

Canada TNA Newsletter

December 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.

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.

New Gamma Knife Center in Toronto

Reprinted with permission from the University Health Network website:
http://www.uhn.ca/About_UHN/programs/KN/gamma_knife_radiosurgery.asp

Krembil Neuroscience Program : Gamma Knife Radiosurgery

What is Gamma Knife Radiosurgery?

Gamma Knife Radiosurgery, a form of stereotactic radiosurgery, is a sophisticated radiation tool known worldwide for its precise treatment to targeted areas of the brain. The "Tools" of the Gamma Knife are the beams of gamma radiation that deliver single doses of radiation therapy with precision of less than 1 mm. The Gamma Knife Centre is located in a new wing at UHN's Toronto Western Hospital and operates as a unique collaboration between the Neuroscience, Medical Imaging, and the Radiation Medicine Programs. Each of these programs are world leaders in their own right and, combined, promise to offer state-of-the-art care for Ontarians.

Role in Treating Neurological Disease

The beams of gamma radiation are specifically programmed to target areas of the brain where surgical access is challenging or too dangerous or are not optimally suited for other medical

treatments. In a single treatment session, 201 beams of gamma radiation focus precisely on the target. The exposure is brief and only the tissue being treated receives a significant radiation dose, while the surrounding tissue remains unharmed.

Who is Eligible for Gamma Knife Surgery?

Patients may be referred to the Gamma Knife Centre for consideration of radiosurgery for the following standard clinical indications:

- Patients with typical Trigeminal Neuralgia who have failed an adequate trial of medications, and may have also failed prior surgical intervention.
- Patients with brain or dural vascular malformations (AVM) suitable for radiosurgery.
- Patients with Brain Tumours may be referred for gamma knife radiosurgery when considered technically advantageous over alternate radiosurgical approaches, or stereotactic radiotherapy. Evaluation by a radiation oncologist is strongly recommended prior to referral to the Gamma Knife Centre.

Patients may be referred to the Gamma Knife Centre for consideration of radiosurgery under a research protocol for non-standard indications. This may include the following:

- Movement Disorders and Intractable (unstoppable) Pain
- Patients with medial temporal lobe epilepsy.

Benefits

- Since Gamma Knife radiosurgery is performed without incisions or general anesthesia, the usual risks associated with conventional neurosurgery, such as neurological deficit, infection and bleeding, are virtually eliminated.
- Patients are discharged from the Gamma Knife Centre on the day of treatment and are usually able to return to their normal activities within 24 hours.
- Associated with lower treatment costs.
- Gamma Knife technology is a recognized safe treatment. It has been in use for more than 15 years and over 300,000 patients worldwide have benefited from this treatment.
- Patients will benefit from the advanced imaging resources at the state-of-the-art TWH imaging centre as well as on-going innovations in imaging. Better determination of the location and extent of the target is key to fully exploiting this new technology for the benefit of the patient.
- Gamma Knife delivers single doses of radiation therapy to targeted areas of the brain with a precision of less than 1 mm. The beam is so precise that the surrounding normal tissue receives minimum radiation.

Referrals

- Only patient referrals that meet the indications for Gamma Knife radiosurgery will be accepted.
- Patients are referred by a specialist to the Gamma Knife Referral Centre for consideration of stereotactic radiosurgery. Patient self-referrals will not be accepted.
- Referrals must include sufficient clinical documentation and diagnostic imaging in order to determine the appropriateness of stereotactic radiotherapy.
- The Gamma Knife Centre accepts referrals for Ontario residents and out-

of-province Canadian residents. Referrals for non-residents or uninsured patients are not accepted at this time.

- Referrals and supporting documentation are faxed or mailed to the Gamma Knife Centre:

Phone: (416) 603-5445
 Fax: (416) 603-5155
 E-Mail: gamma.knife@uhn.on.ca

Patient Referrals - Gamma Knife Centre
 Toronto Western Hospital
 Room MC 3-449
 399 Bathurst St.
 Toronto, ON M5T 2S8

Cerebral Spinal Fluid Leaks

One of the potential complications of the MVD (Microvascular Decompression) is a CSF leak when the fluid spills out through an opening in the dura. This can occur immediately, or anytime during the first few weeks after surgery. According to the literature from the USA it is one of the more common complications of an MVD occurring in about 5 to 7% of cases.

What is the Cerebrospinal Fluid (CSF)?

- It is clear, colorless liquid that circulates in the ventricles and subarachnoid space.
- CSF is produced by the **choroid plexi**, located in each of the 4 ventricles.
- CSF circulates around the spinal cord and the brain.
- It provides a cushion to prevent injury to the brain and spinal cord
- Distributes nutritive materials to and removes wastes from nervous tissue
- In adults, the total volume of CSF in all the spaces combined is normally about 150 mL.
- Between 400 and 500 mL of CSF is produced and reabsorbed daily.

Symptoms of a leak

- clear fluid drainage from the nose, incision, back of throat, or ears
- headaches, which are more severe in the upright position

Complications

Meningitis

Treatment

In most cases the leak heals itself with best rest.

If that is not effective, then the pressure of the CSF is reduced by a lumbar puncture drainage.

In rare situations, surgical repair is required.

Question sent to Dr. Kaufmann regarding CSF Leaks: In your experience is CSF Leaks an issue following any of the percutaneous procedures or is it only a possible complication after the MVD?

Dr. Kaufman's response:

CSF leak doesn't occur after the needle procedures. Following MVD it occurs as often as 5% of the time in some published series. In my experience doing now 600 MVDs, we encounter a persisting CSF leak in only 1%.

The leaks can show as CSF draining from the incision. If this occurs, usually in the first day or two, we apply more sutures to the skin, after freezing the area. Leaks may also show as a salty water drip felt at the back of the nose, dripping then down the throat or out the nose when leaning forward. The CSF travels through any hole in the dura and then through the air sinuses of the mastoid bone and finally through the eustachian tube.

This usually stops on its own, or with sitting up for a couple of days or rarely after draining some CSF by a spinal tap. If all that fails to stop the leak, then reoperation to better seal the bone edge of the craniectomy is done. If the leak is left untreated, there is a risk infection will occur, as bacteria come up from the nose, along the same course the CSF goes down.

Anthony

Some Updates

From Dee in Saskatoon: It is my 1 year anniversary for my MVD and I am doing ok, still suffering from headaches and hope to have my neurologist give me some answers. I am off all

meds and only taking some OTC tylenol for the headaches. I attended the Dr Kaufmann meeting in Regina and found it very informative and invited him to come to Saskatoon in the spring for the same type of meeting and he said YES, so that is something to look forward to for our group. I continue to get calls from other sufferers on a regular basis and hope that I am helping them on their path to find their answers.

From Susan in Regina: I have had TN since 2006. It has been a constant struggle to balance work and my family while taking Carbamazepine. On October 22 of this year I had an MVD done by Dr. Kaufmann in Winnipeg. I am now off all medication and am pain free. I'm enjoying life all over again. God has living angels all around us and I think Dr. Kaufmann is one of them.

From Jan in Calgary: I'm still medication and pain free 5 years after my MVD.

From Gaye in Calgary: I had an MVD 3 years ago. I have a few attacks when brushing teeth, washing face, putting on cream and eating. I am on 900 mg of Gabapentin and now am adding Tegretol. The Gabapentin is making me very tired and feeling quite dull most of the time. I think I felt better on the Tegretol. I just want to end the pain.

From Bev in Calgary: Since getting home from the meeting last Thursday and getting the good news of being a candidate for the MVD procedure, I am so excited I can't wait to have this operation and get my life back. Because of being allergic to Tegretol, I have had to come off it quickly and since Saturday, I fill like I have come out of a thick cloud. Now I know I was depressed on it. I feel like laughing again. I am only on 1500mg of Gabapentin daily at this point and increasing it every 3 days by 300mg until I have no pain.

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.

Calgary Meetings scheduled for 2009:

Thursday, Jan 22 **

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 January 10th at 10 am – Wascana Center – Rooms 1, 2 and 3. Contact Faye at (306) 751-0761 or regina@catna.ca for more information.

Faye and the group in Regina are to be congratulated on an excellent seminar presented by Dr. Kaufmann on Nov 22. There were 112 people who attended this meeting.



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 at (905) 853-9849 or Sandra at (905) 284-9215 or both by e-mail at Toronto@catna.ca for meeting information.

Niagara Region

The next meeting will be Sunday, Dec 7 at 2 pm. Contact Brenda at (905) 937-6178 or Niagara@catna.ca for location and/or directions.

Brenda was the subject of a Newspaper article in the Oct 21st edition of the St Catharines Standard. Her and Roger allowed themselves to be interviewed and shared their experiences.



Thanks very much. It is great that you both were willing to share your stories.

Peterborough

Contact Marilyn at (705) 742-1486 or 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 for meeting information.

Online Diagnosis

If you have facial pain and would like to have a diagnosis based on your symptoms, check out the “Trigeminal Neuralgia – Diagnostic Questionnaire” which is located on the web site of the Oregon Health and Science University <https://neurosurgery.ohsu.edu/tgn.php>

Of course this can never replace a real diagnosis made by a neurologist or neurosurgeon, it is interesting to see how your symptoms fit into the picture of Trigeminal Neuralgia.

Potential Canadian Studies

Dr. Zelma Kiss from the University of Calgary is considering various studies of Canadian TN patients. She is requesting feedback from us to help in the planning of the studies. Your feedback is important. At this point she is trying to determine if Canadians with TN would be interested in participating in one or more of these studies. You are not being asked to sign up for a study at this time.

1. Comparison of Percutaneous Rhizotomies with Stereotactic Radiosurgery

Based on the best evidence available 3 years out from stereotactic radiosurgery (SRS or radiation) or percutaneous surgical rhizotomy, overall patients are doing the same; about 60% of patients are pain free. If these two procedures seem so similar we would like to do a randomized controlled clinical trial comparing SRS to rhizotomy (numbing) surgery. This would require Canada-wide cooperation and careful follow-up over 5 years or longer.

Patients would be seen by their neurosurgeon. If the doctor and/or patient decide that an MVD or medications are not options, and that a rhizotomy is the best option for that patient, he/she can enter the study.

Patients in the study will be randomly assigned to have either a Rhizotomy or Stereotactic radiosurgery. This means that a flip of a coin will decide which treatment they have. If they are assigned to the Rhizotomy group, it would be their neurosurgeon's decision which procedure would be done: Balloon, Glycerol, or Radiofrequency. If the patient is assigned to the SRS group, then they would be treated with whichever radiation machine is in that community (like the Gamma Knife or Novalis).

After the surgery, patients would be assessed by a nurse and neurologist at regular intervals to evaluate the success of the treatment. The neurologist will not be aware of which procedure was done – just that a treatment was completed. This is called “blinding” and in this case, it is only the person who measures the outcome who is blinded. The patient knows which treatment they had, they are not blinded.

2. TN in Families

Trigeminal Neuralgia is reported to be familial in about 5% of cases. Dr. Kiss would like to hear about these cases and have a geneticist and/or neurologist examine these families, draw some blood tests, to determine if there is a genetic link we can find.

3. Registry of people with trigeminal neuralgia in Canada

This would involve signing up to a database (likely via your doctor initially) and then keeping track of the medical and surgical treatments and their side effects that you experience. It will likely be internet based; therefore will require coding to maintain confidentiality.

Questionnaire

If you have already responded to this survey – Thank you. If not, can you please complete and return it to: Jan Williams, Suite #207, 15 Everstone Dr. SW, Calgary, AB, T2Y 5B5

If you and your doctor decided a “numbing surgery” was a good option for you, would you be willing to participate in a study comparing a percutaneous rhizotomy with stereotactic? You would have to agree to having either of these treatments and a flip of a coin decides which.

- Yes
 No

2. If you have family members with TN, would you be willing to bring them to a neurologist for examination (to determine if they really do have TN) and agree to blood tests being drawn from you and family members and sent to the University of Calgary for research purposes? We would also want blood tests from brothers/sisters without TN.

- Yes
 No
 No because they don't live near a centre with a neurologist
 No – I have no living relatives with TN

3. Would you be willing to participate in a Canada-wide registry of TN patients and fill in regular questionnaires?

- Yes Name _____
 Address: _____
 Phone: (____) _____
 Email: _____
- No