

Bleeding Disorders Newsletter
Winter 2012



*Bleeding Disorders Program
& Hemophilia Ontario*
South Western Ontario Region

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Hemophilia Ontario – Southwestern Ontario Region

SWOR Services

Hello everyone, as you know Matthew has been working on a contract basis in SWOR since the middle of last year as I took on more responsibilities with the provincial office resulting from a sick leave. While Matthew took on the day to day tasks in the office and ran many local programs and events, Terri-Lee continued to attend clinic, run Pinecrest Adventures Camp and was able to participate in the programs and events. In December 2011, Terri-Lee and Matthew were asked, and agreed, to continue to perform their revised roles in a more permanent capacity, now when you call the SWOR office (519-432-2365) you can talk to either Matthew or Terri-Lee. We look forward to working with you in 2012.



Photo -- Karen St. Peter-Catton, Chuck Catton and their son Aidan with Matthew Maynard of Hemophilia Ontario at a tree planting commemorating the Tainted Blood Tragedy. The tree planting was held at McNaughton Avenue Public School, Chatham, Ontario

Make yourself a great day – Terri-Lee.

Membership

Hemophilia Ontario invites you to join us as a member. There is no cost to join. By becoming a member you are entitled to:

- Notification and right to attend all national, chapter and regional meetings of members
- Entitlement to vote on any vote taken by members
- Right to serve on CHS and Hemophilia Ontario Boards of Directors
- A free subscription to the CHS national newsletter
- A free subscription to Blood Matters, Hemophilia Ontario's news magazine (hard or soft copy, your choice)
- Receive regular eblasts updating what's happening in SWOR (soft copy only)

To become a member simply complete and return a Membership Form, available at clinic through your RSC, email mmaynard@hemophilia.on.ca or thiggins@hemophilia.on.ca or call 519-432-2365 to have a copy mailed to your home. If you have any questions, please do not hesitate to call the office 519-432-2365 and speak with either Matthew or Terri-Lee.

Would you like to give some time to...?

All chapters of our hemophilia society, right across the country, depend on volunteers to assist in or run various programs that meet the needs of our members living with inherited bleeding disorders. SWOR, as a region of Hemophilia Ontario, is blessed to have a staff person – but the staff person is not solely responsible for everything that takes place. Volunteers are needed!

Throughout the year we have a variety of events that occur, some to educate and inform, some to raise awareness and funding (to provide a variety of benefits for our members) and Camp Pinecrest which is a fun **and** educational time for our kids. Volunteers can give their time in a variety of ways. Some desire to be on a committee/council which means a monthly commitment. Others wish to give their time as an episodic or event volunteer. No matter which you prefer we have a place for you!

So, please feel free to send me an email, Marion Stolte, at mstolte1972@gmail.com or Matthew Maynard, our RSC (Regional Service Coordinator) at mmaynard@hemophilia.ca. We'll then add your name/phone number and email to our list of volunteers and get in touch with you. Looking forward to working with you this coming year.

Marion A Stolte, SWOR Volunteer Committee

Volunteer of the Year – Nominate the person who makes the difference!

Every year South Western Ontario Region celebrates our volunteers who contribute so much to the programs and events throughout the previous year! Each year we endeavour to recognize one person as Volunteer of the Year at our Regional General Meeting. We would like to hear from you as to who you think should be nominated to receive this special recognition. You can call or email to tell us why you think the person you're suggesting is the volunteer of the year. So, if you would please send an email **by February 15th**, to me, Marion Stolte, at mstolte1972@gmail.com or Matthew Maynard, our RSC (Regional Service Coordinator) at mmaynard@hemophilia.on.ca or call 519-432-2365, we would greatly appreciate it.

Thank you, Marion Stolte, SWOR Volunteer Committee

2012 The Year at a Glance

2012 will be unprecedented in the opportunities to participate and bring awareness to hemophilia in the region

January 25th 50/50 Draw to the London Knights vs. Kitchener Rangers hockey game

March 1st – 2nd Opening Doors – Closing the door on Stigma

March 3rd Education Conference and Regional General Meeting

April 15th Polar Bear Dip (fundraiser) on World Hemophilia Day, Little Beach, Port Stanley, ON Celebrating World Hemophilia Day by educating the community while raising funds for regional programs

April 21st Hemophilia Ontario Annual General Meeting – Ottawa, Ontario

May 25th CODErouge 1st Canadian Conference on Bleeding Disorders in Women

July Member Event –date TBA – Kustermans Berry Farm

July 8th – 12th World Federation of Hemophilia Congress – Paris, France

July 9th 5th Annual Golf Tournament for Hemophilia and Inherited Bleeding Disorders, Highland Golf and Country Club, London, ON Funds raised through this event provides training, education, financial assistance and moral support to more than 300 children, youth, and adults with an inherited bleeding disorder in our community

July 21, 2012 Ride for the Record

August 22th – 26th Pinecrest Adventures Camp, Camp Menesetung Goderich, ON This 5 day residential camping experience for children with a bleeding disorder and their siblings aged 5-15 years, provides respite to parents while providing the campers the opportunity to experience camp as all children do. The only camp in Ontario specifically designed to meet the special medical needs of these children which *includes* their siblings, offers knowledgeable and specially trained volunteer staff (medical, co-directors and counselors) on site 24 hours per day. August 21st will be a staff training and preparation day on site.

September Hemerocallis for Hemophilia September Daylilies joint regional fundraiser

September 21st – 23rd Just the Guys, Camp Ki-Wa-Y, St. Clemens, ON This three region event held at Camp Ki-Wa-Y in Kitchener Waterloo provides fathers (or male role models) and their sons from Southern Ontario (SWOR, CWOR, TCOR) the opportunity to learn more about hemophilia and other inherited bleeding disorders and meet others that face similar challenges

September Adult Education Session – TBA

October Youth Speakers Bureau - TBA

October Commemorative Tree Planting - TBA

November Winter Celebration – details TBA

November Bleeding Disorders Awareness Month

November / December Holiday Wreaths, Swags and Pots sales

December 1st HIV/AIDS Vigil

SAVE THE DATE – Saturday March 3rd, 2012

The South Western Ontario Region Education sessions and Regional General Meeting are being planned for Saturday March 3rd, 2012.

A full educational event for adults and children in the inherited bleeding disorders community of South Western Ontario and will include the Annual Regional members meeting.

Watch your mailbox for the information package coming soon.

HOY Rep required

Hemophilia Ontario Youth (HOY) is back and we need an SWOR representative. Are you an affected youth between 14 – 25 years of age living in south western Ontario? Are you able to participate in up to 4 planning teleconferences during 2012? Are you interested in helping to plan 2 provincial trips and a local activity or two with the RSC? If you answered yes, please contact Matthew Maynard at mmaynard@hemophilia.on.ca or call 519-432-2365.

Take the Plunge in 2012

Sunday, April 15th join us at Little Beach in Port Stanley, ON



Celebrate World Hemophilia Day with us by jumping in a lake! Again this year, SWOR is recognizing World Hemophilia Day with a Polar Bear Dip. Your help raises funds to support programs for the more than 300 people living with hemophilia, von Willebrand disease and other bleeding disorders and their families living in South Western Ontario.

Pledge Forms are available online at <http://events.hemophilia.on.ca/polarbear.php>

For more information or directions, contact Matthew at 519-432-2365 or Mmaynard@hemophilia.on.ca

Our Very Own Man in Motion

On Thursday, November 24th, 2011, Barry Puskas (at right) was honoured to be one of the 7000 individuals chosen across Canada to carry the Rick Hanson 25th Anniversary Cross-Canada Relay Medal in Wallaceburg.

It was a great day for all involved!



Pinecrest Adventures Camp

In 1992 Pinecrest Adventures Camp began in tents in the back yard of a cottage. Member John Meyers and Nurse Liz Clegg developed this unique program to bring together regional youth and provide them with a safe camp experience. Today, twenty years later, we continue to pay tribute to their vision and dedication to the region's youth.



This five day residential camping experience for children with a bleeding disorder and their siblings aged 5-15 years provides respite to parents while providing the campers the opportunity to experience camp as all children do. The only camp in Ontario specifically designed to meet the special medical needs of these children which *includes* their siblings, offers knowledgeable and specially trained volunteer staff (medical, co-directors and counsellors) on site 24 hours per day.

Planning for Pinecrest Adventures Camp has begun! The Camp Committee has completed the first of many meetings. We are pleased to share that Nick Higgins has been selected as the Director and Bret Rivard as Assistant Director. In the next newsletter we will share more details about our theme, staff and our exciting plans for the 20th Anniversary Gala – yes it's our 20th year and we are going to celebrate! Please hold these dates on your calendar:

What: Pinecrest Adventures Camp

When: Wednesday August 22nd arrive 6 p.m. until Sunday August 26th pick up 11 a.m.

Where: Camp Menesetung, Goderich Ontario (directions provided in confirmation packages)

Sunday following closing ceremonies we will be holding a community lunch and retrospective of Pinecrest Adventures Camp. Current and past campers and their families, volunteer staff and interested community members are invited to join us, details to follow.

Wreaths, Swags and Pots oh MY!



We have had another successful year with our Holiday Wreaths fundraiser, Sam's driveway was filled to the sidewalk! Again this year our net profits were approximately \$1800 and the feedback of our new and previous participants was fantastic. So many help with this project by collecting the orders and delivering everyone's order! Thanks to our volunteers - Kathleen, Sam, and Rob who pulled together the orders for pick up and delivery.

Thank you to Michelle and John Lepera and Karen and Chuck Catton for coordinating sales in both Windsor and Chatham, you were outstanding. And finally thank you to those that sold, and those that purchased the Wreaths, Door Swags and Holiday Pots this past holiday season. Hope you will join us next year!

You make a Difference!

Every year SWOR picks a theme for our November Appeal – this past year – You make a difference!

SWOR would like to express our gratitude to the many individuals and companies that provided support and help, sponsored events, provided prizes and participated in events in 2011. Your contribution is making a difference in our communities in South Western Ontario and beyond - probably more than you know. To Baxter, Bayer, Pfizer, and Novo Nordisk, your continued support of all regional programs has made a difference helping us to provide strong educational programming to our members.

Thank you to the Bleeding Disorders Program staff for your dedication and contributions with your ongoing commitment to individuals and families living with inherited bleeding disorders is making a difference to the whole community!

2011 has been a year of many accomplishments and opportunities. We look forward to continuing to make a difference in 2012!

Winter Celebration

December 3rd sunshine after a week of rain – the sun did not last but it did not rain. SWOR's Winter Celebration was held in Windsor at the Ojibway Nature Centre. Thanks to everyone who participated and helped out. Johnny and Julia started us off with some crafts as families arrived. We were then visited by Heather from the centre who introduced us to a fox snake and let us on one of the trails. We were joined by a local family of deer who did not seem to mind that we were in their space. We were fortunate to have Michele who is a volunteer with Lets Talk Science (<http://letstalkscience.ca/>). She had everyone making coagulating slime (no factor required). Everyone then learned the power of reaction using a pill bottle vinegar and baking soda – I am not sure who got the best bottle top launch – but the adults were up for the challenge as much as the children! Lastly Michele taught us how to get the DNA from a banana! This type of lab work is a regular part of her work for her master's research with song sparrows. It was fascinating to see what steps need to be done to be able to get DNA to test. Julia and Johnny had planned for all ages and our time together went quickly.

Special thanks to Johnny and to Julia for their work planning and working with everyone during the day. Special thanks to the Ojibway Nature Centre and to everyone who made the drive to Windsor for the Winter Celebration. If you know anyone interested in Science and in Windsor Michele is looking for more volunteers in the Windsor area to be able to participate at more schools and events like ours. We look forward to seeing you all at the Regional General Meeting in March!

PS Lets Talk Science is hoping to grow the volunteers available in the Windsor area, if you know someone in school or sciences in the Windsor area that might be interested have them contact Nicole Kaiser at nkaiser@letstalkscience.ca



Financial Assistance

The goal of the financial assistance policy is to provide exceptional financial support to people with bleeding disorders and their families to reduce the burden caused by their condition. To be eligible for financial assistance, these individuals must be members of Hemophilia Ontario or, if not, clients of one of the province's hemophilia treatment centres, and in financial need.

Financial support is generally provided to cover reimbursement of items specific to bleeding disorder needs including, but not limited to, tutoring, dental costs, medication, hospital parking, taxis to hospital, gas to attend clinic, assistive devices (e.g. Medic Alert bracelets, crutches, braces...), equipment (e.g. protective helmets), in-hospital costs (e.g. TV, telephone) and other emergency funding. Hemophilia Ontario will pay the first bracelet, first year of membership and a replacement bracelet if worn out. Lost bracelets are the responsibility of the family except under exceptional circumstances.

Hemophilia Ontario is the payer of last resort and will first of all attempt to have these costs covered by other social agencies including government. When an individual's costs are to be reimbursed by a social agency at a later date, Hemophilia Ontario can enter into an agreement whereby the funds are advanced and then later recovered.

Each year, Hemophilia Ontario allocates a set amount of money for this fund and once these funds are exhausted, no further claims will be processed in that year. For information about the new guidelines or to receive the Financial Assistance Forms to complete and submit with receipts, please contact your local RSC.

Freedom of Information and Protection of Privacy Act (FIPPA)

On January 1, 2012, Ontario hospitals become subject to the *Freedom of Information and Protection of Privacy Act* (FIPPA).

The purpose of FIPPA is to provide the general public with a right of access to information held by institutions, while protecting the privacy of individuals whose personal information is held by institutions.

Medic Alert Information

With the arrival of FIPPA it is felt that the distribution of Medic Alert information to the Canadian Medic Alert Foundation should now be the responsibility of the patient/guardian. Medic Alert can be reached at www.medicalert.ca or 1-800-668-1507.

[Factor First Wallet Cards](#) have in most cases replaced the Medic Alert wallet cards. These are updated at annual assessments and/or as treatment information changes. Included on the card are your name, diagnosis, treatment options and Bleeding Disorders contact information. In the event of an emergency you should present the card to Emergency Room staff. This information will be helpful in updating your Medic Alert should you wish to do so.

Let's Talk About

Many patients of the local Bleeding Disorders Program do come to London Health Sciences Centre for an annual assessment – many do not. As patients graduate from the pediatric program to the adult program, graduation from attending annual assessments also seems to occur.

Recently, within the pediatric program, team members have begun chatting informally with older adolescents about lifestyle choices, including alcohol and drug usage, sexual relationships, and other issues which at times can be difficult or embarrassing to talk about with family, friends or healthcare providers. This is our attempt at assisting our younger patients at becoming empowered in asking for information or assistance at any time, without fear of being lectured at, talked down to, or moralized. These conversations are not always easy, as we have known most of these young men since infancy or toddlerhood – but we are trying to step out of traditional instructional roles and open up some dialogue. Intimate personal issues and choices can be difficult to navigate for any adolescent (or adult); and can be even more challenging to those with hemophilia. Our goal is to try to talk openly with our patients about the choices they may be thinking of making – and to help assess the risks and benefits which might be associated with any lifestyle choice. As well, we are hoping to foster a sense of trust with our patients, so that if they find themselves with a healthcare issue related to any activity choice, they will not delay seeking our assistance in managing these issues. Our role as healthcare team members in the Bleeding Disorders Program is not to judge our patients, but rather to ensure that they receive appropriate and timely healthcare.

It is our hope that by engaging in frank and open discussions with our younger patients, many of them will continue to return for ongoing assessment once they have graduated to the adult program. Hopefully they will see our team members as a resource for any physical/psychological questions they may have – and will not avoid annual assessments for fear of being lectured at.

Please know that we are not limiting our willingness to discuss these topics to our adolescent patients. As a healthcare team, we are open and willing to discuss challenging topics with our adult patients as well. Hopefully we will be able to provide you with straightforward answers or suggestions for any questions you may have about sexual activity, relationships, tattooing, piercing, drug and alcohol use, and any other topics which may be affected by your Bleeding Disorder. We are willing to discuss these issues with you in a non judgemental manner – and appreciate your feedback if we are not totally successful in minimizing the moralizing!

If you are looking for an online resource that may answer some questions around these topics, please check out Bayer's "Speaking Frankly about Hemophilia" website – www.frankly.net. This website does offer reliable information written by young men for their peers. And, as always, please feel free to discuss any issue of concern with the healthcare team members from the Bleeding Disorders Program.

Mary Jane Steele, PT, Physiotherapist, Bleeding Disorders Program
maryjane.steele@tvcc.on.ca



On Thursday October 27, 2011 South Western Ontario Region of Hemophilia Ontario planted its third tree in Chatham Ontario as part of the memorial forest across the country and in commemoration of the tainted blood tragedy. We were honoured by



McNaughton Avenue Public School's entire staff and students participation in our planting ceremony. Aidan Catton, a student at the school, was joined by his extended family and Matthew Maynard to remember, honour and celebrate those impacted in the local and hemophilia community by the tainted blood tragedy. If you would like to know more about the tree planting ceremonies across Canada please visit:

<http://www.hemophilia.ca/en/commemoration-of-the-tainted-blood-tragedy/>

Photo - Karen St. Peter-Catton looks on as Chuck and their son Aidan are finishing the tree planting, commemorating the Tainted Blood Tragedy

World AIDS Day 2011

SWOR participated in the World AIDS Day vigils in Stratford on November 30th and in London on December 1st (the actual World AIDS Day). Matthew Maynard spoke about the impact of HIV and the tainted blood tragedy on him personally, on his family, and also the impact on SWOR and the Canadian Hemophilia Society. The focus of the Vigils was Remember – Honour – Celebrate – Cure. The transmission of HIV and hepatitis as a result of the treatment transfusions was a new awareness for many of the participants.



Western Ontario Opening Doors Counselling Initiative presents...

Opening Doors: Closing the Door on Stigma, March 1 & 2, 2012

This is an excellent opportunity to further our understanding of the stigma that accompanies the HIV virus and reflect our own biases.

[Click here to register today http://woodci.eventbrite.ca/](http://woodci.eventbrite.ca/) or contact Matthew 519-432-2365 for more information about this event.

WOODCI is proud to have Louise Binder, Lawyer, Activist and PHA, joining us as our Keynote Speaker at dinner on Thursday March 1st.

Louise's impressive HIV advocacy and outreach includes involvement with such great organizations as: Toronto People with AIDS Foundation, Provincial Women's AIDS Organization, the Canadian Treatment Action Council, the Federal Ministerial Council on HIV/AIDS, the Community Advisory Committee of the Canadian HIV Trials Network, Blueprint for Action on Women and Girls and HIV/AIDS, the Canadian Advisory Committee for the HIV+ Children's Hospital Project, Global Coalition on Women and AIDS Leadership Council and is currently vice-chair of Voices of Positive Women.



To view a short clip of our Keynote, Louise Binder, click [here](#)

I am a survivor!

Survivor benefits for spouses and children of long-term survivors covered by the Multi-Provincial Territorial Assistance Program (“MPTAP”)

→ Were you directly infected with HIV through the blood system?

→ Are you covered under the MPTAP compensation plan?

→ Did you marry or have children since September 15, 1993?

If you answered yes to these questions we need to hear from you.

In the late 1980's the Multi-Provincial and Territorial Assistance Plan (MPTAP) was introduced. It included a survivor benefits for the spouse and dependants of the primarily infected person. Spouse and children were defined as the spouse as of September 15, 1993, and dependant as a natural child as of September 15, 1994 or adopted child as of September 15, 1993. Following the death of the primarily infected person the spouse as defined is entitled to \$20 000/yr. for 5 years. Dependants are entitled to \$4000/yr. for 5 years for each child that is under 18 or between 18 and 25 and attending a secondary or post secondary educational institution full-time.

At this point there are an unknown number of directly infected long-term survivors who may have married or entered a spousal relationship or had children since September 15, 1994. **We would like to find out how many of our members are in this situation.**

If you signed the MPTAP agreement and have subsequently married, your new spouse or any children born are not entitled to survivor benefits! The Canadian Hemophilia Society would like to hear from you if you are in this particular life situation. Some of our membership have expressed a desire to seek modification to the MPTAP agreement for those long-term survivors who have decided to start a family.

If this applies to you, we want to help. The CHS is prepared to lobby provincial and territorial Health Ministers with a view to extending survivors benefits to **all** spouses and children of directly infected long-term survivors covered by the MPTAP including those spouses and children who were not part of the claimant's lives at the time of applying and being accepted under the plan. The advocacy work would be undertaken by a task force (small working group) and overseen by the CHS National HIV-Hepatitis committee.

At this point in time we would like to hear from anyone in our membership who is in this situation – a ‘head count’ will be useful during the lobby process. Any information you provide to the CHS is kept in the strictest of confidence; no personal information will be divulged during the lobby process

We are also looking for those individuals who are prepared to join the working group and help bring this to fruition. One of our members, Marc LaPrise, will be leading the working group that will be helping to advise the HIV-Hepatitis Committee as they coordinate the lobby effort. *This is your chance to stand up for your rights as someone who was infected through the blood supply and wants to take responsibility for their new role in life as a mother or father or life partner.*

Contact Michel Long at mlong@hemophilia.ca or 514-848-0503 ext. 225.





IMAGINE

The sound , vibration, and excitement to see nothing but bikes as far as the eye can see !

Well that is happening with 18, 000 or 32 kms of nothing but bikes. Come out and help Hemophilia Ontario break the world record of the



LARGEST PARADE OF BIKES !

Saturday, July 21, 2012
Western Fair District, London, Ontario



REGISTRATION FEES: \$30.00 for bike and \$40.00 for bike with a passenger.

Fees include an official Guinness Ride T-shirt, secure motorcycle parking while you enjoy live entertainment (bands/comedians) contests and food. (Secure parking extends until 3 pm the following day.)

Early Bird Draw: July 1st 2012 (then the prices rise by \$10.00 per person)

ACCOMMODATIONS: Discounted accommodations for out of town riders available at the Hilton, London, Ontario. (For reservations please call: 1-800-210-9336).

For camping options see website for details.

ENTERTAINMENT: Comedians Al King and Paul McCullen then listen to the music of Pete Dorian, Murmur, Bender and Bonfire. Headliner TBA



REGISTER NOW: Call toll free: 1-888-838-8846 or register online at www.ridefortherecord.ca.

For more information, email Brendon at recordride@gmail.com.

All proceeds from this Guinness World Record Event will go to Hemophilia Ontario, whose mission is to improve the health and quality of life for all people with inherited bleeding disorders, and to find a cure.



A great day of contests & prizes !

See Web Site for Sponsorship, Vendor Areas, Club Tables and Volunteer Opportunities

Web Site: <http://www.ridefortherecord.ca/>