

# CANADA TN ASSOCIATION NEWS

February/March 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. 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](mailto: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.

I'm late getting this newsletter out this month - sorry. Perhaps I'm like the Groundhog and hiding out until spring.

We would really like to make this little newsletter interesting and valuable to you. Please send me your stories, ideas and suggestions so we can include them in future newsletters.

Wishing you each many pain free days and nights.

Jan



Happy  
Valentines  
Day

## Alberta's improved Drug Plan

In December of last year, our Premier announced an "improved" drug plan for seniors on Blue Cross. Currently each person pays 30% for each prescription of approved drugs to a maximum of \$25 per prescription. The "improved" plan assigns a deductible to each

person based on their income. A person will pay 100% of the prescription costs until they reach the deductible amount after which the prescriptions are free for the rest of the year.

For example, a single person with an income of \$31,326 will pay 100% of drug costs until they have paid \$658.

There is a list of approved drugs on the website – but Trileptal (Oxcarbazepine) and Lyrica (Pregabalin) have not been added to that list so patients still must pay 100% of those drugs and none of those fees goes towards the deductible.

For more information, contact Alberta Blue Cross at 1-800-661-6995 or check their website [www.ab.bluecross.ca](http://www.ab.bluecross.ca). You can also check Alberta Health and Wellness at [www.health.alberta.ca](http://www.health.alberta.ca)

## A TN Story

Bev from Calgary has really exciting news. She had an MVD done in Winnipeg on Jan 20<sup>th</sup> this year. Bev has had facial and head pain since 1984 but was only diagnosed with Trigeminal Neuralgia in 2006. At that time she was put on Tegretol which did reduce the pain – BUT she developed an allergy to the drug. She had a rash, swelling, difficulty breathing and generally felt awful. Next she tried Neurontin and ended up taking 3600 mg a day with some effect – but the pain was still there.

So she went to Winnipeg in January during the coldest winter in ages! She met with Dr. Kaufmann and his team on Monday, had

surgery on Tuesday, and was discharged back to the hotel on Wednesday. She was well enough to fly back to Calgary on Saturday.

The TN did not disappear totally at first, but she was able to reduce the Neurontin and when I talked to Bev she was delighted to report 2 ½ days with no pain at all.

Congratulations Bev – best wishes for a speedy recovery.

### **Calgary Group Members News**

**Jill** has had TN since 2003. She had Balloon Rhizotomies in 2004 and 2007 and is currently pain free.

**Anne** is in a period of remission and is enjoying not pain and no drugs.

**Mike** has had TN since 1985. After struggling with various drugs he has decided to consult with Dr. Kaufmann. Good luck Mike and keep us up to date with your status.

**Jan** (me) is still pain free and drug free since the MVD in 2003.

**Olive** is new to the group – she wants to thank Phoebe for the phone call about the meeting. Olive has been diagnosed with TN since 2005. She has other complications and is currently consulting with a Neurologist.

### **Notes from the TNA Conference**

*The following notes were written by Ashley, a 23 year old College student from Boston. Ashley has been diagnosed with TN 3 years ago and is still in pain after an MVD. She has given us permission to share her notes.*

Leading research at the moment:

#### **Microvascular Decompression Surgery**

The MVD is the only currently available treatment that addresses the cause and presents a possible "cure." Formerly, doctors recommended trying all the medication first, and only sending a patient for an MVD if no combination of meds could help the pain. New research suggests that an MVD should possibly be considered FIRST. Doctors are finding more and more that most cases of TN are caused by blood vessels compressing the nerve. Leaving the vessel there, even if your pain is well

controlled on medication, can cause future damage. As the vessel pounds against the nerve, more and more nerve fibers are damaged, giving you less of a chance for full recovery, and also causing more pain and new types of pain so that medication will lose its effect over time. If you have a compression, you don't want to wait and allow time for permanent damage to develop.

The leading study at the moment says that getting an MVD within the first 7 years gives you the best chance of avoiding damage, but a major new study, which is about to be published, will show that 3 years is more accurate. Important to note: no matter how long you've waited, an MVD can always help. It's just that after a certain amount of time there may be residual pain from damaged nerve fibers (although it is nothing like the electric pain). Also, once that vessel is moved, the nerve can regenerate and heal itself, and eventually stop sending pain signals.

GO TO AN EXPERT. The more MVDs the surgeon has done, the less likely you are to have complications and the more likely you are to emerge pain-free. It has been found that many people have had MVDs where no vessel was found, but if a more experienced surgeon went in, they WERE able to find a compression. You have to know where to look.

Scary statistic: Nearly 2/3 of the MVDs performed each year are done by a neurosurgeon who has never before done this particular surgery! These surgeries have a significantly higher rate of complication than those done by more experienced surgeons. By contrast, there are 3 surgeons who perform 29-107 MVDs per year, and have extremely low complication rates (this is in the US. I think there is a 4th in Canada with similar results. *Yes – Dr. Kaufmann in Winnipeg does about 55 – 60 MVDs a year*).

Multiple MVDs have helped many patients. Either a compression was missed the first time (even if others were found and taken care of), or veins have grown back. Sometimes veins will grow back UNDER the initial Teflon pad, or even between the fibers of the nerve itself. Again, an

experienced surgeon would know better where to look.

### **MRIs**

Although many doctors are saying that the thin-cut MRI can show blood vessels on the nerve, just as many say it's useless, and have found compressions on many, many people with clean MRI's. They just finished a study that concluded that MRI's helped 2/5 of the time, and didn't show what was actually there 3/5 of the time. In the future it may get more accurate, but at the moment you can't depend on that for a diagnosis other than for ruling out tumors, aneurysms, etc. So have it done if you want (it would certainly give you peace of mind going into surgery already knowing there is definitely something there), but DO NOT dismiss surgery because nothing shows up.

MRIs CAN show the Teflon padding inserted during surgery, so if you have pain that suddenly comes back, they can check to make sure the padding hasn't slipped (this happens very rarely). However, sometimes veins will grow back beneath the padding, and these may not be seen on the image.

### **Typical versus Atypical TN:**

For all of us with so-called "atypical" pain, this is very important. The nomenclature currently used in diagnosing TN is very confusing and often inaccurate. The leading doctors/researchers are trying to change this, but it's difficult to make information wide-spread, and they haven't yet reached a consensus on how to classify types of TN.

Basically, though, the latest research shows that ATN is often a case of TN that has progressed. The more constant, burning pain happens when the deeper, larger nerve fibers are damaged, as opposed to the smaller surface ones that cause the lightning bolt pain, so if you have a compression, it can start as TN and as that blood vessel pounds deeper into the nerve, become ATN. This is one of the reasons why you should go for the MVD earlier on. Some people may skip straight to the ATN because their nerve was strong enough to handle the initial damage, but not the deeper damage. Also, some research indicates that an arterial compression may cause typical pain, while a

venous compression is more likely to cause more Atypical pain. The location of the compression may also make a difference. More research is being done to investigate this. Interestingly, a very experienced surgeon can often tell exactly what kind of compression you have and where to find it simply by how you describe your pain.

Considering this, you should not believe doctors who tell you that ATN is more difficult to treat than TN. They made a big point of this at the Conference. While it's true that "atypical" pain may indicate a more damaged nerve, the same treatments can still be applied and may have just as much success. The initial success rate for an MVD is around 90% for "typical," and only drops off to about 80% for "atypical" (again, often because there is residual pain due to damaged nerve fibers, but this pain is usually significantly less than TN pain, and may be possible to cure as the nerve heals).

If you're being told you have "untreatable" TN because it's "atypical," or if you get the dreaded "atypical facial pain" diagnosis, SEE A DIFFERENT DOCTOR. TN is still so rare that most doctors don't recognize it, and even some specialists only know the old generalizations, which are rapidly changing.

## **Support Group News**

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### **Calgary**

New dates: Meetings are the 20<sup>th</sup> day of each month (if the room is available) at 1:30 pm in the Heritage Meadows Superstore. Contact Jan at 295-0987 or [calgary@catna.ca](mailto:calgary@catna.ca) for more information.

Calgary Meetings scheduled for 2009:

Friday, Feb 20  
Friday, March 20  
Monday, April 20  
Thursday, May 21 \*\*  
Saturday, June 20

\*\* note date change

### **Regina**

The next scheduled meeting will be February 7 at 10 am – Wascana Center – Rooms

1, 2 and 3. Contact Faye at (306) 751-0761 or [regina@catna.ca](mailto:regina@catna.ca) for more information.

Dr. Kaufmann and Regina members  
November 2008



### Saskatoon

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

### Toronto

SUNDAY'S at 9:30 a.m. at the THORNHILL COMMUNITY CENTRE, 7755 Bayview Ave. Thornhill. All are welcome; please bring a support person with you. If you would like to meet with Sandra or Kathy at a different time please let us know and we can make some other arrangement. If you live in York Region you can contact Kathy to arrange a meeting there. We can be reached at [toronto@catna.ca](mailto:toronto@catna.ca) YOU DO NOT HAVE TO BE A MEMBER OF CATNA TO ATTEND TORONTO OR YORK REGION MEETINGS All are welcome! Sandra and I look forward to meeting you.

Feb 22/09      March 29/09      Apr 26/09  
May 31/09      June 28/09      July 26/09 Aug  
30/09      Sept 27/09      Oct 25/09 Nov 29/09

### Niagara Region

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

### Peterborough

Contact Marilyn at (705) 742-1486 or [peterborough@catna.ca](mailto: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](mailto:Winnipeg@catna.ca) for meeting information.

### Letters

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*From Lorraine in Calgary:*

Tonight I had some time to get on the computer & opened up the link in the newsletter email. I have been reading about other peoples TN stories & have found it to be very interesting. I think I would like to put my story on the forum as perhaps if other people read my story it could be helpful. You never know, sometimes the smallest bit of information is important. I was helped by your support group & would like to give back.

I had my MVD July 8th of this year & I'm doing very well & by 2 weeks after the surgery I was completely weaned off the medication (Tegretol & Lyrica). I have had no further TN pain, except for a little aching in my face after chewing licorice. I may have overworked the muscles in my jaw as having TN for almost 4 yrs. I stayed away from anything chewy.

You can post your story and comments directly on the forum – go to [www.catna.ca/talk](http://www.catna.ca/talk). It would be great to have more discussion on that message board.