

CANADA TNA NEWS

April/May 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: (403) 295-0987. Canada TNA is associated with the TNA Association in the USA.

Hopefully this newsletter finds you well and pain free. I'm feeling a little guilty living here in Calgary as we have had a great winter - not too much snow and now I believe spring is here to stay - at least that is what the gopher said Feb 2nd.

April will see the first meeting of the Canada TNA support group in Winnipeg. We'd like to have a group in each area of Canada. If your home does not have a group - please let me know and we'll try and help you get started. Sometimes even a small group where people meet for coffee on a regular basis is really helpful and worth while.

Jan

Announcements



April 22, 7 pm Dr. Zelma Kiss will speak in Calgary.

April 10th - 7 pm - First Winnipeg Meeting

TN Stories:

If you are willing to share your story, please let us know. We'd love to hear from you!

In 1989 I was formally diagnosed with MS and the first signs of TN reared its ugly face a short time later. At the time I was employed as a pilot and the authorities required a solid

diagnosis so I was seen by physicians from the "top of the list"

The TN was infrequent enough that I did not medicate and I was "fast tracked" through the rhizotomy program. I had a total of six Rhizotomies before I started down the medication path.

A lengthy trail led me to a family physician who is experienced in pain management and is authorized to prescribe opiates. It must be appreciated I have several very strong reasons for not taking this type of drug. First I overcame the nonsense about addiction. When it is for pain there is no addiction. At one time I was on a very heavy dosage of an opiate. I came off of it with no difficulty under the doctor's supervision. The pain was under control! I felt good too.

Finally I ended up on methadone, an anti depressant (being used for pain, technical stuff) and a prescription muscle relaxant. The methadone was a gradual replacement for the morphine.

Methadone has been given a bad reputation by some who do not know about what they speak. It is associated with the street drug scene whereas I personally have no negatives at all. It is even inexpensive, does not fatigue or make me feel any different.

My doctor was on top of this whole process and now keeps close watch. The process required a physician willing to put in the time, specifically knowledgeable, licensed appropriately (to prescribe opiates and methadone).

Now I am closely monitored and still am subject to some muscular dysfunction and pseudo nerve attacks. I live close to a normal life. Sometimes I still get a muscle spasm with some of the associated pain but I do not usually have the intense unmistakable TN pain. Sometime I will get "break through" pain

and need to spank it with an endocet, but I am mostly pain free. I do not walk around like a zombie. When I say close, I do not expect nor look for more improvement. I am however, able to do, with caution, most things TN prevents.

I have a life! I smile now and do not want to kill myself anymore.

Name withheld

Study on MVD from Lyons, France

There was a study published in the Journal of Neurosurgery concerning the effectiveness of the MVD. This was a study done at the University of Lyon in France. They followed 362 patients for up to 18 years to measure the effectiveness of the MVD.

Their conclusion was: *"Pure MVD can offer patients affected by a primary TN a 73.38% probability of long-term (15 years) cure of neuralgia. The presence of a clear-cut and marked vascular compression at surgery (and possibly-although not yet reliably-on preoperative magnetic resonance imaging) is the guarantee of a higher than 90% success rate."*

The definition of success in this study was pain free with no medications.

Support Group News

Everyone is welcome to attend a support group meeting. You do not need to be a member of CaTNA although we will be happy to have you join us.

Alberta

Calgary:

The Calgary Support group meets once a month. Contact Jan for information 295-0987 or calgary@catna.ca.

The next meetings will be:
Tuesday, April 22/08, 7:00 pm

Guest: **Dr. Zelma Kiss**

Dr. Kiss will talk about a research project at the University of Calgary and will answer any questions. If you wish to attend, please contact Jan for more details.

May meeting - TBD

Manitoba

Winnipeg:

Contact Marion at (204) 697-9459 or Winnipeg@catna.ca for dates and locations of the meetings

The first meeting will be held April 10, 7 pm at the Health Sciences Center. At that time future meetings will be determined. Dr. Kaufmann will attend the next meeting in May/June.

Ontario

Newmarket

Contact Kathy (905) 853-9849 or Sandra (905)284-9215 or email Toronto@catna.ca for locations and dates.

Niagara Falls and Area

The first meeting for this group will be Feb 23. Contact Brenda at Niagara@catna.ca or (905) 937-6178 for location and time.

Peterborough

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

Toronto (Thornhill)

The group meets the last Sunday of each month at the Thornhill Community Centre, 7755 Bayview Ave at 9:30 am. Contact Kathy (905) 853-9849 or Sandra (905)284-9215 or by e-mail Toronto@catna.ca

The next meetings are: Feb 24th and Mar 30th.

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.

West Toronto

Contact Valerie at (416) 588-4951 or westto@catna.ca for dates and locations

Saskatchewan

Saskatoon

Contact Dee at (306) 382-5666 or by e-mail at saskatoon@catna.ca for dates and locations.

Regina

Contact Faye (306) 751-0761 or by e-mail at regina@catna.ca .

Balloon Compression Rhizotomy

Medications are the first treatment usually prescribed for Trigeminal Neuralgia. In many patients the disease can be treated for years using the various drugs available. However, for those patients who are unable to control the pain with drugs alone or for whom the side effects of the drugs becomes intolerable there are surgical options available.

One of these options is the "Percutaneous Balloon Compression Rhizotomy." This is a procedure during which the Trigeminal nerve root is damaged by compression with a balloon at the end of a needle. The term "Rhizotomy" actually means to damage a nerve root. The "Percutaneous" means through the skin.

With the patient under a general anesthetic, a needle is passed through the cheek into the skull so that its tip lies along the Trigeminal Nerve. A small catheter with a balloon at the end is passed through the needle and the balloon inflated for a minute or two to cause an injury to the nerve. The neurosurgeon uses X-rays and/or a fluoroscope to ensure the needle and catheter are in the correct place.

This procedure is a good option for those patients who are hesitant to undergo a craniotomy and MVD procedure either because they are reluctant to have major surgery or they have another health problem making surgery too dangerous.

About 90-95% of patients will find that the TN pain disappears immediately after the balloon procedure although for some patients it may take a day or so for the pain to go away completely. The pain free period varies from person to person, but half the people will still be pain free after 5-8 years. This procedure can be repeated if necessary.

Most patients will experience some degree of facial numbness post operatively. This will decrease over time. The numbness indicates the nerve has been damaged which is the aim of the surgery.

There may be some weakness in the chewing muscles after the surgery. This is usually temporary and will resolve over the first few weeks.

A small percentage of patients (up to 5%) may experience some complication. These complications include meningitis, some difficulty chewing, a cheek hematoma, double vision, loss of the corneal reflex, anesthesia dolorosa, a sudden rise or drop in blood pressure, cerebrospinal fluid leaks and meningitis and an outbreak of cold sores.

Patient Information

Pre-op

- The anaesthetist and neurosurgeon will likely order some blood tests, a chest X-ray, ECG and in some instances an MRI.
- You may be advised to stop taking any aspirin for 2 weeks prior to the surgery to help prevent bleeding.

Post-op

- You will be given a schedule for the withdrawal of any drugs you are taking for TN. Follow this schedule closely as drugs such as Tegretol should not be stopped abruptly.
- Ice packs against the cheek will decrease bruising and swelling
- Report any of the following symptoms to your doctor immediately:
 - Headache not relieved with Tylenol
 - Fever
 - Stiff neck
 - Drainage of clear fluid from the nose or down the back of your throat
 - Chest pain or shortness of breath

You should be able to resume your normal activities within a week

Note: this was the topic of discussion at a recent Calgary meeting. Of 8 people who had a BCR, all had initial pain relief that lasted on average 12-18 months. It has been repeated in 3 people and they are currently pain free.

Disclaimer: 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 on your own care.

Letters

From B in Calgary:

Thanks so much for your message. I really appreciate it. This is new for me, I've had some jolts in these areas before but I guess the cold air is so bad right now that it's actually causing like a "flurry" of jolts and then it stops and starts again....as a result I've had to increase my Tegretol which just makes me more nauseated and dumb and have even had to use morphine which honestly just dampens it down a bit.

I really think when the pain gets that bad they should just knock us out, it's the only time TN pain stops is when we're asleep so it makes sense to me if it's uncontrollable and unbearable, let us sleep where the pain doesn't go...unfortunately I am in the process of shopping for a new TN neuro so I can't really address it with anyone but my fellow TN'ers and my GP!

I really appreciate getting the newsletter as I haven't been able to make a group meeting in a long while, they moved their meetings to the afternoon which is my worst time due to meds and pain ...and now this new teeth/cheek/nose getting worse so at least I can read the newsletter if I can't be at a meeting!

Thanks again and it is nice to know I'm not alone!

Note to the Calgary group from a new member:

You were a huge help to me in my time of need. Just knowing there is somewhere to go for support is good & I read all the news letters!! - I also ordered both those books from Barnes & Noble _ they are Great!!

From S in Alberta:

Dear Jan I was unable to attend the support group. I am not doing so well and will see my Dr. again on Feb 26. Please tell what I should ask my Dr for. Such as referral to specialist or Drugs that may be more helpful. He presently has me on 75mg of Lyrica twice a day. doesn't seem to help much!

Thank you for any help you can send my way
Reply:

Hi, I'm sorry to hear that you are not doing well. I can sure understand how that affects your life.

It seems that everyone reacts differently to different drugs so it is hard to know which one will work for you. If you attended Dr. Toth's presentation he seems to be an advocate for combinations of drugs – a little of two or three rather than a lot of one. That is what I ended up doing and I think it helped.

There is a fairly extensive list of drugs which can be used for Trigeminal Neuralgia. Some may not be appropriate for you depending on which other drugs you are taking and what other health issues you must deal with. The most common drugs are (I copied this off the internet):

- Carbamazepine (Tegretol)
- Baclofen
- Phenytoin (Dilantin)
- Oxcarbazepine (Trileptal)
- Gabapentin (Neurontin)
- Pregabalin (Lyrica)
- Other medications: clonazepam, sodium valporate, lamotrigine and topiramate.

You may want to discuss the possibilities of getting a referral to a Neurologist with your doctor – or even a neurosurgeon if you are at the point where you need something done and drugs don't seem to work.

Don't give up. There are options out there and something will work for you. Unfortunately you may need to try a few things before you land on the right answer for you.

Please: Let us know what you would like to see in this newsletter.