Support Group

Eastern Ontario Support Group

Happy FIFTH ANNIVERSARY to the Eastern Ontario Support group. From just three people at our first meeting we now number 20 people strong and we are strong. We are all in various places in our battles with TN but in sharing our journeys we find hope and the strength to carry on.

Our group consists of people from Kingston through to Cornwall and north to the hills of Gatineau! We are a group of people who enjoy coming together to encourage and support each other along the journey of TN. We swap stories, laugh, and even cry at times. Share news on where we are at in our TN journeys and what paths we have travelled. Most of all we are always open and looking to welcome new members to our group.

For more information and the time place of our next meeting please contact Jane at cmusicstudio@cogeco.ca or by calling 613.936.6977

Vancouver and Lower Mainland Support Group Update

Coordinator: Ann Hopkins

Vancouver & Lower Mainland Group Meeting Time: 1.00 – 3.30 pm
G.F. Strong Rehab Centre.
Social Sciences Seminar Room 189, Main Floor,
4255 Laurel St.
(Laurel at W. 26th, one block east of Oak)

Friends, family members and supporters are very welcome.

It’s a longish walk to the meeting room so if you need a wheelchair give me a call and I’ll organize one. Or if you want to have a chat or have questions please make sure you call or email me.

To get in touch: contact Ann Hopkins, email: annhopkins@dccnet.com, phone: 1 604 741 0662
4945 Laurel Ave, Sechelt, BC VON 3A2

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, 500 - 11th Street, S., Lethbridge, AB.

Coordinator: Marion Guzik, past president / founder TNAC email mguzik@telus.net Phone: 403-327-7668

PLEASE READ THE FOLLOWING IMPORTANT MESSAGE FROM OUR TREASURER!
TREASURER’S REPORT

Spring is on its way & time to think about colourful garden bulbs and blossoms to greet us every day with a happy smile. From Beautiful BC to our members across this wonderful country I send a big smile and hope everyone is free of TN pain.

Your committee - Jane, Ann & Joya needs input from members who are talented and comfortable using a computer, yes I know you are all talented however computers can be daunting for some of us who belong to a generation who were not educated with these modern communications tools.

Firstly to those members who have access to e-mail we need to know if you prefer receiving Newsletters and membership renewals via e-mail, if so please send me an e-mail JOYA@TELUS.NET accepting your approval so that we can changes to our communication process. Please be assured we will continue to mail Newsletters & Membership Renewals to members who prefer mail communication.

Secondly please advise in the same e-mail message if PayPal would be more convenient for forwarding membership renewals and your kind donations. The more members who sign up for Pay Pal and these proposed changes will help TNAC reduce overhead costs. These savings will allow TNAC to continue to support TN research.

Our membership fiscal runs July 1st to June 30.

Thanks everyone for your consideration regarding these changes, just send a quick e-mail-joya@telus.net

My best to everyone for a wonderful sunny spring, Joya Dickson

Trigeminal Neuralgia And Multiple Sclerosis

What is multiple sclerosis?

Multiple sclerosis is a disease of the brain, spinal cord and optic (vision) nerves. There are multiple areas of involvement that usually occur at different periods of time. The fatty material (myelin) that surrounds nerves is often damaged (causing a scar or plaque) and nerve impulses are impaired. The body’s own defenses attack the myelin (autoimmune disease). Many kinds of symptom are present including abnormal sensations, muscle weakness, impaired coordination and balance, visual impairment and trigeminal neuralgia. Women are affected more than men and the disease usually starts in young adults. back to top

How often do patients with trigeminal neuralgia have multiple sclerosis?

Approximately 5 percent of patients with trigeminal neuralgia have multiple sclerosis and about 2 percent of patients with multiple sclerosis will develop trigeminal neuralgia. Most patients with multiple sclerosis and trigeminal neuralgia (about 85 percent) will first develop other symptoms of multiple sclerosis before the trigeminal neuralgia and the diagnosis of multiple sclerosis is usually established before they develop trigeminal neuralgia.

How does trigeminal neuralgia differ between those with or without multiple sclerosis?

Patients with multiple sclerosis are much more likely (about 20 times) to develop trigeminal neuralgia than patients without multiple sclerosis. Patients with trigeminal neuralgia and multiple sclerosis are more likely to be younger than those without multiple sclerosis. Patients with trigeminal neuralgia and multiple sclerosis are more likely to develop it on both sides of the face (approximately 20 percent of patients) than those without multiple sclerosis (approximately 5 percent of patients), but it is rare for anyone to have it on both sides of the face at
Although compression of the trigeminal nerve is a common cause of trigeminal neuralgia in those without multiple sclerosis, it is unlikely to be the cause in those who have multiple sclerosis where the cause is a demyelinating scar or plaque.

How can the Magnetic Resonance Imaging (MRI) be helpful in patients with trigeminal neuralgia and multiple sclerosis?

If a high resolution MRI is done with appropriate sequences in patients with multiple sclerosis, lesions are usually seen somewhere in the brain and are often seen in the area that carries messages from the trigeminal system, especially in those with trigeminal neuralgia and multiple sclerosis. Special MRI sequences such as T2 FLAIR (fluid attenuated inversion recovery) are particularly effective in showing multiple sclerosis lesions. It is a good idea to do these imaging sequences in patients with trigeminal neuralgia whether or not they have been diagnosed with multiple sclerosis.

What is the medical treatment for patients with trigeminal neuralgia and multiple sclerosis?

Patients with trigeminal neuralgia and multiple sclerosis respond very well to the medicines that are used to treat trigeminal neuralgia. Carbamazepine and oxcarbazepine are the two most effective medicines. However, patients with multiple sclerosis are more likely to develop unpleasant side effects such as worsening of their multiple sclerosis symptoms with added weakness and fatigue from these and other medicines used to treat trigeminal neuralgia.

What is the neurosurgical treatment for patients with trigeminal neuralgia and multiple sclerosis?

Since trigeminal neuralgia in patients with multiple sclerosis is caused by a demyelinating plaque and not vascular compression, the surgical treatments recommended are those which cause direct nerve alteration and partial damage. These can be accomplished by minimally invasive, out-patient procedures such as needle rhizotomy (especially Radiofrequency Electrocoagulation and/or glycerol) or Gamma Knife radiosurgery.

What are the results of treatment of patients with trigeminal neuralgia?

Almost all patients with trigeminal neuralgia including those with multiple sclerosis can get relief from face pain. The minimally invasive procedures (Gamma Knife radiosurgery and needle rhizotomy) are very effective and are especially attractive for patients with multiple sclerosis as these procedures are well tolerated. Further benefit can occur from improvement in other multiple sclerosis symptoms, which often results from the lowering or eliminating the medicines needed to control trigeminal neuralgia. However, it is not unusual for there to be a need for more than one procedure during the patient’s lifetime as trigeminal neuralgia sometimes returns. Multiple sclerosis patients are more prone to recurrence because they may occasionally develop face pain on the other side and often poorly tolerate medicines used to treat trigeminal neuralgia.

Cyberknife Radiosurgery

February 8, 2012 — Cyberknife radiosurgery to relieve trigeminal neuralgia refractory to medical management is a promising, viable alternative to more invasive treatment for this painful condition, researchers conclude from a small study.

“The patients that we’re dealing with have failed so many other treatments and are miserable because they’ve had this chronic pain limiting their lifestyle and adversely impacting their lives,” coauthor Orlando Ortiz, MD, from Winthrop-University Hospital, Mineola, New York, told Medscape Medical News.

“This is a tremendous advance and another viable option for trying to help them.”

Their findings were published online January 25 in the Journal of NeuroInterventional Surgery.

Lesioning the Nerve

Many interventions for trigeminal neuralgia unresponsive to medical treatment with anticonvulsants and antidepressants are predicated on some form of lesioning of the trigeminal nerve, Dr. Ortiz said. “The thinking is if you lesion the nerve, you break the circuit of referral so the patient does not feel the pain.”
Such lesioning has been done with surgical techniques, such as percutaneous balloon compression, glycerol rhizotomy, or thermal radiofrequency rhizotomy, targeting the nerve at the level of the foramen ovale. Open microvascular decompression has been the gold standard, he noted.

More recently, stereotactic isocentric gamma knife and linear accelerator radiosurgery has demonstrated improved success rates, but it has also come with “notable” side effects, including numbness, varying degrees of dysesthesias, trismus, anesthesia dolorosa, masticator weakness, and diplopia, Dr. Ortiz explained.

“The Cyberknife system delivers a nonisocentric beam of radiation that is better suited for targeting the trigeminal nerve with greater fidelity. The technique is also more comfortable for the patient,” Dr. Ortiz said.

“The Cyberknife gives very high-dose radiation to a very small, tiny target. It’s very precise and it creates a surgical strike on that portion of the trigeminal nerve which achieves a symptomatic response,” he said.

“The lesion must be accurately targeted, and doing so presents a bit of a learning curve to those practicing the procedure,” he added. “We’re only targeting a small 6-mm segment of the nerve 3 mm away from the brain stem, so we have to be exact. This is why we do both a computed tomography (CT) scan and a magnetic resonance imaging study, and we fuse the 2 tests in order to optimize our targeting.”

The CT scan is performed with contrast material injected into the cerebrospinal fluid via a single atraumatic lumbar puncture.

In the current study, which was led by Dr. Ortiz’ colleague, Bryan M. Lazzara, MD, also from Winthrop-University Hospital, 16 patients with trigeminal neuralgia (11 women, 6 men; mean age, 69 years; range, 36 - 90 years) underwent Cyberknife stereotactic radiosurgery between May 2007 and July 2009.

Of these patients, all but 1 had tried medical therapy first, and 4 had undergone surgery but without success.

After an average of 12 months following the Cyberknife treatment, 88% (14/16 patients) showed partial or complete relief of their pain, Dr. Ortiz said.

“The average time to achieve maximum response was 1.9 months, and this ranged from the first follow-up visit at 3 weeks to as late as 6 months after radiosurgery,” he said.

Side effects were reported in 2 patients. One was pain free after treatment but developed “a bothersome feathery dysesthesia in the V2 and V3 distribution” after 13 months, the researchers report. The other patient reported a mild jaw hypoesthesia 2 months after treatment, but this was not bothersome.

The investigators are continuing to perform this procedure and accumulate data in more patients.

“This doesn’t even require a craniotomy, so it is something to seriously consider as a possible option. I think physicians should be aware that there is another treatment alternative out there,” Dr. Ortiz said.

“It’s very reasonable to try medical regimens first, and go up the ladder of invasiveness. Most folks can get some relief with those interventions and that’s great,” he added. “But if you need to start thinking about something invasive, you’ve got to put this on the options list as something to think about.”

**Severe Methodological Flaws**

Commenting on this study for Medscape Medical News, Gary Gronseth, MD, professor of neurology at the University of Kansas, Kansas City, agreed that the technique looks promising, but pointed out that it does not represent a breakthrough for the treatment of trigeminal neuralgia.

“The magnitude of benefit is similar to that observed by other techniques that target the proximal portion of the trigeminal nerve, such as balloon compression,” he said.

“Second, as with most studies of procedural interventions for trigeminal neuralgia, this study has severe methodological flaws including the absence of a control group and the absence of any structured outcome assessment,” Dr. Gronseth said.

Unfortunately, the knowledge of what works best for the treatment of trigeminal neuralgia will not improve much, he said, “until well-designed comparative effectiveness studies are performed.”

Colin P. Derdeyne, MD, professor of radiology, neurology, and neurological surgery at Washington University School of Medicine, St. Louis, commented to Medscape Medical News that the Cyberknife
Electrode attached to the layer of the brain associated with movement of the face, neck, arms and legs.

In the first surgery, an electrode is surgically placed on the tough protective layer covering the motor cortex area of the brain and then hooked up to a programmable device. Once the patient is awake after surgery, electronic pulses from the device are adjusted to stimulate the brain in such a way as to reduce pain. Once the pain is consistently reduced by at least 50%, a second surgery is done to more permanently connect the electrode and to insert the programmable device under the skin, often near the collarbone. A connecting wire from the device goes up the back of the neck and under the scalp to the electrode.

Pros and Cons Motor Cortex Stimulation is not a perfect solution for chronic pain. As with most treatments, some patients get no pain relief. As yet, there are no studies that show this procedure provides long-term pain relief. In addition, the stimulation device has only been approved by the FDA to treat movement disorders and spinal pain conditions.

However, this procedure has provided amazing pain relief to some people in terrible pain for whom no other treatment has worked.

Tiffany Smith … A Lawyer’s Story

By Pamela Unverzart

If track shoes were made personalized for those that plan to change the world at breakneck speed, 26-year-old Tiffany Smith’s name would be emblazoned in bright fluorescent colors across the finest pair made. Born with a passionate disposition concerning the racial and socioeconomic disparities in the world, Tiffany remembers being interested as early as elementary school in using the law as a means to help bring balance back to these injustices. Having skipped the fourth grade, Tiffany often found herself debating with older students. Her unique ability to win those debates blossomed in middle school, further cementing Tiffany’s desire to do her part in changing the world by becoming a top-notch litigator.

This extremely intelligent young woman dreamed of pursuing a career in dispute resolution and graduated from high school at the tender age of 16, a year of college credits already tucked securely under her belt. After receiving her undergraduate degree cum laude at 19 from American University, Tiffany took a two-year hiatus from her studies to work full time for a prestigious law firm in Washington D.C. before heading to The Ohio State University to earn her Juris Doctorate degree. Then with the first year of law school successfully behind her and the smell of victory wafting in the air around her, Tiffany’s thoroughly mapped out course for success was suddenly road blocked with a sudden on-set of severe facial pain. As is the case with most facial pain sufferers, Tiffany recalls the date and time the first pain struck, and that date – May...
17th, 2007, while she was getting ready to attend a surprise birthday party for her then-boyfriend – changed her life forever. The pain lanced through her head like lightning, and each time it happened it was so intense she thought she was going to die.

Frequent visits to the emergency room for pain relief dotted her summer calendar, yet no one could find anything wrong with her. Added to her already full research curriculum at her summer job was the new challenge of researching symptoms and specialists in an attempt to find a reason for her increasing pain. Desperate to find the cause – and treatment – for her pain, Tiffany tracked down doctors in many specialties. Surprisingly, a well-trained allergist who “was the first doctor to think to look up my nose,” recognized what appeared to be large polyps and immediately sent Tiffany to an Ear, Nose and Throat specialist who confirmed the existence of sinus polyps. Bilateral sinus surgery excised the benign polyps, but they quickly returned, and follow-up surgery was done within six months.

The pain in Tiffany’s sinus cavity was eradicated with the second surgery, but left behind was debilitating right-sided facial pain that defied any treatment. Never a quitter, Tiffany pulled back on her running shoes and relied on her stores of drive to continue through the grueling law courses while she searched for answers. Because of the rivalry typical of students reaching for elite careers, showing weakness in law school was not an option, so Tiffany kept to herself, letting only the Dean of Student Affairs, a handful of professors, and very few friends know about the pain she was suffering. Although the university worked to accommodate her schedule, her grades suffered. As she recalls, “I felt like I spent more time in the hospital than in class... and my doctors would always joke that they had never seen a patient hooked up to IV pain medication studying 1100 page thick law books sprawled open across the hospital bed.” Worse even than the decline of her grade point average was the loss of her social sphere as understanding friends eventually fell by the way side. Tiffany explains, “The first time someone finds out you’re in the hospital they send flowers. By the third time all they can do is tell you they’re sorry. By the fifth or sixth time they only respond with, ‘Oh, no, not again.’ It’s the nature of humans to pull away from what they can’t understand,” she adds with more than a hint of sadness in her voice.

Doctor after doctor returned with no clear cut answer. Though her doctors tried numerous combinations of anticonvulsants, antidepressants, muscle relaxers and pain-relieving opiates - nothing worked. Being eventually diagnosed with atypical facial pain came as no great surprise to Tiffany who, by that time, had researched everything she could concerning her symptoms and possible causes. Getting few answers and limited assistance from the myriad of doctors she’d dealt with, Tiffany turned to the Mayo Clinic for help. So the day after taking her Bar Exam to cement her career as a full-fledged attorney, Tiffany flew to the Mayo Clinic to begin another grueling exam, this time one consisting of medical tests, numerous doctors’ consultations, and committee meetings.

Consensus from the Mayo doctors confirmed the diagnosis of atypical trigeminal neuralgia (now referred to as TN type 2a), and because of the atypical nature of her face pain – a constant, deep, boring pain in the upper two pathways of her trigeminal nerve interrupted with intermittent zaps of sharp, lance-like electric shocks – the doctors were doubtful the usual course of therapies such as Gamma Knife, rhizotomy, balloon decompression, or microvascular decompression surgery would work. Greater still was the concern these procedures could exacerbate her condition. After a battery of studies and discussions, motor cortex stimulation (MCS) was chosen as the best option for controlling her pain, but because of the experimental nature of its use for trigeminal neuralgia patients, Tiffany first underwent Mayo’s four-week pain rehabilitation clinic to ensure she had pursued every natural course of pain control possible.

Preceding surgery, Tiffany returned to D.C. to begin her career in the field of international white collar crime with the prestigious law firm she had worked with prior to law school. Facing challenges head on and winning was not strange territory for this new attorney, but overcoming the challenge she was facing with her health was taking its toll. After undergoing the four-week pain rehabilitation clinic, her pain management anesthesiologist in Washington D.C. suggested a sphenopalatine ganglion block, a procedure that uses topical anesthetic applied by means of a long, thin needle with a hollow handle saturated in a solution of 4% Lidocaine and other anesthetizing medications. The needle is inserted through the jaw and maneuvered up
until it meets the appropriate nerve bundle, where the local anesthetic is topically applied and left in place for approximately 45-60 minutes, which results in the desired nerve block. Two procedures later Tiffany was left with little pain relief, and worse, unexplained pain that had temporarily taken up residence on the left side of her face as well. Although Tiffany was sure the new condition of left-sided face pain was only temporary, its existence put a halt on the Mayo Clinic’s agreement to perform the motor cortex stimulation.

Desperate for relief, Tiffany sought a second opinion from a renowned Cleveland Clinic neurosurgeon who had recently moved to The Ohio State University Medical Center. Although he agreed that MCS was her best – if not only – option, he suggested they first try peripheral nerve stimulation (PNS), as it carried significantly lower risks. Tiffany underwent this procedure in May of 2010.

PNS is a neuromodulation technique in which electrical current is applied to the peripheral nerves in an effort to ameliorate chronic pain. A trial period with temporary electrodes generally lasts about a week. If sufficient pain relief occurs, then a permanent system is implanted. For superficial peripheral nerves such as the trigeminal, individual leads are placed just under the skin, overlying the nerve. In Tiffany’s case, pain relief was again minimal, so the Ohio State surgical committee approved her neurosurgeon’s request to perform MCS surgery. Ohio State struggled to get Tiffany’s insurance to cover this costly (and as yet, “experimental”) surgery, so Tiffany, with her typical drive and initiative, attended TNA’s 20th Anniversary conference in an attempt to find answers from other patients who had endured insurance battles over coverage for MCS. There, she found a renowned neurosurgeon from Michigan who could perform the surgery for substantially less money and who had better success rates.

Due to the increasing and debilitating nature of Tiffany’s pain, she decided to take leave from work in mid-July 2010. In September of 2010, Tiffany flew to Michigan to undergo the grueling MCS process. The procedure, usually only employed when all other pharmaceutical and surgical treatments have failed, involves brain surgery with all its risks, including infection and surgical complications. During the MCS operation, electrodes were attached to the cover of Tiffany’s brain, and after a four-day trial period, the electrodes were attached to wires run under her scalp, down her neck, to a programmable neurostimulator device that doctors implanted in her chest. The goal of MCS is to interfere with the chronic pain signals by sending electrical pulses to the brain. Tiffany had now suffered such severe facial pain for over three years that she considered the surgical risks that lay before her incidental to the possibility of pain relief. Even so, recovering from MCS surgery was the worst experience in Tiffany’s life. Only one thing made it worth it: the surgical procedure was wildly successful in reducing her pain. Describing the outcome as a “miracle,” Tiffany’s pain that on a good day seldom fell below a five and bad days tipped the scale at several notches above 10 had been reduced by 80 to 90%.

Tiffany’s journey through torturous facial pain appeared to be at an end, but her joy was short-lived and bittersweet. Just when she thought she was “finally going to get her life back,” disaster struck. Although extensive pain relief was achieved through the procedure, physical healing was unfortunately nonexistent, and within weeks Tiffany flew back to Michigan weakened and sick, puss oozing from the surgical site. Although rare, there is a risk of the body rejecting the foreign material implanted in the brain, and Tiffany’s neurosurgeon believed that was the case in her situation, so she was put on medication and sent back to D.C. to recover. But recovery did not happen. Growing weaker each day, Tiffany sought a second opinion from an infectious disease doctor in Maryland. One look at the now raging infected wound spurred the doctor to have Tiffany immediately hospitalized. Three days of mega doses of antibiotics failed to control the infection that had now overtaken Tiffany’s immune system. Despite her pleas and much to Tiffany’s dismay, doctors insisted that her life-line to pain relief had to be removed or the infection would kill her. With no other options, Tiffany cried as she consented to have the neurostimulator removed. Within 24 hours after removing the MCS device, Tiffany’s excruciating facial pain had returned. Tiffany’s immune system took a major blow from the infection that had raged through her body, and she suffered a secondary infection as a result of the battery of antibiotics used to treat her. The pathway back to physical health was long and slow, but it was the emotional wound suffered from the return of her facial pain that left this
born optimist feeling lost and defeated. Short term disability from the law firm where she had just started her career allowed Tiffany the time to stay at home to heal physically, but it was with the help of a caring therapist, loving family, a few steadfast friends and Tiffany’s own resilient nature that eventually allowed her to see a future beyond her sick bed.

Like the tattoo she had engraved on her wrist in ancient script, “perseverance” is the word Tiffany uses to describe making her way through the last four years. Selflessness would also best describe this young woman. Downplaying her own suffering, she decided to turn her talents toward helping start a young person’s initiative within TNA – The Facial Pain Association in order to bring support to the younger generation suffering this devastating disease. TN is most likely to occur in people over 50 and no matter the age of the person, dealing with its painful symptoms can be devastating. However, younger sufferers bring to the table their own unique set of issues. Building relationships (and families), establishing careers, finding insurance, the lack of financial resources, and simply finding the wherewithal to keep living while dealing with the possibility of a long lifetime of unrelenting pain are monumental tasks for the young to overcome. Tiffany will be chairing the committee, working to strategize with others in an effort to discover different ways of helping those who find themselves in similar circumstances. You can hear the excitement take over this young woman’s voice as she discusses the possibilities.

Resiliency and perseverance are understated when used to characterize Tiffany. Despite the return of her pain, she is ecstatic to return to practicing law and find a way to have a successful career. Determined to beat the odds in dealing with her disease, she is already researching the next possibility of pain relief by studying transcranial magnetic stimulation. When asked what got her through the past few years, hope is the word Tiffany finds first, but she is quick to add that “hope is a luxury and something that you’re not always able to rely on. It is easily crushed. So when hope lets me down, faith pulls me through.” And in times of most need, she turns to her favorite scripture, Romans Chapter 5 verses 3 and 4, “And not only so, but we rejoice in our suffering; for suffering produces perseverance; perseverance, character; and character, hope.” These inspirational words encompass the very soul of this hard working, driven, young woman. Tiffany’s hope and excitement for the future have been heightened with the news that the Facial Pain Research Foundation has initiated research in an effort to find an actual cure for those suffering with neuropathic facial pain, not just a band aid for its symptoms -and a timeline of no more than 10 years to find that cure promised by the Foundations’ founding fathers. This hope keeps her moving toward a brighter future, advocating for others in similar circumstances will help her find peace through her own tribulations, and love and faith will overcome all. Tiffany will succeed, her running shoes once again readied for the race, and in her success, others will follow to find their own hope.

Contacting TNAC

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

Do you have an article for the newsletter? Do you have a topic you’d like covered? Do you have a drug you’d like profiled? Please let us know. Deadlines for newsletter submissions are:
May 30th
August 30th
Nov. 30th
Feb. 28th

Special Thanks to Ann Hopkins for her submission of articles for this newsletter!