

CANADA TN ASSOCIATION NEWS

December 2009

Canada TN Association

Canada TN Association (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 in Canada. Membership in CaTNA is \$10 per year if Newsletters are received by email - \$20 per year if Newsletters are received via Canada Post.

NEW ADDRESS:

Canada TN Association,
c/o Jan Williams;
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White Rock, BC, V4B 4B9
Email: jan@catna.ca;
Phone: (604) 560-2412.

Canada TNA is associated with the TNA Association in the USA

Greetings everyone!

You'll notice from the new CaTNA address that I have moved to sunny BC. (Perhaps I'm exaggerating the sunny part a little bit). I only wish I could have brought all the good friends I had in Calgary here to BC with me.

As soon as I finish unpacking and am settled I'll be looking to see if there are any people with TN here in White Rock/South Surrey. People with TN sometimes feel very much alone thinking that no one else truly understands. That is why support groups are such a good idea - not only is the group a comfortable place to be because every one "gets it" but information on what is available in that community can be shared. So, 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. Jan

Special Event – Guest Speaker

Regina: Saturday, Dec 5, 2009, 1 p.m.

Dr. Tim Mrazek, ND,
Natural Wellness Centre

Wascana Rehabilitation Centre
2180 - 23rd Avenue, 2nd Floor, Rooms 1,
2 & 3

Contact Faye for more information.

A TN Story

Greetings, I am now just over four months post op MVD. My procedure went pretty much as Jan's and I have to date had no sign of pain or any other sensation related to the TN. I still have numbness around the surgery site but that is acceptable compared to the pain I experienced with TN.

Dealing with the constant pain of TN and the medications (Tegretol and Lyrica)

Merry
Christmas



has an affect on the way the brain processes information and how you relate to your daily environment. It is a slow process and you are not (I wasn't) aware that you are changing because of the TN and medications. After the surgery I was in a hurry to get back to my old self but it wasn't coming and people told me to be patient and that I had just had a major surgery. I couldn't put my finger on it exactly but I felt different and therefore I thought it wasn't normal.

Finally I gave into the new feeling I was experiencing and it was then that I realized that the new -me- was a good thing and I didn't want to go back to the way I used to feel. It is good on so many levels and not something that I had anticipated. I just wanted to get rid of the electrical lightning bolt shocks in my face but I ended up with more.

You know when you're having a problem with your computer and you reboot to get things running smoothly again? Well that's how I feel. I feel like I've had a reboot and things are now running smoothly again. It's the best way I can describe it. I have since learned that severe, constant and debilitating pain can have many adverse affects on a person and when you remove that, there is going to more of a change than just losing the pain.

I would be interested if anyone else has experienced such feelings or noticed other differences in how they feel besides just being pain free. If you have any questions for me regarding living with TN and my MVD, please don't hesitate to ask.

James

Tegretol (Carbamazepine) review

Carbamazepine is an anticonvulsant and specific analgesic for trigeminal neuralgia. In some cases Tegretol is used as a diagnostic tool – if the pain is relieved, then the diagnosis of Trigeminal Neuralgia is confirmed.

The dosage will vary from person to person, but normally people start with 100 mg per day and increase by 100 mg every 3 or 4 days until either the pain stops or the dosage reached 800 mg per day. The drug is divided into 3 or 4 doses unless the CR (Controlled Release) pills are used in which case the drug can be taken once or twice a day.

There is an impressive list of the effect of combining Carbamazepine with other drugs. Before taking this drug or starting any new drug, check with your doctor and/or pharmacist to make sure the two drugs can be taken together. Anyone taking this drug should have regular blood work done to monitor liver function and blood cells and the drug can depress bone marrow function.

Once you start taking this drug, you cannot just quit suddenly, the daily dose must be slowing reduced.

There are many side effects from Carbamazepine. Some of these will decrease as your body becomes accustomed to the drug. Most people find the drowsiness and dizziness will decrease after this for 2 – 3 weeks. However, you should talk to your doctor and discuss all the effects that you notice.

Finally, the bad news: Even at Christmas, Carbamazepine and alcohol do not mix.

Cat's Story, Vancouver Island

I was a very healthy 26 year old woman in 1996 - just had a baby girl actually, when out of the blue I was struck by immense pain on the right side of my face - covering the whole right side. After two false starts where they pumped me full of antibiotics for a non existent sinus infection, I had the great fortune to meet an ER doc who diagnosed TN and started me on Tegretol.

Four years later the drugs (Amitriptyline and Tegretol) were not working so well. I ended up in the hospital for two weeks, sedated so that they could get me rehydrated and eating again. I was referred to a Neurosurgeon in Vancouver and had an MVD done.

I woke up in Neuro ICU with an unbelievable headache and facial paralysis and numbness. By three months after the surgery my facial pain was back worse than ever and my face was still paralyzed. I was told that they had damaged the Trigeminal Nerve during the MVD. To top it all off they stapled me up crooked which has caused neck problems since then. A year after the surgery I finally got most of my facial movement back - lost a good portion of my teeth and found that things were worse than before.

I was put on methadone for "pain management" surprisingly I went into a two year remission. Then it came back with a vengeance.... I have decreased feeling and sensitivity on the right side, but when the attacks come and sometimes just out of the blue I have a burning sensation like somebody pressed an iron to my face and turned it on.

I've had TN for 12 years and things seem to be going from bad to worse - my new GP (the old one retired) wants to take me off all pain medication and put me on migraine drugs. I went through all this before - I do not have migraines - I have Trigeminal Neuralgia facial pain! I've hit a

wall emotionally. For years I've disagreed with the name "the suicide disease" because I loved life so much I could never think about taking my own no matter how bad it got..... Now I understand.

Since the failed MVD I've seen 5 Neurosurgeons and Neurologists and none of them have seen a case of facial paralysis after a MVD. I am told I am not a candidate for any surgical procedures because of the damage done before. I'm 8 months into an 18 month waiting list to go to the pain clinic here on Vancouver Island.

I would really like to be in contact with anyone else who has a similar story or who can offer any advice. I'm trying to remain positive for both me and my family. My husband is really supportive but I'm not sure he can fully understand the frustration and pain I feel. Thanks for letting me share my story. Cat

Support Group News

Calgary

Contact Bev at (403) 289-2876 or Phoebe (403) 283-6784 or by email calgary@catna.ca for more information.

Note: John Block still needs our prayers.

He has finished the radiation part of his lung cancer treatment and is still taking chemotherapy. John - we are thinking of you and wish you well.

Regina

Scheduled meetings:

Dec 5th - special guest

Jan. 9, 2010,

Feb. 6, 2010,

Mar. 13, 2010

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

Contact Kathy or Sandra for dates and locations of meetings.

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.



A big Thank you to the people who look after organizing the support group meetings in the different cities.

TNA – the Facial Pain Association News

We are closely associated with the Facial Pain Association in the USA. Each CaTNA support group is also an official TNA support group.

The TNA has a promotion ongoing for anyone who joins or renews their membership will receive a free copy of the book: ***Striking Back! The Trigeminal Neuralgia and Face Pain Handbook.***

CaTNA

Please note our new mailing address:

Canada TN Association
c/o Jan Williams
1234 Merklin Street, #309
White rock, BC V4B 4B9

You can get involved – we need people to help with the local support groups, finding a space to hold meetings, phoning members with meeting dates and times, being available to talk to people with TN.

We also need some people to put some life into our message board – start a conversation about TN or about life with TN so that when someone goes to the message board there is something to see.

If anyone would like to contribute something to this newsletter, that would be wonderful too. The newsletter is published 6 times a year – the beginning of Feb, April, June, Aug, Oct and December. We would like to hear your story.

Hope everyone enjoys a wonderful pain-free holiday season.

