

A publication of



Hemophilia Ontario  
Hémophilie Ontario

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VOLUME 8 • NUMBER 1

# BLOOD *matters*

Help Stop the Bleeding

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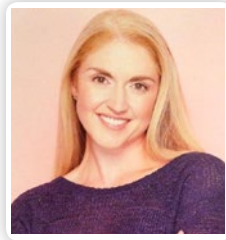
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Hemophilia Ontario  
Hémophilie Ontario

Hemophilia Ontario is a certified chapter of the Canadian Hemophilia Society



## President's Message

by Maia Meier

Our most important responsibility is staying connected with our community. The recent Canadian Inherited Bleeding Disorders Needs Assessment helped us connect with you to learn your hopes for the future. This needs assessment took a cross Canada approach to collect as much information as possible. The process also had the benefit of ensuring Hemophilia Ontario is using our limited resources effectively and not duplicating efforts of our partners.

Ontario led the way as we cast a wide net to gain as much community input as possible on "What's Next?". We e-blasted, posted to social media and our website, and tried to get our YouTube video to go viral! For those offline we promoted the surveys at events and held consultations with our Regional Councils. At each stage, drafts of the plan were posted to the website for comment. Every piece of input during the process was recorded and a response document was posted making our best effort to respond to all input. As a final plan neared, a consultation was held in Ontario which welcomed all staff and volunteers to participate.

We are committed to keeping you informed of our goals and progress. You'll notice our list of goals frequently posted in Blood Matters and the progress on these goals are posted in our annual report. The Board regularly reviews our goals and in consultation with our community the goals may be adapted to respond to ever changing needs.

This year we've taken steps to stay more connected with our community. We have a new Board of Directors email address ([secretary@hemophilia.on.ca](mailto:secretary@hemophilia.on.ca)) to which you are encouraged to bring questions or comments to the Board. In addition to regular updates in Blood Matters we have posted regular Board updates in our monthly e-blasts.

In 2017 we've prioritized a governance audit to earn accreditation from Imagine Canada. This will ensure we are meeting best practice standards for Boards. You'll notice a list of Board and Board Committee members listed on our website and regularly in Blood Matters. We are looking forward to community consultations throughout the province to hear your ideas and suggestions to aid in reaching our goals for the future. And we encourage you to participate in the engagement survey you will read about in this magazine.

Your participation is what keeps us on track and fuels us to keep going. We're always striving to do better! If you have good ideas, we want to hear them. Watch for Board Members in our red shirts at community events. We're eager to connect with you and hear your story!

Maia Meier

President, Hemophilia Ontario 📌

# What's in this Issue?

Spring 2017 Volume 8, Number 1

- 02 Leadership Messages
- 04 Hemophilia Ontario News
- 08 Bleeding Disorders & Research News
- 09 HIV/AIDS & Hepatitis C News
- 10 Hemophilia Ontario Youth (HOY)
- 11 BleedHERS
- 11 Regional Highlights
- 11 Hemophilia Ontario Calendar
- 12 How To Get Involved



## Executive Director's Message

by Jenna Foley

My first letter in Blood Matters! Since joining Hemophilia Ontario in December 2016, there has been a nonstop flurry of activity. My focus in the first three months was to meet as many people as I could, and learn as much about the programs and services we deliver as possible. It has been a wonderful experience and the members of the community have been so warm and welcoming; I am looking forward to meeting everyone and learning about how we can work together and grow Hemophilia Ontario in the coming years.

There is an incredible opportunity this year to shape Hemophilia Ontario into an organization that is meeting the needs of its members, bringing people together, and advocating for continued improvements in care. The bleeding disorders community's strongest asset has always been its people, and all of you readers are part of that continuing tradition.

Throughout 2017, we are going to deliver the programs everyone is used to seeing. It's important for me to learn about them directly and for the membership to recognize that Hemophilia Ontario will continue to be the organization they know and value. But we are also going to spend this year talking to stakeholders, evaluating our progress, and developing a version of Hemophilia Ontario that can be more effective in years to come.

We want to hear from you, your families, people who are no longer involved, and people who have never been involved. We will look at everything: staffing structure, policies and procedures, programs, and communication formats. There will be opportunities for you to have feedback at every level from the nitty-gritty to broader values conversations and establishing overall organizational priorities.

There is a survey available now online (<http://hemophilia.on.ca/>). This is the first step of our engagement process, but it will continue throughout the year. After the Annual General Meeting on April 8th, we will be having a Social Summit to provide feedback in a relaxed, informal, small-group environment. We will have a series of focus groups in June, available in each region of the province, to dive deeper and get more specific input. Look for updates on the status of the survey in each issue of Blood Matters this year, and please attend a webinar to be held in late November or early December that outlines the overall engagement process outcomes, the changes that are being implemented, and a preview of programming for 2018 as a result.

If anyone has questions or suggestions at any time, I would encourage you to reach out to me and start a conversation. I am looking forward to meeting as many individual members as possible this year, building relationships, and growing Hemophilia Ontario as a team. Please don't hesitate to be involved: to learn, to share, and to be part of the journey. ♦

Thank you to our sponsors:

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PROGRAMS



## Hemophilia Ontario Annual General Meeting

Please join us on Saturday April 8th, 2017 at 10:00am for our Annual General Meeting

Things you can look forward to:

**Presentations by:**

**Dr. Robert Klaassen**

**Dr. Michelle Sholzberg**

**Social Summit & Rountable Visioning**

**Lunch**

### Board Nominations

This year three regional (SWOR, OEOR and CWOR) delegates and two directors at large will be elected. If you are interested in being a Board Member or if you wish to nominate someone to stand for election, please contact Jenna Foley, Executive Director for a nomination and/or proxy form. ♦



**Hemophilia Ontario**

*please join us*

### Annual General Meeting

**Saturday, April 8, 2017**  
**St. Andrew's Club and Conference Centre**  
 150 King Street West, 27<sup>th</sup> Floor  
 Toronto, ON M5H 1J9

9:30am Registration  
 10:00am Annual General Meeting  
 12:00pm Lunch  
 1:00pm Guest Speaker – Dr. Michelle Sholzberg

3:00-5:00pm Roundtable Visioning and Social Summit  
*Join us downstairs at Earl's after the AGM for snacks, drinks, and a chance to meet other members, share your ideas, and identify Hemophilia Ontario priorities for the coming years.*

**RSVP to Susan Turner by Monday, April 3, 2017**

Email: [sturner@hemophilia.on.ca](mailto:sturner@hemophilia.on.ca)  
 Toll-Free: 888-838-8846 ext 11

## We Want to Hear from YOU!



**H**emophilia Ontario is launching a multi-phased engagement process this year. The first step is taking 5-10 minutes to complete our anonymous survey. You can access the survey here: <http://hemophilia.on.ca/>

### We want everyone to fill this out!

That includes patients, family members, long-time volunteers, and people who have never been involved before. Please take time to complete the survey and distribute it to your contacts in the bleeding disorders community.

### Results will be shared throughout the year in each issue of Blood Matters.

It is as important for us to let you know what we have heard as it is for us to hear it. Not only that, but your input will have a direct impact on future programming decisions. Join us for a webinar later this year to learn about how we are implementing your suggestions.

### This is just the beginning...

Stay tuned for more engagement and feedback opportunities throughout the year, including a focus group series coming to a location near you in June 2017. ♦

## CHS Rendez-vous Sponsorship 2017

**T**he Canadian Hemophilia Society (CHS) is bringing Rendez-vous to Toronto this year! The conference will take place May 25th-28th, 2017. Rendez-vous will feature presentations, workshops, and exhibits on cutting-edge trends in research and treatment for hemophilia and other inherited bleeding disorders.

Rendez-vous is an invaluable opportunity, in only one weekend, to gain new knowledge at the medical and scientific sessions and community workshops, to network with peers and friends, to visit the pharmaceutical industry exhibits and to participate in the CHS Annual General Meeting. You can find more detailed information about Rendez-vous here.



**RENDEZ-VOUS**  
**TORONTO** 2017  
 MAY 25-28 MAI

## **Hemophilia Ontario will sponsor two individuals to attend, to a maximum of \$2000 to assist with:**

- \* Registration to Rendez-vous 2017;
- \* Hotel accommodation in Toronto at the conference location, arriving on May 25th and departing May 28th, based on single occupancy;
- \* Banquet ticket for one person (additional guests are at delegate's own expense);
- \* Transportation based on the most economical option based on the recipients' home location.

## **Because of the opportunity presented by hosting Rendez-vous in our home province, Hemophilia Ontario is offering a partial subsidy of up to \$500 for an additional three individuals.**

*For both the \$2000 and \$500 subsidies, selected delegates must submit receipts for reimbursement.*

### **Eligibility criteria for all sponsorships:**

- Applicant must be a person with hemophilia, von Willebrand disease, a rare factor deficiency, or a platelet function disorder, including carriers, their immediate family members, or long-time volunteers;
- Applicant must be able to communicate in English or French, the official languages of Rendez-vous;
- Applicant must have been an active volunteer in the inherited bleeding disorders community for at least the past year;
- Applicant must be committed to volunteering with Hemophilia Ontario for at least the next two years;
- Applicant must agree to attend all conference activities, including medical symposium, CHS Annual General Meeting, and community education sessions;
- The selected candidate will provide a report to the Hemophilia Ontario Board of Directors within one month of the conclusion of the conference, explaining the knowledge gained at the conference, and how Hemophilia Ontario might use this knowledge to enhance our mission;
- Within one month of the conclusion of the conference, the selected candidate(s) will write an article for Blood Matters sharing their experience with the inherited bleeding disorders community.
- The selected candidate's fulfillment of the latter three criteria will be considered by Hemophilia Ontario when reviewing future applications for funding opportunities.

**The deadline for applications is April 9, 2017.** To submit an application, please go to:

<https://hemophiliaontario.typeform.com/to/GuT1fw> 💧

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## International Twinning Projects

by Marion Stolte

Over the years Canada as a country, various provinces as well as clinics have been active in twinning with other countries. Our desire has always been to lend our strength and what we have learned over the years to help other countries move forward in achieving greater health, greater advocacy and an increased ability to be self-sustaining in hemophilia care.

Currently there are four organizational twins – three with provinces and one with National. Three of them are in their final year of twinning. Each one has had unique challenges yet there have been similarities such as language and cultural differences to be aware of and to work through. As well, transportation to and from clinics and hospitals is a challenge and technology can be a boon or bust! So, patience and willingness to try new avenues for connecting is vital. Key word: flexibility!

- 1) Hemophilia Ontario with Tanzania – final year of twinning. There has been an increase in the PWH diagnosed along with the implementation of a patient registry. People are beginning to self-infuse as they now have access to products via WFH's Humanitarian Aid program. There has also been an offering of a medical symposium in collaboration with the HTC twins. The society is also beginning to use "whatsapp" to help members communicate more easily with one another and help eliminate the sense of isolation.
- 2) Manitoba with Mongolia – second year of twinning. Strategic planning, education days with a focus on women and children, plans for a physiotherapy workshop are some of the activities being accomplished. During this session they used a hot/cold pack video (with a translator) and then passed out hot/cold kits as well as tensor kits. Ingredients in each kit were donated by various CHS-MB volunteers, friends, family, church community. They are also effectively collaborating with other agencies such as: the American Center for Mongolian Studies, WFH, WHO and Canadian Embassy in Mongolia.
- 3) Quebec and Nicaragua – final year of twinning. There have been many challenges, due to political issues, with last minute cancellations or with promises that haven't turned into action (plans for an HTC medical training or for government purchase of clotting factor products). Using Facebook proved to be a more reliable form of communication.

- 4) CHS and Bangladesh – final year of twinning. Much has been accomplished, including patient needs assessment survey; increased numbers of PWH identified; success of HSB educational programs; using technology to give three webinars; strategic planning workshops along with volunteer and youth leadership development sessions. For the final year, the focus is on developing and implementing four national committees: volunteer development, youth leadership, fundraising and communications. This is being done by a point person in CHS and HSB taking one of the areas and moving it forward, with the rest of the twinning committee encouraging and offering resources.

How exciting to see the interest there is to invest in lending our strength to others. Through twinning we are reminded of the importance of not taking for granted what we have here in Canada – the excellent care for those with bleeding disorders. In fact, it wasn't that many years ago that we faced similar struggles with hemophilia care and the stigma that has been attached to living with this condition. Volunteering and serving others in the larger, global community brings with it inner joy and satisfaction. Let's keep up the excellent work in our country and our provinces so that we can be strong for others!

Marion Stolte

Chair, International Projects Committee

Chair, CHS-HSB Twinning Committee ♦



## Twins of the Year!

**H**emophilia Ontario and the Hemophilia Society of Tanzania have been awarded Twins of the Year for 2016. The award is granted to the organizations that demonstrate a high level of commitment to the partnership, excellent communication, teamwork, and achieved objectives.

Congratulations to all those involved for your dedication and hard work on this endeavour! ♦



## Invitation to Your Shared Experience

*by Matthew Maynard*

**W**e held our first meet up of the all Ontario adult network for adults with a bleeding disorder in Toronto on Sunday March 5th. It was a chance to share and hear the lived experience, to ask your questions or answer one or two, in a safe, respectful and inclusive network. The topics covered ranged with participation from those in their 20s to 60s, with some good stories, some funny stories, and some not so good or funny. We touched on the need for community-based research and for advocacy as individuals, as an organization and in our communities.

This is just the beginning. We will have other meet ups throughout the province this year, and will be exploring together other opportunities to make this network accessible to all.

Would you like the next meet up closer to your contact Marc Laprise, volunteer lead or Matthew Maynard, Facilitator. You can call, or text (519.432.2365) or email [mmaynard@hemophilia.on.ca](mailto:mmaynard@hemophilia.on.ca) ♦

## 5 New Webinars to Help You Live Better

Hemophilia Ontario is pleased to present a series of educational webinars for individuals, families and caregivers affected by bleeding disorders.

You can participate in all the webinars in 2017 or just the ones that are of interest to you.

|                  |  |
|------------------|--|
| <b>April</b>     | Pain Management and your bleeding disorder   |
| <b>June</b>      | Maintaining an active and healthy lifestyle  |
| <b>September</b> | Individualized and Personalized Approach to Therapy  |
| <b>November</b>  | New Treatments on the Horizon  |
| <b>December</b>  | Hemophilia Ontario: A look at the results of the 2017 engagement process and an overview of 2018 programming |

Don't see the topic you just want to learn about, explore, or just get the facts? Contact us!

Subscribe to our email list, follow us on Facebook and Twitter, and keep an eye on our website for information throughout the year on specific dates and how to participate in the webinars. ♦

## HO is Going Green!

Please consider going green by joining our email list! Help the environment as well as Hemophilia Ontario while still receiving your favourite magazine – *Blood Matters* and you'll also receive all of Hemophilia Ontario's program notifications too.

Please contact Susan Turner, Administration and Programs Coordinator, at 1-888-838-8846 ext. 21 or [sturner@hemophilia.on.ca](mailto:sturner@hemophilia.on.ca) to ensure you continue to receive this newsletter.

## Ontario Government's Patient & Family Advisory Council

Ontario is establishing a Patient and Family Advisory Council to advise government on health priorities that have an impact on patient care and patient experiences in Ontario.

The council will involve patients, families, and caregivers in the policy development process, ensuring that their needs and concerns are understood, and will help the health system become more responsive, transparent and accountable. Members of the council will be chosen through an open public process and will represent Ontarians from across the province.

The deadline for Patient and Family member recruitment is April 10th, 2017.

You can find more information at:

<http://health.gov.on.ca/en/public/programs/pfac/default.aspx> ♦



## The Standards of Care

As a member or patient of the inherited bleeding disorders community, you may be familiar with the Canadian Comprehensive Standards of Care, but just in case you aren't, or need a refresher, we're here to help!

The Canadian Comprehensive Standards of Care are used by your Hemophilia Treatment Team, and guide best practices for the treatment of your inherited bleeding disorder. They specifically outline who your core team members are, and who your extended team members are. The standards also highlight the services available and responsibilities of each treatment centre. These are all really important features for the optimization of your own inherited bleeding disorders care.

To access the complete Canadian Comprehensive Standards of Care document, you can visit the Canadian Hemophilia Society's website where you will find it listed under the Care & Treatment tab. For the direct link, you can access it here:

<http://www.hemophilia.ca/en/care-and-treatment/comprehensive-care-standards/> ♦

# Hemophilia Ontario's Financial Assistance Policy

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. Please note that submitted requests must directly reflect the individuals bleeding disorder related needs. Hemophilia Ontario reserves the right to contact medical personnel for addition information as necessary when considering submitted requests.



Financial support is generally provided to cover reimbursement of items including, but not limited to, tutoring, dental costs, assistive devices (e.g. MedicAlert bracelets, crutches, brace), equipment (e.g. toddler protective headwear), in-hospital costs (e.g. telephone and TV) and other emergency funding. Hemophilia Ontario will pay for a first time MedicAlert bracelet and the first year of membership and replacement bracelets if they are worn out. Lost bracelets are the responsibility of the family, except under exceptional circumstances.

Hemophilia Ontario is the payer of last resort. Members are required to attempt to have these costs covered by other social agencies including medical plans and the government. Hemophilia Ontario reserves the right to request copies of such documentation in support of the submitted request. 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 that year. Requests submitted by December 31st will be considered pending availability of funds. We are unable to carry claims over into the following year.

For information about the guidelines or to receive the Financial Assistance Forms to complete and submit with receipts, please contact your local Provincial Coordinator. 💧

Bleeding Disorders & Research News

## What is the Congenital Bleeding Disorder Factor Concentrate Working Group (FCWG)?

by Sarah Crymble, Hemophilia Provincial Coordinator

There are many committees that work year round in the background to improve the care of patients with bleeding disorders and to understand the utilization of clotting factor concentrates. The FCWG is a subcommittee of the Ontario Blood Advisory Committee (OBAC). OBAC is an external advisory group to the Provincial Agencies Trillium Gift of Life/Blood & Specialized Programs, formally the Blood Programs Coordinating Office.

The FCWG is a multidisciplinary advisory group with a mandate to develop effective and efficient factor concentrate utilization practices with a goal of reducing wastage and optimizing use in Ontario.

As a multidisciplinary group, the committee consists of an adult and pediatric hematologist, Nurse Case Manager, patient advocate, a representative from both the MOH and CBS, and the Hemophilia Provincial Coordinator.

To meet the committee goals the group:

- Reviews available date
- Makes recommendations for improvements in data collection and analysis
- Reviews evidence-based guidelines and standards
- Reviews new and anticipated products
- Connects with other provincial and national organizations.

For more information on the Congenital Bleeding Disorders Factor Concentrate Working Group, please contact your patient representative Matthew Maynard (mmaynard@hemophilia.on.ca) or committee member Sarah Crymble (crymbles@smh.ca). 💧

# A Big Thank You from the Factor Concentrate Redistribution Program

by Sarah Crymble, Hemophilia Provincial Coordinator



**W**e are nearing the end of the national product switch and the majority of the patients in Ontario have made the transition to a new product. This was an enormous undertaking for the province, consuming additional patient time and human resources from the clinics.

This was also a time where we needed to ensure we were reducing the national stock of FVIII product before all patients had made the transition. Ensuring the majority of products were infused has greatly decreased the potential wastage that could have occurred without managing the transition.

The Canadian Blood Services reached out to the Factor Concentrate Redistribution Program (FCRP) and our counterparts in British Columbia to assist in depleting the remaining FVIII product before all patients transitioned.

In October 2016 we were asked to assist with approximately 6,000,000IU of two FVIII products. With the diligent work of the clinic nurses and data managers, we have been able to utilize over 5,500,000IU to date. By supporting the smaller provinces as they transition we were able to ensure little to no wasting of a valuable resource. We are not completely finished and I don't know if we can use 'every last drop' but we will try to.

We thank those who have delayed their transition, those who have mixed multiple vials to make a dose and clinics for taking calls from the FCRP day after day asking to utilize just a bit more product.

Collectively ensuring little to no wasting benefits everyone and a BIG thank you from the FCRP.

Sarah Crymble & Antonette Travas 💧

HIV/HCV News

## Hemophilia Ontario Stakeholders of Canadian Blood Service

by Matthew Maynard

**T**here are many ways Hemophilia Ontario and you are stakeholders in Canadian Blood Services. Members participate in recruiting new donors, sharing their stories of how the services and products are making a difference every day, and volunteering with a local blood donor clinic are just a few of the many ways we as individuals and together are supporting the safe and secure blood services in Ontario.

We are represented on the Ontario Nunavut Regional Liaison Committee (ONN RLC), to share the concerns and support of the bleeding disorder community. Willy Van Klooster, Co-Chair ONN RLC states:

*"This November will mark 20 years since Justice Krever released the report of The Commission of Inquiry into the Blood System in Canada. One of his key recommendations was the formalization of a mechanism for Canadians to provide ongoing input and feedback to the then new Canadian Blood Services. The Ontario Nunavut Regional Liaison Committee is one of four across our country with representation from donors, recipients, healthcare professionals associated with blood products, those connected to organ transplants and other ordinary Canadians who meet for two full days annually to provide input and feedback into the blood system to ensure the safety and sustainability that Justice Krever envisaged."* 💧

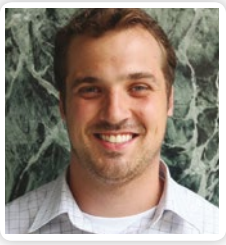


## HCV Settlement Agreement

by Matthew Maynard

**S**till have concerns for you or your family members impacted by hepatitis C? The distribution of support has started from the court decisions of 2016. For a great summary see the article in the latest edition of Hemophilia Today ([http://www.hemophilia.ca/files/HT\\_MAR\\_52\\_1\\_FINAL.pdf](http://www.hemophilia.ca/files/HT_MAR_52_1_FINAL.pdf)) by Francois Laroche. For full details on the rulings and the latest developments on the HCV Settlement Agreement, visit the website [www.hepc8690.ca/home-e.shtml](http://www.hepc8690.ca/home-e.shtml)

If you or someone you know has questions please contact Matthew Maynard Provincial Coordinator of Adult Services. You can text or call 519-432-2365 or email: [mmaynard@hemophilia.on.ca](mailto:mmaynard@hemophilia.on.ca). 💧



## Blood Safety & Supply Committee Update

by Paul Wilton

The Blood Safety & Supply Committee is a CHS committee that is responsible for staying abreast of the latest research and scientific developments in blood, blood products and their alternatives, emerging pathogens and transfusion safety measures. Below is an update from Ontario's committee representative, Paul Wilton:

- A new variant Creutzfeldt-Jacob Disease (vCJD/CJD) test shows promise.
- Research on Hepatitis E virus shows the highest risk is in the community from food and water.
- Ireland has moved to a 1-year donor deferral for MSM, combined with a 5-year deferral for anyone reporting a Sexually Transmitted Disease.
- The Emicizumab Phase III Haven I trial has attained its primary endpoint showing significant reduction in bleeding among patients with inhibitors using emi prophylactically
- Afstyla (Single-chain FVIII from CSL Behring) was licensed in Canada in December.
- Texas researchers reported promising pre-clinical results with oral delivery of Factor IX.
- Uniqure reported data on second cohort of 4 hemophilia B gene therapy patients but did not provide expression levels.
- Fitusiran (RNA interference, Alnylam) reported positive results from 16 inhibitor patients. No adverse effects were reported.
- Spark/Pfizer reported additional Phase I/II trial results with hemophilia B gene therapy. Two patients out of 9 showed rises in ALT levels but these were successfully controlled with a short course of steroids, not affecting FIX expression. ♦

Our Hemophilia Ontario Youth program is currently in a rebuilding phase. This program is available for youth ages 16-26 who are affected by a bleeding disorder. We are committed to building a group that will be directly involved with the bleeding disorders community and organization.

In 2017, we will be holding a youth summit in Toronto. We want to hear what youth have to say and what kind of programming they want to see in the future. Does this sound interesting to you? Do you know someone who would be interested, or do you have ideas you'd like to share with us? We want to hear from you!

Please contact Alex McGillivray at [amcgillivray@hemophilia.on.ca](mailto:amcgillivray@hemophilia.on.ca) with your feedback. ♦

### Hemophilia Ontario Youth (HOY)



## The CHS James Kreppner Memorial Scholarship & Bursary Program

To honour James Kreppner's memory, the Canadian Hemophilia Society (CHS) Scholarship and Bursary Program has been renamed the CHS James Kreppner Memorial Scholarship and Bursary Program. James was a lawyer and long-time volunteer and member of the CHS Board of Directors and a highly respected, articulate and exemplary activist who passed away in 2009 due to HIV and hepatitis C-related complications. The CHS James Kreppner Memorial Scholarship and Bursary Program is an on-going tribute to honour James' dedication, intelligence and commitment to the CHS and community service.

The application deadline is April 30th, 2017. To access the scholarship criteria and the application form, please visit: <http://www.hemophilia.ca/en/support-and-education/james-kreppner-scholarship-program/> ♦

## National Endowment Fund - University of Ottawa

The objective of this award is to provide financial assistance to students registered in a post-secondary program in a recognized Canadian institution whose lives or families were affected by the tainted blood tragedy between 1980 and 1989 inclusively. The amount of the bursary may vary according to the number of applicants in any given year.

The application deadline is April 30th, 2017. To access the fund's criteria and application form, please visit:

<http://www.hemophilia.ca/en/hcv-hiv/national-endowment-fund-scholarship--university-of-ottawa/> ♦



**Hemophilia Ontario will be hosting it's Wellness for Women: W2 conference in 2017. Please make sure you save the following date and spread the word!**

Regional Highlights



**W**e've been busy across the province over the winter months with activities taking place in every region. In late January and early February, TCOR and OEOR families enjoyed watching an OHL game. TCOR got a chance to watch the Mississauga Steelheads, and for OEOR it was the Ottawa 67's. TCOR families also had a blast taking part in an interactive education session done by Pam Hilliard, physiotherapist at SickKids.

March has also been a busy month as all of our regions held their Regional General Meetings. Some of the highlights include presentations by various leaders within our communities. Ottawa families learned all about Navigating the ER from Heather Perkins, Nurse Coordinator at CHEO. Families in TCOR enjoyed learning about leading a healthy lifestyle with a presentation called A Practical Guide to Living a Healthy

Life by Heather Gardner, Toronto Fitness Leader, and in SWOR, Dr. Jardine, Hematologist of the Bleeding Disorders Program at London Health Sciences gave an excellent presentation on The Future of Bleeding Disorders Care.

TCOR also recognized two volunteers for their outstanding service to the community in 2016. Congratulations to Neil Mentuch on receiving the President's Award for his professionalism during a transitional time, and to Paul Golding on receiving the Community Volunteer Award for his dedication to the TCOR Hemophilia Golf Classic.

Thank you to all of our 2016-2017 volunteers, including those who have retired from their positions, and thank you to all of the new volunteers who have joined us as council members for the 2017-2018 year. We look forward to working with you! 💧



Hemophilia Ontario Calendar



SUNDAY APRIL 23 - SWOR Polar Bear Dip

SATURDAY APRIL 29 - Sudbury Spring Hemophilia Clinic

JUNE - Hemophilia Ontario Focus Groups (Cross province locations)

SATURDAY JUNE 24 - CWOR & TCOR Annual Zoo Walk

JULY 30 - AUGUST 26 - YMCA Camp Wanakita (C1, C2 & C)

AUGUST 23-27 - Pinecrest Adventure Camp

SEPTEMBER 15-17 - Just the Guys Weekend

SEPTEMBER 20 - OCTOBER 1 - Women's Wellness Weekend


Dates are tentative and may be subject to change.

# How to Get Involved ...

Hemophilia Ontario welcomes the interest of individuals in our organization. The Board of Directors is elected at our Annual General meetings for a one year term. Each region elects a Regional Council at their Regional General Meeting.

**For further information please contact:**

**Hemophilia Ontario**, 4711 Yonge St., 10th Floor, Suite 10100, Toronto, ON M2N 6K8

 [info@hemophilia.on.ca](mailto:info@hemophilia.on.ca)

 [@HemoOntario](https://twitter.com/HemoOntario)

 [/HemophiliaOntario](https://www.facebook.com/HemophiliaOntario)

 [/HemophiliaON](https://www.pinterest.com/HemophiliaON)

 [HemophiliaOntario](https://www.youtube.com/HemophiliaOntario)

 [hemophiliaontario](https://www.instagram.com/hemophiliaontario)

# How You Can Help ...

Your generosity is the key to providing programs and services to individuals with inherited bleeding disorders. No other organization in Ontario offers these supports to those living with and / or affected by inherited bleeding disorders. With your passion, commitment and dedication we know we can make a difference.

**HERE ARE SOME OF THE WAYS YOU CAN HELP:**



## DONATE

Make a donation, please visit:

<http://events.hemophilia.on.ca/payments.php>

Donate monthly through direct debit or on your credit card

If your employer has a charitable donation program, have an amount taken off each pay cheque

Leave a bequest in your will



## FUNDRAISE

Volunteer at a fundraising event, such as Bingo

Join an event, such as the Polar Bear Dip, and obtain sponsors

Nominate Hemophilia Ontario as your company's charity of the year



## CAMPAIGN

Become a Hemophilia Ontario campaigner. Tell your family, friends and colleagues about our work



## VOLUNTEER

Become a Hemophilia Ontario volunteer. Each and every one of our six regions across Ontario are always looking for volunteers to become active and involved. Give a little bit of time, or give a lot. Whatever time you can give will be greatly appreciated.



**Hemophilia Ontario**  
**Hémophilie Ontario**

HEAD OFFICE

4711 Yonge Street, 10th Floor, Suite 10100, Toronto, ON M2N 6K8

[www.hemophilia.on.ca](http://www.hemophilia.on.ca)