

## Trinity's Story...

I am writing this as a mother with a daughter that was diagnosed with Transverse Myelitis. Trinity was diagnosed in September of 2009 when she was only 14 months old. ...

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HAPPY BIRTHDAY TO US!  
The CTMA celebrated its  
2<sup>nd</sup> birthday, July 12<sup>th</sup>,  
2012.

A note from the  
President (Pg. 2)



## + Vice President Introduction

"We must remember that one determined person can make a significant difference, and that a small group of determined people can change the course of history."

## Welcome to the team!

I am proud to have been awarded the honour of becoming the Vice-President of the Canadian Transverse Myelitis Association this past month. I look forward to contributing, along side a great team to help bring development, awareness and assistance to this association and disease throughout Canada.

beside my experience in event planning, I intend to work on engaging communities through awareness initiatives to ensure the visibility of the Canadian Transverse Myelitis Association.

"I've learned that you shouldn't go through life with a catcher's mitt on both hands. You need to be able to throw something back. "

Tracey Flynn, Vice President  
tracey@mytm.ca

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**Kimberley Kotar**

*President*

*Canadian Transverse  
Myelitis Association*

## A note from the President...

I am not sure that I entirely grasped what I was committing to when I founded the CTMA, but I knew that I wanted to make a difference in the TM community and in the lives of those living with rare neuroimmunological diseases. While our progress may be slower than I thought, it has been steady and we are helping people across Canada adjust to their diagnosis and deal with the issues they face as a result.

I am very happy to announce that July 12, 2012 was the 2<sup>nd</sup> anniversary of the Canadian Transverse Myelitis Association! As we move forward into our third year, I wanted to update everyone on the current and upcoming events at the CTMA.

There is a new face on the Board of Directors, I am very excited about the addition of a new vice-president and feel that we will make more advances in our long term goals as a result. We also have a new support group leader in the province of British Columbia. Please join me in welcoming Tracey Flynn and Valerie Shalay to the CTMA team.

Our motto has been "*Soaring Beyond*" and this year we have put in place *The Soaring Beyond* grant to invest in those with TM and other neuroimmunological diseases that want to 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. Everyone on the board of directors is very proud of this initiative and we hope that more people in the TM community will take advantage of this wonderful opportunity.

During this next year we hope to be able to launch a pediatric division within the CTMA to help infants and children of all ages face the challenges they may have due to a TM diagnosis. We would like to fund travel costs to those children and teens that would like to attend the Victory Junction Gang Camp so that they can experience the same thing as their peers.

As always, I am honored and proud to serve you this past year. Please let me hear from you at any time and you can email me at

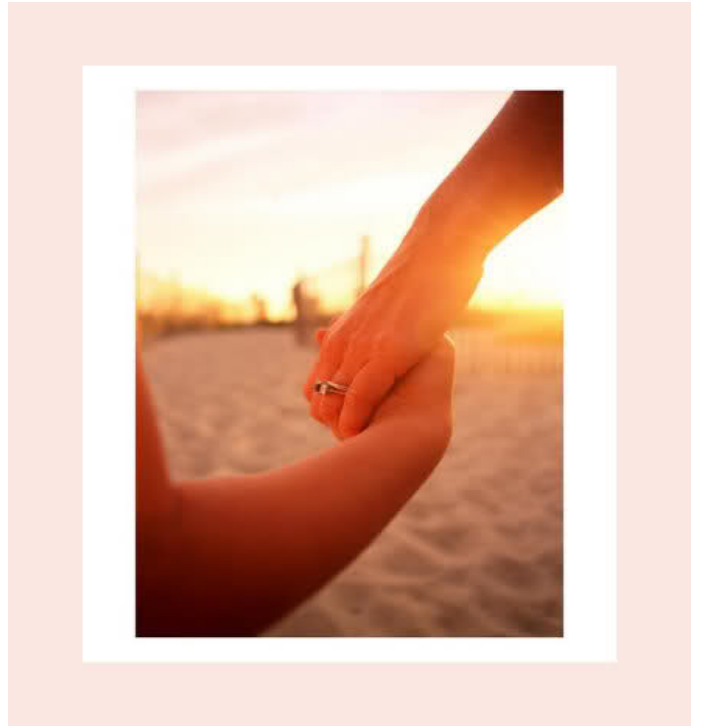
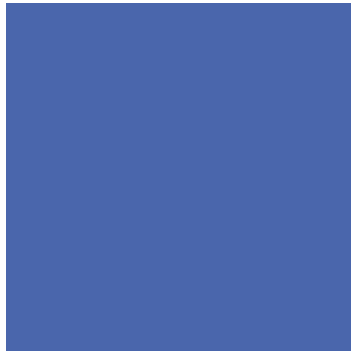
[kimberley@mytm.ca](mailto:kimberley@mytm.ca)

The level of dedication of our board of directors is incredible and I eagerly anticipate that we

will *soar beyond* all expectations this year as we get closer to fulfilling our mission through the CTMA.

Sincerely,

**Kimberley**



# Trinity:

## The love of a mother, a life cut short.

I will admit that at that time I thought that it was one of the worst things that could ever happen. But now I am able to say that it was the beginning of a long journey that I feel blessed to have been part of.

That day in September was one of the worst days of my life. In a matter of 5 minutes my daughter went from running around playing in our living room to screaming on our living room floor because she was not able to move. We rushed her to the hospital and up until that moment, I never felt so lost and confused.

The doctors didn't have any idea

what was wrong with her, it was 10 hours later, after a hospital transfer that we found out what was wrong with Trinity and the diagnosis of Transverse Myelitis was made. It was after the transfer to a larger hospital in Kingston, Ontario that the steroid treatment was started, to stop and reduce the swelling of her spinal cord.

Within the first 2 days of Trinity's hospitalization we had a meeting with the doctor's to discuss the next plan of action as they did not think that she would live. (I knew in my heart she would live) as it effected

Her at a high level of her spinal cord and she had been touch and go since her arrival. After 2 weeks the doctors realized that she would defy all odds as she began to strive and proved the doctors wrong every chance that she could. This is when everyone began to see her attitude and zest for life.

Originally , Trinity was paralyzed from the neck down but after an IVIG treatment she began to re-gain some use of her upper body and when she began physical therapy so did our journey. We spent 9 months in an in-patient rehabilitation centre and

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Another 2 years in out-patient rehabilitation as well as in home therapy 2-3 times a day, 7 days a week.

As a mother, the hardest part for me was to watch my daughter in pain and crying because she did not want to do the therapy as it hurt. I can only imagine how scared and confused she must have been being so young (barely a year old) and went from running and playing to being trapped and not able to move. I have asked myself many times how she did it as I myself was in tears through many of the therapy sessions.

I was an active part in her therapy, in and out of the rehabilitation hospital putting my life on hold to take care of Trinity. I have never regretted my choice to do that and I never will, it was a decision as a mother that I had to make and I am thankful everyday that I was able to be such an active part in her rehabilitation, as I know that some mothers or fathers are not able to, for financial or other reasons.

Eventually Trinity regained use of her arms with limited upper body strength, but I was still her legs and that was a job that I was happy to have as long as I had her. Trinity could commando crawl across the floor, but she still needed help with almost all aspects of everyday life. She never gave up and always persevered through the exercises that the therapists would give her. She was definitely a determined girl, I think it was through her that I was able to keep going and never

let the "what ifs" get to me. I took comfort in knowing that even though the therapy was hard and she struggled some days, it was what Trinity needed and that was always my number one priority.

Though the long nine months in in-patient rehabilitation was hard on both of us it would not prepare me for the first time that Trinity noticed she was different (though she never let it stop her from doing anything). She had asked me only once why she couldn't walk and all I could say behind the tears was "Because you are so special that God decided that you didn't need to walk."

Trinity was in daycare as the therapist thought it was best to have her in a setting with other children to get used to the interaction and learning everyday things, and to be part of a group and have the same privileges as all of the other kids her age. The other children knew she was different but she was treated no differently.

I am going to recount a story as it was told to me, One day the kids were playing outside and since she was in a wheelchair (not a power chair) she couldn't move as freely without help and one of her friends came and asked her to go and play in the sandbox, she simply said "I can't, you need to help me. Trinity can't walk." It was then that we learned she was wise beyond her years, because when the little girl asked why? She simply said as I have told her so many times "because Trinity is special but I am the same as you." This story still

makes me cry.

A year or so later when Trinity and I were drawing, she asked me to draw her and her little sister. So I drew her and her sister and when I was done she proceeded to tell

"After 2 weeks the doctors realized that she would defy all odds as she began to strive and proved the doctors wrong every chance that she could. This is when everyone began to see her attitude and zest for life."

me "That girl's not me mommy, that girl can walk and Trinity can't" – this broke my heart. There was never a time when she asked why her sister could walk and she couldn't or that she was embarrassed or ashamed of her paralysis. She embraced it and never let it get in her way or stop her from doing anything she wanted to do.

It was a long, stressful and emotionally draining process for me as well as Trinity but it was through her therapy that we developed a deep and unbreakable bond that I would not trade for anything in this world. Our bond went beyond the normal

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mother & daughter bond it was different. It was something special that I will cherish for as long as I live.

I am writing this with a heavy heart and a memory of my beautiful daughter as Trinity passed away March 29, 2012. It makes her journey and our bond all that more special to me.

I made sure that I told Trinity how beautiful she was everyday so she knew how special and beautiful that she truly was. Trinity was such an old soul, wise beyond her years and she was my whole world.

I had spent so much of my time over the past three years caring and taking care of Trinity that after she passed away I felt as if she had taken part of me with her. She taught me more in her short life than most people have the privilege to learn or experience in a whole lifetime. It is through our children that we can seek inspiration and learn some of life's greatest lessons.

It was through Trinity that I learned that you should live life to the fullest, and not let anything get in the way of doing what you want to do, as she never did. She never let the paralysis get in her way and I take peace in knowing that I helped her in every way that I could to give her a happy and full life and to never feel any different than anyone else.

The most important lesson that I could pass on to other parents of children with TM is to never treat your child any differently and love them with all you can. I know from experience that it makes all the difference in the world to a child with TM.

## Summer Sport Sitting Volleyball

### What is Sitting Volleyball?

Sitting volleyball is a discipline of disabled volleyball that is played while sitting on the floor. The sport is governed by the same set of rules as the able-bodied game, with a few minor rule modifications.

### Who can play?

At the non-international level, sitting volleyball can be played by anyone. One of the greatest features of sitting volleyball is the fact that it provides the opportunity to easily integrate able-bodied athletes and athletes with a disability on a more level playing field.

For international competition, sitting volleyball is open to athletes with a physical disability who meet the minimum disability requirements for volleyball. An athlete's disability must be permanent (either progressive or non-progressive). Athletes with progressive physical disabilities (i.e., muscular dystrophy, multiple sclerosis, etc.) are given a temporary classification and must be classified at each competition.



Sitting volleyball is governed by the World Organization Volleyball for Disabled (WOVD). The WOVD has adapted the FIVB (Federation Internationale de Volleyball) rules for use in sitting volleyball. The rule modifications for sitting volleyball include, but are not limited to, the following:

- The height of the net (1.15m for men and 1.05m for women) and the size of the court (10m x 6m) are reduced for sitting volleyball;
- The positions of the players are determined and controlled by the positions of their buttocks. This means that the hand(s) and/or leg(s) of the players may lie in the attack zone (back-row player during an attack hit), in the court (server during the service hit), or in the free zone outside the court (any player during the service hit); and
- Players must remain in contact with the court at all times when playing the ball. The stand up, rise or take steps is forbidden.

For more information:  
[www.volleyball.ca](http://www.volleyball.ca)  
 or send an email to:  
[disabled@volleyball.ca](mailto:disabled@volleyball.ca)

## Upcoming Events

### Friday, August 3<sup>rd</sup>

Transverse Myelitis Awareness Pub Crawl

Time: 6:00pm

Place: Peel Pub, Peel St. Montreal, Qc

### Saturday, August 4<sup>th</sup>

#### Red Dress Run

We will have guys and gals alike, running and walking the streets of Montreal in *Red Dresses* to raise money and awareness for Transverse Myelitis

For more information please contact Kimberley  
[Kimberley@mytm.ca](mailto:Kimberley@mytm.ca)

Come and join the President from the CTMA in your RED DRESS to support the fight against TM!



### Tune-In!

#### To CJAD on Friday mornings with Andrew Carter!

Andrew will be running the Montreal Oasis Half-Marathon in September to help raise awareness for Transverse Myelitis.

Our President and founder Kimberley Kotar is his running coach. She will be featured on Andrew's broadcasts Friday mornings with tips on running and talking about the association.

[www.cjad.com/Shows/AndrewCarterShow/Podcast.aspx](http://www.cjad.com/Shows/AndrewCarterShow/Podcast.aspx)

### Recommended Readings

You may find these readings useful and informative. We have tried to pick a mix of science-based research as well as inspirational self-help readings!

- **Idiopathic Transverse Myelitis and Neuromyelitis Optica: Clinical Profiles, Pathophysiology and Therapeutic Choices.** Amer Awad and Olaf Stuve, *Curr Neuropharmacol.* 2011 September; 9(3): 417-428
- **Evidence-based guideline: Clinical evaluation and treatment of transverse myelitis. Report of the Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology.** T.F. Scott, E.M. Frohman, J. De Seze, et al. *Neurology.* 2011 December
- **When Walls Become Doorways: Creativity and the Transforming Illness.** Tobi Zausner
- **The Power of Now – A Guide to Spiritual Enlightenment.** Eckhart Tolle.

If you should require any other information about any of these readings or would like a copy of the research articles, please contact Kimberley ([Kimberley@mytm.ca](mailto:Kimberley@mytm.ca))