



Trigeminal Neuralgia Association of Canada

Fall 2008 Newsletter



Support Group



Eastern Ontario Support Group

Time for one last summer BBQ!!!!

We are planning to meet in Stittsville September 27 for a late summer BBQ lunch! If you live in Kingston, Ottawa, Cornwall, Gatineau or even Montreal let's plan to get together. We will also try to meet once more before the snow flies ... but who knows – after all we don't know when that snow will start again!

For more information contact Jane at cmusicstudio@cogeco.ca or by calling 613.936.6977

Vancouver and Lower Mainland Support Group Update

Coordinator: Ann Hopkins
Vancouver and Lower Mainland Support Group

What: Meeting and Social
When: October 4 2008
Time: 1 - 3.30 pm
Speaker: Anar Dossa from Medication Info UBC
Bring your questions about meds

Please feel free to bring guests, family or supporters.

For further information contact Ann Hopkins at 1-604-741-0662 or cell 1-604-989-3777

Lethbridge Support Group Coordinator Marion Guzik

The Lethbridge Support Group meets every second Saturday of the month at 2:00 p.m., in Rm A., Lethbridge Senior Centre, 1100 - 11th St. S. Lethbridge, AB . Our next scheduled meeting is Sept 13, 2008.

Message from the Treasurer,

My apologies to the Executive and members regarding the proposed change to the fiscal year, it was not until the day prior to our AGM that I realized I would be sunning myself in the California Desert each year in Jan and part of February therefore I would be unable to process new memberships until some time in March which is far too late for issuing receipts.

As of August 26 less than 50% of members have renewed for this current fiscal, if any members have not received renewals please call or e-mail Joya Dickson at 604-943-7913, Joya@telus.net or send renewals to 854 Jackson Way, Delta BC V4L 1W4 Kindly advise address changes so that we can update our records to ensure our newsletters are mailed to correct locations.

The Executive would like to take this opportunity to thank all those members for their renewals and very kind donations, our cause will one day be addressed by medical

researchers and we can all live in hope for pain free days and nights.

Ask Dr. Kaufmann

Dr. Kaufmann is the medical advisor of TNAC. If you have questions about TN and/or TN interventions send them to "Ask Dr. Kaufmann"

Please send questions to: president@tnac.org or 613.936.6977



Marijuana Eases Nerve Pain Due to HIV

Study Shows Smoking Pot Provides Pain Relief From HIV-Related Neuropathy

By Kelli Miller Stacy WebMD Health News

Editor's Note : I realize that this newsletter is about TN not HIV however I also know that a few TN sufferers are legal cannabis users and thought this article may be of interest to others looking for options to treat neuralgia pain.

Aug. 6, 2008 — Smoking pot may help relieve pain in patients with HIV-related neuropathy, a form of nerve damage that leads to burning and tingling sensations, which can be hard to treat with traditional medications.

"Neuropathy is a chronic and significant problem in HIV patients as there are few existing treatments that offer adequate pain management," researcher Ronald J. Ellis, MD, PhD, associate professor of neurosciences at the University of California, San Diego School of Medicine, says in a news release.

Ellis and colleagues compared medical marijuana to a placebo (fake drug) in 28 patients with HIV-related neuropathic pain that was not adequately controlled by pain medications, including opioids.

The team randomly assigned each participant to smoke either medical marijuana (cannabis) or a cigarette that resembled marijuana but did not contain the drug's active chemical, THC. The National Institute on Drug Abuse supplied both products.

The participants smoked the material four times a day for five straight days, then abstained for two weeks, and then followed the same experiment again. Each person also continued to take prescribed painkillers during the trial.

Smoking the pot provided much greater pain relief than smoking the placebo. Forty-six percent of participants had clinically meaningful pain relief with pot compared to 18% with placebo. Pain relief varied from "strong" to "mild to moderate."

The researchers say that medical marijuana significantly reduces HIV-related neuropathic pain when added to the patient's already-prescribed pain management regimen and may be an "effective option for pain relief" in those whose pain is not controlled with current medications.

The findings, which appear online in the journal *Neuropsychopharmacology*, add to a growing body of evidence that shows that medical marijuana can be a potent painkiller for patients with neuropathy. However, the substance

can have a negative impact on certain mental skills.

Ellis' team also warns that long-term smoking of cannabis can cause lung problems. Alternative delivery methods are approved in Great Britain and Canada and are being considered by the U.S., according to background information in the journal article.

SOURCES: News release, University of California, San Diego. Ellis, R.J. *Neuropsychopharmacology*, Aug. 6, 2008.



Anti-seizure medications: Relief from nerve pain

Anti-seizure drugs often are used to help control the type of pain caused by damaged nerves.

Anti-seizure (anticonvulsant) medications were developed primarily to reduce or control epileptic seizures. But they can also help control the burning, stabbing or shooting pain sometimes caused by nerve damage. These drugs seem to work by slowing or blocking pain signals from damaged nerves.

Why does it hurt?

Nerves can be damaged by many things, including injury, surgery, disease or exposure to toxins. For example, some people with diabetes develop numbness and pain (peripheral neuropathy) in their hands and feet. People who have shingles often continue to have pain (postherpetic neuralgia) after the shingles have cleared up.

This pain occurs because the damaged nerves are firing inappropriately and sending pain signals even though no tissue has been harmed. This type of

pain can be debilitating and is often difficult to control.

How do anti-seizure drugs help?

The exact mechanism of action isn't fully understood, but anti-seizure medications appear to interfere with the overactive transmission of pain signals sent from damaged nerves.

Many anti-seizure drugs work in several different ways to block pain signals from damaged nerves. You may be best served by taking two or more of these drugs simultaneously.

Some anti-seizure drugs work particularly well for certain conditions. For example, carbamazepine (Carbatrol, Tegretol) is widely prescribed for trigeminal neuralgia — a nerve disorder that can feel like jolts of electricity running through your face. A newer form of this drug, called oxcarbazepine (Trileptal), has fewer side effects.

Side effects limit treatment

Anti-seizure drugs have been used to treat nerve pain for more than 50 years, but their use is limited by the severity of side effects they produce.

Older anti-seizure drugs — carbamazepine, phenytoin (Dilantin) and valproic acid (Depakene) — can damage the liver. Other side effects include rash, nausea, vomiting, double vision, loss of coordination, drowsiness and headache.

Because these older drugs generally have more side effects than do the newer anticonvulsants, they often are used only when the newer medications prove ineffective. Despite the fact that they're older, they can be at least as effective as the newer drugs for pain relief.

Newer anti-seizure drugs

Many new anti-seizure drugs have been developed in the past 15 years. Some have proved effective for relieving the pain caused by damaged nerves.

- Gabapentin (Neurontin)
- Lamotrigine (Lamictal)
- Pregabalin (Lyrica)
- Tiagabine (Gabitril)
- Topiramate (Topamax)

Gabapentin has the fewest side effects, so it typically is the first anti-seizure drug tried in people experiencing nerve pain. It's particularly effective in the treatment of postherpetic neuralgia, diabetic neuropathy and migraines.

Research is continuing

As scientists learn more about the way anti-seizure drugs work, this information will be useful in determining which drugs may work best for what types of nerve pain. Pain caused by nerve damage can be disabling, but anti-seizure drugs sometimes provide relief when nothing else works.

Mayo Clinic, Nov. 2006



TNAC Bank Account

Joya Dickson is our new treasurer and membership chairperson. She has been away from winter weather for the past couple of months but is now back to reality! If you recently sent in a membership to TNAC and are wondering why you did not get a receipt ... well it was just because Joya has been away! Thank you for your patience as we complete the change over and get everything caught up!



AGM Update

Did you miss attending the AGM? Not to worry, we will keep you up to date.

The TNAC AGM was held by teleconference in June to allow members from across Canada to participate. Despite this our actual attendance was quite small.

Topics discussed included a review of TNAC finances and a proposed change to the bylaws allowing for a change in our membership year.

Though several members voted by mail or email on the by law change it was determined that the number of members voting was not sufficient to justify the change. In addition to this, as noted earlier, our treasurer is currently away during January and February making bookkeeping of memberships difficult at this time of year. Therefore it was decided to maintain the current membership year of July 1 – June 30th each year. It was also decided that any new or renewing membership received in the last quarter of a year (April / May / June) would count for membership for that year AND the following membership year. This is a fairly standard practice in most organizations.

So ... if you have not yet renewed your membership please do so asap. A membership renewal form is included with this newsletter to assist you.

Please note that our policy is to use the old or previous years membership list for the first newsletter mailing of each new membership year. Therefore, if you have not renewed this will be the last newsletter you receive (unless you renew, of course). Our next newsletter is due to be mailed in November and will be distributed to 2008-2009 TNAC members only.

If you are not sure of your membership status please contact Joya Dickson at 604-943-7913, Joya@telus to see if you have renewed or not.

Thank you for your cooperation and renewal! We love having you all on board!



Contacting TNAC

Want to know how to reach us? We can be reached by using the following email addresses:

For information on membership or general information:
president@tnac.org
613.936.6977
TNAC, 1602 Walton Street
Cornwall, ON, K6H 1W2

For information on support groups:
support@tnac.org

For information on advocacy:
advocacy@tnac.org

To reach our past president
treasurer@tnac.org



VICTORY STORIES

Summitting the Largest Freestanding Mountain in the World

As a 'neuralgian' and long time TN sufferer climbing Mt. Kilimanjaro in Tanzania, Africa has NOT been on my list of things to do! Last January, when the Joints In Motion email crossed my desk I didn't pay a lot of attention to it but for some reason it caught my interest. So ...

On August 6th I found myself at Montreal's Trudeau Int'l Airport bound

for Kilimanjaro International Airport and joining a team of 30 Canadians attempting to summit Mt. Kilimanjaro as a fundraiser for the Arthritis Society. I had no idea how my TN and my AD (Anesthesia Dolorosa) would take the exposure to the elements or the altitude of the mountain but I had done my best to prepare and I was off.

Kilimanjaro is in Tanzania, Africa. In August the temperatures during the day are around 27C dropping to around 10C at night. Humidity is very low. It was the nicest summer weather I had seen all season! On the mountain the weather is quite a bit colder. Nights were often around 0C and day times anywhere from 7 – 17C depending on if we had sun or not. Above the cloud line the sun is quite strong and the risk of sun burn quite high.

The trek up and down the mountain took us a total of 7 days and six nights. Each night was spent in a tent. Yes, we went 7 days without running water, showers, or even 'real' toilets. We did have chemical toilets provided by the trekking company which was step up from what others had but ... it's not the same as home. A warm sleeping bag and good sleeping pad were your best friend each night. The boiled water they gave us for our water bottles (that we put in the foot of our sleeping bags) helped too. Good hiking boots, poles, and gaiters were your friends by day.

Each day we spent hours hiking and climbing. By day 2 we were at 10 000 feet of altitude. That was when I discovered a strange fact – my TN and my AD love altitude. Or maybe they hate it and I love it. I don't know. All I know is from day 2 on I had zero TN pain and zero AD discomfort. Even the numbness from my rhizotomy four years ago disappeared. I discontinued my TN meds (I am on 25mg of topomax a day for residual TN pain left after my MVD) and also discontinued the topical treatments I use for AD (neuragen, emla

and zostrix). My face felt totally normal – completely the same on both sides. The realization that I no longer had one side of my face feeling twisted, crawling, tugging, pulling, etc. actually brought tears to my eyes. I hiked for a while trying not to just sit and blubber away. I had forgotten what it was like to feel 'normal.' At that point I seriously considered moving to a high altitude city! I have heard stories from people who have experienced tremendous pain and discomfort at high altitudes. For me it was a total pleasure!

As for Kili itself ... each day was a stretch in terms of physical and mental ability. Day one was a 20K hike, mainly up steps cut into the path. Day 2 was 7 hours of a steep uphill rocky path. Day 3 was 9 hours – steeply up to 12 000 feet then steeply down again as part of acclimatizing to high altitudes. Day four was only 6 hours long but included 'the wall.' This is a 3 hour scramble up a steep rock wall that often included reaching for foot and hand holds. It was tough going but exciting and a great feeling of accomplishment to reach the top. Day five was our short day – 3 hours up a steep incline to base camp. At this point we rested. Trust me, we needed it.

Each morning you awoke to listen to your body complain of aches and pains, sometimes in places you never knew existed. Each day you got up and carried on anyway. Each day you battled the altitude and wondered if this was the day you would get a headache or experience the nausea that altitude can cause. Each night that you went to bed without being sick was a victory! All of us were an open book. If we felt sick, hurt, headache, tired – didn't matter what – we shared how we felt. This allowed us to encourage and support each other. Nothing was hidden on this trip. The open communication and the open support was one of the most incredible things I have ever experienced. Seven days without the

comforts of home and not one argument, frustration, irritation in the group. Not one! Just total cooperation and support between each of us. The openness also allowed me to share about life with TN and AD and the impact of not experiencing any symptoms at all! It was great to share, be heard, and understood.

Life should always be like that. We simply accepted each other as we were and where we were and encouraged each other to succeed each step of the way.

The summit attempt on Kili is done at night. We left base camp at 11PM on day five and climbed in the dark by headlamp for almost 8 hours. At times you were almost asleep on your feet. The temperature dropped to -20C with a very high wind. The cold was so intense you were sure you'd never be warm again. But then, when you were convinced you could go no further, you reached Stella Point. Stella Point is the top of the mountain but not the highest peak. At Stella you have another hour to go but the excitement of reaching Stella, along with the thrill of seeing the sun starting to peak over the crest of the mountain, was all we needed. At 6:48AM on Friday August 15 we made it to Uruhu Peak – the roof of Africa! I will never forget the feeling of succeeding in making it to the summit. Each of us in our team was making this trek in honour of someone who couldn't do it. Each of us had a reason beyond ourselves for being there. As we looked at the sign on the peak, the sunrise around us, and at each other we could do nothing more than embrace and let the tears run down our faces. There are no words to describe the feeling.

At the summit the oxygen level is only 50% of what it normally is. Therefore you don't stay at the top long and you come down fast. What took 8 hours to ascend took us only 3 to descend. After a one hour nap we descended another

4 hours to our final camp of the trip. The final camp is very crowded and very noisy but after 16 hours of hiking we were all in our tents by 8PM and slept soundly all night.

The final day, day seven, is a short 4 hour hike out of the rain forest. We found out that 2 people had died while we were on the mountain. It was a reminder of the fact that not everyone succeeds. A reminder of the importance of teamwork. A reminder of the importance of listening to your guide and doing what you are told to do. We also found out that monkeys throw things at you when they want you out of their space. We would be innocently hiking down the path and boom --- a hunk of tree or brush would slam down in front of us. Up in the branches would be a monkey glaring down at us. The guides told us they were protecting their babies.

At Mwembe gate we signed the book saying we had made it to the peak and back out safely. It was humbling to meet person after person who had not succeeded in making the summit. Talking to those who did not achieve their dream made our success more precious and also made our hearts ache as we knew and understood how hard people had tried, how much they had given, and how difficult it would be to get so far and not make it all the way.

Life on Kili is about taking a chance. It is about putting your trust in your guide and moving ahead even when you realize that you are not really totally prepared. It is about trusting your guide to get you through the moments when your lack of preparation leaves you not knowing what to do.

Kili is also about learning to look only far enough ahead to place your feet and keep on advancing forward. It is about not looking too far ahead and not looking too narrow either.

You can look up at your goal as you walk but if you do you'll miss the rocks and roots in your path and trip and fall. Looking at the path ahead can also be overwhelming – at times it will seem like you will never get to where you are going. The path looks so long, so hard, so far it is totally discouraging and will make you give up. Looking up while you walk also changes your perception and balance. The ground below you looks level but when you look up you realize it isn't quite level at all. Next thing you know, over you go or your stagger like a drunk. Looking too far ahead simply doesn't work.

You can also look down right at your feet and place your feet right where they need to be. You'll be safe that way – your feet will find a sure path. But at some point you will find you've come to a point you can't get across and you'll have to go back and re direct. Looking straight down – looking too narrow - prevents you from planning ahead.

Kili is about learning to look always just far enough ahead in life to mark your path for the next little while. It is about taking time to stop and look at your goal – to treasure it in your heart at each stop and to check your progress towards it regularly. It is about taking the time to look back and reflect on how far you've come and the progress you've made. Looking back on the path behind you inspiring encouragement to keep to the path ahead.

Trekking up Kilimanjaro is a lot like life with TN. You have to take a chance to move ahead regardless of how prepared you feel. You have to learn to keep your goal in your heart and move towards it by looking ahead just far enough to make progress but not so much that you lose perspective.

On any given day, life with TN is a challenge. The path ahead may look

long and hard, even insurmountable. If you look at all you have to do it can be discouraging, tiring, too much, throw you off balance, and make you want to stop. If you focus right on where you are – focus on the TN – then you can find yourself in a place where you can't go any farther and have to backtrack. But if you learn to treasure your goal and dreams in your heart and to focus just far enough ahead to keep on moving forward you will reach your goal. No matter how hard it may seem, when you get there, just like trekking Kili, if you look just far enough ahead to keep on going, it really isn't so bad at all. And when you stop and look back you realize just how far you've come.

After all ...

I may HAVE trigeminal neuralgia but it does not have me! TN is NOT who I am. It is only something I live with.



TNA Presidents Pin

This September, at the TNA conference in Detroit, MI, Marion Guzik, founder of TNAC, will be presented with the TNA President's Pin. As a gesture to bond international groups this pin is presented in order of foundation dates. It is a TNA Diamond Pin that is to be worn by each President in turn for a 2 year period. The UK was the first in line for this honour.

Dr. A. Kaufmann will receive the pin on behalf of TNAC and will present it to Marion at a meeting of the Lethbridge TNAC Support group. Congratulations to Marion for being honoured as the founding president of TNAC and her years of hard work and commitment to serving people coping with TN on a daily basis.

Look for more information and photos in upcoming newsletters and on our website!