Boy what is a beautiful day! Approximately 125 caring and compassionate members of the TS community came together at Evergreen Brickworks in Toronto for the 6th Annual Trek for Tourette. The Trek is a 5km walk/trek and is the only national fund raiser of its kind for the Tourette Syndrome Foundation of Canada.

The event was designed to be relevant to those impacted by TS. Just as the weather is very unpredictable in the month of March in Canada, so too is TS. Just as TS is different for everybody who has it...so too was the weather different in each of our 16 national locations.

It was a festival atmosphere with face painting, a photo booth, a craft table, raffle prizes and live music provided by the guitar stylings of Ian Coll and Ben Kettner, two young musicians with Tourette. Together we raised $33,000 in support of the National Office of the TSFC and the GTA Chapter in support of our work in education, advocacy, self-help and the promotion of research. Nationally, the Trek is expected to raise $160,000.

CBC covered the event with a piece on national CBC Radio Canada in English and French as well as the 11 p.m. CBC Toronto News. This type of media coverage is critical to building awareness of TS and our mission as an organization... so thank you CBC!
On a cold Saturday night in January, the GTA & Hamilton, Halton & Niagara Chapters of the TSFC hosted the second ever Sea of No Cares Youth Rock Concert at The Crooked Cue in Mississauga. It was a magical night for all who attended as Ian Coll, Justin McCourt, Emily Etherington-Philips, Liam McPherson, Jordan Vilemaire, Nicolas Stackhouse and Dylan Murray threw their fears into the sea of no cares.

This wonderful group of youth challenged their teenage anxiety and their Tourette to perform in front of a very supportive crowd of 228 music fans, friends and very proud parents. Their talent, hard work and courage helped to raise almost $5000. Emily Etherington-Philips, who performed that night, had this to say: “Performing in the Sea of No Cares event is a memory I will cherish for the rest of my life. Having an opportunity to perform with so many talented musicians was truly a gift. It gave me the confidence to go ahead and audition and be accepted to my region’s most challenging Musical Theater Program. In collaborating with other artists I found a group of what I am certain will be lifelong friends.”

This concert is representative of the best of what the TSFC does.....educating and engaging an informed, tolerant society, building a generation of new advocates for our mission & vision and helping our youth build confidence, self-esteem and centers of competency.

For upcoming workshop dates, see page 4
Coach’s Corner: full disclosure

How time flies....time to register my child again for their favorite spring and summer sports.

And time again....to decide whether or not I want to disclose my child’s neurological challenges to the sport association, and by doing so, the coach of my child’s team. The inevitable questions come back to me. Will my child be labeled? Will he or she be treated differently or indifferently because I write the words Tourette Syndrome on the registration form.

What could happen if I do? What could happen if I don’t...and there are issues?

I share my thoughts with you today as both a father and an experienced baseball coach. Over my 11 years leading house league and competitive baseball teams, I have had the pleasure of coaching kids with TS and/or many of the conditions associated with TS. I do mean pleasure....because those families are now friends of my family and I have seen these children grow in baseball and grow as young men and women.

In roughly half of the cases, the parents did not initially choose to disclose their child’s condition to me until something happened on the field...either between children or with a coach.

My sons actively participated in baseball, hockey, football and golf. We would all agree that sport is exceptionally important in the physical and emotional development of our children...it was for mine. Our kids learn how to be a part of a team, they learn that effort equals reward and most importantly....that they are entitled to achieve success when they work hard and invest in that success. Our exceptional children need this positive reinforcement and structure perhaps more than other children!!

Speaking as a father, my wife and I made select decisions to disclose and not disclose our children’s TS. Generally, we were uncomfortable in writing anything under the medical conditions section of the registration form. That level of disclosure just seemed to public for us. We were more comfortable speaking directly to the Head Coach and/or Team Manager before the season started to have a frank one-on-one discussion in support of the success of our child. Really without exception, the team leaders responded with compassion, concern and most importantly, sought information from us to ensure our child had an amazing experience in sport.

I have modeled their example as a coach myself....to this day.

Speaking as a coach....by disclosing your child’s condition, the coaching staff can and will react more appropriately to the presentation of symptoms. Goodwill is generated with a coach when they understand the unique challenges of your child and how they should best respond to any difficulties they may encounter -Coach Doug

Speaking as a coach....by disclosing your child’s condition, the coaching staff can and will react more appropriately to the presentation of symptoms. Goodwill is generated with a coach when they understand the unique challenges of your child and how they should best respond to any difficulties they may encounter.

Coaches have a right to be concerned as it is their responsibility to make appropriate decisions in the best interests of your child’s safety.

What if that Head Coach shared with his counterpart the fact he had a young man with TS on his team and that sticking his tongue out was a “tic” and out of the young boy’s control? Clearly the young man’s tics were both high frequency and high severity...could the situation have been avoided with a short conversation between coaches? We will never know....

Then there is the question of safety?

There were times when my wife and I made the difficult decision to have our sons not play due to concerns over tics, attention deficit issues and their safety. You may be faced with a situation where your child’s tics are so distracting that you may have a choice to make as well. But what if the Coach made that decision for you?

Can a hockey player protect himself in the corners if his eyes are blinking closed or his head is shaking? Can a shortstop or pitcher protect himself from a hard line drive if their tics are a distraction or they are shivering out of left field? Coaches have a right to be concerned as it is their responsibility to make appropriate decisions in the best interests of your child’s safety.

How would you handle a coach removing your child with TS from the field of play over safety concerns? I can tell you that I mentor many young coaches and I tell them one thing about safety... It is non-negotiable and clearly their responsibility when the child is in their care. If they don’t have all of the information to make an informed decision, they may make the wrong one....and it wouldn’t be their fault.

No one can tell you what decision to make as a parent. Clearly, my experiences would suggest that disclosure and understanding are the preferred option.

I write this article with deep appreciation to Mike Smith and Sandi Hanslep-LePage of the Port Credit Minor Hockey association... and in honour of an 11 year old ballplayer on the Waterdown Wolves and the wonderful children I have had the pleasure to coach all of these years. -Coach Doug

Monthly TS Support/Information Nights

Have you or your family member been recently diagnosed? Are you looking for information about TS and other associated disorders? Are you hoping to connect with someone you can relate to? Monthly meetings are held in Toronto, Peel Region and York-Simcoe. Everyone is welcome. Please drop in.

PEEL REGION
3rd Tuesday of the month
7:00pm - 8:30pm
The Lowe-Martin Group offices
6006 Kestrel Road
Mississauga, ON
(Northwest corner of Britannia & Kestrel, & Britannia)
Complimentary parking

TORONTO
3rd Tuesday of the month
7:30pm - 8:30pm
St. Leonards Church (in the Library)
25 Wanless Avenue
Toronto, ON
(East of Yonge, North of Lawrence, near Lawrence subway station)

YORK-SIMCOE REGION
3rd Wednesday of the month
7:00pm - 8:30pm
Pierre Burton Resource Library (The Training Suite) on the south side of Rutherford, just east of Islington
4921 Rutherford Rd
Woodbridge, ON

DURHAM REGION
1st Wednesday of the month
7:00pm - 8:30pm
Whitby Public Library
405 Dundas Street West
Whitby, ON
We are very excited to announce that we have secured two significant grants to support educational programming in the GTA. The Longos Foundation has generously agreed to provide $9,000 over three years to fund the expenses associated with our School In-Service Program. This is a wonderful service that provides trained volunteers to facilitate interactive, educational sessions about TS in local schools and classrooms. This funding means that we will be able to respond more quickly to more families who would like to help their children's schools learn about more about TS.

The RBC Foundation has also committed $5000 over the next two years to sponsor our Allied Professionals Workshop Series to educate community service providers about TS. This funding allows us to reach out to more organization that impact our TS community, such as GO Transit, Police Services, Teachers/EA Colleges & programs, etc. Our goal is to work towards a more informed, tolerant society where people with TS and other associated disorders are better understood and accepted for who they are.

We are very proud to report on the successful launch of our new Living, Loving and Learning workshops in March and April. Very successful sessions were delivered in Whitby, Mississauga and Toronto to provide information to individuals, families, educators and service providers about Tourette Syndrome and other associated conditions including ADHD, OCD, LD and Dysfunction in Sensory Integration. These highly informative workshops were facilitated by Tisha Etherington-Phillips, an educator, advocate, author and loving parent of four young people with TS.

A second series of Living, Loving and Learning workshops is scheduled for the fall, so mark them in your calendar now!

The exact locations will be included in our summer newsletter.

September 27th – Toronto
October 18th – Peel
November 1st – Durham
November 22nd – York-Simcoe

There is an astonishing variety of books, videos, pamphlets and other resources related to TS available through the TSFC website. This one is a must-have for any family with a recent diagnosis:

Understanding TS: A Handbook for Families
A compassionately written handbook for family and friends of those newly diagnosed with TS.
Available in French and English.
Member Price: $18.45
Non-Member Price: $28.45

Whether you are an educator yourself or a parent trying to advocate for your child, this book is a great place to get information about supporting children with TS in school:

Understanding TS: A Handbook for Educators
This essential resource offers overviews of TS, OCD and ADHD along with lots of useful classroom strategies. Available in French and English.
Member Price: $18.45
Non-Member Price: $28.45