

Canada TNA Newsletter

October/November 2008

Canada TNA

Canada TNA (CaTNA) is a network of support groups and individuals who are dedicated towards sharing information and support to people who have Trigeminal Neuralgia and other facial pain. Membership in CaTNA is \$10 per year. Newsletters are available free by e-mail, and for \$6 per year by Canada Post. Contact: Canada TNA, c/o Jan Williams; 15 Everstone Dr. SW, Suite 207; Calgary,

AB, T2Y 5B5. Email: calgary@catna.ca; Phone: Phone: (403) 295-0987. Canada TNA is associated with the TNA Association in the USA.

The information in this newsletter is not intended to diagnose or offer advice on treatment of TN. Its sole purpose is to provide information so that you, working with your doctor, can make informed decisions about your own care.

Canada TNA has been providing information and support to groups across Canada for two years this October. We have 87 paid-up members and 7 active support groups. Hopefully this year we will establish new groups so that we have at least one group in each province.

I attended the TNA's Conference in Dearborn, Michigan in September. It was a great conference but the best part was meeting people from different areas of Canada and the USA. Over the next few months I'll try and share new ideas with you that were discussed at the conference.

There was a suggestion that maybe we should have a TN Conference here in Canada. It is an idea that deserves some consideration and I would be delighted to hear your ideas. Would you attend a Canadian TN Conference? Would you be willing to travel to Winnipeg, Toronto or Calgary?

Jan

Support Group News

Calgary

We decided that most people prefer an afternoon meeting so as to avoid driving across the city at night. The Superstore has corrected the noise problem in their Community room so we can now hold our meetings there again.

New dates: Meetings are the 20th day of each month at 1:30 pm in the Heritage Meadows Superstore. Contact Jan at 295-0987 or calgary@catna.ca for more information.

Regina

Faye has been talking to Dr. Kaufmann about a visit to Regina this fall. As soon as the details have been organized, she will let you know. Hope everyone from Saskatchewan can attend.

Contact Faye at (306) 751-0761 or regina@catna.ca for meeting information.

Saskatoon

Meetings are held the second Sunday of each month. Contact Dee at (306) 382-5666 or Saskatoon@catna.ca for meeting information.

Toronto

Contact Kathy at (905) 853-9849 or Sandra at (905) 284-9215 or both by e-mail at Toronto@catna.ca for meeting information.

Niagara Region

Meetings will start again for the winter this month. Contact Brenda at (905) 937-6178 or Niagara@catna.ca for meeting information.

Peterborough

Contact Marilyn at (705) 742-1486 or peterborough@catna.ca for meeting information.

Winnipeg

Contact Marion at (204) 697-9459 or Pat at (204) 269-2003 by phone or email at Winnipeg@catna.ca for meeting information.

My TN Story – by Rose

Since I was struck with TN pain
My life has never been the same

With stabbing pain, I sit and wait
Feeling drained in a frozen state.

I have been so full of fear
Always left very close to tears.

When would it go ? I never did know
To look at me - it doesn't show.

The meds made me drowsy
Always feeling so lousy.

It comes and goes without any warning
So I pace myself, starting each morning.

I meditate, tai-chi each day
Praying it will go away.

When all is well, the fear subsides
And let's me lead a normal life.

I am so thrilled, and then do shudder
As I know one day there'll be another.

PAIN.....

When or where, I do not know
Each time it happens, I feel the BLOW.

Submitted by Rose James, Pickering,
ONTARIO

This poem is one of the poems in the new book published by the Trigeminal Neuralgia Association called "End the Pain". It is available for purchase through www.endthepain.org or www.suzannegrenell.com

End the Pain gives a voice to what it is like to live with TN but it also gives great hope that "together we will end the pain".

*The retail price for **End the Pain** is \$12.50. but it is on sale at \$10.00 through the end of October 2008.*

Glossopharyngeal Neuralgia

Glossopharyngeal neuralgia is a condition very similar to Trigeminal Neuralgia but affecting a different nerve (the 9th cranial nerve). Patients experience episodes of severe pain in the tongue, throat, ear, and tonsils.

Some possible causes for this type of nerve pain (neuralgia) are:

- Blood vessels pressing down on the Glossopharyngeal nerve
- Growths (lesions) at the base of the skull
- Tumors or infections of the throat and mouth

The pain occurs in episodes like TN and may be severe. It can sometimes be triggered by:

- Chewing
- Coughing
- Laughing
- Speaking

- Swallowing
- Slow pulse and fainting may occur when the pain is severe

The most effective drugs are anti-seizure medications, such as carbamazepine, gabapentin, and phenytoin. Some antidepressants, such as amitriptyline, may help certain people. These drugs are not as effective with Glossopharyngeal Neuralgia as they are with Trigeminal Neuralgia.

Surgery can be done to take pressure off the Glossopharyngeal nerve. This surgery (MVD) is generally considered effective in about 75% of people. A radiofrequency rhizotomy can also be performed.

My TN Story – by Helen

I can't remember exactly when I had my first twinge of facial pain. I know it was before 1981. It started very mildly. It felt like I had a tooth ache but that was not possible because I have worn upper and lower dentures since 1963.

As the years passed the attacks became more frequent and more severe. The pain also spread. It would strike at just about any time. Eating became a true challenge. So did talking and that was a disaster as I was an elementary school teacher. I remember clearly having to stop reading to the children because I just couldn't tolerate the pain caused by the movement. Standing outside on supervision in the winter saw me repeatedly come in with tears of pain from both the cold and the TN.

At the time I was in my mid 30s and traditionally TN does not strike that age range, or so they believed at the time. My doctor's first diagnosis was for cluster migraines. I took so many medications for migraines that I can't even remember what they all were. None of them gave me any relief.

Eventually my doctor referred me to a neurologist who diagnosed TN. He admitted that it was strange in one 'so

young'. He ordered an MRI and subsequently sent me to a neurosurgeon.

The surgeon very bluntly told me that I would have to have the surgery because the pain would become so intense I could no longer tolerate it. I was terrified! I had never been in a hospital (except for my birth) and to have my first time to be one of cranial surgery was absolutely, unbelievably frightening. The surgeon also recommended the sooner the better as the recuperative powers of the human body deteriorate with age.

January 1992 saw me undergo the Janetta procedure (MVD). I awoke in intensive care without pain and it was the first time in so very long. The surgery was a great success.

From that time to this I have had only minor flare ups. It was about 2 years ago. When they occur, I go back on Tegretol for whatever length of time is needed until the TN goes back into remission. I am currently completely pain free and off all medication.

If it hadn't been for my friends and my faith I don't know how I could have coped with the overwhelming fear I had to live with. In retrospect I wish I would have had access to the Internet, to a support group, to a book called "Striking Back". My life would have been much easier. Be that as it may, I survived and having the surgery was the best thing I could have possibly done. I still have a tender spot on the back of my skull where the incision was made but that is my only side effect and it is a small price to pay for the miracle of living pain free after all my years of agony.

I should add that when I had my surgery I was led to believe that it would be a cure forever. I now know that is not the case and that once you have TN you have it for life. Having said that, if you have this problem, do seek help. There were no other options offered to me and thus the MVD was the route I went. I still believe it was the best option for me and I basically am free of TN. I consider it one of the miracles of modern medicine.

I urge everyone who reads this and suffers from TN or knows someone who

does to seek help. If your family doctor can't help you, get him/her to refer you to a neurologist. MVD is no longer the only option and there are other less invasive treatments. Just don't suffer in silence. Be pro active. Your quality of life depends upon it.

Letters

Hi Jan,

First of all, thank you very much for all the time you spend and the work you do for the TN cause. Just by going to the web site and attending one support meeting (Thornhill meeting chaired by Kathy Somers), I have learned so much about TN. I am almost done reading through 'Striking Back' and I will then tackle 'Insights'. They are excellent books and I appreciate your having recommended them.

I have not had a definitive diagnosis of TN by a neurologist yet but the Ear/Nose/Throat specialist thinks I have it. I seem to be in the very early stages of TN in that I have only had 6 major attacks since May 12, 2008. I also have shocks on a daily basis but these shocks have gone down significantly in the last week to 0 to 2 shocks per day. I'm hoping it's all going away for good (perhaps I'm dreaming or in denial) or maybe I'm going into a remission period. Who knows? I am not on any medication so far and would like to keep it that way, but from what I have read and heard, it might be impossible to avoid. For now, it's one day at a time. The 1st referral I got from the Ear/Nose/Throat specialist for a neurologist 4 weeks ago, I have not heard from yet. The 2nd referral from my family doctor to see a neurologist in Mississauga where I live, has secured me an appointment 8 months away (what a joke!!!) and this pass week, I now have a 3rd referral for Dr. Peter Watson. I got his name from someone at the CATNA support meeting. I'm hoping to hear from his office within the next week. I guess there's a real shortage of neurologists in Ontario or is it throughout Canada?

Do you know of other TN sufferers in the Mississauga/Brampton/Oakville/Milton area?

Keep up the good work on the Newsletters. I appreciate the news and the stories and I'm sure many others must as well. I have already registered on the CATNA forum as user id 'nickie'.

Bye for now and thanks again. I'll keep in touch.
Kind regards, Nickie

Note: the CaTNA forum is at www.catna.ca/talk

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Hi Jan

Great Newsletter. In this issue 'complementary' methods were mentioned. I would like to hear more about the - bio-feedback, nutrition, vitamins etc.

....I switched to decaf coffee and tea 3 years ago - and I do feel it has helped me. I also lean toward a low fat diet (but find it difficult to stick to it). Rose
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Canadian Research on TN

Dr. Kiss from the University of Calgary has asked for our help in determining if there is enough of an interest in looking at two main issues:

- What is the relationship of families with TN?
- Is there a difference in long term pain relief in patients treated with stereotactic radiosurgery verses other rhizotomies?

We will be sending out a questionnaire in a few weeks and hope that you will each take the time to fill it out and return it.