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The TS Press

Newsletter of Tourette Canada, Victoria Chapter





Join us for the 7th Annual Trek for Tourette Sunday, March 29th

Polish Hall, 90 Dock Street, Victoria

1pm Meet and Greet/Registration

2 pm Walk to Dallas Road

Picture taken during Victoria's Trek 2014.

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How to Reach Us

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OUR MISSION

Tourette Canada/ Victoria Chapter is a national voluntary organization dedicated to improving the quality of life for those with or affected by Tourette Syndrome through programs of: education, advocacy, self-help and the promotion of research.

OUR VISION

All people who have Tourette Syndrome will lead quality lives as accepted and valued members of an informed, tolerant society.

The TS Press is a publication of the Victoria Chapter of the Tourette Canada. The contents/articles are published as information only; members are advised that the views/presentations may not apply to each person with TS. Please consult your physician for the best treatment for you. Medical information / opinions are those of the authors and are not necessarily those of the Chapter or the Foundation. Every effort has been made to locate the copyright owners of the material quoted in the text. Omissions brought to our attention will be credited in a subsequent printing. Grateful acknowledgement is made to all publishers / authors for their reprint permission.

Calendar of Events

- Trek for Tourette March 29th, 2015
- Parent Support Group date and time TBA. Please contact victoriachapter@tourette.ca
- Mt Doug youth hike and BBQ May 3rd
- National Conference, Niagara Oct, 2016

Tourette Canada Victoria Chapter Administrative Committee

President Andrea Hasey

Secretary Jonathan Berry

Treasurer Judy Rogers

Director at Large Kate Andrzejewski

Director at Large Allison McLeod

Director at Large Elizabeth O'Hara

Director at Large Fawn Engel

Director at Large Pam Harrop

Director at Large Jessica O'Hara

TSFC Victoria Chapter gratefully acknowledges the continuing support of:



7th Annual Trek for Tourette – 2015



About the Trek

Trek for Tourette is a 5km walk held annually on the last Sunday of March in communities across Canada in support of the Tourette Syndrome cause.

It is Canada's only national fundraiser for Tourette Syndrome.

Trekkers register to trek online, creating an online profile that they can use to participate by raising pledges and winning prizes. Prizes include: the signature green toque, water bottles, and top prizes of picnic baskets, boots, & Hallmark gift baskets.

The next Trek will be held on Sunday, March 29th, 2015 at 1 pm at the Polish Hall – 90 Dock Street, Victoria.

1:00 Registration and Meet and Greet: 2:00 TREK along Dallas Road: 3 pm - Return to Polish Hall for snacks and drinks

All Community Treks are organized by local volunteer coordinators. The Tourette Canada National Office provides lots of support including: prizes, promotional materials, signage, insurance coverage and more. It's a really rewarding experience and lots of fun.

Please donate to the local Victoria Trek at: https://www.donationaid.com/victoria-trek
For further information please contact: victoriachapter@tourette.ca

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Presidents Message

The past six months have been very busy for the Victoria chapter of Tourette Canada. I have really enjoyed meeting many new families and professionals through my role as president. I feel lucky to be part of such a strong and unique community.

Lots has happened for the chapter in the last six months. A number of families from Victoria attended the National Conference, which was hosted by the Vancouver Chapter. Five families from Victoria travelled over to the Renaissance Hotel in Vancouver for a weekend of education, connection and fun. There were some wonderful speakers addressing on a great variety of topics including:

- ADHD by Dr. Don Duncan
- Positive, Strength-Based Approach by Charlie Appelstein
- TACTICS Crowd Sourced Research on TS+ by Ethan MacDonald

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Thursday night began with a variety of check-ins. The Mom's Group and Dad's Group check-ins were hosted by our very own board members Allison McLeod and Jonathan Berry. They both did a great job and I know Vancouver Chapter appreciated their support. Friday and Saturday were two full days of sessions and the weekend culminated with a fabulous banquet and dance in the Ballroom of the Renaissance. Victoria tore up the dance floor!

Our membership in Victoria continues to grow with many new families participating in our youth events and parent support groups. Our youth events have included a recent Geocaching outing with 25 participants and an earlier mini-golf outing. Our parent support group has been running every 4-6 weeks on a Sunday afternoon and remains open to those who are interested. We usually have about ten people and there has been a lot of positive feedback from the group. Watch for upcoming dates and events.

The executive of the local chapter have been busy with in-services at a number of schools in Victoria. These have included presentations to classrooms, new teachers and school staff. Recently we have been asked to play an official role with the Greater Victoria School district around TS + education and support. We are pleased that the schools have been so welcoming to our message and we look forward to strengthening our partnership.

Trek for Tourette is just around the corner. This is Tourette Canada's most important fundraiser of the year with many cities across Canada participating. The trek provides an opportunity for connection, it raises awareness, and we welcome anyone who would like to join, no matter where on the island they might live. This year's event will be held on Sunday, March 29th, at the Polish Hall in Victoria (1:00 meet and greet, 2:00 marks the start of the trek). Please join us for a fun and picturesque walk along Dallas road. Please see details in this newsletter.

Finally, you may have noticed the name change for the National office. TSFC is now officially known as Tourette Canada. Our emblem and colors have changed to blue and yellow, with the kite as a symbol, although the Trek colours and symbol (the boots) have remained the same. There was much thought and consideration given to this change by both our national office and our national board, and they are excited to launch the new look for Tourette Canada. Please be aware that new national website is still being populated with all the information they want on there, it will take a few weeks, but it already looks great.

I hope to see many of you at the Trek!

- Andrea



National Conference, Vancouver, October 2014 Reflections from local Victoria families

- The conference was so very informative and I received more information and knowledge in 2 days than I had in the last 10 years, I wish I had known and gone when my son was younger. (Victoria Parent)
- Excellent keynote speaker, Dr. Mort Doran, advocate of the Tourette Syndrome Foundation of Canada (TSFC), and named a member of the Order of Canada. (Victoria Parent)
- I got to interact with a bunch of other people with Tourette. It let me know that other people were having the same struggles I was. (Victoria Youth)
- A great weekend full of connecting with families, listening to great speakers and great dancing at the banquet (Victoria Parent)

Facebook: Our Chapter has started a Facebook page. We are just getting going, but are hoping to keep up-to-date information about family outings, support groups, and other happenings on this page. This is a closed group – all you have to do is request to join. The group is called Tourette Canada, Victoria Chapter. www.facebook.com/groups/TSFCvictoria/

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"The Monkey on My Back"

A Story of Perseverance and Success

Our son, Neil was diagnosed with Tourette Syndrome during his Grade Three year.

We quickly became acquainted with the local chapter of the Tourette Foundation of Canada which was an incredible source of support, information, and practical assistance.

With the support of the chapter, we were able to attend two national conferences, and



Neil also attended two summer camps for young people with Tourette at Camp Zajac, near Mission, BC. Through these events, our son met other young people of his own age who live dynamically with Tourette. A key moment in Neil's life was his meeting and interaction with Dr. Duncan (Dr. Dunc) McKinlay as he participated in Duncan's "Tic Orchestra" at the Edmonton conference: a life changing experience.

True to his name which means "passionate and courageous, Neil has lived a dynamic and enthusiastic life, with years in scouting, dance training, and teaching himself to play guitar and drums. He has served as a page in the Youth Parliament of BC, travelled solo to England at the age of ten, participated in summer camps throughout his adolescence, and was a member of his school choir and drama group, as well as a peer counsellor in high school.

In Grade 7, Neil won the St. Andrews School Trophy for public speaking: His topic was "The Monkey on My Back", and he spoke about his life with Tourette, humorously, informatively, and passionately. In high school, he struggled academically, but excelled in Drama and Music. His particular strength is listening with compassion to the problems of his friends. Neil graduated in June 2014 with his class, receiving an award for "Determination and Perseverance".

In his emergent year as a young adult, Neil is a student in the General Arts Program at Camosun College and holds a part-time job. He was a cast member of "A Christmas Story, the Musical" at McPherson Theatre, this Christmas, plays drums every week for mass at St. Joseph's Parish, has a delightful girlfriend and a wide circle of friends. He also has a positive relationship with his parents. (Written by Colleen Croswell)

Benefits of Membership

The local executive of the Victoria chapter has been quite busy in the last few years supporting the many causes of Tourette Canada. Our activities have included:

- hosting a successful conference with guest speaker, Dr. Duncan McKinlay
- · presenting in-services at schools throughout the lower island
- hosting youth events for our families of children with TS+
- facilitating regular parent support groups
- answering emails and phone calls from families in need of support or resources
- attending National conference and facilitating the parent check-in on the first evening
- managing the many administrative duties of the local chapter.

All of the above is done on a volunteer basis. Our executive is happy to provide this support to our community because we understand how important this kind of support is to our families. We have received support in the past and now we are able to carry on the tradition and give back.

As volunteers, the tools and guidance we receive in large part come from the National office and the fabulous talented individuals that work and volunteer there. They provide us with:

- manuals and training on parent and school support
- documents on up-to-date research and interventions for TS/TS+
- many different tools for education and awareness
- administrative support for the local chapter
- support with local media and technical advice on email, social media, etc.
- opportunities to connect with other chapters and share ideas/supports
- and when we ask, whatever the question, they do their best to provide us with a response that is both helpful and meaningful.

Given we are so dependent on them for what we know and do, we feel it is important that all of us support this cause by purchasing a membership with Tourette Canada. Not only do you help the cause of spreading awareness and support for others, you support the local chapters and their many endeavors. Membership also entitles you to: free local youth events, parent support groups; access to our resource library; and reduced fees at National Conference.

Please give consideration to purchasing a membership and supporting this great organization. www.tourettecanada.ca

Useful link: In the fall of 2013 Victoria Chapter was excited to welcome Dr. Duncan McKinlay for a series of educational workshops. This link will bring up the recording of the family workshop – a two hour presentation packed with very helpful information:

http://keltymentalhealth.ca/event/2013/10/leaky-brakes-impulse-control-related-disorders-workshop-parents-and-caregivers

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Applesauce-Oat Muffins (Gluten-Free and may be Dairy, Soy and Egg-Free)

Ingredients:

½ cup granulated sugar

½ cup butter or margarine (or coconut oil – untried but could work) at room temperature

½ cup vanilla yogurt (dairy or soy, coconut or rice)

1 cup unsweetened applesauce

2 large eggs (or egg substitute (Ener-G) works great)

2 cups Gluten Free All Purpose Flour (note – check your mix, if it doesn't have Xanthan Gum add one tsp)

1 teaspoon baking soda

2 teaspoons gluten-free baking powder

2 tablespoons (heaping) flax seed meal

¹/₄ cup certified gluten-free oats (or use quinoa flakes – always a good sub for oats)

1 ½ teaspoons cinnamon

½ teaspoon. nutmeg

½ cup baking raisins OR ¾ cup of frozen raspberries

cinnamon-sugar mixture for the tops

extra oats for the tops

Directions:

Preheat the oven to 350 F (static) 325 F (convection)

Oil or line muffin cups and set aside (makes approximately 15 regular sized muffins or 48 mini-muffins)

Combine the sugar and butter in a large mixing bowl, beating until fluffy. Add in the eggs or egg substitute, applesauce and yogurt, and mix well.

In a separate bowl, whisk together all the dry ingredients. Gradually add them into the wet ingredients and beat until incorporated. Stir in the raisins or raspberries last.

Fill muffin cups to 2/3 full and then sprinkle cinnamon-sugar and additional oats on top.

Bake for approximately 20 minutes for mini-muffins, 25-30 minutes for regular sized muffins. Transfer to a wire rack to cool completely...Enjoy!