

CANADA TN ASSOCIATION NEWS

June/July 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; 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.

I hope everyone is ready for a wonderful summer.

This month I am asking for your help. I need someone who is willing to co-host the Calgary support group meetings. I also think we need someone to help out in Winnipeg as well. So if appreciate the opportunities of talking to others with TN and want to see the meetings continue - please let me know.

Jan

A TN Story

This was written by Christina about her husband, Mario

Mario has had TN for over 20 years. He had a glycerol rhizotomy injection and developed chemical meningitis. At that time the surgeon said that most likely he was allergic to the glycerol, he was kept in intensive care for over a week, let me tell you it was a nightmare.

Over the years the TN came and went some time more severe than other times, for about 15 years it was not too bad, he was able to control it with medication (mainly Dilantin).

About 3 or 4 years ago it came back with a vengeance. It took us a while to get to see a specialist since the previous surgeon was no longer practicing. Through our own research and the help of some friend, we were introduced to Gamma Knife treatment, I think the the Gamma Knife was new in Toronto. At that time we were not part of your support group, not many people know about TN.

To make a long story short we finally were referred to Dr Hodaie, who is the head of the Gamma Knife Centre. August of 2006 Mario

had the Gamma Knife surgery but it did not work, the pain was brutal, he had to increase his medication up to 2700 mg of Gabapentin and 300mg of Dilantin a day. He got some relief for a couple of years until September/2008 when the pain came back again really bad.

In Jan 2009 Dr Hodaie performed an MVD we think that it partially worked, after the surgery the pain concentrated only on the lower jaw, where as before it was on the full side of the face. Again the pain was unbearable; the medication was not doing much to relieve the pain. Less than a month later Dr Hodaie performed a Radiofrequency Rhizotomy, - again he developed meningitis and was hospitalized for 5 days with high fever headache and whatever else.

The good news is that Mario has been pain free since the Rhizotomy surgery, he is continuing to reduce medication, and he is off the Gabapentin will start to reduce Dilantin. We are keeping our fingers crossed and pray that it will not come back.

MRIs

What is an MRI?

Magnetic resonance imaging (MRI) uses radiofrequency waves and a strong magnetic field rather than x-rays to provide remarkably clear and detailed pictures of internal organs and tissues.

Example of an MRI shows a tumor on the trigeminal nerve



Because the MRI can give such clear pictures of soft-tissue structures near and around bones, it is an excellent choice to look at structures inside the skull.

No radiation exposure is involved with an MRI.

How should I prepare for the procedure?

Because the strong magnetic field used for MRI will pull on any ferromagnetic metal objects implanted in the body, MRI staff will ask whether you have a prosthetic hip, heart pacemaker (or artificial heart valve), implanted port, infusion catheter (brand names Port-o-cath, Infusaport, Lifeport), intrauterine device (IUD), or any metal plates, pins, screws or surgical staples in your body. In most cases surgical staples, plates, pins and screws pose no risk during MRI if they have been in place for more than four to six weeks.

Tattoos and permanent eyeliner may also create a problem. You will be asked if you have ever had a bullet or shrapnel in your body or ever worked with metal. If there is any question of metal fragments, you may be asked to have an x-ray that will detect any such metal objects.

Tooth fillings usually are not affected by the magnetic field but they may distort images of the facial area or brain, so the radiologist should be aware of them. The same is true of braces, which may make it hard to "tune" the MRI unit to your body. You will be asked to remove anything that might degrade MRI images of the head, including hairpins, jewelry, eyeglasses, hearing aids and any removable dental work.

The radiologist or technologist may ask about drug allergies and whether head surgery has been done in the past. If you might be pregnant, this should be mentioned.

Some patients who undergo MRI in an enclosed unit may feel confined or claustrophobic. If you are not easily reassured, a sedative may be administered. Roughly one in 20 patients will require medication to reduce the anxiety associated with claustrophobia.

How is the procedure performed?

The patient is placed on a sliding table and positioned comfortably for the MRI examination. Then the radiologist and technologist leave the room and the individual MRI sequences are performed. The patient is

able to communicate with the radiologist or technologist at any time using an intercom.

Depending on how many images are needed, the exam will generally take 15 to 45 minutes, although a very detailed study may take longer. You will be asked not to move during the actual imaging process, but between sequences some movement is allowed. Patients are generally required to remain still for only a few seconds to a few minutes at a time.

Usually people with TN will be given a contrast material (gadolinium) to enhance the visibility of tissues or blood vessels. This is given intravenously about 2/3 of the way through the exam.

What will I experience during the MRI procedure?

MRI causes no pain but some patients can find it uncomfortable to remain still during the examination. Others experience a sense of being "closed in," though the more open construction of newer MRI systems has done much to reduce that reaction. You may notice a warm feeling in the area under examination; this is normal but if it bothers you the radiologist or technologist should be notified.

If a contrast injection is needed, there may be discomfort at the injection site and you may have a cool sensation at the site during the injection. Most bothersome to many patients are the loud tapping or knocking noises heard at certain phases of imaging. Ear plugs may help.

A TN Story from Calgary

My name is Lorraine Roth, I'm from Calgary & I had Trigeminal Neuralgia for almost 4 years. Here is my "success" story.

My experience with Trigeminal Neuralgia started in early September of 2004 a few days after I'd been to the dentist to have my teeth cleaned. I had a strange feeling in one of my teeth on the right side, lower jaw. I thought perhaps it was going to require a root canal but after an x-ray I was advised that there was nothing wrong with my tooth. About a week after these symptoms, I started having very sharp, excruciating pains. I saw an endodontist who diagnosed TN and started me on Tegretol. The Tegretol initially took away the pain but then it came back and the dosage had to be increased. In all I saw my dentist multiple times, two dental

specialists, my family doctor and a neurologist.

This whole experience was very upsetting to me as over the past few years I'd had major surgery for breast cancer, a hysterectomy, I was being treated for high blood pressure & I'd had thyroid cancer 7 years before. I was also very busy at work & didn't have time to be in & out of the office while trying to determine what was wrong with me.

I took early retirement from my job in June of 2005, as I felt I wasn't functioning well & because of the previous illnesses I'd had, I needed to put my health first & deal with the Trigeminal Neuralgia.

Then in Jan. 2006 they discovered a small spot on my right kidney which turned out to be a renal cell carcinoma & in March I had my right kidney removed. About a month after my surgery, I started getting major attacks of TN. The attacks were much more severe & lasted for over an hour. During an attack I would have to lay perfectly still & because it was too painful to swallow,

I then saw a homeopathic physician who gave me a homeopathic remedy. It was a liquid called Aconite which I started taking immediately & the attacks stopped. Aconite comes from a plant called Monkshood & is very poisonous if ingested

By this time I needed 600 mg of Tegretol a day & along with the Aconite I didn't have any more severe attacks, but periods of pain still would come & go. Sometimes eating or talking would trigger pain.

I had been occasionally going to the Calgary TN Support group meetings & learned there would be a seminar about Trigeminal Neuralgia at the Foothills hospital & the speaker was Dr. Anthony Kaufman, a neurosurgeon, who specialized in the MVD procedure as well as other non-invasive procedures.

Even though I had been relatively pain free for a few months, my husband Jim & I decided to go listen to him. We were both very impressed with Dr. Kaufman & learned a great deal that afternoon. One thing he emphasized was if we were in remission now, we should form a "plan" to deal with the TN when it returns, as it most certainly would return. We made the decision that if the pain returned; I would look into having the MVD.

On Christmas Eve of that same year my pain returned, even though I had been on the medications all along. I tried to replace the Tegretol with Lyrica (75 mg twice a day), but the effect was extreme. I felt like I was spinning,

could barely walk & it was very frightening. The pain in my face got very strong so I increased the Tegretol back to the 600 mg & continued to take the Lyrica but at a lower dose. Although my doctor told me I could increase the dose of Tegretol to 800 mg, I knew I couldn't handle that amount of the drug, as I was so tired all the time I was having a difficult time functioning & I had lost all my motivation to do anything.

Now I was taking 2 drugs, an increased dose of the Aconite & was having acupuncture a couple times a week, but nothing was working anymore.

Since we had already decided that I would set into motion the process required to have the MVD, I contacted Dr. Kaufman in Winnipeg. He was happy to help me. He thought that it was a blood vessel compressing the Trigeminal nerve and I needed an MVD.

I was scheduled to have my MVD on Tuesday, July 8th, 2008. My husband & I went to Winnipeg & had a consultation with Dr. Kaufman on the Monday, July 7th, where he showed me the pictures of my MRI & pointed out the vessel that was pushing against my Trigeminal nerve. He felt confident that he could help me & I was very impressed with his compassion & his ability to explain everything in such a way as to make it easily understood. My surgery was the next day.

The rest is history. I spent the rest of the week in hospital & was able to leave for home on the following Friday, after the surgery. As per his instructions, I weaned myself off all my medication within 2 weeks. I did however have a slight tremor that lasted for approximately a month..... apparently a side effect of going off the drugs that my body was now used to. Dr. Kaufman's nurse practitioner called me at home on 2 separate occasions to see how I was.

For several months after the surgery, I did have some "sensations" in my face on occasion, but it was never the sharp, electric like pain of TN, but simply a little aching after I had eaten something that required a lot of chewing. Occasionally I still have a slight aching if I eat something that is quite chewy which could possibly be muscle pain in my jaw, but I have never had another sharp pain since the surgery.

I feel wonderful.....I've got my life back, including my motivation to do all sorts of things.....I'm back to the old me & I've never been so grateful & so happy to be alive. My positive attitude is back. I no longer take any drugs for TN. I hope that part of my life is behind me

I am hopeful that I won't ever suffer from TN again, however, if the pain ever did come back, I wouldn't think twice about calling Dr Kaufman!!

It's difficult to have a positive attitude when you're in pain & drugged, but it's imperative that you do not give up! I put up with TN for almost 4 yrs because I really didn't want to put myself through another surgery, but eventually I became much more afraid of going into my senior years with the pain & living my life being on drugs.

Support Group News

Calgary

New dates: Meetings are the 20th 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 for more information.

Our next meeting will be June 20. This will be my last meeting as I have decided the Pacific Ocean is calling my name and I am moving to the West coast over the summer. I have enjoyed working with the folks in the Calgary group since 2003 – you are a wonderful group of people and I appreciated your kindness and support during a very difficult time for me. I hope we'll keep in contact via e-mail.

Someone needs to step forward and take over the meetings. The room is booked until the end of the year and is available after that for a small fee. Please contact me if you are interested in helping.

At our next meeting on June 20th I will have a video of Dr. Kaufmann's presentation on the Canadian Perspective of TN treatments,

There will be no meeting in July.

**Hope everyone enjoys a great summer –
Jan**

Regina

There will be no meetings during July or August. 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.

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 for location and/or directions.

Peterborough

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

Winnipeg

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

Don't forget – we would love to hear from you and to include your story in the next newsletter.

If your group is doing something special, please let us know so we can include the information in this newsletter.

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