A publication of
Hemophilia Ontario
Hémophilie Ontario

FALL 2017
VOLUME 8 • NUMBER 3

BLOOD matters

Help Stop the Bleeding

PM #42837517

President's Message

by Maia Meier

As 2017 comes to a close and we look back on the year, I see a year of growth. We've had several changes this year in Hemophilia Ontario which have led to us taking a closer look at who we are, who we serve and how we can best serve and support all our members.

Through our outreach and interaction with the community this year we have determined areas we need to work on and what's important to you and your families. I'm looking forward to some of the new programming that we'll begin offering in all 5 regions of the province, allowing for everyone, no matter where they live, to have access to the same programs. We're excited to be offering information and resources on topics such as peer support, women's care, and the pediatric to adult transition time. Please watch our webinar on our YouTube channel and see the information in this issue and online for more details on our 2018 program plan.

I would like to wish everyone a very healthy, happy holiday season and look forward to a successful 2018 with our Hemophilia Ontario family!

Maia Meier
President
Hemophilia Ontario

Executive Director's Message

by Jenna Foley

Wow! Here we are; the end of 2017, one full year after I was first hired and countless conversations later.

My main concern is to thank each and every one of you for your time and support this year. I felt welcomed and encouraged, despite the heavy workload we shared. There was a lot to do, with multiple competing priorities, but it always felt like a team effort. Many hands make light work and we would not have been able to accomplish everything we did this year without the commitment and dedication of all involved.

This year has been non-stop action from launching new programs with grant funding from the Ontario Trillium Foundation and the Ministry of Tourism, Culture and Sport, to the engagement process (including the Social Summit, online engagement survey, and focus groups series), Rendezvous in Toronto, record-breaking years for Wanakita and Pinecrest summer camps, to traditional programming like Just the Guys and W2, and incredible events in every region of the province. It was a trial-by-fire whirlwind of an initiation.

Throughout that action-packed calendar, I spoke with hundreds of community members and learned more every day. Your feedback and suggestions are greatly valued and I hope you see them reflected in the changes we are rolling out.

On that note, there are a number of big and small changes coming in 2018. Hemophilia Ontario is here to serve the community, and we want to do that as efficiently and effectively as possible. Read the rest of this issue for more details and look forward to seeing us in your community soon.

One change coming next year, that isn't mentioned anywhere else yet, is the move to make **Blood Matters** a primarily electronic resource. For years we have asked people to opt-out of receiving a hard copy, but the majority of issues are still distributed in print. For multiple reasons, we are now going to do the reverse and ask you to let us know if you want to opt-in to receiving a physical issue in the mail. Otherwise, **Blood Matters** will be distributed as usual online and by email.

Do you want to keep getting **Blood Matters** in the mail? Let us know! Contact me by phone at 888-838-8846 x 17 or jfoley@hemophilia.on.ca. Otherwise, I look forward to sending you the electronic version in the New Year; join our mailing list to make sure you don't miss out.

Again, from the bottom of my heart, thank you for your participation, patience, and ongoing dedication. I wish you a safe and joyful holiday season and look forward to getting back to work together in the New Year!

Jenna Foley
Executive Director
Hemophilia Ontario

BLOOD matters
Hemophilia Ontario

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Return any undeliverable items to Hemophilia Ontario at the address listed above.

Hemophilia Ontario
Hémophilie Ontario

Hemophilia Ontario is a certified chapter of the Canadian Hemophilia Society

What's in this Issue?

Fall 2017 Volume 8, Number 3

Hemophilia Ontario Calendar

APRIL 14

Hemophilia Ontario Annual General Meeting

** Dates are tentative and may be subject to change.*

Thank You

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

Letter from the Editor

by Tom Beer

Celebrating Change & Challenge

This issue reminds me of the wisdom of the statement, "If you want to overcome self-doubt, make a habit of action". Over the past year there have been challenges and changes and even some expressed doubts that have had impacts on those involved in any way with Hemophilia Ontario and what it does and plans to do.

In this issue of **Blood Matters**, you will read of the exhaustion and exhilaration of the leaders, workers and volunteers who have conducted surveys, been part of seminars, treated and spoken to many affected by blood disorders, leading to a multitude of realizations of the impacts on and reactions of those affected.

If, after reading this edition of **Blood Matters**, you realize that there's something that you intended to do but haven't – DO IT. Complete the survey, contact Jenna or Matthew, help a newly diagnosed person or their family to find the help you know they'll need and which you know is available. This is action. This is Doing, not thinking about doing it or regretting that you coulda, shoulda, mighta, woulda, but didn't.

My work is prompted by what I read from the many contributors. This edition of **Blood Matters** expresses the next step in an Action Plan for Hemophilia Ontario.

The messages help us celebrate talents and abilities, whether by organizing a street sale, developing a webinar, being on staff at one of the successful camp experiences, and so much more. Whatever your role, pat yourself on the back as you see how much you contributed and how you enabled others to succeed and deal with their issues related to blood disorders.

As you read of Chad White's journey and his battle with Hemophilia A, you will appreciate his anger at the changes to his life, and his reactions and realizations as LIFE happens to him.

Several of the articles showcase the Hemophilia Ontario and CHS programs that have had and/or will have an impact on those involved with blood disorders across Ontario.

As you read this edition of **Blood Matters** you will be impressed by the many successes of the newly developed provincial/ local teams. This edition helps to recognize the many changes in personnel and programs across Ontario and Hemophilia Ontario and to celebrate the positivity being engendered by all.

Have these changes and actions been easy? No! As an ancient Chinese philosopher said, "The brook would lose its song if you removed the rocks and pebbles".

As the team reflects on this year's actions, they are setting the stage for the year to come. Thinking with confidence, 2018 is full of possibilities and positive challenges.

The major reason for setting a goal is what it makes you DO to accomplish it. Goals are exciting because they provide focus and aim for action. As this issue demonstrates, goals cause us to stretch and grow; to become better. Having a plan of ACTION is important.

But, you must celebrate the things you do, and the person you are that allows you to make a difference in the lives of others. Look forward to growing further so you can do even more for those on whose lives you can have an impact.

We must never forget to recognize what's gone well and to purposefully stop and celebrate it.

This edition does that. We celebrate the advances, the changes, the accomplishments, positively, – on purpose.

Read on…

Tom Beer
Contributing Editor
Hemophilia Ontario

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.

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 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 HTCs;
- 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/XlQ45m

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.mcss.gov.on.ca/en/mcss/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.

Able to Play

Hemophilia Ontario is thrilled to be partnering with the Ministry of Tourism, Culture and Sport in a very unique Ontario Sport and Recreation Communities Fund grant. This funding, $47,308 over two years, is committed to providing physical activity opportunities for children affected by inherited bleeding disorders across the province.

These funds are intended to promote physical literacy and build the foundation for life-long activity, which we know to be essential for joint health as well. In 2017, the funding was used to support sports and physical activities as part of the Just the Guys, Wanakita, and Pinecrest Adventure Camp programs. We look forward to expanding that to include Community Camp in 2018.

The feedback has been overwhelmingly positive so far, with comments from participants like:

"Trying new things at camp makes me feel better about being active at home because I don't have many sports to try at home. And now I'm more comfortable to try it at home because I know how to."

"There are lots of people here to support me."

"I feel better when I see other kids with hemophilia play too."

The Ontario Sport and Recreation Communities Fund is a program of the Government of Ontario with support from the Government of Canada. For more information on how your family can participate in 2018, contact Jenna Foley at 888-838-8846 x 17 or jfoley@hemophilia.on.ca.

Engagement Survey

A year-long online survey gathered input and suggestions from 99 members. Here is a look at who we heard from and what they said.

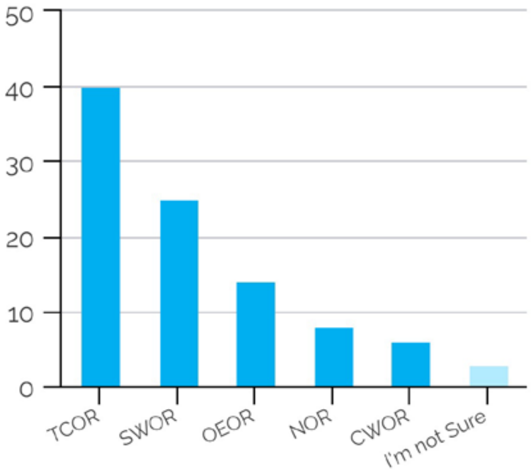
How do our programs rate?

The average response to "How well do Hemophilia Ontario programs reflect the needs of you and your family?" is 3.41

Program	Ranked #1	Ranked #2	Ranked #3
Summer Camps	27	12	9
Community Camp	13	13	5
Local Education	13	14	13

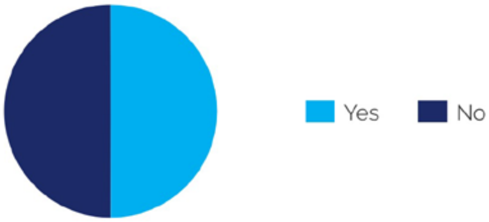
Top 3 Programs

When asked to rank our top three programs, these were the highest rated (both by number of votes and with weighted rankings)



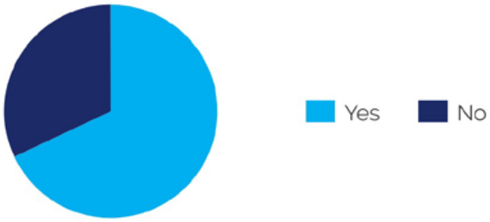
Respondents by Region

The percentage of responses according to which Hemophilia Ontario region they represent.



Do you donate to Hemophilia Ontario?

The #1 answer that would impact the decision to donate in the future was "Understanding the impact of your donation."



Did you volunteer in the last 2 years?

74% of respondents who indicated volunteering in the past two years said they volunteered for fundraising events.

42% of all respondents said having more local events would influence their decision to volunteer in the future.

Engagement Survey

A representative selection of responses

Hemophilia Ontario makes me feel:

- Welcome
- Neutral
- Sad
- Part of a community
- Somewhat connected
- Accepted and included
- Like there is someone to help
- Valued
- Frustrated
- Empowered
- Part of a unique community
- Worried
- Normal
- Ambiguous
- Like I have a voice
- Ashamed
- Hopeful
- Educated
- That I belong and there are people who care
- Undervalued
- Supported
- Hemopheliated

I wish Hemophilia Ontario would:

- Help patients within the medical system and advocate on their behalf;
- Provide more educational programs;
- Engage members more strongly, provide stories that are of more relevance;
- LISTEN and take my feedback;
- Have more to offer in the North;
- Educate on the need for vigilance regarding sustaining good treatment for people with bleeding disorders;
- Help me make more connections locally;
- Do presentations in smaller towns and not just the big cities;
- Do educational sessions in our local community;
- Do more weekend programs that are accessible for those that cannot get to the out of town events;
- Consider doing Community Camp every year
- Move forward from its past and focus on the needs of the younger membership.

The top priorities for Hemophilia Ontario should be:

- Fundraise
- Regain member trust
- Volunteer engagement
- Scholarships for students
- Rebuilding once-vibrant regions
- Youth education and empowerment
- Awareness in the community
- Employment
- Define and align with the needs of the community
- Community Camp, educational programs, community outreach
- Advocacy around the Standards of Care
- More programs in the North or assistance with travel costs
- Providing gadgets like "ultraviolet vein finders" to all the members
- Contact DIRECTLY and PERSONALLY with its members
- Education for women on diagnosis and treatment
- Getting hemos together to become buddies
- Focus more on member wants and less on the politics behind things
- More communication, especially with newly diagnosed patients and families
- Research in gene therapy, less invasive treatment options, and longer lasting factor products
- Ageing, helping those affected with HIV, HCV, compensation, etc.
- Member engagement and increasing membership overall

Engagement Survey!

If you were unable to participate in the engagement survey online, we would still like to hear from you! These questions can be answered and submitted by mail to Hemophilia Ontario, 4711 Yonge St, 10th Floor, Suite 10100, Toronto ON, M2N 6K8 or fax to 888-958-0307.

Are you a Hemophilia Ontario member?

☐ Yes ☐ No

Which region do you represent?

____

Did you attend any of these programs in the past two years?

- ☐ Hemophilia Ontario AGM
- ☐ Local Regional General Meeting (RGM)
- ☐ Webinar Series
- ☐ Just The Guys
- ☐ Community Camp
- ☐ Wellness for Women (W2)
- ☐ Local education events
- ☐ Local social gatherings
- ☐ I did not attend any events in the last two years
- ☐ Other

Have you or anyone in your family been supported through the Financial Assistance or NEW programs in the last two years?

☐ Yes ☐ No

On a scale of 1 to 5, how well do Hemophilia Ontario programs reflect the needs of you and your family?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

Of the following list, which Hemophilia Ontario program do you feel is the most valuable to its members? Which is the second-most valuable? Which is the third-most valuable?

- ☐ Annual General Meeting (AGM)
- ☐ Local Regional General Meetings (RGMs)
- ☐ Webinar Series
- ☐ Just The Guys
- ☐ Community Camp
- ☐ Wellness for Women (W2)
- ☐ Local education events
- ☐ Local social gatherings
- ☐ Summer Camps (Wanakita and Pinecrest)
- ☐ Financial Assistance
- ☐ Now Experience Wellness (NEW)
- ☐ Hemophilia Ontario Youth (HOY)

Please complete the following sentences:

Hemophilia Ontario makes me feel:

____

____

____

I wish Hemophilia Ontario would:

____

____

____

Top priorities for Hemophilia Ontario in the next 1-2 years should be:

____

____

____

Do you donate to Hemophilia Ontario?

☐ Yes ☐ No

What would influence your decision to donate in the future?

- ☐ Directing your donation locally or to a specific program
- ☐ Understanding the impact of your donation
- ☐ Better communication with donors
- ☐ Donor events and networking opportunities
- ☐ Increased recognition of donors
- ☐ More diverse options for donating
- ☐ I am satisfied with the current donation processes
- ☐ I am not interested in donating
- ☐ Other

Have you volunteered with Hemophilia Ontario in the past 2 years?

☐ Yes ☐ No

If yes, how have you volunteered?

- ☐ Regional Council
- ☐ Board of Directors
- ☐ Fundraising Events
- ☐ Committees
- ☐ Other

What would influence your decision to volunteer in the future?

- ☐ Shorter time commitments
- ☐ Event-specific volunteering
- ☐ More decision-making opportunities
- ☐ More local events
- ☐ Knowing other volunteers
- ☐ Opportunity to mentor others
- ☐ More recognition of volunteers
- ☐ I am not interested in volunteering
- ☐ Other

Is there anything else you want to tell us?

____

____

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Focus Group Feedback

Over two months in Summer 2017, Hemophilia Ontario completed a series of focus group sessions with its members. These conversations will help set organizational priorities and assist with program planning for 2018 and beyond. A total of 38 individual members were engaged across 11 sessions. The same questions were asked at each focus group, but every session was unique due to the dynamics of the participants involved.

The questions included were:

1. Think back over all the years that you've been involved with Hemophilia Ontario. What is your fondest memory?
2. Looking back at the last five years of Hemophilia Ontario events and activities, how would you rank the organization on a scale of 1 to 5 where 1 is Poor and 5 is Exceptional? Why did you choose that score?
3. How effective is Hemophilia Ontario communication? Do you feel you get all of the information you need when you need it?
4. If you were inviting a friend to participate in Hemophilia Ontario, what would you say in the invitation?
5. What do you think individuals and families with inherited bleeding disorders need most from Hemophilia Ontario?
6. Aside from personal information about your treatment or upcoming appointments, what information would be helpful in an email update from the clinic? (Changes to clinic hours, Information about medication availability, new research findings about hemophilia, other?)
7. How should Hemophilia Ontario balance its online and in-person activities?
8. How should Hemophilia Ontario reach out to newly diagnosed families or individuals who have never been involved before?
9. Suppose that you were in charge and could make one change that would make Hemophilia Ontario better. What would you do?
10. In what ways is your life different because of your participation with Hemophilia Ontario?

There were a number of recurring themes over the series of focus group sessions. Some of the identified priorities were:

- The need to grow our membership base;
- The importance of collaborating with the clinics;
- Establishing a special semi-annual event to reach out to newly diagnosed families;
- Re-establishing mentoring or family matching programs;
- Ensuring a big voice for Hemophilia Ontario at the CHS table;
- Becoming more results focused and able to articulate what we have achieved; and
- The importance of sharing stories from the membership

If you would like to read the full report, visit http://www.hemophilia.on.ca or contact Jenna at 888-838-8846 x 17 to receive a copy by mail.

2018 Program Plan Preview

You have spoken and we hear you! Thank you for sharing your priorities with us over the year. It is Hemophilia important that you see the needs of your family reflected in the organization and we are working to make sure that is the case.

Across all forums, some themes were repeatedly highlighted:

- The need for more local programming;
- A desire to support families and provide opportunities for connection;
- How to reach out to newly diagnosed families to ensure they are informed and encouraged;
- Potential for improvement in handling pediatric to adult transitions in care;
- The importance of advocacy at the individual and community levels.

We know the organization is in a financial crunch, with years of cutbacks resulting in fewer staff and less resources available. But, with a vision and commitment to honoring the feedback from our members, the resources we do have can be reallocated to ensure we are the most effective, efficient, and responsive possible.

In the coming year, you will see:

- A new staff position added, dedicated to planning and implementing programming equitably across the province;
- A minimum of three events in every region, providing education and social opportunities to members closer to where they live;
- The return of the peer support Family Matching program, with a new name and stronger infrastructure, to offer meaningful connections between individuals and families in a flexible format that suits their individual needs;
- A bigger, better, ANNUAL Community Camp program that focuses on providing education and support to address a wide range of needs;
- A commitment to providing support in the clinic environment, building stronger relationships with our health care providers, and engaging new members;
- New webinar topics, to increase opportunities for education right from home;
- Continued member support and advocacy, both for individuals and the community at-large.

Sometimes change is hard, and you can't always make everyone happy. We hope you will participate in many of our events this year, and that your family will be stronger, more educated, and better connected as a result. If there are things you would like to see in the future, the best way to see that happen is to get involved – let us know if you like the changes or what you would prefer to see in the years to come. We are here for you, so let us know how we can help!

2018 Program Plan Preview

Regional Programs

- Peer Support Education and RGM
- Women's Care Education
- Pediatric-Adult Transitions Education
- Clinic Attendance

Provincial Programs

- Reimagined Peer Support Program
- Webinars
- Annual Community Camp
- Blood Matters
- Financial Assistance
- Member Support

Youth Programs

- Camp Wanakita
- Fresh Pine and Pinecrest Adventure Camp
- HOY (2019 Event Planning)

Events and Activities

- AGM (April 14th, 2018 in Ottawa)
- Golf Tournament
- Zoo Walk
- World Hemophilia Day Event
- Holiday Event
- More to be announced!

HOPE TO SEE YOU THERE !

THE LARGEST INTERNATIONAL
MEETING FOR THE GLOBAL
BLEEDING DISORDERS COMMUNITY

GLASGOW, SCOTLAND • MAY 20-24, 2018

ORGANIZED BY: WORLD FEDERATION OF HEMOPHILIA
HOSTED BY: THE HAEMOPHILIA SOCIETY

www.wfh.org/congress

THE HAEMOPHILIA SOCIETY

WFH
WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

Who We Are & Who You Should Contact for What

As we roll out the new program plan, we, also, have some changes happening internally. The staff will be completing the transition to a fully provincial service delivery model, with the hopes of providing more efficient, consistent service to our members.

Jenna Foley – Executive Director

888-838-8846 x 17
jfoley@hemophilia.on.ca

Jenna is in charge of the organization's overall activities. Contact her directly for the financial assistance program, the new peer support program, the advocacy committee, and feedback/questions/comments you may have at any time. If you have concerns about a program or service, please let Jenna know.

Matthew Maynard – Provincial Coordinator, Member Support

888-838-8846 x 15
mmaynard@hemophilia.on.ca

Matthew will be expanding his support worker role to the entire province. Contact him directly related to registering with a clinic, accessing community services, support for individuals impacted by HIV/HCV, or general bleeding disorder inquiries. Matthew also oversees the webinar series and the Adult Network.

Alex McGillivray – Provincial Coordinator, Member Engagement

888-838-8846 x 14
amcgillivray@hemophilia.on.ca

Alex is taking on the new provincial clinic attendance role, providing information on programs and services to individuals and families at their clinic appointments across Ontario. This role plays an integral part in our relationship development with the health care provider teams and also directly with our members. Alex will continue to lead the agency social media accounts and other communications.

Susan Turner – Provincial Coordinator, Administration and Events

888-838-8846 x 11
sturner@hemophilia.on.ca

Susan will continue to provide administrative support from our Toronto office. Contact Susan if you would like to make a donation, or if you have questions about fundraising events or tax receipts. In addition to the golf tournament, zoo walk, and bingo sessions, Susan will also be developing new fundraising activities for the province. Let her know if you have any suggestions or if you would like to be a volunteer.

Stephanie Morrison

smorrison@hemophilia.on.ca

Stephanie has supported our Northern Ontario regions for years, playing an integral role in the education services and social opportunities available. There is a new program in development for Northern Ontario called VEINS (Valuing Equity in Northern Services). We hope to be able to share good news about this program and Stephanie's involvement in the near future!

Emily McCormack – Fresh Pine Project Coordinator

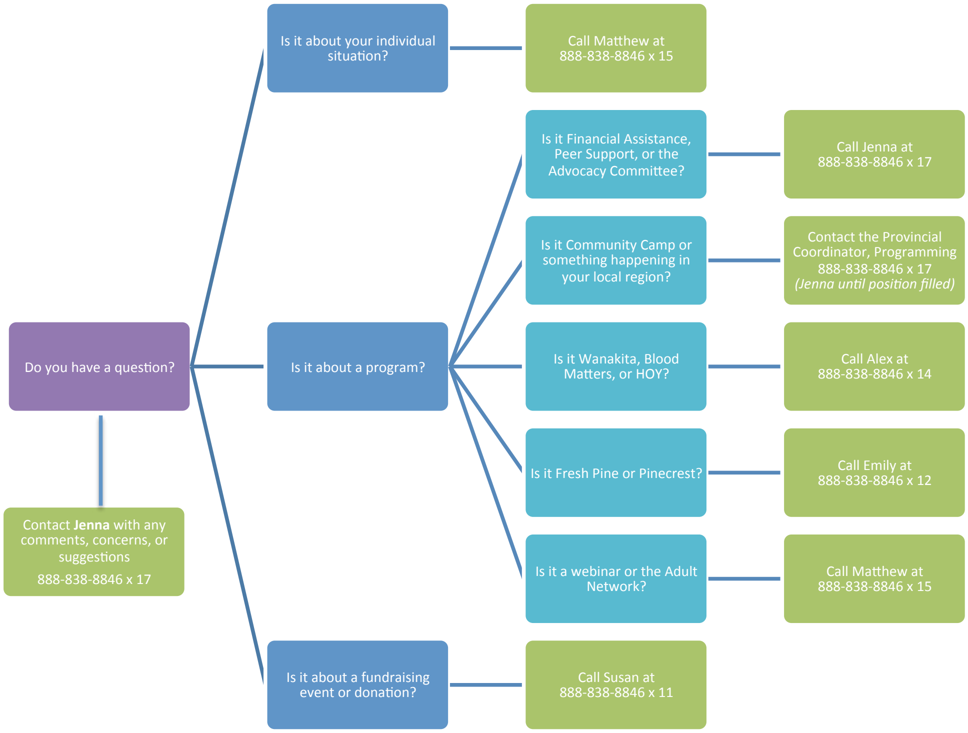
888-838-8846 x 12
emccormack@hemophilia.on.ca

Emily has joined the Hemophilia Ontario team to implement the Fresh Pine program, a youth engagement initiative to redevelop a sustainable program for children and youth in Southwestern Ontario, funded by the Ontario Trillium Foundation. Ideally, the redesigned program will be able to be replicated across the province in 2019. Contact Emily to find out what opportunities for involvement will happen near you, or to discuss the Pinecrest Adventure Camp program for 2018.

Still to Come – Provincial Coordinator, Programs and Regional Involvement

Hemophilia Ontario is looking to hire a new full-time staff member, who will be responsible for delivering the regional programs and engaging with councils. The 2018 program plan has new and different opportunities to engage the membership in ways that may be more flexible and appealing than traditional council involvement. Those who enjoy participating in their local council, and who want to continue to discuss and plan opportunities for engagement that are specific to them, are encouraged to do so. This new position will serve as the liaison and facilitator between those council-led activities and staff-supported events.

Do you think that sounds like a job for you? Contact Jenna for more information.



PLEASE NOTE:

AS OF DECEMBER 31ST, 2017, ALL HEMOPHILIA ONTARIO SATELLITE OFFICES WILL BE CLOSING WHEN THE STAFF TRANSITION TO THEIR PROVINCIAL ROLES. PLEASE UPDATE YOUR MAILING LISTS TO ENSURE ALL HEMOPHILIA ONTARIO COMMUNICATIONS ARE DIRECTED TO THE MAIN TORONTO OFFICE AT 4711 YONGE STREET, 10TH FLOOR, SUITE 10100, TORONTO ON, M2N 6K8.

The Fresh Pine Project

by Emily McCormack

There is a very exciting new opportunity in Southwestern Ontario, the Fresh Pine Project. I have been involved with Hemophilia Ontario from a very young age, having a brother with Hemophilia, and I am looking forward to leading Fresh Pine this year.

I have been working as a volunteer for the past seven years at Pinecrest and have used this experience to grow as a leader. I look forward to begin using the skills I gained though this experience in a professional capacity with the Fresh Pine Project. When I was young I had the chance to attend Pinecrest Adventure Camp and I have many fond memories of connecting with my brother and making new friends at camp. Fresh Pine is all about youth engagement, connecting with kids and families, to learn what they want to see in a re-envisioned Pinecrest program. How can we build something sustainable, effective, and fun? This year, I hope to meet with many of you to learn what is important for your families in a youth program and try to build something fresh and new together. It would be great to build a model that we can replicate across the province.

This project was made possible through the Ontario Trillium Foundation. The Fresh Pine Project will run until August 2018 and include local youth engagement opportunities beginning in the New Year. For more information, or to find out how you can become involved, I can be contacted at EMcCormack@hemophilia.on.ca or by phone at 888-838-4486 ext. 12. I look forward to meeting more members from the bleeding disorders community and having the opportunity to connect with them in the upcoming year.

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 January 31st, 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 February 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: ______________________________

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Address of School: ______________________________

City/Town: ______________________________

Province: ______________ Postal Code: ______________

Course Curriculum Entered/Major: ______________________________

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PEP Talk Electronic Newsletter for CHS Families

Our goal is to raise awareness about the program and to create a stronger community.

PEP Talk was created to provide a community for CHS families who have participated in a PEP workshop and to build on their learnings. PEP Talk is currently delivered to over 160 CHS members in English, about 4 times per year. Currently, only set in English, we are happy to provide French translation of the notices in the newsletter. In the future, we hope to be able to provide a PEP Talk with French language videos and linked articles.

Raising a child with an inherited bleeding disorder is a significant challenge that impacts the entire family. The Parents Empowering Parents program was designed to address this need by affirming positive parent/child behaviours while focusing on the unique problems faced by parents of children with bleeding disorders. PEP was introduced to CHS families in 2009 and PEP workshops have been delivered all across Canada. Want to know more? Please visit CHS PEP at https://goo.gl/Hdcagg.

Would you like to subscribe to PEP Talk?

The direct link is:
https://goo.gl/A3nvQd

Check out our latest and past issues of PEP Talk at:
https://goo.gl/3aXHz1

PEP PARENTS EMPOWERING PARENTS

2017 Final Progress Report for Hemophilia Ontario's Twinning Projects

compiled by Richard Minja and Candace Terpstra

Tremendous progress has been made in Tanzania through the Twinning including: the identification of over 100 members with haemophilia (up from 24), ongoing educational activities for members were held each year of the Twinning, a support network was established through the use of Whatsapp, the Executive Committee Board is now comprised of patients and family members, limited treatment with factor is now available through the WFH Humanitarian Aid Program (rather than only FFP), regular care is now available at the Muhimbili National Referral Hospital using a basic hemophilia care team- this year adding a physiotherapist, in-country diagnosis is now available along with the implementation of a national registry, the Ministry has pledged their support to the Society's efforts and government/hospital plans include the purchase of factor product in Tanzania, something not previously considered.

Activity	Was the activity fully, partially, not accomplished or modified? Please explain	Measureable outcome(s) of activity
Family Day	Fully accomplished - Original plan was for 50 participants to attend, but due to miscommunication regarding the date, in the end 40 participants attended. Full program was executed, including games for youth, meeting of mother's group, and psychosocial workshop.	• 2 families new to the NMO attended and were enthusiastic about the support of the NMO. • Youths discussed the possibility of forming a youth committee of NMO. • Mothers group shared experiences with one another. • Psychosocial workshop on the challenges of gaining and retaining employment for PWH.
Organize WHD Outreach and Awareness	Fully accomplished - Radio presentation by HST President and TV presentation(s) by Dr. Rwezaula aimed at increasing public awareness about bleeding disorders but primarily to identify new families	• Five new families identified this year bringing total number of patients to 108 • New patients identified include families from southern part of the country
Translate booklet and print 200 copies in Swahili	Partially accomplished - Booklet, available in English (2016) was translated into Swahili	• Electronic copy of Swahili translation provided to HST for proof reading and printing
Educational/Support Programs for families, mothers and youth	Fully accomplished - Family Education Day - Sessions included i) a presentation on hemophilia by Dr. Rwezaula, followed by Q & A ii) an extensive presentation on the importance of physiotherapy in management of muscle and joint bleeds and rehabilitation followed by one to one consultations with patients and families by Mikala (newly appointed physio from the basic care team) iii) presentation by Irene Chami WFH and iv) a review and update of patient and family needs, visioning exercise to assist the Executive Committee in planning future goals and activities and a presentation on fundraising by HO Twinning partners	• 35 patients and family members attended Family Education Day with a full day of sessions. • First presentation on physiotherapy - essential in a country where supply of factor is limited. • Ongoing communication and support provided through the use of Whatsapp and sms. These methods of communication are widely used by the youth as well as parents and family members.
Board training (including the Executive Board, officers and key volunteers	Partially accomplished due to time restrictions Twinning partners and Executive Committee members reviewed recommendations prepared by the HO team in four categories i) organizational ii) Executive Committee iii) Programs and iv) Financial Results of the planning/ visioning exercise with the members including a review of patient and family needs, and identifying priorities which will be used to establish future activities of the organization. Action Plan for 2018 - four possible objectives outlined, Executive to complete timeline and identify members responsible for each activity	HST is currently working on a number of issues with regard to the recommentations such as: • a country wide vision of care • growing the membership and plugging the members into the organizational education and support activities • growing the number of volunteers and organizing Committees beyond Mothers and Youth to include fund-raising (using volunteers from the Education Day) • maintaining good relations with Muhimbili HTC • growing the Executive Committee Board to include others with skills not currently represented, add representatives from other areas of the country or specific groups in addition to Mothers and Youth • follow through with succession planning at AGM • increase youth programming • establish an annual budget so funds can be raised to support the programs
Advocacy with the MoH and medical teams at HTC (including HTC team and Hospital Director)	Fully accomplished Representatives from HST and HO met with Prof Magimba, Assistant Director Non- Communicable Diseases and Dr. M. Kalomo, Special Assistant to the Director - MOH Tour of the Hospital to meet with the members of the Hemophilia Care Team including Hemophilia Nurse, Doctor in the Clinic, Laboratory Technologists, Blood Bank Personnel, and more recently a Physiotherapist has been added	• Regular meetings between the HST with the MOH have generated recognition of: Muhimbili, the national referral hospital, as the leader and key provider of in-country diagnosis and care for patients with bleeding disorders. They have an established a basic hemophilia care team and are responsible for the national registry of patients with bleeding disorders (108 patients) • Ministry recognized the importance of HST outreach to identify new patients and fully supports the HST in all of its efforts - to improve care
Travel by Ontario Team to Tanzania	Fully accomplished	• Visit by two representatives from Ontario - July 19-24, 2017

TCOR Hemophilia Golf Classic

TCOR's 18th Annual Golf Tournament took place on September 8, 2017 and was held at Nobleton Lakes Golf Club. Over 60 people participated raising $16,000 for TCOR programs and services! Our sponsors were: Barrick Gold Corporation, Red Hat Organization, Bioverativ, Pfizer, Martine Celej, Neal and Smith Barristers & Solicitors, Fitzpatrick Electrical, Friends of the Oulahen Family, Perry Bitterman, R&R Staffing, Cross Filtration, Cambridge Filter Management, MacKenzie Investments, and Shawn MacDonald.

Thank you to Justin El Rassi for speaking on behalf of the TCOR community at dinner about his experience at Camp Wanakita!

A special thank you to our 2017 Golf committee. This tournament wouldn't be possible without your hard work. The committee members are David Neal, Maury Drutz, Gerry Mudge and Paul Golding. A special thank you to Gerry Mudge who is retiring from the committee after many years on the committee!

And finally, the day wouldn't run so well without the help of the tournament Volunteers: James Beckwith, David Goodman, Kathy Lawday, Jerry Laviolette and Rick Griffith! Thank you!

YMCA CAMP WANAKITA

2017 STATISTCS

63

NUMBER OF CAMPERS

This year, Hemophilia Ontario saw a record high number of registrations to attend YMCA Wanakita and a total of 63 campers attend.

CAMPER DIAGNOSIS

Hemophilia A: 40	von Willedbrand Disease: 8
Hemophilia B: 12	Platelet Disorder: 1
Factor 13: 1	Glanzmann Thrombasthenia: 1

CAMPER GENDER

Female: 5
Male: 58

NUMBER OF INFUSIONS

With a record number of campers this year, we also saw a record number of infusions.

# of Self Infusers: 19
#of New Self Infusers: 1
# of Infusions: 207

Hemophilia Ontario Camps!

YMCA Camp Wanakita

Hemophilia Ontario continued its decade long partnership with YMCA Camp Wanakita by sponsoring children to attend summer camp in 2017. This year, Hemophilia Ontario experienced a record high number of registrations and had the most campers to attend in the history of the program.

Pinecrest Adventure Camp
25th Anniversary

The following is an excerpt of a speech made at the Pinecrest 25th Anniversary Reunion event on November 26th, 2017 by Emil Wijnker.

I find it truly amazing that I'm standing here celebrating 25 years of Pinecrest Adventures. Pinecrest has been a fixture of my summers almost every single year since it started in 1992. I've been fortunate to have participated in Pinecrest from three very distinct perspectives: first as a camper, then as a staff member, and finally, now, as a parent.

In what seems to have become something of a tradition over the years, I first learned to self-infuse at camp. In addition to everything else that summer camp was, Pinecrest had become a sort of training ground for hemophiliacs. We would not only learn to play gaga-ball and build campfires, but we would also learn to mix our factor and access our veins while away from our usually obliging parents. The independence and confidence that came along with being able to treat your own bleeds was an integral part of the development of my character as well as my perspective on my hemophilia care. Camp not only taught me that it was OK to be a hemophiliac - that I could have hemophilia and still have fun - but it also taught me that I

could learn to manage my own condition and lead whatever fun life I wanted to – at the same time. If hemophilia couldn't hold me back from enjoying summer camp, why on earth should it hold me back from enjoying life?

In 2014, I would become involved with Pinecrest in a way that 8-year-old me never would have imagined. I was now the parent of a child with a bleeding disorder sending their child to camp for the first time. Now, three years later, all four of my children attended Pinecrest this past summer. To hear about – and assist with – the planning of camp from this new perspective brings me not only feelings of nostalgia, but pride as well. A lot has changed since 1992: advances in Bleeding Disorders care mean that almost none of our campers have obvious effects of bleeds. Hemophilia is now a highly manageable condition. Hemophiliacs are able to lead next-to-normal lives and can integrate into almost any program or camp they would want to. And yet, there is still a place for Pinecrest. There is value in having a place for children affected by a Bleeding Disorder to discover that they aren't alone – that there are others just like them, asking the same questions and sharing the same concerns. There is value in having a place where they can not only be told – but be shown – that having those questions, and sharing those concerns is OK, and that there are answers, and that everything really will be fine. There is value in continuing to build on 25 years of tradition and watching the next generation learn to live their best life – hemophilia and all.

Just the Guys 2017

Families came from across the province for a Marvel themed weekend from September 15-17th for Just the Guys, a program that focuses on the father or male role model learning about the care and treatment of their child's bleeding disorder. The quest for the Infinity Stone began on Friday night and finished on Sunday. From campfires, to challenges, to outdoor activities supported by the YMCA staff, everyone had a chance to share and participate. Our education sessions with Dr. Anthony Chan, Chad White, and Heather Perkins were empowering for all ages. The youth leaders Johnny, Luke, Matt, Trevor and Jordan made sure all the children were having fun. Special thanks to our nurses Heather Perkins and Kay Blyth, special guest Vanessa, our planning committee, and our sponsor, Bayer.

Message from the CHS President

by Paul Wilton

On behalf of the Canadian Hemophilia Society and our Chapters, Congratulations to Hemophilia Ontario on the twenty-fifth anniversary of Pinecrest Adventures! We recognize Pinecrest is one of the best programs offered for people with inherited bleeding disorders in Canada. Think of all the families who have learned they're not alone. Think of all the campers who learned how to self-infuse. Think of all the leaders Pinecrest has developed who contribute to our community. Thank you to all of the volunteers, staff, and campers who have helped make this program a success.

We are excited to share with you changes in our national staffing structure to begin the 2018 year. David Page will be stepping down from his role as National Executive Director at the end of this year. On behalf of our community, I thank David for a lifetime of dedication to our community. We are pleased that David will be continuing with the organization in a training, mentoring and support role as our Director of Health Policy. It is with gratitude and excitement that we share the news that two trusted members of our community, Helene Bourgaize and Deborah Franz Currie will serve as interim co-directors for a period of eighteen months. We look forward to experiencing their further success with the CHS and witnessing the difference they make for our community. The CHS Board will regularly review this structure and we welcome your feedback. For more detailed information on our new CHS staff structure please see the latest edition of Hemophilia Today or our website.

We wish to acknowledge the work Hemophilia Ontario has completed on their focus group report. We appreciate all of the input community members have provided. We intend to work closely with Hemophilia Ontario to learn from this input. We will report back in future articles about some of the things we've learned from these sessions and changes we're making in response.

We're here to serve you. We want to work together with Hemophilia Ontario and our community members to improve the health and quality of life of people with inherited bleeding disorders and to find cures. If you see something you think we can do better, we want to know. We welcome your comments, suggestions or questions at any time. Please feel free to call, mail or email me or any member of our friendly staff team.

Paul Wilton
President
Canadian Hemophilia Society
president@hemophilia.ca
1-800-668-2686

Canadian Blood Services (CBS) Tender Update

The CBS announced factor concentrate contracts for 2018-2020 on November 1, 2017. As a result of the recent tender process, some changes are coming to the products that will be available as of April 1, 2018. For more information about how these changes could impact your treatment, please contact your Hemophilia Treatment Centre team.

The Role of the Social Worker within the HTC

by Diana Cottingham, MSW, RSW

The Comprehensive Care Bleeding Disorder teams at the hospitals include social worker staff. The social worker is available to care for the social and emotional effects of the condition and treatment on the patient and family. In addition, the social worker can explore the financial impact of the condition. Issues addressed might include adjustment to and coping with the diagnosis of the bleeding disorder as well as practical concerns related to the patient's diagnosis such as income replacement options; absence from school or work; and practical problem solving. Social workers can refer you to a variety of resources such as camps, government assistance programs, support groups and sources of financial assistance.

Financial assistance programs that may be available to families include:

Assistance for outpatient drug costs, (medications requiring a prescription):

- Workplace Drug Plans or Trillium Drug Plan (TDP)

Government Insurance programs:

- Employment Insurance (EI) Sickness Benefits
- EI Compassionate Care Benefits

Private Insurance programs:

- Short-term Disability Benefits
- Long-term Disability Benefits

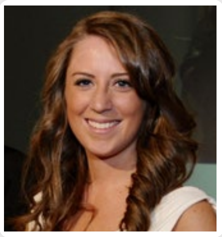
Other Programs:

- Assistance for Children with Severe Disabilities (ACSD)
- Ontario Disability Support Program (ODSP)
- Disability Tax Credit
- Medical Expenses Tax Credit
- Northern Health Travel Grant

Most families state that their lives are not the same, after a family member has been diagnosed with a bleeding disorder. The diagnosis brings changes to your life and the whole family. Each person copes with stress in their own way. Families have told us that they feel frightened, worried, sad, guilty, and angry. These are normal, common human emotions. Often, talking to family and friends or a member of the health care team, can be helpful and help you to feel less alone. A consultation with a social worker might help add new and creative strategies for coping in daily life. Adequate sleep, healthy nutrition, exercise and good self -care are basic techniques to deal with stress. The social worker is available to support you as you learn what works for you, as well as provide supportive counselling as the health condition impacts yours and your family's quality of life.

If you have any of the above concerns, please feel free to contact the social worker. The Canadian Hemophilia Society and the local Hemophilia chapters have helpful resources for your family and group opportunities to get together with other patients and families who have a bleeding disorder.

Diana Cottingham MSW RSW
Social Worker
Sick Kids, Bleeding Disorder Program



Hemophilia Ontario Advocacy Committee Report

by Amy Griffith

Everyone should have a team, and that team will look different for everyone. It could involve colleagues, family members, close friends, new acquaintances bonded by circumstance, old connections, or people you didn't even realize you need: that is, until you need them. What makes a team thrive is support, and there is no bigger team than the one that supports a person with a bleeding disorder.

That bleeding disorder team begins with each person's Hemophilia Treatment Centre (HTC). While many of us are aware that these centres exist throughout the province, even the most educated of members may not be aware that hand- in- hand with these HTCs, is the Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders. Developed in 2005 as the Ontario Hemophilia Comprehensive Care Standards they were adopted nationally in June of 2007 by a multidisciplinary committee including members of the Canadian Hemophilia Society. The document was created with the intention for use by HTCs, hospital administrators, and provincial Ministries of Health. Its vision: "to provide comprehensive care to all individuals with inherited bleeding disorders, guided by clear standards, facilitated by engagements with stakeholders, and driven by the needs and best practice resulting in best outcomes." The focus of these standards is essentially on the structural and resource requirements necessary for a HTC to "effectively provide care", as well as on its "functions and responsibilities". In short:

"Medical care for hemophilia is specialized. A person with hemophilia must receive care from healthcare workers who have expert knowledge of the bleeding disorder. The wide- ranging needs of people with hemophilia and their families are best met through Hemophilia Treatment Centres rather than by individual doctors."

- World Federation of Hemophilia: Organizing a National Programme for Comprehensive Hemophilia Care.

Comprehensive care is the recommended method of care delivery for enabling people with inherited bleeding disorders to have access to effective and expert health care. Therefore, the purpose of these national standards is to encourage HTCs to adhere to uniform practices that are desirable, accountable, transparent and organized, and are based on principles that include enrolment, accurate diagnosis, genetic counselling, management, prevention, treatment, rehabilitation, and advocacy.

Advocacy

Much like what we do everyday as patients and caregivers, the standards of care dictated by the Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders works as an advocate for both individuals with inherited bleeding disorders and the whole patient group. The document aids patients in their understanding of what is expected of their HTC, alongside the core care team and services that they are entitled to, as a patient visiting that HTC. Standards help in ensuring equitable access and quality evidence-based care across Canada, coupled with data gathering tools such as My CBDR. The goal is that when this better understanding of comprehensive care is established, gaps in care and resources are more evident, and advocacy strategies can be developed to fill these gaps.

However, effective care is the responsibility of not only the HTC team, but the patients themselves. As patients, we and our families are partners with the HTCs in care decisions and therefore are accountable to HTC appointments and clinic visits.

In early 2017 Hemophilia Ontario made an active decision to advocate for its membership by establishing the Hemophilia Ontario Advocacy Committee. This committee, made up of membership from across Ontario, specialists outside of our organization, staff and our Executive Director, came together to expose gaps in existing care, services and resources, and to develop a work plan to help bridge these gaps. One area of need across the province was determined as the use and availability of resources and services within Hemophilia Treatment Centres, as various inconsistencies were revealed at all centres. Each HTC works alongside its own unique hospital administration to determine the staffing and resources available based on a magnitude of factors, including budget, staffing structure and clinic availability. Each HTC is aware of the Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders and strives to achieve attainable and equitable care for all their patients with inherited bleeding disorders.

However, this responsibility for equitable and accessible care does not fall solely on the HTCs and their staff. As patients, it is our responsibility to remain diligent in our own care, by attending all scheduled clinic visits. The importance of attending your clinic and using the HTC resources that are available is paramount. When patients skip regularly scheduled appointments or fail to use the inherited bleeding disorder specialists available to them, whether in clinic or on outside referral (social work, physiotherapy), hospital administrators see this as a reflection of the lack of need for these services and resources. If we wish to advocate for more available and easily accessible resources and personnel, it is important that any that already exist are being used, or we as an organization risk losing what we already have, let alone gaining any more.

As a patient followed in an adult care clinic, I understand the frustration that comes along with a clinic visit that I believe lacked value. However, I need to take a step forward in taking responsibility for my visit, and not expecting that my clinic will develop a visit unique to my needs. To advocate for a clinic visit that honours and values both your time and needs, consider the following:

1. Contacting your clinic ahead of your scheduled visit. Advocate for the type of care you expect during your appointment. (I would like to be seen by a physiotherapist for my knee. I would like to have blood taken and tested for iron deficiency.)
2. Preparing your current health and care concerns prior to your visit, to better maximize your time with your HTC physician, nurse team and any specialists.
3. Arriving prepared with any materials you require to ensure you leave with your questions answered and care satisfied (note book for taking notes, factor first card for dosage updates, an updated log of your prophylaxis regimen or My CBDR, questions that you would like answered before your visit ends).

In order to move our standards of care forward and for our HTCs to grow and thrive, we, as patients, need to be prepared to advocate for what we need, remain present in HTC clinic visits, and work hand in hand with our HTCs and Hemophilia Ontario to ensure patients across Ontario are receiving equitable access to care, resources and services.

One Man's Journey

by Chad White

No matter what happens to you; it doesn't have to define who you are or who you want to become. This is what 44-year-old Chad White wants others with hemophilia to know. Chad's journey has been nearly unbearable at times, but he is using his battle to inspire others. He was diagnosed with Mild Hemophilia A as a child, which came as quite a shock since there wasn't any family history. As Chad got older, he became engulfed in sports and always strived to be the best in every aspect. He used sports as an outlet for his anger and a mask, so no one would know what he was fighting. He felt that if he could be the best at everything no one would ask him what was wrong.

Chad became angry at hemophilia and thought if he ignored his condition, he could push through life full force. He was making decisions that had a negative impact on his life and pushing away the people around him. Chad didn't want anyone to know he was different, and he thought by staying active and living a full life, no one would notice. He says he was practicing "excessive perfectionism", but there were so many things happening around Chad that he couldn't control, it only made his mental and physical health decline even more.

In 2009, Chad was faced with a major medical decision. He was diagnosed with a stomach cancer gene that would cause him to develop cancer very soon in his future. He made the decision to have his stomach removed, and cancer was found during the surgery. He knew then he made the right decision and was able to continue with no chemo or radiation. His physical recovery was hard, but his mental recovery was just beginning. Chad knew something had to change.

Chad White has four amazing kids. His first marriage was severely troubled and ended in divorce. His depression worsened and he felt like there was no hope. He met someone and fell in love with an amazing woman! Jocelyn embraced his journey and his kids and they got married and started a new life together, but he was still angry at his illness.

Chad began bodybuilding and pushing himself physically but the rage just worsened. He hated hemophilia. He blamed hemophilia. He was angry, extremely depressed, and began drinking excessively. He realized that it was quickly taking over his life. He wanted to be a better husband and a better father. He didn't have any friends, because of his anger. Chad had moments when he didn't want to live anymore. He came to a point where he realized that he was either going to "make his life, or take his life". Chad made the courageous decision to seek treatment for his mental health. He was diagnosed with PTSD as a result of trauma from his medical conditions. Chad went into a nine-week inpatient therapy program to save his marriage and save his life.

Through his treatment, he realized that he had been "afraid of his story". He was embarrassed by his journey and his trials but realized the very thing that he has been afraid of was the same thing that could give courage to others if he would speak out. He began sharing his story with some of the people at his local hemophilia chapter and saw how other people were being inspired by how he had overcome so many obstacles. He has discovered that when he inspires other through his story that it has brought purpose to his pain.

Chad is currently playing competitive soccer and competing in bodybuilding shows. He has linked up with #HemoLife and wants to tell others not to give up, no matter how hard their struggle may be. He wants to share his story with as many people as possible and hopes to one day speak at the World Hemophilia Conference. His favorite line is "I couldn't control the waves so I had to learn how to surf". It is clear that Chad White has overcome a lot of major hurdles and has found his true strength, not by hiding his story but by sharing it!

Community Advisory Committee Report for the CHS Hepatitis & HIV Committee

Edited from a report by Guy-Henri Godin, CHS Volunteer

This is my report as a CAC (Community Advisory Committee) member of the CTN (Canadian Trial Network). The CAC has 9 permanent members who review, in teams of two, all proposed medical studies and vote on the acceptability or not, plus 2 apprentices to help with the reviews, and 3 readers that share their comments and cannot vote but will eventually replace members stepping-down.

We reviewed CTN S 309. That study CTN S 309 is known as the Switch Beta Liver trial: 46% of people infected with HIV and Hep C have problems with a fatty liver, getting even more problems to follow treatment effectively.

Thibault Mesplède, a post-doc student working at the Jewish Hospital in Montreal, made a very technical presentation on Capacity Building, HIV drug resistance and beyond. He explained how every new generation of ART (anti-retroviral therapy) and new molecules are improved to diminish the rate of resistance.

A number of studies were approved for further research, which is exciting for the future. The CAC will be different at next meeting because four members are up for renewal, some others are not sure if they are coming back or not. I completed the 4th year of my 7 years mandate (permanent seat for the CHS), and I am very happy about it.

The CTN added a new page about a toolbox for everyone on our website at: www.hivnet.ubc.ca/toolbox. There is also a presentation available by Dr Nadine Kronfli, with Jewish General Hospital, who received a grant from Gilead to study the level of Hepatitis C in Montreal prisons and the treatments available.

http://www.hivnet.ubc.ca/2017/09/guest-blog-dr-nadine-kronfli-hcv-treatment-canadian-prisons/

Finally, we pay tribute to the great Biomolecular researcher and World class scientist Dr. Mark Wainberg who was the head of CTN for many years, and who unfortunately drowned in Florida one year ago.

http://www.hivnet.ubc.ca/2017/07/marina-kleins-tribute-mark-wainberg-ias-2017-video-text/

Our next meeting will take place at the Westin Bay shore hotel, Vancouver, from April 23rd to 26th, 2018, and in Montreal at Loews hotel, from October 15th to 18th, 2018.

Stay well and Happy Holidays Season to all!!!

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.

Wellness for Women: An Empowering Weekend

Wellness for Women (W2) is a bi-annual weekend conference organized by Hemophilia Ontario. Created and designed by women for women, the goal is to engage with ladies across Ontario who are affected by inherited bleeding disorders. This year, the overarching theme was 'Your health, your voice!'

The conference offered a myriad of speakers, panels, discussions, and social events. The welcoming environment provided an opportunity for women affected by an inherited bleeding disorder to learn, question, share, and support one another.

Dr. Paula James was one of the conference speakers and she presented her Let's Talk Period initiative to the women in attendance. She spoke about her current research on hemophilia carriers and the correlation between bleeding disorders and angiodysplasia, small vascular malformations in the gut.

The event continued with a panel discussion in which women were encouraged to share their personal experiences, such as raising a child with bleeding disorders and being affected by hemophilia or Von Willebrand Disease.

It was empowering to listen to each individual's account and to see the support amongst this community of women.

Yvette Perrault, co-founder of the Aids Bereavement and Resiliency Program of Ontario (ABRPO) who is also a committed counsellor and community organizer, spoke on the topic of why your resilience matters, connecting to her experiences as a caregiver to families and communities.

After breaking for lunch, we divided into two groups. One group listened to Heather Perkins (Hemophilia Nurse Coordinator at the Children's Hospital of Eastern Ontario) speak about navigating the ER while the second group listened to Lisa Thibeault (Hemophilia Nurse Coordinator at the Kingston Health Sciences Center) and an individual affected by an inherited bleeding disorder as they engaged individuals in a #periodpower talk.

That evening, participants chose between a tour of the Kingston Penitentiary and a Paint Night event at 4Cats studio – a great way for the women to get to know one another in an informal setting.

Dr. Mary Anne Jamieson spoke on the final day of the conference. Her topic of discussion was How I Can Help and How Can I Help. Dr. Jamieson focused her talk on the medical and surgical management of women with bleeding disorders in all age groups.

Hemophilia Ontario wrapped up the weekend by presenting their peer support opportunities, upcoming programs, and awards presentation. As the only conference in Ontario for women with inherited bleeding disorders, the weekend offered an extremely informative and supportive environment that engaged and empowered all who attended!

Article from:
https://letstalkperiod.ca/wellness-women-empowering-weekend/

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

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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.

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.

Hemophilia Ontario
Hémophilie Ontario

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