin is the cost.

Drug Interactions: There are no apparent interactions between gabapentin and other anti-convulsants. Antacids, especially those containing aluminum & magnesium (ex. Maalox), should not be taken within 2 hours of taking gabapentin. It can decrease the effectiveness of gabapentin by approx. 20%.

Warnings & Precautions: Do not take gabapentin if you have had an allergic reaction to it or any of its ingredients. *Allergic reactions are uncommon but seek medical attention if this occurs. Symptoms of an allergic reaction may include: swelling of face or throat, hives or difficulty breathing. In rare cases leukopenia (a lack of white blood cells) can occur. Avoid taking alcohol while on gabapentin as it may cause an alcohol intolerance/ adverse effect. Until one determines how you will react to this medication, do not drive or operate machinery that requires mental alertness or coordination. Neurontin is eliminated through the kidneys and will not be removed from the body as quickly in people with a reduced kidney function. Your doctor may reduce your dosage as required. For women, speak with your doctor if you are pregnant or plan on becoming pregnant to discuss the risks. Studies have shown that gabapentin does cause defects in animals. Gabapentin has been found to be excreted in breast milk. In children under the age of 12, safety and effectiveness has not been established.

Adverse Effects: Check with your doctor as soon as possible if you experience adverse reactions of: poor

coordination, flu-like symptoms, persistent sore throat or fever, "fuzzy" thinking, suicidal ideation, memory loss, vision changes (involuntary eye movements, blurry or double vision), swelling in ankles, trouble speaking or drooling. Other side effects may include: dizziness, drowsiness, dry mouth, constipation, increased appetite, nausea, nervousness, tremors, involuntary arm/leg movements or back pain. Side effects frequently ease as your body gets used to the medication. This is not a list of all side effects. Some people experience side effects other than those listed. Contact your doctor or pharmacist if any symptom worries you.

Dosage: Gabapentin can be taken with or without food as it has no effect on the extent or rate of absorption. It is available in capsules: 100mg., 300mg., & 400mg. dosages and in tablet form of: 600mg. and 800mg. dosages. The initial starting dose is usually 300mg. three times per day. The dose may be increased depending upon the response. Neurontin may be effective at 900--1800mg./day (in divided doses). The usual maximum is 3600mg./day, but some people have tolerated 4800mg./day. Gabapentin should not be stopped abruptly and should be discontinued over a period of about a week or longer. Peak concentration has been seen within 2 to 3 hours. In normal kidney function, the elimination half-life averages 5-7 hours. (Half-life is the time it takes for half of the medication to be eliminated from the body).

*** For educational purposes only. It is intended to provide generalized information and is not intended as medical advice. For additional information on this or other medications please contact your doctor or pharmacist. Ensure to inform your doctor about all prescriptions, over-the-counter, herbal medications and*

supplements you are taking prior to taking any medication.

If there is a medication you would like to see featured in this section please let me know! contact cmusicstudio@cogeco.ca or Jane at 613.936.6977

Thanks Pat for your hard work in researching and writing up this information!

Helping out at TNAC

CALL FOR NOMINATIONS

TNAC calls on all members to consider joining the Board of Directors. We may not have board experience but we do all have TN. Please seriously consider whether or not you would like to contribute.

Experience is not a prerequisite. Your interest and enthusiasm are what count. . Involvement includes attending meetings by teleconference, and communication by email. You can help with membership, the newsletter, support groups, supporting research, phone support, promotions, etc.

You can nominate yourself or after first getting permission, nominate someone else. To nominate someone, you must be a current member and a member in good standing with TNAC and everyone who is nominated must be a member and a member in good standing or become a member and a member in good standing.

If you are nominating yourself, or another person, please submit a brief biography and a few relevant words (Do you have TN or support someone with TN?)

Are you a member of TN support group or other relevant support group? Do you have previous experience with charitable organizations? Plus any other relevant experience of interest).

TNAC is governed by the Revenue Canada regulations for registered charities. TNAC has charitable status and this enables us to write tax receipts to those who donate funds to support TNAC.

The Board of Directors sets priorities for the coming year and administers the society. Goals include: creating a supportive community for TN sufferers, including the start up of local support groups, meaningful and timely communications, national fundraising, development of the TNAC Medical Advisory Board, and support for TN research. We are a small group with a big task, but we are slowly moving forward on all fronts

For information or to nominate someone please contact Marion Guzik, nominations chair, at mguzik@telus.net or by mail to Marion Guzik, 1514 Lakemount Blvd. S Lethbridge, AB, T1K 3K4

Nominations must be received on or before April 30, 2009.

Call for Nominations
1514 Lakemount Blvd., Lethbridge, AB T1K 3K4

NOMINATION FOR OFFICE FOR THE TERM 2009-2011

I hereby place in nomination for the Term 2009 – 2011 the following candidate(s) for the positions(s) of:

Name	Address:	Ph.and email
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Position / area of interest for board service: _____

Name:	Address:	Ph and email
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Position / area of interest for board service: _____

Positions/ areas of interest for board service include: newsletter / phone support / support groups / research / education / promotional work / vice president / secretary /general support (in other words – would just like to help out as I can)

Nominated By: _____ Signature: _____

Address: _____

Email: _____ Phone: _____ Date: _____

If you wish to apply for any of these positions yourself, please fill in on that position

Please attach a brief biography of self or person you are nominating. Please include relevant information such as history with TN, participation in TN support group or relevant support group, experience with charitable organizations, any other relevant experience. Please note that though we do ask about relevant experience, such experience is not a pre requisite to volunteer with TNAC.

Please return to : TNAC Elections,
1514 Lakemount Blvd. S. Lethbridge, AB T1K 3K4

Must be received on or before April 30, 2009