

CANADA TN ASSOCIATION NEWS

October/November 2009

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 if Newsletters are received by email - \$20 per year if Newsletters are received via Canada Post. Canada TNA, c/o Jan Williams; 15 Everstone Dr. SW, Suite 207; Calgary, AB, T2Y 5B5. Email: calgary@catna.ca; 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.

Greetings everyone. I cannot believe it is already fall - winter is in the air.

There will be some changes to Canada TNA in the next few weeks. I am thinking about leaving Calgary and have already sold my condo. That means the "headquarters" of CaTNA will have a new address as soon as I decide where I want to live. The Calgary group will continue with the help of Bev and Phoebe.

The Toronto group is looking for a new location for its meetings - so watch the messages for the new location.

Remember, if you would like to start a group in your area, please let me know and I'll do what I can to help you. For some people the group meetings are the first time they realize they are not alone is dealing with this disease of TN.

Jan

MVD in the Elderly

Those of you who receive the TNA updates will have recently seen the results of a study of the effectiveness of the MVD in elderly patients. This study looked at over 100 people aged 65 and older who had an MVD for Trigeminal Neuralgia.

They discovered that the rate of complications from the surgery and the

success of the MVD in relieving pain was very similar to what has been reported in younger patients (younger than 65).

The bottom line is that age seems not to be a big issue in deciding whether or not a person can have an MVD.

A TN Story

As a TN patient on Tegretol was driving down the freeway, his car phone rang. Answering, he heard his wife's voice urgently warning him,

"Herman, I just heard on the news that there's a car going the wrong way on the TransCanada. Please be careful!"

"It's not just one car," said Herman. "It's hundreds of them!"

An "atypical" TN Story

I am a 53 year old male in good health. I used to be excellent health. Three and a half years ago I was struck in the mouth with a hockey puck during an old-timers hockey game. It shattered the roots of my teeth and broke the maxilla jaw. Since then I have been in constant pain and it is getting worse. Low pain score of two in the

mornings, average pain score of 4 - 5 and spikes of 8 - 9.

I have had root canals, MRI's, cat scans, been treated at the chronic pain clinic in Calgary, visited with Dr. Kiss in Calgary a year ago (at that time she did not think surgery was an option) had acupuncture, naturopath, oral surgeons and numerous other attempts at pain control.

I have a list of drugs I have tried. Some worked for three to four weeks, some didn't at all and the side effects are just devastating to me and my work.

Right now I am still searching for a solution for me. I'm continuing with the Pain Clinic and am very hopeful that something can be done. It is hard to remain positive when nothing so far has had a long term effect.

I attended my first meeting with the Calgary group in September. It is good to know that I am not alone in the struggle.

John

Special Event

The TORONTO CHAPTER of Canada TNA
Invites you to join us for an INFORMATIVE DINNER on SATURDAY OCTOBER 17/09

ITHACA: GREEK/MEDITERANEAN CUISINE

Dr. Anthony Kaufmann, Neurosurgeon from Winnipeg Health Sciences Center will be joining us for the evening. (*bring your questions*)

At this time we have space for 70 people. In order to help those with TN we ask at this time to keep it to 1 **TN** person, 1 support person. (This way those with **TN** can gather as much information as they need.) We want to hear your stories successful or not!

Cost: \$37.00 per person (alcohol is not included)

\$5.00 per person (included in cost of the dinner) *will go to the Toronto chapter for fundraising. (Flyers, purchase/ mailing of books, advertising etc.)*

Dinner must be prepaid by cheque to: Kathy Somers or Sandra Arangio to guarantee your place for dinner. Please contact Kathy at 905-853-9849 and Sandra at 905-284-9215 for address information.

Support Group News

Calgary

New dates: Meetings are the 20th day of each month at 1:30 pm in the Heritage Meadows Superstore. Contact Bev at (403) 289-2876 or Phoebe (403) 283-6784 or by email calgary@catna.ca for more information.

Calgary Meetings scheduled for 2009:

Oct 20 Nov 20

Please remember John Block in your prayers. He is starting his treatment for lung cancer this month.

Regina

Meetings will start again in the fall. Contact Faye at (306) 751-0761 or regina@catna.ca for more 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

Meetings are the last Sunday of the month at 9:30 a.m. in the THORNHILL COMMUNITY CENTRE, 7755 Bayview Ave. Thornhill.

Oct 25/09 Nov 29/09

Note from Kathy: CATNA Toronto Chapter meetings: Sunday November 29/09 will be the last meeting held at the Thornhill Community Centre. The community center will be closing for renovations. Sandra and

I are looking for another room for us to meet. Until then we will try and have temporary locations each month. We don't meet in December so that gives us some time to find space for us. Meetings will continue else where and we will let you know. If anyone has any ideas for us to meet let Sandra or I know. **NEW LOCATIONS WILL BE POSTED SOON AS POSSIBLE!**

Niagara Region

Contact Brenda at (905) 937-6178 or Niagara@catna.ca for location and/or directions.

Peterborough

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

Letters

Hello Jan

just found your address from a support group. I have just been told I probably have this disorder. Right now I'm waiting to see a neurologist but may take awhile. I'd like to see this Dr. Kaufmann in Winnipeg because what I've read he's probably a specialist in this area. Do you know who can refer me to himis it my family dr. or the neurologist?

Right now the family dr. is trying me on antibiotics but I'm sure that's not going to work for me. I am also on a low dose of carbamazepine.

Nobody understands what pain is unless they've experienced it. As I'm writing this I'm really depressed and crying. Some days I just can't stop crying. My husband has left to work out of town because he can't stand seeing me in pain. So right now I'm feeling alone fighting this disease.

I have a low tolerance for drugs and am afraid they might try to do an MRI which is like being buried in a casket alive.

Do you know if they can put you out for these MRI's? If they can it might take up to a year to get one in BC here.

I would appreciate it if I could find a person to talk to who can help me out in the next steps. I live in B.C. and I feel like no one has heard of this and thus no one understands what I'm going through. Right now I'm just feeling like I'm losing everything.

Answer: I am so sorry that you are suffering with Trigeminal Neuralgia. It is certainly a difficult disease to deal with and as you describe the pain can be horrible.

The good news is that there is help out there and for most people a way to get rid of the pain. Sometimes you need to try a few different things before something is effective. Whatever you do don't give up!

Carbamazepine is one drug that most of us have used at one time. It seems to get rid of the pain – but the cost is the side effects. There are lots of other drugs that work for some people either in place of the carbamazepine or along with that drug. I would suggest you start by going to Dr. Kaufmann's web site where he lists the drugs he has found to be most effective for TN. He does have a great website that is really informative. Look at all the tutorials – they are excellent.

http://www.umanitoba.ca/cranial_nerves/ccndho.me.htm

As for a referral to Dr. Kaufmann, your family doctor can do that for you. The details are on his website.

You are not alone. I know of at least 2 others in your city with the disease. Since no one can "see" it sometimes it feels like people don't believe you or that no one but you has this – not true!

Another suggestion I have is that you go to the message board/forum that we have here in Canada. It is a place where you can post messages and receive replies from other Canadians. At least you'll be able to start a conversation with someone who understands how you feel.

Note: I will forward any replies to this lady if you send them to me. Jan