The CTMA has been hard at work over the past few months. I want to begin by reminding all of our readers to continue to check in on our website (www.mytm.ca). We have updated the look of our site to try and make it easier to read, to navigate and have more information available now in both English and French.

In February, we had a free seminar in Montreal on “Healthy living strategies for people living with rare neuro-immunological diseases”, with Dr. Valerie Namer and Celine Chabee, Coach ACC. We had great positive feedback from the attendees and look forward to future opportunities to offering free education to all effected by Transverse Myelitis. We have bridged relationships in the community to assist us in finding resources for those with rare neuro-immunological diseases and are working hard to continue to grow that base and offer regional resources available online this year for you!

We are actively still working on our application for an official awareness day for Transverse Myelitis in Canada. As we continue to develop more activities, resources and general awareness, I have to say I feel honored to be a part of it.

One of the upcoming events to keep your eyes and ears open for is our Red Dress Run Weekend in September! This was an extreme hit last year. Everyone had such an amazing time and it was done in support of our association! We are definitely looking forward to another year and hope that we can continue to annually celebrate this weekend with...
great people and fun times. The CTMA is proud to announce that we will be involved at the Montreal Rock n' Roll Marathon this year by hosting a water station... and finally the CTMA is looking to film a documentary about life with TM to submit to the Neuro Film Festival in the coming months!

I want to finish off with a quote that I read today that struck a chord with me. “The reason we struggle with insecurity is because we compare our behind-the-scenes to everyone else’s highlight reel”. With that, remember that everyone struggles even if it isn’t apparent. So be fair to yourself. Do not look at others in envy, or sadness for we all have moments of darkness, but the most beautiful people are the ones who’ve struggled, who have known loss, who have been tested but find their way out of their dark place and can see the light they shine on those who love them and learn to shine it on themselves.

Tracey Flynn
Vice-President
Canadian Transverse Myelitis Association

Brighten the lives of those affected by Transverse Myelitis by wearing the Canadian Transverse Myelitis Association’s Glow-in-the-dark silicone rubber wristband.

Bring awareness and support to those who live with Transverse Myelitis by purchasing and wearing these bands and help us in shining the light!

($ 3.00 each or $ 5.00 for two)
To order your silicone bands contact:
info@mytm.ca

Sports & Activities — Adaptive Sailing

Who doesn’t want to feel free and independent... especially on a nice cool body of water in the summer months?

The original Sunbird sailboat used for adaptive purposes in Canada was presented to Rick Hansen in 1986. Given to him by minister Margaret Thatcher, in it's first year it logged 22 sails. It gave those individuals who struggled with mobility the ability to leave their wheelchairs behind and take up a sport independently. Sailors range from recreational novice to expert competition and is one of the fastest growing adaptive sports!

Adaptive sailing promotes freedom and independence. Even those with no movement below the neck are able to sail by themselves (with the use of the sip n’ puff technology.)

(Now available in many provinces throughout Canada.)

(img src: www.disabledsailingbc.org)
‘Though She Be But Little, She Is Fierce.

My Daughter’s Journey with Transverse Myelitis

“Mommy, what is wrong with me?” Those are words that no parent wants to hear from their child and yet there I was, being asked that very question by my then three year old daughter. I stood in the school playground, blinking back tears, daring not to breathe lest a long pent up sob escaped my lips. All around me kids were running wildly, toddlers shrieking in delight, babies enjoying the warmth of the sun on their faces but my world just went into a blur. My sweet little girl had just been accosted with the usual barrage of questions “Why do you walk so funny? What are those weird things on your legs?” And the dreaded, but seemingly inevitable, “What is wrong with you?” I am now used to being asked those questions on a daily basis and although she has been in my presence while adults, yes adults, have asked “What is wrong with her,” this was the first time that she seemed to really grasp what was being said. I always welcome the chance to explain her situation and while I did so to the children who had posed the questions, my daughter put her head down and walked slowly away, shoulders slumped in defeat until she could go no further and she fell to the ground where she simply stayed. By the time I reached her side, the tears were pouring silently down her cheeks and she looked up at me and asked that question that continues to haunt me to this day. “Mommy, what is wrong with me?”

My beautiful Seattle Shayne-Marie Lennox was born into this world on May 8, 2008, a chubby-cheeked glorious ball of bliss. She started smiling at one week of age and has never stopped. People couldn’t help but smile when they saw her; there was just something so inviting, so warm, so intriguing about her. She hit all her baby milestones on time and was never sick, except for a slight cold that she developed at the beginning of Aug 2009, when she was just over 15 months of age. Nothing major, we thought, just a simple cold. She was still well enough to join in the festivities of her brother’s birthday party, showing off her new acquired words of ‘mommy, daddy and up’. It was such a glorious day, that Aug 4th. We enjoyed not only an early birthday celebration for my son, but a ‘welcome home’ celebration for my nephew whom my sister and her husband had just brought home from Ethiopia after a lengthy and ache-filled battle. Life was grand! Laughing at Seattle running in that awkwardly adorable way of a toddler, I remember taking a mental snapshot of the kids chasing bubbles and kicking a ball to their father Shane, knowing that it would serve me well in the days to come, as I was heading into the hospital the next morning for another spinal fusion (I have spondylosis and was getting my first surgery redone as well as a spinal reinforcement through my abdomen.) I will forever be grateful that I took the time to mentally store that image. For two days after I was released from the hospital, Seattle was admitted. Her minor cold had stayed with her for the week I was hospitalized and she seemed a bit lethargic but was still happy and moving around. Until she was laid in her crib one night and was found in the exact same position the next morning. That is when we took her to the nearest hospital, where she was noted to have weakness of her extremities and additional bilateral weakness of her face. With a possible diagnosis of Guillan-Barre Syndrome, she was rushed by ambulance to BC Children’s Hospital in Vancouver. They admitted her directly to the intensive care unit and within a few hours she stopped moving altogether, completely paralyzed from the neck down, unable to breathe on her own.

Nothing could have prepared me for seeing my baby, so tiny, so precious, so perfect, lying in that big bed, tubes running all over her, hooked up to so many machines keeping her alive. Nothing could have prepared me for watching her be intubated, continued on page 4...
continued from page 3

an image that my mind tried to shield me from; to this day I just remember blackness at that point, with brief flashes of doctors surrounding her and shouting out orders that I did not understand. Nothing could have prepared me for having to ask a group of doctors if my baby was going to survive. Nothing could have prepared me for the answer of ‘we just have to wait and see’; a standard response that we would hear constantly in the weeks to come. After days of diagnostic investigation, including a cerebrospinal fluid analysis examination, an MRI of her brain and spinal chord and a nerve conduction test, she was diagnosed with Transverse Myelitis, with damage done from her the upper C level down to T 6/7. Transverse Myelitis is a neurological disorder caused by inflammation of the spinal cord, with the exact cause uncertain. I was actually prepared for that answer, as I had witnessed the exact same scene in 1995 when my best friend became ill with TM, just a few weeks before high school graduation. I knew what we were in for. And I could handle the paralysis. What I prayed for now was for her mind to stay the same; that the little feistiness, she still wanted to use her pre- jedem. her right hand to control her left and try to get it to do things. That’s my girl! Twenty-three days after admittance, on September 4thh, her breathing tube was removed and she was put on BiPAP support, which is a portable ventilator that was fitted to her face with a mask and she would periodically have it taken off for a few minutes at a time to see if she could breathe on her own. It was at this point that her cheery personality returned and everyone would remark how they had never seen anyone smile with a BiPAP mask on; nurses and therapists not even assigned to her would stop by her bed for what they called ‘a Seattle smile.’

Her strength also started to return and she was soon able to lift her left arm and move her right leg. She was moved out of her private room and into the open ward of the ICU for about two weeks before she was finally settled into the transitional area, where I was no longer allowed to stay so I moved into a different wing of the hospital. Many family members and friends travelled in to help with his care. The doctors suggested that we not shield our boy from what was happening and it was him, in fact, that woke Seattle. He wasn’t allowed in her room but would instead stand in the ante-room and speak to her through the glass door and during one of those times, 14 days after being intubated, she finally opened her eyes and she looked directly at her beloved big brother. That marked the beginning of her recovery. Physio started coming in to stretch her arms and legs, her fingers and toes, so as to not let atrophy set in and she was casted for her arms and legs. She was soon able to lift her left arm and move her right arm. She was moved out of her private room and into the open ward of the ICU for about two weeks before she was finally settled into the transitional area, where I was no longer allowed to stay so I moved into a different wing of the hospital. The phenomenal care and love the nurses gave my daughter is the only reason I was able to walk away from her side each night; they are truly courageous, compassionate and selfless people. I owe them the world; they saved mine. Seattle had stabilized and seamed people. I owe them the world; they saved mine. Seattle had stabilized and seamed people. I owe them the world;
quite frightening; it brought about so many questions. Would we feel confident enough to use the machine, to suction her when she started to choke? What if we did it wrong and we were so far from the hospital? Would I be able to handle a child who couldn’t move, who was attached to a machine and still be able care for my 4 yr old son on my own, as Shane had to go back to work at this time? We were told on a Friday to take the weekend to think it over. We decided we could do it and that being home all together would be the best for both children. Monday morning, we walked into the transitional section together, to see our daughter BiPAP free, with her nurse saying that she had been off it all night; that she had fought three nurses off when they had tried to put it on her so they left it off to see how well she would do without it. She never needed it again. It was at that point that her doctor told us just how unbelievable she was, how much of a miracle; that the general consensus when she was admitted, was that she would remain paralyzed from the neck down with probable brain damage. Even though they had never wavered from the ‘we just have to wait and see’ spiel, I knew that was their thoughts, but it was still shocking to hear it be spoken aloud, none the less. The next day we were transferred into the regular hospital unit, to make sure that her breathing would remain stable, to see if she could start eating puree and be strong enough to cough it up and not aspirate. She flourished and her breathing and eating stabilized. Almost two months after we had arrived, we carried our baby girl out of the hospital. I shed happy tears for her. I shed broken, bereft tears for the families that I watched walk out those same doors without their children. At that moment I felt like the luckiest person in the world. I still do.

We headed straight to the Sunny Hill Rehabilitation Centre to begin the next chapter of recovery. She swam, she did play therapy and soon she was able to sit on her own if placed in the position, albeit slouched over with her belly almost touching the floor. She was beginning to commando crawl using her right arm to pull her body forward, the true definition of a heartbreakingly beautiful sight. She started to eat and, besides a persistent uti, she continued to get better. We were there less than a month when we pulled her out after getting a call that my father was sick with osteomyelitis and had been admitted to the ICU where my parents live and that we needed to go there right away. He has also had a spinal fusion and had received a spinal block to alive the pain but had contracted septicemia. After many rounds of dialysis and more of the dreaded ‘wait and see’, he recovered, although with some serious ailments. My family has definitely been hit hard but we fight back and we win. My mother is a breast cancer survivor. My sister was hit by a drunk driver when she was sixteen and broke her back and has Herrington rods holding her spine together, and a few years ago she became extremely sick with an illness that had us all worried we were going to lose her. She too still suffers some long term effects. My own health history is a bit messy; Cyclic Vomiting Syndrome began when I was a teenager but that thankfully only flares up now when I am in extreme pain and vitiligo began around the same time, as well. I’ve had multiple back surgeries and Christmas 2011 was spent in the Neurological Critical Care Unit with an unexplained brain issue (I cite stress), as well as a year spent with what doctors called ‘an unexplained persistent pelvic bleed’ that required nine blood transfusions within eight months (again, I cite stress). Doctors said I wouldn’t be able to have any more kids, but in true family form, I proved them wrong and I welcomed a baby girl in January of this year; a welcome surprise! We are a true Warrior Family. Today, everyone is happy, (somewhat) healthy and loving life. Which isn’t to say we don’t have our breakdowns; our moments of helplessness, for how a family could go through so much and not have them? Just the other day, I had a breakdown of epic proportions after Seattle came to me at night, crying and unable to sleep, saying “I can’t keep up with the other kids and it’s because I’m not good enough.” This was coming from the girl who doesn’t cry. Ever. I knew that moment would come and thought I had prepared myself but I certainly hadn’t. How do I explain why she can’t keep pace with other kids her age, even though she is pushing herself to her limits? How do I explain to her just how impressive, how amazing, how mind-blowing it is, that she is able to do what she does? That’s one of the reasons that I love and encourage dance. She can look at herself twirling and spinning in the mirror and see what she wants to see. That usually entails seeing herself leaping and doing acrobatics like the performer Pink! After Seattle came to me that night, I showed her a video of Pink strapped into a harness and spinning high through the air. I figured that showing her that through hard work, determination and courage, that anything is possible and that she herself could very well be doing the same type of acrobatics when she gets older. It certainly worked. She now refers to herself as ‘Pink’ more often than not and demands that people, friends and strangers alike, watch how well she can jump and spin. My girl’s still bringing smiles to people’s faces!

After we returned home following my dad’s recovery, Seattle continued with the commando crawl and lots of physio and occupational therapy. Swim therapy seemed to work wonders and really helped in getting her to ‘feel’ her legs. Seven months in, she ‘walked’ towards me in the water with the aid of her therapist. Around the seven month mark is also when she started to speak again, ‘up’ being the first word, with “Daisy” (as in duck) a close second. March 29th marked the day that she first held the standing position that I had placed her in and she threw a ball to me. Twice! We were at Strong Start (a parent participation pre-school program) and there wasn’t a dry eye in the house. Slowly but surely, she regained enough strength and was relearning how to

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walk by her second birthday, with the aid of a walker. It gave her a sense of independence and it wasn’t long before she was casting it aside and trying to walk without it, even though she would fall every few steps. Nothing kept her down then, nor does it now. My girl is strength personified.

The doors opened and there she was ready to go: “What do you mean we are allowed to leave the ICU for fifteen minutes and take her around the hall? Seriously?” Another mental snapshot taken that I will cherish for my remaining days.

She still has a long road of recovery ahead of her. Her body gives out and she falls dozens of times a day; full on body slams into the ground but while all the adults around wince in pain, she picks herself up with an “I’m ok! Or “It’s alright. I can DO this!” accompanied by a fist pump and she just keeps on going. We are extremely worried about the effect the hard falls will have on knees and spine over time. Her core strength fatigues easily and her hands are still somewhat weak, although she is able to use a pencil and print her name! She uses a wheelchair for long distances or for when clonus flares up, although she doesn’t care much for the wheelchair and would rather push herself to exhaustion, until she is literally propelling herself forward with her neck muscles. She needs rigorous physical therapy and more surgeries; her next one will be a cutting and lengthening of her tendons.

We were making many trips to the hospital at this point so they could follow her recovery and, as I’m sure many parents and patients old enough to remember can attest to, it was quite difficult to walk back into the hospital. Each time, all of the memories and feelings would come flooding back—there’s the spot in the hallway where I collapsed on her second day in the ICU and I had to be picked up off of the floor. There’s the bathroom where I had a panic induced vomiting attack while she underwent her initial MRI. There’s the lawn that I ran to in the middle of the night where I sank to my knees and begged, pleaded and made deals with the universe to bring her back to us. Three years on, I can now walk into the hospital and, while I still have those painful flashes, I remember different things, positive memories like that same lawn being where I would take my son when he visited and we would blow bubbles and kick a ball around. Or that play area over in the corner? That’s where we took Seattle on her first journey beyond the ICU doors, when in celebration of getting to one hour BiPAP free, a nurse had styled her hair into wee little pigtails and had her waiting for us in a stroller as a surprise.

She had been receiving Botox injections into her left calf to relax her muscles but after the cast came off after the third go around, we discovered it had been more detrimental than positive so we have stopped them. A main focus right now is to help her paralytic bladder. We recently tried a medication that would allow her to hold urine in for longer periods of time, which would hopefully ease up the overwork of her kidneys, as well as diminish her risk of uti’s, which are very common with this type of injury. She had been hospitalized over Christmas holidays with a severe bladder infection and it was terrifying; she started to lose all function again and we thought she was having a relapse. Thankfully, she bounced back quickly that time, however, she didn’t respond well to this particular medication so we need to go a different route, probably catheterization multiple times daily. On the days when all of this becomes overwhelming, I just remember how lucky we are that she is still here, that she is able to move, that she is still our little girl. She is headstrong and determined, stubborn and defiant, which is both glorious and irritating all at once. But an irritation that I gladly welcome!

We still get asked ‘what’s wrong with her’, which makes me want to scream when it is worded that way but I know that people are just curious and I will always share her story as I think its an incredible, inspirational one that is meant to be told. I would just prefer it be asked in a more sensitive way, like “May I ask what’s happened to your daughter?” Many people are encouraging to her, cheering her on and telling her what a great job she is doing and for that I am so very grateful. Families will come over to share their own stories of a sick family member and a few times, little girls have even asked her where they can get a cool pair of AFO’s like hers, which makes her feel pretty special.

But it has been very hard on the entire family in various ways. Emotionally it’s tough for her big brother, who gets dragged along to many of the appointments and who feels slighted at times by the attention his sister gets. Life definitely centers around her

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recovery; there’s spinal clinics, Botox treatments, MRI’s, ultra-sounds and renal scans, castings for AFO’s and multiple monthly meetings with her specialized paediatric doctor, neurology, urology, nephrology, physical therapy, it never seems to end. This is her life and it won’t change anytime soon. Financially it has hit us hard; it seems like we just haven’t been able to catch up since that first hospitalization. We moved from Vancouver to Kelowna just over a year ago; it’s a more affordable place to live, we are closer to family and because I felt that Seattle wasn’t getting the help she needed as the waiting lists in Vancouver were too long. Travelling around Van city to various appointments was daunting as well; sometimes getting to just one appointment would be a day long outing which would include multiple city buses, the sea bus, sky train and way too much walking for my little boy, who would have to miss school, as I had no one to care for him. It’s much easier to get around now, although the move certainly made it harder financially and our income took a big hit. And within weeks of us moving, she suddenly began getting many treatments in Vancouver that she hadn’t been receiving while we actually lived there. We travel 776 kilometres (8 hours) round trip from Kelowna to BC Children’s twice yearly for her Spinal Clinic, as well as three recent trips for Botox therapy, trips for urology, a trip last month for an MRI and so many more. Sometime we are driving down twice a month. Although we have applied for help from every single place we are aware of, we get denied, at times being told that she is ‘too able-bodied’, which I don’t understand. She needs AFO’s (one pair or two pairs a year depending on her growth spurt) which are $3000.00 a pair, not including the cost of constant adjustments. She needs many diapers which are an astronomical cost to us, not to mention her various medications and gas, meals, lodging and wages lost to get to all these appointments. Hopefully there is an organization out there that we have missed or perhaps one will change their mind and be able to help us or point us in the right direction. She needs all of these things to maintain her recovery and honestly, if our parents hadn’t been covering the costs for many of these things, she would be without them. It is overwhelming and exhausting. I have gone from humbled and feeling ashamed while asking for assistance, to confused as to why she has been denied, to just absolutely livid that the big organizations that claim to help those in need seem to be the ones that keep us running in circles. We need help and we just aren’t getting it. It makes me sad for my children that disappointment has become such a way of life that they just readily accept it. My kids get excited for trips to the Ronald McDonald House in Vancouver like other kids get excited for a trip to Disneyland. We try as best we can to make those stays ‘mini-holidays’ for them and it really does feel like one; the house is overflowing with fun for the kids who stay there; it’s a place where they can make new friends and just be themselves, without all the comments and stares. It’s also a great place to meet other adults who understand. It’s a wonderful place that has been added to my list of things to be grateful for!

I truly am happy that we made the move though. She now has a wonderful physiotherapist through the Central Okanagan Child Development Association who works with her every other week, as well as a phenomenal team of doctors who truly care and are always available to answer our questions.

She even got to do Equine Therapy through the COCDA last summer, which I’m hoping she will get to do again. She loved getting to ride “her” horse and it was incredible to see the transformation in her core strength. It’s a short therapy season, usually twice a week for 6-8 weeks and to see her go from being slouched over and unable to hold herself fully up in the saddle during the first week, to standing in the stirrups while the horse walked around the track by week six, was phenomenal and brought tears to my eyes. The healing power of animals is truly something to behold. She also spends every single day during the summer months swimming in our surrounding lakes and that’s awesome therapy, even though she thinks she’s just playing in the water!

Unfortunately, once Seattle is officially registered into the school system this August, she will be dropped as a client of the COCDA - one more issue to worry about.

She’s starting kindergarten this fall and I’ll admit I’m terrified to let her out of my sight, even though she will have an aid to help with toileting and outside playtime. I’m so scared that she will be teased for needing pull-ups, of not making it to the bathroom in time and having an accident. I’m scared of her falling and me not being there to help her up. I’m scared of the names she will undoubtedly be called and not being able to distract her attention, such as I did when kids imitated the way she walks behind her back, while calling her a zombie. It will happen. People can be cruel. But they can also be kind and compassionate and I just have to hope that she will one day find that core group of friends that show her nothing but love and support. I believe with my entire heart that because of her, of what she has done and what she will do, that someone will one day say to her “It’s because of you that I didn’t give up.” It’s certainly because of her that I don’t give up. I can’t hate TM because that would mean hating my life. I never ask why it happened because I already know the answer; she is strong enough, we are strong enough. I can’t curse TM but can only try to aid in raising awareness and hoping that one day a cure and an answer will be found. I can’t be scared because she’s not. And being fearless is what’s brought her so far. As the quote goes, “she is clothed in strength and dignity and she laughs without fear of the future.”

So I try to live my life like her. Without fear, ignoring the pain and drawing strength from her courage. And that is why I was able to give her my answer on that warm spring day last year. My answer is the same now as it was then and the same as it will always be;

“Nothing is wrong with you, my sweet love. You are perfect just the way you are. You are my hero.”

You are my hero.
You are perfect just the way you are.
Nothing is wrong with you, my sweet love.
New Technology that can help

Chronic Pain Tracker Lite mobile application

This app has been found to be one to be the most precise when it came to describing pain in details. It has pain intensity, description, location and duration as well as how quickly the onset of pain occurred. One unique aspect that might be beneficial to someone with pain in different areas, such as conditions like transverse myelitis, NMO, ADEM and optic neuritis, where the pain location is on an image of a body (front and back) on which you can put intensity colors where the pain is located. It also has pain triggers, effective treatments, medication tracking and other symptoms lists which are easy to modify with additions.

This pain app also has a general note section you can use as well as a milestone section where you can note a medication change, surgery, lifestyle change, doctor change and a note section there to specify details.

The reports section can draw information from each section or can do a full draw down daily. One advantage to the paid version is you have the option of having more than one pain journal stored. You could have, for example; one for migraines and another for transverse myelitis which would have entirely different pain scales, locations and symptoms. Overall this is an effective journal that can meet most needs. The reports are thorough and can be broken down how you please. This application was the most detailed and flexible pain tracker with a great reporting system.

Happy Birthday to Us!

Canadian Transverse Myelitis Association celebrates its 3rd anniversary this July!

This newsletter is published by:

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www.mytm.ca

CTMA’s mission is to forge an enduring and cooperating social group, whose members support patients diagnosed with transverse myelitis and other neuroimmunological disorders.

Visit the Canadian Transverse Myelitis Association at MyTM.ca

Suggested Readings

Books:

Peer Reviewed Journals:

For a copy of the journal articles contact info@mytm.ca
A new fundraising program....

Rona Ottawa
Spring/Summer 2013
Renovation Event

Save 5% at Rona and Rona will send a donation to the CTMA!

Want to save 5% on your next home improvement project?
Want to help Rona to make a donation of up to 5% back to the Canadian Transverse Myelitis Association?

Head over to both Ottawa Rona locations and receive a discount card in support of the Canadian Transverse Myelitis Association. Rona, a Canadian company, is partnering with several charities for this pilot project, which will save you 5% on any purchase and in addition send a donation of up to 5% our way.

You don’t have to pay a cent for the charity card-download it from our website- http://mytm.ca/1958/rona-ottawa-springsummer-2013-renovation-event/ or contact us at info@mytm.ca or any of the two Rona stores and keep the card in your wallet for all future purchases!
It's a win-win all around!

Rona is located at 585 West Hunt Club: (just down the road from our new facility at 245 West Hunt Club)

and at 1880 Innes Road:

Events Across Canada....

Over 370 runners and walkers including Valerie Shalay (CTMA support group leader for British Colombia) came out the first ever 5km Walk/Run for Neuromyelitis Optica (NMO) on May 26th, raising over $23,000!

Proceeds raised by the event benefited the VCH NMO Clinic and Research Program at UBC Hospital through the VGH & UBC Hospital Foundation and the Guthy-Jackson Charitable Foundation which is currently the only foundation worldwide specific to Neuromyelitis Optica.

The purpose of this event is to raise awareness about NMO and to raise much needed funds for NMO research.
For more information on the VCH NMO Clinic and Research Program at UBC Hospital visit nmo.vchri.ca.