



Canada TN Association Newsletter

August 2010

Greetings all. I hope everyone is enjoying a wonderful summer. I thought that I would be in the wettest part of Canada moving out here to the west coast – but that is sure not the case this summer. We've had a great summer with lots of sunshine and no rain. In fact they are all wishing for some rain out here because everything is so dry.

If anyone has a few days this summer, consider going to the TNA's 20th year Anniversary Conference at the Mayo Clinic in Rochester August 28-29th. I can give my personal recommendation for these National Conferences. I've been to two of them and they were both excellent.

I'm still looking for stories and ideas for this newsletter. I'd love to hear from you. Starting in 2011, we'll have only 4 newsletters per year – one for each season – except if there is something new and exciting to report. Jan

Swallowing Pills

There is a group of researchers in Calgary who have done some study on ways to help children and others who have difficulty swallowing pills. It seems there are some techniques that can be used to make the “medicine go down” easier. These techniques might be applied to anyone who has trouble swallowing – including someone with TN.

It seems that the position of the head when swallowing can open the throat so that things slip down easier. Each individual has a preferred position that works best for them so there is a 14 day trial period where people practice each day with their head in each one of the five main positions. At the end of the 14 days a preferred position is identified.

The 5 positions are

- Head in a normal face-forward position
- Head tilted upward
- Head tilted downward
- Head turned (45°) to the right
- Head turned (45°) to the left

The patient is instructed to place the pill on the back of the tongue while facing forward. Then take a small sip of water, turn or tilt the head to the desired position and swallow. It is important take a SMALL sip of water since too much will get the pill floating around the mouth.

For the practice sessions people are advised to use candies. Small candies like tic-tacs work well.

There are videos of the training sessions on-line at <http://www.ucalgary.ca/research4kids/pillswallowing>

Support Group News

Calgary

This group will meet the third Tuesday of each month at 1 pm at Confederation Park Senior Citizens Centre, 1112 - 13 St. N.W. Room #4. Contact Bev for more information.

The next meeting will be August 17, at 1 pm. Dr. Kiss will be speaking to the group. Everyone is invited to come. Bring a guest.

Best wishes to Gaye and Bonnie who both had successful MVDs in Winnipeg this spring. We are waiting to hear from Mary who had her MVD in Winnipeg in July.

Niagara Region

Please contact Brenda for details on the location and date of the next meeting.

Regina

Meetings are held monthly at the Wascana Rehabilitation Center, 2180 - 28th Avenue, 2nd Floor, Rooms 1,2 & 3. Contact Faye for specific details.

Meetings will start again in September.

Toronto

The Toronto group meets at the Thornhill Community Centre, 7755 Bayview Ave. on the last Sunday of the month. 9:30 a.m.

July 25/10 August 29/10

Please note – the meetings will continue at the same location until the end of the year.

Akira's TN Story

I'm finally spurred on to send my TN story. In July 2009 I underwent the Radiofrequency Percutaneous Rhizotomy surgery at Vancouver General Hospital. Dr. Christopher Honey performed the successful surgery that has given me my life back. I no longer am debilitated by the constant piercing pain of TN.

In early May 2008 I had my teeth cleaned ultrasonically. This is what triggered the onset of the TN pain. I had experienced previous sharp tinges of what was to come for a few years previously. My family doctor diagnosed the TN on my initial visit with my face contorted in pain. I have many drug allergies. Was prescribed Tegretol initially, but reacted negatively to that and was then prescribed Gabapentin. I took one dose at night and the next morning upon arising went into anaphylactic shock and was taken to hospital by ambulance and kept under observation. They suspected I'd had a stroke as the right side of my face was paralyzed by the TN.

My heart was fine. The only relief I experienced until the surgery was from

occasionally applying a topical ointment that contained a local anesthetic.

Akira Hanson
Vernon, BC

Trigeminal Neuralgia on YouTube

If anyone is interested in short videos on-line, check out YouTube. You will find several short videos on TN.

One I found was produced for the Facial Pain Association, formerly the Trigeminal Neuralgia Association in the USA. It aired on MSNBC, CNBC, Fox News, and the Discovery Health Network. The link is: <http://www.youtube.com/watch?v=YfKEVlqR14Y>

There are several other videos there too, but a word of caution, not all are totally accurate. Whenever you see something on the internet, remember to check the source – does it come from a reputable organization like the Mayo Clinic or the TNA? If not, use your common sense to decide if it is accurate or not.

MVD after failed Gamma Knife

There was an article in this year's Journal of Neurosurgery concerning the benefit of an MVD in those people who had previously had a Gamma Knife treatment for TN.

The authors studied the medical records of 28 patients who had a gamma knife treatment and some time later opted for an MVD.

They found that there was an increased risk of numbness and tingling after the MVD, but 60% of the people reported a good or excellent result as far as control of the pain. They concluded that in spite of some difficulties during the surgery with adhesions, "an MVD is an appropriate and safe rescue therapy following Gamma Knife Surgery".

Mary's TN Story

Judy's TN Story

I can tell you exactly what I was doing when it first happened. I bit into a Harvey's hamburger in 2000. Luckily it was diagnosed only after a couple visits to the doctor and dentist. I was referred to Dr Klassen at the Lougheed. He sent me for an MRI to rule out MS – no MS found – thank the good Lord. I was put on Tegretol by my family doctor and continue to take it to this date.

I have had some issues over the years but it all came to a head in December 2008 when the pain hit and lasted for hours and I felt like I was literally frozen. I could not move a muscle without extreme pain. I went to urgent care and they gave me Percocet over the span of a few hours – the pain finally stopped. I went back to my family doctor and he gave me morphine and referred me back to Dr Klassen. Luckily I got in to see him quite quickly. He put me on Topamax as well as the Tegretol. He also ordered another MRI and he referred me to Dr Kiss. I did not do well at all on the Topamax but I continued to take it until I saw Dr. Kiss.

She examined me and gave me my options for surgery. I choose the MVD as it seemed to have the longest time before a reoccurrence. I had my first surgery in May 2009. All seemed to be fine. I was released from the hospital on a Friday and the pain returned Sunday.

I had my second MVD in November 2009. I was pain free for 5 months.

I met with Dr Kiss in the spring of 2010. She suggested the balloon decompression. I had that done July 9th. I had all the numbness that is described in the Striking Back book plus the cold sores! The pain started again on the 12th. I thought maybe a few days to settle down (I did read that in the book somewhere). Well I started to count the number of tics a day and they are back to the same as before. Dr Kiss did another balloon compression on July 29th. I hope and pray this one works for me.

I've had TN since May, 2005. It was diagnosed in July by a dentist (I thought it was a bad toothache) the dentist said my teeth were fine. He suggested that I see a neurologist as it could be TN. He had seen this before.

I first tried Tegretol, and had a terrible reaction. I ended up going to the Emergency Dept. with swollen joints and an inability to breathe properly. I stopped Tegretol, and started Neurontin. I did not like the side effects of this... extreme fatigue and ongoing confusion being the worst. Last drug I took was Lyrica, and this worked well until early 2009. Side effects for me with Lyrica are minimal.

I had the MVD surgery in June, 2009 by Dr. Kiss in Calgary. Result was phenomenal and immediate, and in a word "miraculous". The pain stopped right away. Recovery was quick, and I went back to work in 3 weeks. Now I feel wonderful! The only residual effect is some minor numbness on the right side of my face (feels a bit like permanent freezing from the dentist), but I will happily live this way any day over the excruciating pain I endured for about 5 years.

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