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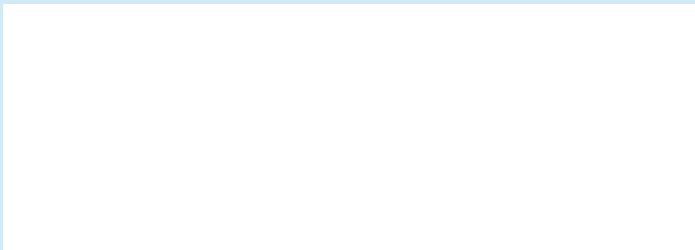
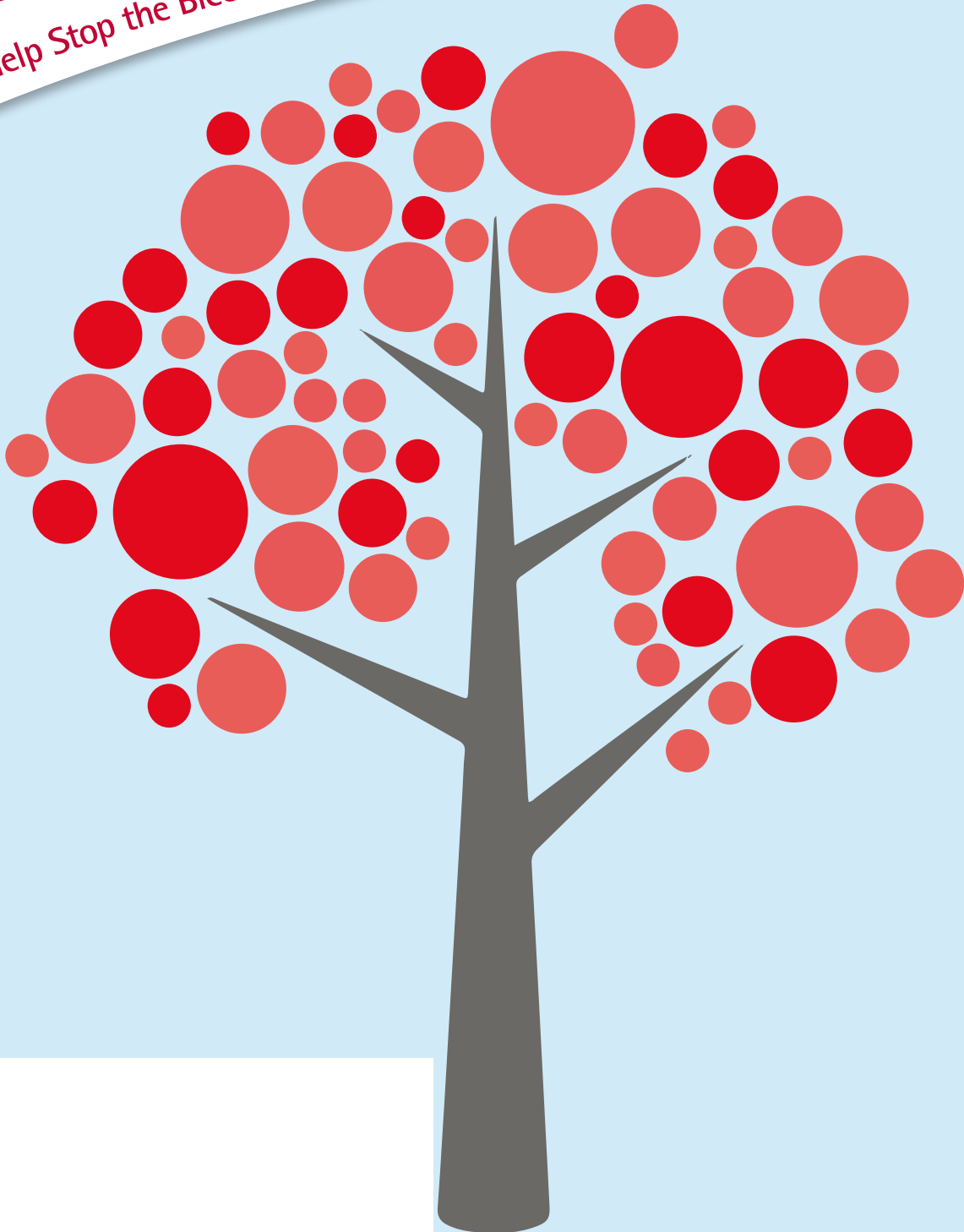


Hemophilia Ontario  
Hémophilie Ontario

SUMMER 2017  
VOLUME 8 • NUMBER 2

# BLOOD *matters*

Help Stop the Bleeding



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Provincial Coordinator  
Northern Programs and Supports

Art Direction/Design and Printing  
Pinpoint Publications

### PUBLISHED BY

Hemophilia Ontario  
4711 Yonge St, 10th Floor, Suite 10100  
Toronto, ON Canada M2N 6K8  
416.972.0641 or 1.888.838.8846  
Fax: 1.888.958.0307  
www.hemophilia.on.ca

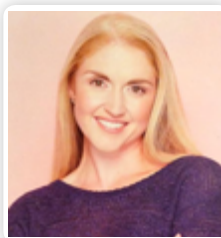
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Hemophilia Ontario  
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Hemophilia Ontario is a certified chapter of the Canadian Hemophilia Society



## President's Message

by Maia Meier

Connection. It's been the theme of this year so far, in connecting with our community members around Ontario, our friends in our bleeding disorders community across the country and also our healthcare partners in our clinics and hospitals. Over the past few months things have been very busy with the completion of our RGM's around the province and our provincial AGM in Toronto. Thank you to those that were able to attend these meetings. It was a pleasure to meet and have some great discussion and feedback on how we're doing and where we're headed.

We completed our provincial advocacy workshop in conjunction with CHS which allowed us to take an in-depth look at our results from the centre assessments. This has led to the creation of an Advocacy Committee which has already met to begin its work.

We were excited to be the host province for CHS Rendez-vous 2017. This was an incredible event combining medical and scientific sessions, community workshops on Aging, Advocacy and Chapter Development, and the CHS AGM. Hemophilia Ontario had excellent representation at this weekend; it was great to see so many people there to learn, network, and connect with others involved in our bleeding disorders community.

A member engagement process has started with an online survey. If you haven't yet done so, I would encourage you to take 10 minutes to complete it and let us know your thoughts. The next step in this process is the focus groups that are being held in multiple locations across the province through the month of June. Again, I encourage you to sign up, come out and discuss what topics and issues you feel are most important as we look to plan our future direction with Hemophilia Ontario.

Summer feels like it's finally here! And with that, things slow down a little for us. But, we still have events coming up including our camps, so please check our social media for posts and updates. I wish you all a happy, healthy summer!

Maia Meier



## Executive Director's Message

by Jenna Foley

If a job can be compared to a relationship, Hemophilia Ontario and I have passed a small milestone: the six-month anniversary. Getting to the half-year mark means both parties have usually had a chance to see each other through high and lows, given some thought to the future, and, generally, feel like they really know each other.

So what do I know about Hemophilia Ontario? I know this is a strong organization, with a long history and some recent challenges. The community has deep roots and generational involvement. While there is an attachment to and appreciation for the programs and activities of the past, there is also a desire for fresh ideas, better use of modern technologies, and increased connection at the local level.

Although it's not for me to say what you know about me, I hope you know that I want to understand the community and ensure our transformation meets its emerging needs. In the last six months, you may have seen that I am not afraid to have difficult conversations, to hear criticism, and to push for action in areas that were overlooked in the past. Overall, my objective is to be approachable, transparent, and inclusive. Am I meeting those goals? Let me know what you think at [jfoley@hemophilia.on.ca](mailto:jfoley@hemophilia.on.ca) any time.

And so, what are our thoughts about the future? Where do we go from here? 2017 continues with our ongoing engagement process, and I do encourage everyone to participate in the many forums we have available. I will be learning more about our traditional programs this fall at both **W2** and **Just The Guys** (more information about both of those can be found in this issue). I am working on a funding strategy to provide long-term stability and diversity in revenue streams, as well as examining how we allocate our current resources to be the most efficient possible.

As part of our online, educational webinar series, I hope you join me at the end of the year for an overall view of our engagement results and the program plan for 2018. December 2017 will mark our one-year anniversary, and I think it will be a great time to look back on how far we have come and how far we can go together.

Jenna Foley

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## Letter from the Editor

by Tom Beer

In the novel "Howard's End" by E.M.Forster, when asked for a definition of education, one of the characters responds, "...only connect..." How fitting that President Maia's message reminds us of the year's theme. What the readers are asked to do is connect their thoughts of the past, with their hopes, aspirations, and visions of the future in our organization. I've used this phrase as a theme, almost as a mantra. It talks, simply, about how we

learn, i.e. only connect what we know with new information and we'll see new opportunities, and become aware of new vistas in our lives and in the ways we live.

But, new is not comfortable. Change is not comfortable. "The world is full of people whose notion of a satisfactory future is, in fact, a return to the idealised past." Robertson Davies

Such is the dilemma of change. To those involved in the engagement process, in the focus groups, and in gathering and interpreting all the information, here is your challenge.

With these opportunities to express yourself, you can influence the future of HO and, more importantly, the future of those with inherited blood disorders. We cannot go back. As you are aware, the sources and amounts of government support are being reduced. Programs and delivery modes are being modified to reach more by using the latest technologies, with webinars and eblasts and postings. We are moving forward.

Helen Keller once said, "The only thing worse than having no sight is having sight but no vision". This edition of Blood Matters is focussed on the vision of connecting with the blood disorders communities, hearing and sharing accomplishments and concerns in an effort to remember the past, to see the present and to develop a "vision" of a shared future, and, to prepare a plan based on a shared belief in what can be.

It's become clear to me, as time has passed, that people's dreams of what can be are rarely, if ever, determined by what is. We must look beyond ourselves and our present, to imagine, to encounter, and to reach out to the "unknown".

The next years are not likely to be easy, nor are they likely to be agreeable, comfortable or acceptable to all. That's the realist in me speaking. That's the dilemma of change.

Some fear it, some see it as a challenge, but all recognize that things will not stay the same. To measure change one acknowledges where you were, recognizes where you are, looks ahead to where you wish to be, and identifies what needs to be kept, what needs to be discarded, and what is needed to move on.

The challenge for HO leaders is not going to be getting input. It is not going to be interpreting the information gathered from the focus groups. It is not going to be melding the results from all these sources with financial constraints, regulatory guidelines and local expectations.

No. Once we accept where we want to be, and how we might get there, the challenge for our leaders, for our boards, for all of us with investments and interests in HO, will be to "get 'er done". No bafflegab, no jargonized language, no hypotheses. Instead, clearly stated goals, clearly stated plans to reach those goals and clearly stated measurement standards and tools to evaluate progress must be used.

Albert Einstein, acknowledging the human need for simplicity and clarity, said it best, "If you can't explain it simply, you don't understand it well enough."

Tom Beer, Contributing Editor ♦

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Hemophilia Ontario

# Social Summit

An event held April 8th, 2017 to solicit feedback from members  
Input was funneled into three categories:



## GOOD NEWS

Things in the bleeding disorders community that are working well and should be recognized or celebrated



## NEEDS IMPROVEMENT

Areas where efforts are currently being made but are not being successful



## NEW IDEAS

Anything that Hemophilia Ontario is not currently doing but should consider

# GOOD NEWS

Results from our Social Summit feedback session



## Comprehensive Care

"Focus on comprehensive care"

"Love my access to physio at SMH"

## Camp

"Camp = Leadership"

"Kids camp where fun and activities are the focus, NOT the bleeding disorder"

"Love camp and that we are getting kids there"

## Involvement

"Willingness of volunteers to fundraise"

"Getting new people involved in the Board/committees"

"Increase in women in leadership roles"

"Enhanced commitment to entertaining multiplicity of voices"

"Engagement survey"

## Opportunities

"Can we extend the umbrella to other related diseases"

"Invigorated approach to accepting new ideas"

"Online applications for events are user-friendly (ie Rendez-vous sponsorship)"

# NEEDS IMPROVEMENT

Results from our Social Summit feedback session



## Clinic Attendance

"Current Hemophilia Ontario clinic attendance model does not work"

"Never see people at clinic (Hemophilia Ontario staff) "

## Website

"Our website needs better/nicer design, be more user-friendly, mobile accessible"

"Website is dismal. Needs to be vibrant, easy to access, links to joining/connecting with others"

"Better or new website needed"

## Engagement

"Information dissemination: # engagement"

"Need more member involvement in Kingston area and programs"

"How to engage different members? We see a lot of the same faces. How do we get the others?"

"Limited community engagement"    "More face-to-face"

"Engage new families/parents"    "Maia needs to introduce herself"

"Newly diagnosed families need to be connected to other more seasoned families"

"Return of new parent and peer-to-peer support groups and programming"

# NEEDS IMPROVEMENT

Results from our Social Summit feedback session



## Advocacy

- "Hemophilia Ontario should focus on advocacy"
- "Resume advocacy leadership roles"
- "Improved awareness of needs of women with bleeding disorders"
- "Increase recognition of importance of sustaining product availability"

## Education

- "Public Awareness Broadcast about bleeding disorders (The Social – Marilyn)"
- "Internet/e-learning with videos and instructions for new families, not just research papers and binders"
- "Webinars included for meetings (AGM, presentations)"

## Relationships

- "No "Us" and "Them" (Ontario vs CHS)"
- "Skilled volunteers"
- "How to transition great camp leaders to Hemophilia Ontario leaders"
- "Be part of solutions rather than barriers"
- "More "We" work together"

## Other

- "Data collection"
- "Lack of knowledge on bleeding disorders at Emergency departments at hospitals"
- "Learning to thrive in a post-tragedy world"

# Hemophilia Ontario

# NEW IDEAS

Results from our Social Summit feedback session



## Research / Advocacy

- "Opportunity to engage in patient oriented research"
- "What are the lobbying laws in City of Toronto and federally and do they affect our advocacy?"

## Programming

- "Just for Girls: Moms and bleeder daughters"
- "Resources for daycare and school education"
- "Parent sessions or activities at camp"

## Fundraising

- "Volunteer based fundraisers vs. heavy staff involvement"
- "Third party fundraising" "Fundraisers that are done province-wide"
- "Cooking class fundraising" "New funding strategies"
- "Financial support from insurance company"

## Engagement

- "Relationships: non-family, couple"
- "Explore new ideas in youth engagement"
- "New Board members"



## Now What

by Jenna Foley

On April 8, 2017, following the Annual General Meeting, Hemophilia Ontario hosted a Social Summit and Roundtable Visioning session for members and stakeholders. The goals for the session were:

1. Members from across the province can meet, share, and discuss in an informal setting;
2. Those conversations lead to ideas about how to improve Hemophilia Ontario programs and service delivery;
3. Members have an opportunity to share what is important to them personally and help shape a vision for Hemophilia Ontario's future direction.

As you can see, we had a lot of participation and began some critical conversations. The input generated from the session also contributed towards shaping our upcoming Focus Groups across the province.

Immediate action is being taken in the following ways:

- Planning is underway to reintroduce a peer-to-peer or family mentorship program for newly diagnosed families early next year;

- An Advocacy Committee is meeting and beginning to work on both provincial and local priorities. More information is available in this issue of *Blood Matters* about their plans;
- A fundraising strategy is being developed to ensure future stability with more diversity in revenue streams for the organization;
- Feedback and engagement processes continue to be offered all year. If you haven't had your voice heard yet, it is not too late. Contact Jenna directly at any time at 888-838-8846 x 17 or [jfoley@hemophilia.on.ca](mailto:jfoley@hemophilia.on.ca) to discuss your preferred method of involvement.

If you are interested in hearing all the outcomes from our 2017 engagement project, as well as getting a sneak peek at our 2018 programming that will be implemented as a result of what we learn, please join our final webinar of the year (late November or early December). Be sure to subscribe to our email lists and follow us on social media to learn how and when to register.

Thanks to Bayer for their sponsorship of the Social Summit and to all the attendees who participated. 💎



## Welcome New Hemophilia Ontario Board Members

### Bojan Pirnat

Bojan Pirnat is a mild Factor VIII hemophiliac originally from the Manitoba Chapter who came to Ontario as a graduate student and

decided to stay after completing his MA. Before coming to Toronto he served on the CHS-MB Board of Directors for 3 years and sat on the Communications and Youth Committees.

He is currently part of the National Bangladesh Twinning Committee and recently his work to build a Youth Committee in Bangladesh with his Twinning Counterpart was chosen as a WFH pilot project to twin Canada and Bangladesh's youth committees.

He also sits on the National Blood Safety and Supply Committee, has

recently joined the Advocacy Committee for Hemophilia Ontario, and sits as a member of TCOR Council.

"My life and my family's life were made immeasurably better by the Hemophilia society, and I would like to put the skills I have acquired to good use helping to maintain and exceed standards of care and service-delivery to people with bleeding disorders. I think it's important for everyone who has benefited from the hard work of previous generations to give their time and effort to make sure the Hemophilia society will always be there to support people with inherited bleeding disorders."

Bojan works at a fashion industry firm and has lately been spending his free time reading biographies, listening to comedy podcasts, and cooking.



### Darlene Villeneuve

Darlene Villeneuve has previous experience as a Board member of 25+ years and delegate to Ontario. She is a committed fundraiser who is employed by the Ottawa Catholic school board as an Educational Assistant. Darlene has hemophilia factor nine and one son with it as well.



### Ryan Kleefman

Hemophilia has always been a very influential part of my life. Having hemophilia has its impacts on the way I live, but the hemophilia community definitely has much further reaching influences. From Pinecrest summer camp to holiday parties, Hemophilia Ontario has always been there. Moving from training to be a camp counselor to becoming camp director to taking

a place on the regional council, I've always been looking for new ways to be involved and influence the community that served me well for many years. Now, taking a place on the provincial board feels right and gives me a chance to give back.

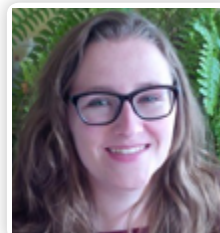
Myself and my wife Rachel (and soon a new, younger addition to our family) currently live in the beautiful town of Grimsby. In our spare time, we enjoy taking hikes along the escarpment and paddling kayaks through the various rivers and ponds. Besides the fantastic scenery, it's not far from McMaster University Medical Centre, where I work as a Genetics Technologist.

I look forward to getting to know my fellow Board Members and taking on the new challenges this position offers.



### Jamie Hill

Jamie Hill is an internal auditor with the Department of National Defense and holds a CPA, CMA designation. He is, also, a grief counselor and a poet. He has been active in the Hemophilia community for many years. In his spare time he enjoys live theatre, travel and is working on a PhD. Jamie currently lives in Ottawa and has Factor IX deficiency.



### Meagan Bordi

Over the past 5 years as a CWOR council member I have seen the hard work being done by Hemophilia Ontario and its volunteers to improve the lives of people with bleeding disorders. I am extremely honoured to be able to work with this board and help our community in any way I can.

## Advocacy Committee Formed

On April 1 and 2, 2017 Hemophilia Ontario participated in an Advocacy Workshop presented by CHS for a group of participants who had been selected for their previous involvement, identified skill sets, and recommended by their clinic team. That workshop focused on the results of the 2014 clinic assessments, and identified priorities for advocacy at the local and provincial level.

The work continued at Rendez-vous, where another Advocacy Workshop was held with support from Brian O'Mahony, Chair of the European Hemophilia Consortium and CEO of the Irish Haemophilia Society. You can read more about this experience in this issue of Blood Matters, in an article by Shelley Hewett.

As a result of these workshops, a provincial operating committee has been struck. The roles for this committee are:

- To establish priorities related to care and treatment for inherited bleeding disorders in Ontario;
- To develop and implement a work plan that addresses those identified priorities;

- To be visible within the bleeding disorder community and provide information about its activities and priorities back to the general Hemophilia Ontario membership;
- To provide information and feedback to the Executive Director about opportunities for advocacy within the sector;
- To formulate positions for the Hemophilia Ontario Board of Directors' review and consideration, where required.

This committee will be providing an update on its priorities and activities in every issue of Blood Matters. As part of the Terms of Reference, the committee is making every effort to include representation from all regions of the province and fill identified skill sets. If you are interested in participating in the committee, please contact Jenna at [jfoley@hemophilia.on.ca](mailto:jfoley@hemophilia.on.ca) to learn about the current membership gaps. The current committee membership includes:

**Michael Bosompra, Amy Griffith, Paul Wilton, Ian Marcinkowski, Matthew Maynard, Maia Meier, Bojan Pirnat, Shelley Hewett** ♦



## Advocacy Training and Skills Development

by Shelley Hewett

This year the CHS started a Canada-wide Advocacy training workshop aimed at increasing the ability of the chapters to advocate successfully for Standards-based Comprehensive Care. The workshop at Rendez-vous in Toronto brought together members from across the country to learn and discuss the subject.

At the workshop we heard from several very knowledgeable and experienced speakers. Some spoke of their experience in successful advocacy campaigns. Others spoke about the Standards for Comprehensive Care and what was learned

from the clinic assessments. A prepared simulation of a meeting with hospital administration was held for us to learn from. It was clear from that meeting that a lot of work and preparation needs to be done in order to be properly prepared for such a meeting. We need to know our stuff!

In 2013 and 2014 assessments of the 25 centers across Canada were completed. A number of strengths were found, however, there were some areas of concern. Many centers reported a serious lack in human resources in one or more of the core disciplines. There was also concern about factor utilization and reporting as the cost to supply therapies represents most of the total costs for the care of people with inherited bleeding disorders. Clearly being able to properly monitor the use of these therapies is crucial. The Canadian Bleeding Disorder Registry (CBDR) was launched in 2015 to help address this problem. However, human resources for data entry must be available at the centers for this system to work as intended. Obviously, there is a lot of work to do!

In Ontario, an Advocacy Committee was formed following our chapters workshop. We have begun the work of developing short-term and long-term goals. The training that we received at our chapter's workshop and the additional workshop at Rendez-vous that was attended by a majority of our committee will be very helpful in attaining these goals. ♦

## Hemophilia Ontario Focus Groups

A series of focus groups is being delivered across Ontario – with more than 20 dates and locations available for anyone with interest to participate. Hemophilia Ontario wants to know what is important to our community today, where we should focus our efforts in the future, and how we can reach out to those who are newly diagnosed or who have not been involved.

The bleeding disorder community is so small, that it becomes even more important to open the proverbial tent and focus on inclusion and diversity. As changes continue at a break-neck pace for treatment and health care funding, our voice and power come from strength in numbers. Together, we can work for continued investment in the Comprehensive Care model, events and opportunities that bring members together to provide support to one another, and a strong provincial body with equitable programs and services across all regions.

A full report of the focus group outcomes will be released this fall, but there is still time to participate. If you were not able to join a group near you but want to share your thoughts and opinions, please take the time to contact Jenna at 888-838-8846 x 17 or [jfoley@hemophilia.on.ca](mailto:jfoley@hemophilia.on.ca). Let us know how Hemophilia Ontario can best reflect the needs of your family and what your personal priorities are for our shared future. ♦

**Let's Talk**  
**Hemophilia Ontario Focus Groups**

As part of our ongoing engagement process, Hemophilia Ontario is undertaking a series of focus groups in June and July 2017. This is your opportunity to tell us what is important to you as we look at our future direction and priorities.

Focus groups will be held with a minimum of four and maximum of eight participants each to ensure the quality of discussion. Register for your preferred location now! Locations that do not have four registrants one week before the focus group date will be cancelled.

There are more than 20 locations across the province, to ensure everyone has the chance to participate close to home. Sign up using the link below before your preferred location becomes full!

<https://hemophiliaontario.typeform.com/to/PvKMq4>



## Women's Wellness Weekend: W2

We invite you to join us and our amazing guest speakers, including Dr. Paula James, Dr. Mary Anne Jamieson, and Yvette Perrault, for an educational and fun-filled weekend in the beautiful city of Kingston, Ontario from Friday, September 29 through Sunday, October 1, 2017.

For more information about this program, or to register, please contact Susan Turner at 416-972-0641 or [sturner@hemophilia.on.ca](mailto:sturner@hemophilia.on.ca)

## The Standards of Care

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 outline who your core team members are, and who your extended team members are. The Standards highlight the services available and responsibilities of each treatment centre. Being familiar with the Standards is important for the optimization of your inherited bleeding disorders care.

To access the complete Canadian Comprehensive Standards of Care document, 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/>



## CHS Rendez-vous 2017 - Patient Perspective

By Amy Griffith

Events like Rendez-vous are always special because it's an opportunity for Canada to show off how we are benefitting the future for those with inherited bleeding disorders, through research, funding, and social advocacy outreach initiatives. It's truly humbling to share

space and time with so many professionals from all over our country, all working towards the same mission. This year was even more special, because as a Torontonians, I had hometown advantage.

Over the weekend of May 25-28, Hemophilia Ontario played host to our partners from nearly every province, as we shared a wealth of experience and knowledge with one another. As a patient and active Board member, two particular sessions stood out for me.

The first was the importance and need for more accurate data gathering, in the form of infusion logs. With the launch of MyCBDR, this process has become more streamlined and accessible for modern day

infusers, with detailed descriptions for both prophylaxis regimens and bleeding episodes. However, unlike any other advancement, it does not come without its hiccups. MyCBDR continues to face challenges, whether it be legally dependent on hospital policy, or logistically having it established in hemophilia treatment centers.

The second was the bright light that shone on women with bleeding disorders, through two beacons: Dr. Paula James and Dr. Michelle Scholzberg. Advocates for women's treatment, diagnosis and the differentiation of their care, both of these trailblazers made it known to many that care and treatment for women is still coming up the pipeline, and has not yet arrived as many may think.

I urge everyone to attend at least one Rendez-vous event in their lifetime, as it is an invaluable way to connect to both your provincial and national bleeding disorder community. We are stronger together. I would like to sincerely thank Hemophilia Ontario for their fellowship funding that made my attendance possible.



(left to right) Matt D, Myrtle T, Sylvie D, Debbie S, Natasha S and Andy S (not seen in photo)

### Thank you to our friends from RBC!

RBC will be making a \$1000 donation to Hemophilia Ontario to honour the team of volunteers from RBC.

This enthusiastic group of volunteers gave their time to help prepare gift bags for the participants at Rendez-vous 2017!

Thank you for your time and support!



## Just the Guys

We invite you to join us for our 2017 **Just the Guys** program as we go on a quest for the Infinity Gauntlet during our Marvel-themed weekend! This year's event will be held Friday, September 15 through Sunday, September 17, 2017.

Online and paper registration will be available the first week of July. For more information, please contact Alex McGillivray at 905-522-2545 or [amcgillivray@hemophilia.on.ca](mailto:amcgillivray@hemophilia.on.ca)

# ✓ Year-to-Date

## ENGAGEMENT SURVEY STATISTICS

# 2017

Hemophilia Ontario launched an online engagement survey earlier this year. The survey is available at <https://hemophiliaontario.typeform.com/to/LRIFXO> and results will be shared throughout the year.

All input will be used to update our programs and services in the future.

Here is some of what was learned so far:

### ✓ 1 WHEN ASKED WHAT PROGRAMS WERE THE **TOP 3** MOST VALUABLE TO OUR MEMBERS:

✓ 47% said Summer Camps (Wanakita and Pinecrest)

✓ 39% said Local Education Programs

✓ 31% said Community Camp

✓ 23% said Hemophilia Ontario Youth (HOY)

✓ These programs represent **47%** of all votes made; nearly equal to all others combined.

### ✓ 2 HOW WELL DO HEMOPHILIA ONTARIO PROGRAMS REFLECT THE NEEDS OF YOU AND YOUR FAMILY? **(3.44/5)**



### 3

WHEN ASKED WHICH REGION THE PARTICIPANTS REPRESENT:

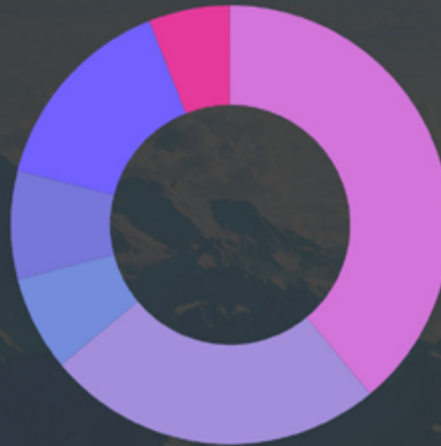
15% of responses represent individuals from OEOR



8% of responses represent individuals from NOR



7% of responses represent individuals from CWOR



6% were Not Sure which region they represented



39% of responses represent individuals from TCOR



25% of responses represent individuals from SWOR

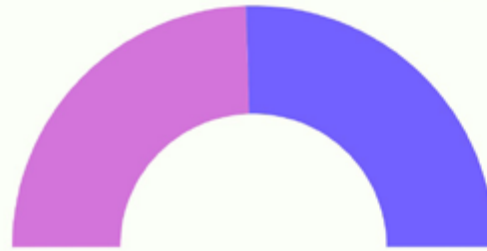


### 4

WHEN ASKED HOW THEY HAVE BEEN INVOLVED:



67% of survey responses indicate they have not volunteered in the last two years.



51% of survey responses indicate they donate to Hemophilia Ontario



## "Is there anything else you want to tell us?"

"Thank you for being proactive and forward thinking. You make a difference."

"I feel very disconnected from Hemophilia Ontario. Our family is now blended and we are not sure if we all would be welcomed."

"Hemophilia Ontario needs to re-earn the trust of its membership. Without trust, there is no way forward."

"Our family truly appreciates the work that Hemophilia Ontario does. You have had a huge positive effect on our family that will last throughout our children's lives."



## Team Building for a Cause

In support of World Hemophilia Day, the Bayer Canada Site Management Group took time out from their usual work to raise funds for the **Hemophilia Ontario Youth (HOY)** program. Teams of 5 or 6 people who don't typically work together were tasked with preparing an attractive gift basket for a lunchtime raffle that was open to all Bayer colleagues at the head office in Mississauga.

The teams had a great opportunity to collaborate and put their creative skills to the test, creating beautiful gift baskets with personally donated items, covering different themes like "Tea Time", "Lazy Sundays", "Movie Night" and "Summer Picnics". The raffle was a huge success, and the team was really proud to collect \$1,030 for such a worthy cause.

**HOY** recently had a very successful event in Toronto, including a presentation by Vanessa Bouskill from SickKids and a planning session for future program activities. The donation from Bayer as a result of their raffle will be put to good use this year, bringing youth from across the

province together to build leadership and connection within the bleeding disorders community.

Would you like to have your own workplace fundraiser in support of a Hemophilia Ontario program? Contact Jenna Foley at [jfoley@hemophilia.on.ca](mailto:jfoley@hemophilia.on.ca) for ideas or planning support. 📌

## Bleeding Disorders & Research News



Whether you are going to the lake for a week or starting out on your around the world tour, plan with your treatment centre and these travel tips from the World Federation of Hemophilia: Tips for Travelers.



## The Adult Network Continues to Grow Across Ontario

The next face-to-face gathering of the **Adult Network** will be in the Central Region at Cavallo-Nero (370 Wilson St. E. in Ancaster, ON) on Wednesday, July 12 from 7:00-9:00 pm.

The **Adult Network** is a chance to share and hear the lived experience, to ask your questions or answer others, in a safe, respectful, and inclusive environment. There are no out-of-bounds topics; join us with your good stories, funny stories, and some not so good or funny. The network is just beginning so we are exploring how to reach out through peer support, community-based research, and advocacy as individuals, as an organization and in our communities.

If you are interested in participating but not available to attend this event, contact us to learn how you can join remotely or plan an event closer to you. Thanks to Marc Laprise, Volunteer Lead, and Matthew Maynard, Facilitator. For more information, call or text to 519-432-2365 or email [mmaynard@hemophilia.on.ca](mailto:mmaynard@hemophilia.on.ca) 📌

# Hemophilia Ontario Webinars

**A Brave New World** – presented by David Page, Executive Director of the Canadian Hemophilia Society  
**Thursday, June 29, 2017 7:00 pm ET**

David will explore how a treatment product is tested, approved, and becomes available for treating your bleeding disorder. He will also discuss some of the treatments currently being tested, or referred to as “in the pipeline.”

**Extended Half Life Products for Bleeding Disorders Treatment** – presented by Dr. Manuel Carcao  
**Tuesday, August 1, 2017 7:00 pm ET**

Join Dr. Carcao to learn about extended half-life products for the treatment of bleeding disorders, how the half-life is extended so the factor lasts longer, and what difference this can make to your care and treatment.

**Individualized Treatment Planning** – presented by Dr. Alfonso Iorio  
**Wednesday, September 20, 2017 7:00 pm ET**

Dr. Iorio is an international leader in individualized treatment planning for people with bleeding disorders. Come learn more about how a personalized treatment plan could benefit you.

To register for one or all of the webinars, contact Matthew Maynard at 519-432-2365 or [mmaynard@hemophilia.on.ca](mailto:mmaynard@hemophilia.on.ca)

## HIV/HCV News

# HIV/HCV Treatment Centres & Support

Each of the Hemophilia Treatment Centres throughout Ontario plays an important role in your care and treatment of your bleeding disorder.

<http://www.hemophilia.ca/en/provincial-chapters/ontario/treatment-centres/>.

Additional support and referral is available from Hemophilia Ontario [info@hemophilia.on.ca](mailto:info@hemophilia.on.ca) or call 519-432-2365.

Finding treatment and support for your HIV and/or hepatitis can also be found on this national website [www.HIV411.ca](http://www.HIV411.ca) or [www.HCV411.ca](http://www.HCV411.ca).



## Hemophilia Ontario Youth (HOY)

# Grand Slam of a Day!

By Matthew D'Addario

The picture shows HOY bonding and learning about their disorders with great company. As a HOY member, I find that things like this small event bring us closer together no matter what differences we have.

During this event we had a seminar on how to go about traveling and/or moving for either school or a job. As a youth that is around the age where I may move for any reason, it was good to learn how to do this safely, know how to find the nearest hemophilia treatment centre and how to properly get product over the border without much hassle.

In closing, I find that we need to have more youth come out and take part in these activities because we are the future of this organization!

If you are ages 16-26 and interested in HOY or know someone who might be, please contact Alex McGillivray at [amcgillivray@hemophilia.on.ca](mailto:amcgillivray@hemophilia.on.ca) or 905-522-2545



## Hemophilia Ontario Calendar

SEPTEMBER 8  
**TCOR 18<sup>TH</sup> Annual Golf Classic**

SEPTEMBER 15-17  
**Just the Guys**

SEPTEMBER 15-17  
**Just the Guys (North)**

SEPTEMBER 29- OCT 1  
**Women's Wellness Weekend: W2**

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)

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 [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)