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Hémophilie Ontario

BLOOD *matters*

Help Stop the Bleeding



We're Here to Help



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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

Well into 2018, we have begun work on our priorities and objectives for this year. We have several exciting new programs and initiatives that are underway, especially at the regional level. Please watch for details on our social media accounts and in this newsletter. I hope you are able to attend the events in your area!

Our Advocacy Committee is continuing to work on various objectives to improve the care and treatment at each of our clinics around the province. This continues to be one of our main priorities, working to obtain the resources that are needed and to eliminate the gaps.

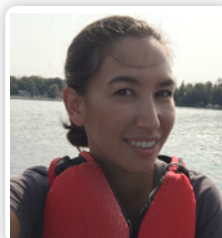
Spring, brings our RGMs across the province. I encourage everyone to come out and participate in your regional educational day and meeting as well as meet our newest program staff member, Natalie Philbert!

We also have our Chapter AGM on April 14th in Ottawa. This will be a great opportunity to come and meet your new board for this next year, learn what Hemophilia Ontario will be focusing on and participate in our educational sessions that day. We are pleased to welcome Dr Alan Tinmouth, who is giving a presentation on "Decision Making and the Future of Bleeding Disorder Treatments in Canada".

I look forward to an exciting and successful year with everyone in our bleeding disorders community!

Maia Meier ♦

President
Hemophilia Ontario



Executive Director's Message

by Jenna Foley

Spring is coming, I can feel it. New life, new growth, new ideas – it is my favourite time of the year.

Hemophilia Ontario has so much to share with you this season; I hope you are as excited as I am. With our upcoming Regional General Meetings, combined with education about Peer Support and how members will be able to support and be supported directly by other members in the near future, as well as our Annual General Meeting with some very forward-thinking presentations, and an all-new staffing model, Hemophilia Ontario wants to serve the community as best we possibly can. We are responding directly to the input we received throughout last year: local engagement opportunities and connecting with other members.

We have restructured the staff roles and responsibilities to better reflect our respective strengths and focus on creating strong partnerships. The biggest partnership we have is with our members – we continue to want to hear from you. If you have thoughts, ideas, concerns, or suggestions at any time, please let us know. The landscape of bleeding disorder care is shifting in a major way and we want to be able to provide the support our members need most.

In this issue of *Blood Matters*, you can read the personal story of a young man with Severe Hemophilia A who was treated with gene therapy in the UK two years ago and has not had an infusion since. You will also meet our new Provincial Coordinator, Programs who is eager to redevelop the networks and local activities at a regional level. There is an opportunity for you to share your thoughts about the recurring tender processes and the impacts of repeated product switches with Ministry of Health officials.

Let's move into the new season together and hopefully feeling warm and sunny about the changes that are underway and still to come.

Jenna Foley ♦

Executive Director
Hemophilia Ontario

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Want to continue receiving a hard copy of Blood Matters by mail?

Please contact Jenna at 888-838-8846 ext 17 or jfoley@hemophilia.on.ca

Thank You

Thank you to our pharmaceutical partners, whose support makes Blood Matters and our many other programs possible.



Bioverativ

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For the safe and optimal use of human proteins



Letter from the Editor

by Tom Beer

"Whether you think you can or think you can't, you're right."

Henry Ford

"I think I can, I think I can, I think I can!"

The Little Engine That Could

Being the Best That You Can Be

What matters to most of us, (and our parents), is living your best life by living up to your potential. BUT... as Henry Ford stated, you must believe that you can, and then, "do" now, the things you set out to do "some day".

As the directors and leaders in HO know, and, as we can see in both Jenna Foley's and Maia Meier's messages there is a great deal of planning and implementing of new programs underway. New programs and initiatives such as Peer Support are underway, and, staff roles and responsibilities are revised to better assist current and new members to manage the shifting landscape of "bleeding disorder care." Making these the best they can be, by delivering the best care and treatment possible, continues to be the goal of the organizations involved with the bleeding disorders communities.

But, as is implied in their messages, "the best" is a moving target. When teaching English, I would remind myself and the students that being an excellent reader in Grade 2 was admirable, but to be an excellent reader in Grade 12 demanded more, more insight, more analysis, more connectiveness to their world. "A man's reach should exceed his grasp, or, what's a heaven for?" (R. Browning). Excellence moves, and, for those directly impacted, the expectations of those being served change as their needs and understanding of their current state develops.

What's happening now is addressed so positively by Obayed Khan in his account of his changing life as a result of gene therapy. As he affirms, "...it's nice to have the option" to live his best life.

Read on...

Tom Beer ♦
Contributing Editor
Hemophilia Ontario

Hemophilia Ontario Financial Assistance Program

Hemophilia Ontario has a long history of providing financial support to members in need through a variety of programs or funds. With decreasing revenues and a health care landscape that continues to evolve, Hemophilia Ontario has rewritten its policies to ensure it can continue to support those most in need.

To receive the complete policy in your preferred format, contact Jenna Foley at 888-838-8846 x 17 or jfoley@hemophilia.on.ca. An overview of the changes included in the new Financial Assistance policy include the following:

- The elimination of the Now Experience Wellness (NEW) program funding, which previously supported physical activity opportunities for youth;
- All applicants must now seek approval prior to purchase in order to be considered for funding. Hemophilia Ontario will not reimburse for expenses already incurred;
- All transportation and parking assistance will be funded directly to the clinics and patients may inquire with their clinic team for support as required;
- Assistance is limited to two grants per

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calendar year per household with a combined maximum of \$750 being available for financial assistance;

- In an effort to respond to requests more quickly, all applications will be handled directly by the Executive Director and decisions made in no more than three business days

Hemophilia Ontario continues to provide financial support, based on availability of funding, to help defray the costs of:

- Expenses incurred in bleeding disorder care, including treatment or prevention of bleeds;
- Emergency transportation services to HTC's;
- First-time MedicAlert products and registrations; and
- Other related expenses determined to be appropriate by Hemophilia Ontario.

Applications can be made by email, fax, or online at:
<https://hemophiliaontario.typeform.com/to/XIQ45m>

OTHER ONTARIO FINANCIAL ASSISTANCE PROGRAMS

Ontario Health Insurance Plan (OHIP)
1 866 532-3161
(Service Ontario INFOline)
Ontario residents are eligible to access healthcare services provided by the Ministry of Health and Long-Term Care.

Ontario Public Drug Programs
1 866 532-3161
(Service Ontario INFOline)
Ontario residents receive drug benefits from Ontario's drug programs. The province has six different programs.

The Trillium Drug Program
1 800 575-5386
This program helps people who have high prescription drug costs relative to their household income.

OHIP+
Beginning on January 1, 2018, OHIP+ will provide free prescription medications for children in Ontario under the age of 25. Beyond the most common

prescriptions, OHIP+ will give children and young people access to more than 4,400 drugs reimbursed under the Ontario Drug Benefit Program, including medications funded through the Exceptional Access Program, at no cost.

Drugcoverage.ca
This website offers information on reimbursement for prescription medications by providing information on the various types of private insurance plans, provincial/ territorial drug benefit programs, drug funding by provincial cancer agencies, and federal drug plans available in Canada.

Canada Revenue Agency – Medical Expenses
1 800 959-8281 (Income Tax Enquiries)
Individuals or a spouse or common-law partner may be able to claim the total eligible medical expenses incurred on their annual income tax return. Keep all receipts.

Ontario Disability Support Program
1 888 789-4199
This program helps people with disabilities who are in financial need pay for living expenses, like food and housing.

Ontario Works
<http://www.mcsc.gov.on.ca/en/mcsc/programs/social/ow/>
or call your local Ontario Works Office
If you are in temporary financial need, Ontario Works can provide you with money, and help you find a job.

Canada Pension Plan – Disability Benefits
1-800-277-9914 (Service Canada)
Canada Pension Plan (CPP) Disability Benefits provide a monthly taxable benefit to contributors who are disabled and to their dependent children.

New Provincial Coordinator of Programs: Welcome Natalie Philbert!

Hemophilia Ontario is pleased to introduce, Natalie Philbert, the new Provincial Coordinator, Programs. Natalie's diverse education and lengthy professional experience brings many skills to Hemophilia Ontario. She received an Honours Bachelor of Arts Degree (B.A.) in 1998 and a Master's of Arts Degree (M.A.) in 2001, both from Wilfrid Laurier University. Natalie has previously been employed in coordinating roles, as well as, many years experience in program development and delivery. She is a Registered Social Service Worker with the Ontario College of Social Workers and Social Service Workers.

Natalie spends her personal time with her family. She enjoys travel and embarking on new adventures. She also brings a particular passion to Hemophilia Ontario, given her own personal experiences with a genetic bleeding disorder. Natalie was diagnosed when she was 18 years old with Von Willebrand Disease and she continues to grow and learn from this diagnosis. Natalie is looking forward to her new role!



Member Support Update

First things first, please take the time to complete our online membership form:

<https://hemophiliaontario.typeform.com/to/ZA0tIX>

Whether you have been a member for 1 month or 20 years, help us make sure we have your most recent contact information!

If you would like a hard copy of our membership form, please contact Matthew Maynard, Provincial Coordinator of Member Support at mmaynard@hemophilia.on.ca or 888-838-8846 ext. 15.

If you have just been diagnosed, going to school, getting started in the workforce, or planning your retirement, Matthew can provide you with any additional support you may need in relation to your bleeding disorder. He can also help you register with a clinic, access community services, and provide support for individuals impacted by HIV/HCV.

Adult Network Update

The goal of the Adult Network is to create opportunities that offer perspective and validation of others by sharing one's own personal story. The Adult Network aims to create a safe, inclusive, and non-judgemental place where members feel comfortable discussing their lived experiences.

Who Is the Network For?

- Adults diagnosed with a bleeding disorder
- Spouses of someone diagnosed with a bleeding disorder
- Parents of children with a bleeding disorder

Why participate?

Each gathering is an opportunity to share, learn, and support and be supported. For more information, contact Matthew Maynard, Provincial Coordinator of Member Support at: mmaynard@hemophilia.on.ca or 888-838-8846 ext. 15.

Member Engagement Update

The first few months of 2018 have been filled with meeting friendly new faces and greeting old friends at clinics around the province. We have started to standardize our clinic presence and attendance at all the Hemophilia Treatment Centres across Ontario.

Alex McGillivray, Provincial Coordinator of Member Engagement, will provide on-site support during clinic visits, assist you with financial assistance claims on-site, and connect you to the appropriate contacts for any questions you may have around Hemophilia Ontario and its programs/services.

Alex has been communicating Hemophilia Ontario's work through the organization's social media accounts and our monthly member e-newsletters. Make sure to follow us on Facebook, Twitter, Instagram!

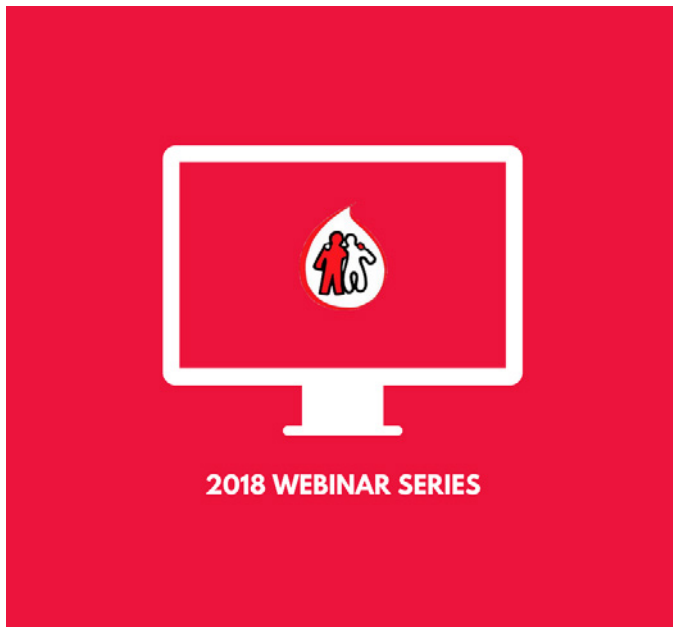
 www.facebook.com/HemoOntario

 @HemoOntario

 @hHemophiliaontario

Monthly Member E-Newsletter Sign Up:
<http://ow.ly/2wxD30idHxs>

Do you have ideas for social media posts, or topics you want to see covered in our monthly updates? Contact Alex directly at amcgillivray@hemophilia.on.ca or 888-838-8846 ext. 14.



2018 Webinar Series

Planning for our 2018 webinar series is underway. Stay tuned for more information about our webinars through our social media accounts and monthly member updates. A schedule with topics should be posted shortly!

Do you have a particular topic in mind? Contact Matthew Maynard, our Provincial Coordinator of Member Support at mmaynard@hemophilia.on.ca or 888-838-8846 ext. 15!

COMMUNITY CAMP VOLUNTEERS NEEDED

Do you have ideas and want to help shape our programs?

Hemophilia Ontario is looking for volunteers to join our Community Camp Committee and help plan this year's program!

Committee meetings are held by teleconference once a month and about 30-60 minutes in length.

For more information, please contact Natalie Philbert, Provincial Coordinator of Programs at: 519-501-4076
or nphilbert@hemophilia.on.ca.

APPLY BY: MARCH 31

Liam Barbour Scholarship Award

The Liam Barbour Scholarship Award is \$500 available to any Hemophilia Ontario members from the CWOR area in their first year of post-secondary education. Eligible applicants must be affected by an inherited bleeding disorder and actively involved with the organization. The deadline for applications is June 30th, 2018. The amount of the award will be evaluated on a yearly basis.

To receive an award, students must send the following information to jfoley@hemophilia.on.ca. Proof of post-secondary registration will be required. The award will be paid in the first week of September 2018. Applications for the 2018-2019 school year will be available in August 2018.

To be completed by student

Family Name: _____

Given Name: _____

Mailing Address: _____

City/Town: _____

Province: _____ Postal Code: _____

Home Phone: _____

Email: _____

Name of School Attending: _____

Address of School: _____

City/Town: _____

Province: _____ Postal Code: _____

Course Curriculum Entered/Major: _____

Fresh Pine Project Update



The FreshPine Project, funded by the Ontario Trillium Foundation has various initiatives for 2018. One of those initiatives is looking to create new local youth engagement opportunities.

By completing this short survey you can let us know what events you would like to see in your community: <http://ow.ly/gBzP30ieKoo>

Hemophilia Ontario Zoo Walk

Save the Date! On June 23, 2018 we'll be heading to the Toronto Zoo for our annual Zoo Walk. All regions and all members welcome. Stay tuned for more information on how to register and how to fundraise. We hope to see you soon!



Gene Therapy: One Man's Story

by Obayed Khan

My name is Obayed Khan; I live in Birmingham in the U.K and I was born with Severe Haemophilia A, the same as both my older and younger brothers. As of February 2016, after my gene therapy treatment, I've not needed to give myself any more doses of Factor VIII for bleeding episodes. This is pretty good news for me since I can't really use either arm due to nerve damage in my left arm from a tumour I had when I was three and so I was unable to actually infuse myself at all.



Currently, I work as a teacher for adult learners, which isn't the most physically demanding job in the world. The only risks of bleeding I usually had to worry about were when I handed out safety scissors and, thankfully, I'm not inept enough to injure myself whilst doing that.

I was informed about the gene therapy study by my doctor, who told me about it because they were currently looking for someone with Severe A and I happened to fit the bill. Apart from my Haemophilia, I have no other major health problems or allergies, and I'm in relatively good shape for someone who visits the gym less often than Halley's Comet visits the earth.

The procedure itself was just one really long injection and then I had to take steroid tablets for a short period of time, but that was it really. I have regular hospital visits for blood tests every four weeks so they can monitor my Factor VIII levels and so far there have been no problems at all. Before the treatment, my levels were under 3%, but my most recent test was 50%. I know the idea of gene therapy sounds very sci-fi but it was actually pretty straight forward. It took about half an hour to inject it all and all I did was sit there and ask the doctor overseeing the procedure about the drawings of various animals in her notepad while we waited.

The most noticeable difference in my life since my treatment is that my veins are no longer as scarred as they were from all my Factor VIII injections. I also have the luxury of being able to travel

Bleeding Disorders & Research News

without worrying about bringing my medication with me in case of emergencies, and now I can take up more dangerous hobbies like sword fighting. I mean, I probably won't but it's nice to have the option.

I fully intend to take advantage of all the new possibilities that are now available to me since I no longer have to worry about bleeds. I'm looking to maybe start a new job abroad (don't tell my current boss) and maybe even get a tattoo (don't tell my mum).

For more information on the trial, the results were published in the New England Journal of Medicine in December 2017:

<http://www.nejm.org/doi/full/10.1056/NEJMoa1708483>

**LEAVE NO PIN STANDING
BOWLING EVENT 2018!**

WHAT: FUNDRAISER FOR HEMOPHILIA ONTARIO
WHEN: SAT APRIL 14 | 3PM TO 5PM
**WHERE: WEST PARK LANES, 1205 WELLINGTON ST W,
OTTAWA**

REGISTER WITH SUSAN TURNER AT
STURNER@HEMOPHILIA.ON.CA OR 416-972-
0641 OR ONLINE AT
[HTTPS://OAN.AKARASIN.COM/OTTAWABOWL
2018](https://oan.akaraisin.com/ottawabowl2018)

Hepatitis C Class Action Update

You may have noticed a national Notice Campaign through television and supplemented by a public relations campaign and social media to alert late claimants of their ability to make a claim under the HCV Late Claims Benefit Plan. Please visit www.HepCclassaction.ca or call 1-866-353-4003 for more information. These new claimants have until March 31, 2025 to begin the application process.

If you or a family member is already a claimant you can get up to date information at <http://hepc8690.ca/> or contact Matthew Maynard, Provincial Coordinator Member Support at mmaynard@hemophilia.on.ca or 888-838-8846 ext.15.



LET'S TALK PERIOD

Let's Talk Period

Let's Talk Period aims to increase awareness of the signs and symptoms of bleeding disorders. As many as 35,000 Canadians may be suffering from a bleeding disorder, but many of these may not understand if their bleeding is normal or abnormal and, therefore, do not seek help. Through her internationally recognized research program at Queen's University, Dr. James, Hematologist at Kingston General Hospital, and her team have developed a self-administered bleeding assessment tool (Self- BAT) that will help inform people about their bleeding and guide them toward the help they need.

Do you experience the following with your periods?

- Having to change protection more than every hour
- Iron deficiency (anemia)
- Frequently soaking the sheets
- Periods consistently lasting longer than 7 days

If you answered yes to one or more of the questions above, you should consider visiting the Let's Talk Period website to take their Self-BAT: www.letstalkperiod.ca

Hemophilia Ontario Youth (HOY)

Hemophilia Ontario Youth (HOY) Program

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.

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 with your feedback.

Hemophilia Ontario Calendar

Hemophilia Ontario Annual General Meeting

April 14, Ottawa

Peer Support Education Sessions

TCOR – March 10, Toronto
 CWOR – March 11, Hamilton
 SWOR – March 17, London
 OEOR – March 25, Ottawa
 NOR – April 21, Sudbury

Women's Bleeding Disorder Care Education Sessions

Coming to all regions in May/June 2018

Community Camp

Camp Wanakita – October 12-14

Pediatric-Adult Transitions Education Sessions

Coming to all regions in November 2018


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

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

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

How You Can Help ...

Want to continue receiving a hard copy of Blood Matters by mail?

Please contact Jenna at 888-838-8846 ext 17 or jfoley@hemophilia.on.ca

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

To 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.



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