

W I N T E R 2 0 1 2

# CTMA

Canadian Transverse Myelitis Association



## A note to you, from us!

"As we approach a new year, it brings me to reflect on my recent year and think about the things that I can do to make 2013 a better year for myself as well as the ones in my life. This is my first year on the committee for the Canadian Transverse Myelitis Association. I was brought on inspired by Kimberley, and driven to help bring more awareness to this cause. It has been rewarding and I am extremely grateful to be surrounded by such a great group of people.

As with all walks of life, there are difficult times and there are rewarding times. I am a firm believer that you must focus on the things that encourage you, inspire you and generally make you feel better, to live a fulfilled life. Be thankful for the things that you have rather than focus on the ones you do not. We all have our inner turmoil and struggles, each unique in their own way as our paths of life have been paved by our own walk of life. I feel as the year ends, there is no time like the present to reflect on some of the difficulties and leave them behind, in anticipation for a brighter year. Make goals for yourself that you can achieve... Even if it means slow and steady, it is the time to move forward and make 2013 the year of gratitude, health, love and support.

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### Stayed tuned for...

#### FREE Seminar

February 9, 2012

CTMA is holding a **free** seminar for those living with chronic illnesses, such as TM, Devic's Disease and Optic Neuritis, and their friends. The CTMA is partnering with Corpotiva Coaching to bring strategies for living with chronic illnesses, information on cranial-sacral treatments and exercises for those with limited mobility. (Montreal, QC)

#### To Register:

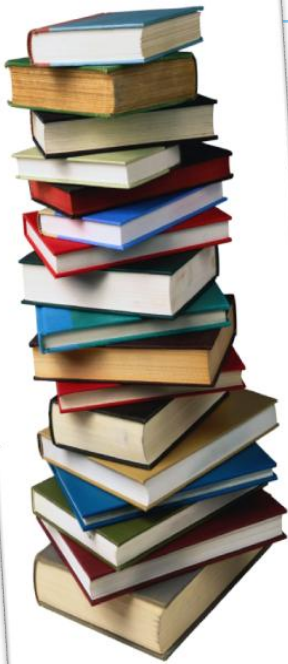
kimberley@mytm.ca  
514-636-9337

#### How to:

Interested in organizing your own fundraising event in your hometown??  
Bake-sales, penny drives  
Races/Runs,  
Pub Crawls,  
Etc.

#### For more information or help:

info@mytm.ca



## (Not so) Light Holiday Readings

We are presenting a selection of recent & not-so-recent articles on the diagnosis and clinical presentation of Transverse Myelitis. As scientific articles go, these are fairly general and easy to read. However, a word of warning: these articles are not intended for a lay audience and contain a lot of “medical jargon”, not exactly holiday reading.

### However, if you're feeling brave, read on:

- 1.) Frohman EM, Wingerchuk DM, **Transverse Myelitis**. *N.Eng.J.Med.* 363, 564-572 (2010) [www.nejm.org/doi/full/10.1056/NEJMcp1001112](http://www.nejm.org/doi/full/10.1056/NEJMcp1001112)
- 2.) Hammerstedt HS, Edlow JA, Cusick S. **Emergency Department Presentations of Transverse Myelitis: Two Case Reports**. *Ann. Emerg.Med.* 46:256-9(2005) [www.annemergmed.com/article/S0196-0644%2805%2900548-2/abstract](http://www.annemergmed.com/article/S0196-0644%2805%2900548-2/abstract)
- 3.) Trebst C *et al.* **Longitudinal extensive transverse myelitis – it's not all neuromyelitis optica**, *Nat.Rev.Neurol.* 7, 688-698(2011) [www.nature.com/nrneuro/journal/v7/n12/full/nrneuro.2011.176.html](http://www.nature.com/nrneuro/journal/v7/n12/full/nrneuro.2011.176.html)
- 4.) Schmalstieg WF and Weinshenker BG, **Approach to acute or subacute myelopathy**, *Neurology*, 75, S2-8 (2010) [www.neurology.org/content/75/18\\_Supplement\\_1/S2.long](http://www.neurology.org/content/75/18_Supplement_1/S2.long)

As we put together a list of suggested readings or articles for both families and health care professionals, we always appreciate your feedback. What **kind** of information you're looking for? If there is a particular topic you are interested in reading about, send us an email ([info@mytm.ca](mailto:info@mytm.ca)) and let us know

## Our recent fundraisers...

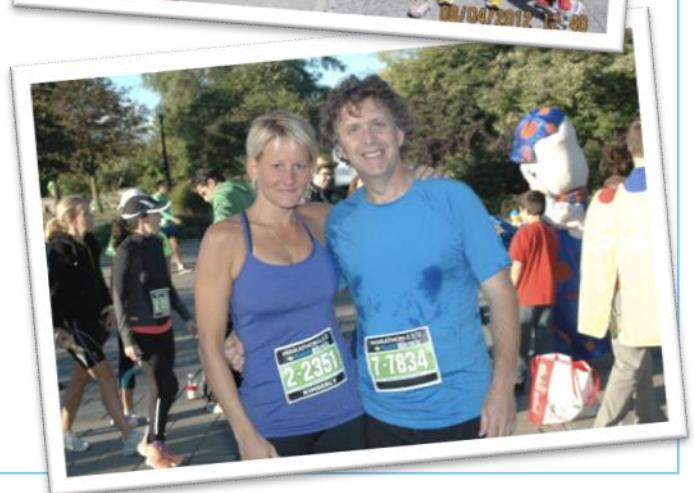
### Red Dress Run

The Montreal Hash House Harriers hosted their annual Red Dress Run to benefit the CTMA. In all a total of \$532 was raised for the Canadian Transverse Myelitis Association and everyone had a ton of fun. Thank you to all of the participants and donors!



### CTMA runs with CJAD in Montreal

On September 23<sup>rd</sup>, CJAD's morning talk show host Andrew Carter ran his first marathon with our President, Kimberley Kotar. Andrew finished the half marathon with a time of 1:58:08 and raised over \$3000 in donations. Kimberley was a weekly feature this summer on CJAD leading up to the run, which allowed the CTMA the unique opportunity to increase awareness about Transverse Myelitis. Thank you Andrew and all who supported this great race!



## Our Newest Support Group Leader!

My name is Valerie and I have Transverse Myelitis. I was 36 years old, a career woman, wife and mother of two girls, aged 2 and 5. Life was pretty good! Then this rare disease came along. My life changed in November 2011 when I was admitted into the hospital with severe flu symptoms and weakness in the legs. Two days later I was completely paralyzed from the toes up to the chest (T5 area). I was given a spinal tap right away but an MRI a few days later confirmed that it was indeed Transverse Myelitis. I remained at the hospital for one month undergoing treatments with the only way to describe my stay as "the worst nightmare of my life". I was then transferred to a rehab hospital where I spent another month learning how to stand and eventually walk again. I progressed from a wheelchair to a walker, to walking on my own over the course of that month, however, I then spent 4 months in physiotherapy building up my strength and endurance to a level that I could manage at home on my own. As my MRI also showed lesions on my brain, my neurologists were uncertain as to whether I had NMO or not (neuromyelitis optica). As a preventative measure to having any future relapses, I underwent 2 months of chemotherapy. What a journey it has been!

Through this experience, I had an amazing support system of family and friends, however, they obviously could not relate to what I was going through. I found the most frustrating part was not having any answers. No one could tell me when or if I was going to walk again, what the stages of recovery were going to be, or what outcomes my treatments would have. There were far too many uncertainties and questions left unanswered. It sure



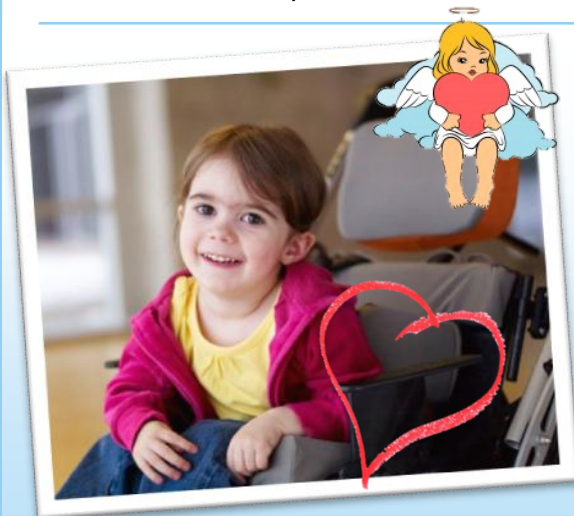
would have been nice to talk to someone who had been through what I had. It wasn't until I was discharged from the hospital and had internet access again that I had a chance to really research my disease and participate in forums. I then found the CTMA and volunteered to become a group support leader. If I can help just one person through that difficult time, then my goal has been met!

-Valerie  
valerieshalay@hotmail.com

## Trinity's Trust for TM Tots

*In March of 2011, a beautiful young child lost her life due to complications from Transverse Myelitis. Last year Trinity's parents reached out to the CTMA and said they wanted to help other children diagnosed with Transverse Myelitis. These events got our Board of Directors thinking about what we can do for children living with TM because they very often have different needs than adults as they continue to grow and develop.*

*This summer, the CTMA was proud to be able to establish "Trinity's Trust for TM Tots" as a result of our two fundraisers. This goal of this trust is to help families who cannot afford the necessary items that their child may need as a result of Transverse Myelitis.*



# Happy Holidays from the CTMA!

## The Soaring Beyond Grant

The Canadian Transverse Myelitis Association believes in investing toward helping those who have been diagnosed with rare neuroimmunological disease become more active. Through our *Soaring Beyond Grant*, we will provide individuals with funds to help them increase their accessibility at home and in the community, and to support them becoming more active and mobile. These monies may be used for any and all equipment or therapies that will help an individual become more active.

For a copy of the application, please contact Kimberley Kotar at [kimberley@mytm.ca](mailto:kimberley@mytm.ca). All applications will be reviewed by an appointed member of the Canadian Transverse Myelitis Association. Grants will be allocated according to our guidelines and available funding at the time of the request.



## How to Donate

Donations can be made by cheque and mailed to:  
263 Malcolm Circle  
Dorval, Quebec H9S 1T6

The Canadian Transverse Myelitis Association also accepts online donations through our secure site; you can donate any amount using your Visa, MasterCard or American Express.

<http://mytm.ca/donate>

## Top Apps

**USAA** – This app is available on Android devices and allows easy access to pay your bills and even deposit checks from your mobile device!

**WebMD** – 24 hr access to health information and decision-support tools!

**TalkBack** – Helps vision-impaired users interact with their devices more easily. Using spoken, audible and vibration feedback.

**IDEAL Accessibility Installer** – designed to make it easier to install current versions of TalkBack, KickBack and SoundBack on their Android devices.



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Here at the CTMA, we are constantly working to bring awareness to people with Transverse Myelitis, their friends, families and health practitioners alike. With a strong base in Montreal, we are working on developing better support systems throughout the country with easy access to information, support, and some fun along the way.

Without the support of our team, readers, followers, friends and families this association wouldn't continue to grow the way that it is. From the bottom of my heart, thank you for all that you've done or contributed to the association. We look forward to another great year.

Happy Holidays and Best Wishes for 2013 from the Canadian Transverse Myelitis Association!

Tracey Flynn  
Vice President"

