

# CANADA TN ASSOCIATION NEWS

August/September 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](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 hope everyone has enjoyed a great summer. Most groups have taken a break over the summer and meetings will start again in the fall.

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 you appreciate the opportunities of talking to others with TN and want to see the meetings continue - please let me know.

As always, we will be glad to help you start a group in your own community. Just contact me.

*Jan*

## ***A TN Story from Regina***

### **Motor Cortex Stimulation Implant**

*By Faye*

My pain started April, 1999. I had a stroke and this is what I was left with. I knew my pain was different from the Classic TN. I tried a variety of medications. None really helped and I did not like the side effects.

In 2001 I went to the Mayo Clinic and they did an enhanced MRI and told me that a Motor Cortex Stimulation might help with the pain. They were willing to do it but had never done the surgery. I refused. They also gave me the name of a neurosurgeon that was doing the surgery in the US. I wanted to have it done in

Canada so that Sask. Health would cover the cost.

In 2006 a friend of a friend called me up and told me she had seen a CTV news cast and that there was a Doctor in Winnipeg who had done the Motor Cortex Stimulation implant and it was successful. I took the information to my GP and asked for a referral. After some problem getting the letter faxed to Winnipeg the referral was finally sent in 2007.

My first appointment with Dr. Krcek was June, 2007. During the appointment Dr. Anthony Kaufmann was consulted to make sure that this was the procedure I needed. I also met a neuro-physicist, Dr. Marshall Wilkinson, who does Transcranial Stimulation. I was told that the Stimulator is a very expensive piece of equipment and that there are only three in Canada. All three Doctors came to me all in a two hour appointment. The decision was made to start the testing with the Transcranial Stimulator. The neuro-physicist, Dr. Wilkinson put electrodes on my wrist and the placed a magnet on the top right side of my head. My pain is on the left side of my face. When he found the right spot, my arm started moving up and down and I had no control over this. He then turned down the machine and my arm stopped moving up and down. Then he continued placing the magnet on my head 20 times with breaks. This was painless. It just felt like someone was tapping on the top of my head. I had to keep a pain diary for the week after and send it to Dr. Krcek. I went to Winnipeg four times for this procedure and had to keep a pain diary and return it to Dr. Krcek each time. He then asked me to do a day of

psychological testing before they would consider doing the implant. After this a date was set for the implant.

I had a pre-op appointment on April 22 with Dr. Krcek. He ordered an MRI that day as he uses it before surgery to map out my brain.

On April 23 I had to be at the hospital at 6:45. Surgery was scheduled for 7:30 a.m. I couldn't eat anything after midnight. The surgery was delayed to 9:30 a.m. because they couldn't track down the device from storage. I rode in a wheelchair up to the doors of the operating room and got up on the operating table myself. They had me put the anesthetic mask on my face, myself, as I am a little claustrophobic. The surgery was four hours long and was in recovery for two hours. The incision is eight inches long. It starts at the top of my head and runs down to in front of my left ear. After rolling back my scalp where the incision was, they cut a 2.5 inch hole and lifted out the section of bone. They then placed a small pad with contacts on it over the section of my brain where the applicable nerves entered the brain. Special silicone coated wires were then run from there, under my skin, down behind my right ear and to my upper right chest where they were connected to a stimulator unit that was implanted there. The electrodes transmit electrical pulses to the area where the pain signals will be blocked)

The Neurostimulator is the power source of the system. It contains a battery and electronics to control the neurostimulation.

There is a remote that controls the Neurostimulator. It can be turned on and off. It can also be used to fine-tune the amplitude, pulse width and rate. This depends on what the Doctor programs it to do; although the Doctor can give me a limited range of control with my remote control

On Friday Dr. Krcek came to see me and brought the Neurostimulator remote. He told me I could go home. My blood sugars had gone high so I was concerned there might be infection. They started leveling out as I monitored them. Saturday morning I had a careful shower. After lunch I was released from the hospital. On Sunday our friends took us to a book sale in a local mall. I walked around and did fine. I wore a hat outside because they told me to keep the incision clean and out of wind and dirt blowing around.

On Monday, April 27 I had a post-op appointment with Dr. Krcek. He set the Neurostimulator at level 2 with no ranges for me.

The only thing I questioned was that sometimes I had tapping noise in the back of my head. Dr. Krcek told me that the incision down was made in my head air got in and that these were air bubbles and that my body would absorb these and within a week they were gone. He told me I could go home and the next day we drove back to Regina.

I can feel the pain is there but doesn't seem to be as bad. On Wednesday evening I had a very intense pain and it took me a long time to get to sleep. I had gone to the gym and because I was feeling so good I over did it. The weather we have been having I'm sure has something to do with it as well.

I go back to see Winnipeg to Dr. Krcek on June 3 to do a follow up appointment. I have an appointment with Dr. Buwembo in Regina to do further adjustments if needed. I shouldn't have to make trips to Winnipeg.

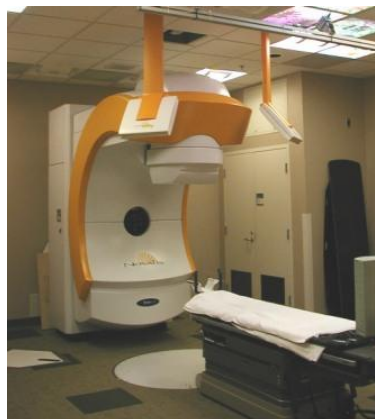
When I spoke to Dr. Krcek I asked him if this would help others who have Atypical Trigeminal Neuralgia and he said, yes, but they would have to do the trial with the Transcranial Stimulator and have psychological testing before he would consider doing the surgery. There is hope for those that are diagnosed with Atypical Trigeminal Neuralgia.

## **Alberta Radiosurgery Center**

In November of 2004 the Alberta Radiosurgical Center opened at the Foothills Hospital in Calgary becoming the first site in Canada to offer the "Novalis Shaped Beam System". This technology allows doctors to remove tumors in the brain, spine, prostate, liver and lungs. The advantage of this Novalis system is its ability to modify the shape of the radiation beam to more closely match the shape of the tumor. Other machines like the Gamma Knife

have a set circular shaped beam.

The radiation beams can be used to purposely damage the Trigeminal Nerve in a similar way to the needle



rhizotomies without the need to pass a needle through the skin into the skull. With its ability to focus radiation to a small area precise area, this machine can protect brain tissue while delivering the radiation needed to the Trigeminal Nerve.

Treatment for TN is a single session.

John, from Calgary, recently had his Trigeminal Neuralgia treated with this Novalis machine. John has had TN for a number of years and has tried a number of surgical options. He originally had an MVD about 12 years ago which was not successful. He has a Radiofrequency Rhizotomy in Ontario and again this was not successful. Here in Calgary since 2003 John has had three Balloon Rhizotomies with limited and short term success from each. He has been on increasing doses of drugs and having more and more trouble with side effects and break-through pain.

In June of 2009 John was treated at the Alberta Radiosurgical center. This is an outpatient procedure. A frame is attached to the head with screws so that exact measurements can be made using CT scans with the frame in place. John says that didn't hurt as they used a local anesthetic. However he said it was a very tight feeling.

The doctors use a computer to program the exact shape, location and amount of radiation needed. The treatment itself is painless. John was put on a table, the head frame was attached to the table so he didn't move and the machine roated around his head delivering the prescribed radiation.

The results of TN treatment by the Novalis system match those of the Gamma Knife with about 58% of patients experiencing excellent pain relief and another 36% having "good" pain relief. It normally takes up to 3 months for the effects of the treatment to become known. For John, the effects of the treatment have just recently begun to show. Currently he has slightly reduced the drugs and is pain free for the first time in a long time. Over the next several weeks he'll reduce the drugs further.

Good luck John!!

### **Support Group News**

Most groups have not met during the summer but meetings will resume in September or at the end of August.

### **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:

Aug 20	Sept 20
Oct 20	Nov 20

### **Regina**

Meetings will start again in the fall. Contact Faye at (306) 751-0761 or [regina@catna.ca](mailto: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](mailto: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.

August 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.

### **CaTNA Fee Change**

Effective immediately, the annual CaTNA registration fees is as follows:

\$10 to receive Newsletters by email  
\$20 to receive Newsletters via Canada Post