A publication of
Hemophilia Ontario
Hémophilie Ontario

BLOOD matters

SPRING 2016
VOLUME 7 • NUMBER 1

Help Stop the Bleeding

PM # 42837517

BLOOD matters

Hemophilia Ontario

2016 - 2017 Board of Directors
Paul Wilton
Julia Sek
Zach Adams
Rob Dinsdale
Phyllis Gray
Amy Griffith
Shelley Hewett
Ashwani Kurichh
Monica Mamut
Maia Meier

Editorial Committee
Tom Beer
Alexsandra McGillivray
Matthew Maynard
Terri-Lee Higgins

Staff
Terri-Lee Higgins
Executive Director

Marina Seliverstova
Senior Accountant

Susan Turner
Administration and Program Supports

Alex McGillivray
Provincial Coordinator
Programs and Communications

Matthew Maynard
Provincial Coordinator Adult Services

Stephanie Morrison
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

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

President's Message

by Paul Wilton

When I was learning how to drive they taught a concept called *Medium Eye Lead Time*. The idea was if you looked out your windshield about 20 seconds ahead of your current position you would be better able to navigate the road and safely reach your destination.

For the past few years Hemophilia Ontario has been driving while paying a lot of attention to the car not just the road ahead. To an extent this makes sense. You can't reach your destination if you don't keep your car well-tuned. We have updated our by-laws to ensure better governance, rewritten our policies to set clear expectations, amalgamated TCOR and Hemophilia Ontario (car sharing to save fuel) and developed a renewed partnership between our regions.

Last year while looking into the distance we saw a major hazard ahead. We saw a threat to our funding. We needed to change course to reach our destination. This required a lot of work to the car. It's clear, we love our car. It's been in our family for decades. We could have taken the approach that our car is a beauty and little should change. Instead we've said "let's take this classic and update it for the modern era". We'll inspect every area of the car and consider any and all updates to make it run at peak performance.

The big challenge in the modern-era for classic cars is new fuel efficiency standards. In a sense there are new efficiency standards for not-for-profits too. Old sources of funding are being phased out. Existing funders set stricter limitations on what they're willing to fund. Everyone wants to see data to prove organizations are actually meeting their goals. Resources both human and financial are limited so everything we do must be aligned with our goals to ensure time and money is used effectively. The expectation is for our car to be a high performance machine and for there to be accountability when we fall short of that standard.

We've made a lot of changes to our car this year to avoid the hazards ahead. We think we're making our classic better than ever. In the next few months we'll have a strategy in place for the next few years for Hemophilia Ontario. Once this strategy is in place it's important that we increasingly look out the windshield ahead. We should remember trying to drive while repairing the car is a risky endeavour. Hemophilia Ontario exists to reach its destination, not to remain parked in a souped up ride. We are here to improve the health and life of all people with inherited bleeding disorders and to find cures. We need to increasingly look outward and ahead to identify opportunities to reach our mission. Once we reach our destination we can retire our car for good.

Thanks for sticking with us for the ride.

Executive Director's Message

by Terri-Lee Higgins

Throughout this process our end goal is to more effectively deliver programs and support while ensuring that we are relevant and what we do is engaging, intriguing, influential, innovative and impactful. As we delve further into the restructuring process we will continue to make every effort to keep you aware of where we are in the process and how it will impact you, our members.

What's in this Issue?

Spring 2016 Volume 7, Number 1

Thank you to our sponsors:

MAGAZINE and PROGRAMS

octapharma
For the safe and optimal use of human proteins
Pfizer

PROGRAMS

Baxter
CSL Behring
Biotherapies for Life™
BAYER
novo nordisk®
Biogen

It has been an interesting process to date. The staff team has had to challenge our assumptions, find out what we don't know, determine where we need to focus and discover what we need to let go of in an effort to best serve our mission and help members see the value of being involved with the organization. What I am most proud of is that throughout this process staff were not concerned whether or not they would have a job when all is said and done, they were concerned that the organization would be able to continue forward in spite of the restructuring. They committed to developing tools that members and volunteers can use to implement member events and fundraisers to build a stronger community. We also reviewed the feedback that you, our members, provided through the fall Member Survey and were provided great insight and information into what our members say we do well, what we don't and identified some gaps. We had offered activities that had low attendance and / or were cancelled but we offered them as regional programs because we believed the information was important. Last year we moved to web based learning offering the same programs as webinars providing participants the opportunity to participate from the comfort of their own home, registrations increased. The feedback tells us we are on the right track and that we need to continue to offer these types of learning opportunities – stay tuned!

Did you know that prior to 1984 Hemophilia Ontario was run almost entirely by volunteers? A grassroots organization, all educational programs, member events, clinics and fundraisers were developed and implemented by those who were the base of our strong community roots – volunteers! Staff were hired with Trillium funding and in 1987 the Ministry of Health Long Term Care AIDS Bureau provided money for staff to support those members infected with HIV/AIDS and Hepatitis C as a result of the tainted blood tragedy. Sadly, the number of HIV infected individuals with an inherited bleeding disorder has declined significantly as our members have passed away. Given this it is perhaps easier to understand why our funding is reducing. The organization was never funded to support our work with individuals living with and affected by inherited bleeding disorders yet this is the population where we focus the bulk of our work. By realigning our priorities to reflect our funding, shifting our focus from regional to provincial and better aligning staff roles and responsibilities, we are building a base for future operations.

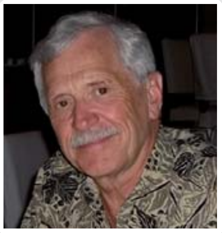
Together we can do this and we're here to assist and ensure that Hemophilia Ontario has a future. Here are a few ways you can be part of the change:

- *We need volunteers who will step up to help the regions and the province remain vital. Can you commit to sitting on a regional council or the Board, help at an awareness raising event or organize a member event such as a BBQ or winter party?*
- *We need you to make a donation – if every member donated $10 annually Hemophilia Ontario would have the resources needed to continue meeting its mission each year.*
- *We need organizers and planners. Can you organize a fundraiser in your region that will help ensure your regions needs are met? Do you have time to be the lead volunteer on an existing fundraiser? As our funding reduces in order to ensure that we will be able to continue to provide education and support the organization must find ways to increase the amount of donations we receive.*
- *We need to you help raise awareness. Participate as a speaker for either HealthPartners or Federated Health educating these groups about our organization, how those you love are affected by an inherited bleeding disorder and how their support through payroll deductions make a difference?*
- *We need everyone to become aware of companies, including your own that have programs that make donations to organizations where you volunteer?*
- *We need you, our members and volunteers, to give us your feedback and help us see from your view what's working, what isn't and how we can adjust or let go.*

Now more than ever we will be looking to you, our members, for help. Please talk to a staff, volunteer, Council or Board member and tell us how you would like to help.

I cannot tell you that by the end of this year that as an organization we will be settled and that nothing else will change, in fact we fully anticipate that we will continue to grow and evolve. I cannot tell you that members will be happy with or appreciate every decision that has been and will be made but know that we will be continually evaluating through this process so that we have a solid base from which to move forward into the future. What I **CAN** promise is that we will build capability in our members, empower our communities and build our member base so that Hemophilia Ontario will continue to thrive.

At any time if you have any questions, concerns or issues with our restructure process please don't hesitate to contact either myself thiggins@hemophilia.on.ca 226-926-8028 (toll free: 1-888-838-8846 ext 17) or Board President Paul Wilton at pwilton3@gmail.com. Here's to our future and all the possibilities it holds.



Editor's Message:

Becoming an agent of change…

by Tom Beer

Over the past few months the culture of change has gripped those involved in Hemophilia Ontario, and, the results of their deliberations are the focus of this issue of *Blood Matters*.

In his book, Embrace The Chaos, Bob Miglani addresses the question," How do we adapt to the changes coming?" Let me tap into Miglani's mind.

Let Go. An agent of change looks to the future. Like the Roman god Janus(January)we look back to learn from the past, but we live in the present and look to the future. As Terri-Lee points out, HO has grown from an organization run by volunteers, to one supported by government and agencies who are now changing priorities, returning the organization to depend more on its funding origins, but, needing to utilize the communication media available for better delivery of programs. Were things better, "back in the day"? They were different. The future of HO is different.

Accept. Change is constant. The world is not. So, accepting that premise, we can adapt. Look at the reports from the regions. Valuable programs are continuing. Many are being expanded. The leaders have accepted that HO is changing and have adapted, and are moving on.

Think "YES", not "NO". We all know someone who, when faced with a "new" idea, begins the discussion with the comment, "I don't think that'll work in our area because…" Look at those who have accepted their new roles in the organization. Ready to move forward? They are.

Control your own actions. Look at the "talk" about the changes in the workplace, in the funding model, in the staff, in the budget, in the organization. Over how much of it do you have control? Not much… except, YOUR REACTION TO THE CHANGES. We have control over our actions! That's it.

Be open to "new". Change is frightening. Often, it creates a sense of isolation. We think, "Nobody seems to be as affected by this as I am." Often, we feel worried and anxious. So, network with others, call your friends, go to a conference, get a fresh perspective. Break the negative pattern and boost your spirits.

As Miglani says, *"You are capable of adapting to anything-you just don't know it yet."*

When I first read the articles by President Paul and Executive Director Terri-Lee, I was struck by the tones of each. They each want you, the HO members, followers, volunteers, staff and countless others who have a stake in the success and future of Hemophilia Ontario to know that change is happening. Change is always frightening, and, often threatening, but, those involved in making decisions about the future of HO are committed not only to the mission of HO, but, most importantly, to the people who are the reason for HO.

They give some of the history of the organization and the reality that funding for this vital endeavour has always been a challenge, now, more than ever. As Terri-Lee emphasises, with the dwindling numbers affected by the tainted blood event, the funding supplied for those members is coming to an end. The organization recognizes the challenges of maintaining the valuable programs already in place, and, is addressing the problems of trying to introduce effective new programs in presentation styles more readily accessible by the modern audience. Throughout the examination, analysis, and deliberations and the "wadda we do now" discussions, as can be seen in all the articles and insights contained in this volume of *Blood Matters*, the planning group never lost sight of what's important here- all those affected by Inherited Bleeding Disorders. They are determined to make the organization stronger by taking advantage of what HO does well, modifying the delivery systems, and using the staff, volunteers, parents, practitioners, and those directly affected by IBDs, to work towards a secure future.

Now that we can see the direction of Hemophilia Ontario, we are asked to join in the journey, the car ride" with the "new" HO.

My little bit of "old guy" wisdom is to point out that we take into account all the expert input, all the assessments, and the risk factors, but, as wellness educator Laura Putnam urges, shift our mindset from trusting the experts to becoming agents of change. "Experts speak to our brains and tend to overload us with facts- using scary statistics and depressing data. Agents of change, on the other hand, speak to our hearts- and they move us." If any organization with which I've ever been involved speaks to our hearts, HO is it.

Look carefully at the articles from the young people who attended the NACHHO conference. The success of the programs offered by HO is evident in their unsolicited support for their experiences. As Hannah writes, "…the sessions provided us the tools to build strong programs today that will carry on into the future and strengthen the legacy of our camps and organization." Each of them has accepted the challenge of becoming an agent of change, a spark to ignite those around them to grow into their potentials.

They live in the future.

They believe in the future.

The message in this issue of *Blood Matters* is clear… The future of Hemophilia Ontario starts today.

Welcome to the future. 🩸

Read on…

Hemophilia Ontario Annual General Meeting

Saturday, April 16, 2016 – Toronto, Ontario

Dear Hemophilia Ontario Member,

Re: HEMOPHILIA ONTARIO'S 60th ANNUAL GENERAL MEETING

This letter is to notify all Hemophilia Ontario Members that the 60th Annual General Meeting will be held at the Ryerson University, International Room, 240 Jarvis Street, Toronto Ontario, Saturday April 16, 2016, beginning at 10 am.

The affairs of Hemophilia Ontario are conducted by a Volunteer Board. At present Julia Sek, Amy Griffith, Phyllis Gray, Maia Meier, Monica Mamut, Rob Dinsdale, Shelley Hewett, Ash Kurichh, Zach Adams and Paul Wilton compose the Board.

Each Regional Council nominates a delegate to the Board, three Directors at Large are elected by members. The immediate past-president is an ex-officio member and the Board will have an opportunity to elect one extra Board Member to serve until the next Annual General Meeting. Board terms are two-years and elected on a rotating cycle.

This year three regional (SWOR, TCOR, and NOR) delegates and one director at large will be elected.

If you are interested in being a Board Member or if you wish to nominate someone to stand for election please complete the nomination form. Please ensure that the person you are nominating is aware of the nomination, and is willing to stand for election. The deadline for receiving nominations prior to the Annual General Meeting is April 11, 2016. Additional Information on Board Member responsibilities, our current priorities and the election process can be viewed at **www.hemophilia.on.ca**

A proxy form* (if you are unable to attend) can be obtained by contacting Susan Turner or by following the instructions below. The form, once completed, may be mailed, faxed (416-972-0307) or emailed to Hemophilia Ontario's Nominations Chair, c/o sturner@hemophilia.on.ca by Monday, April 11, 2016.

Should you have any questions, leave a message for me at 416-972-0641.

Please RSVP your attendance to Susan Turner;
sturner@hemophilia.on.ca or call toll free: 1-888-838-8846
local: 416-972-0641.

Sincerely,

Zach Adams,
Secretary

* Proxy, Nomination, and Membership forms can be obtained by contacting Susan Turner, or downloaded online:

Proxy & Nomination Forms **http://bit.ly/1U52JWR**

Membership Form **http://bit.ly/1UKZra4**

Come and Hear from Dr. Carcao Why The Past, The Present and The Future Means There Are Brighter Skies Ahead

Dr. Manuel Carcao, Hematologist
The Hospital for Sick Children

Brief Biography – Dr. Carcao is a Clinician Investigator in the Division of Haematology/Oncology (Department of Paediatrics), Associate Scientist in the Child Health Evaluative Sciences program at SickKids and Associate Professor of Paediatrics at the University of Toronto. He is also a member of the Hemostasis program in Haematology.

Dr. Carcao received his medical degree in 1990 and a Masters of Science degree in Clinical Epidemiology in 2007 from the University of Toronto. He joined the division as a faculty member in 1999 following completion of haematology/oncology and hemostasis fellowships (1995-1999).

Dr. Carcao's clinical and clinical translational research interests are in the area of the inherited and acquired bleeding disorders of children with a focus on the haemophilias. He is co-director of the Paediatric Comprehensive Care Haemophilia Program at SickKids and past President of the Association of Haemophilia Clinic Directors of Canada (AHCDC).

Source: **http://www.sickkids.ca/AboutSickKids/Directory/People/C/Manuel-Carcao-Staff-Profile.html**

60th Birthday Celebration

As you know, Hemophilia Ontario is celebrating it's 60th birthday and we want to celebrate it with you!

The day's events will be filled with fun and will take a walk down memory lane to honour and recognize our past, present, and future.

We'll be learning about the history and achievements of our organization through the stories of our community with speakers such as Betty Ann Paradis, Paul Wilton, and Jeff Beck to name a few.

Please make sure to join us to share your story too!

We look forward to seeing you!

Dreaming Big, Being Bold – The Big Unveil!

So exactly how will the restructure impact you, your family, the programs you have attended and the supports you have received? Through this article we share with you the goals of an engaged team, passionate about their work, as we work together with our members and volunteers to build a path to the future.

At the core of all decisions in determining what 'forward' looks like is the following credo: We will inform and support members as they make important decisions for their health and wellness related to their inherited bleeding disorder. This means we will need to be focused and specific in the work we do and target opportunities for active engagement with a goal of increasing member acquisition and increasing engagement of existing members.

There are four key connectors that will be the basis of our new work foundation with a focus on alignment, consistency and repetition at the forefront. These connectors are:

Intake and Coordination Services: we will be the first point of contact / a resource to the medical teams and IBD patients. Coordinated community resources will include an introductory tool, navigation map and member acquisition and retention strategy.

Programs and Education: we have completed a review of key provincial and regional programs and identified those that will continue, those that will be refined and those that will no longer be provided.

Media and Communications: we are developing a monthly calendar of social media topics, determining our advertising base and strategically realigning this aspect of our work. Be watching for our new monthly information e-mails!

Fund Development: training and support materials will be provided to support volunteers to implement fundraising events. Staff are developing these resources and supports allowing for consistently run successful fundraisers. As our staffing decreases we must build capacity within our member community to confidently continue to generate revenues.

Our regions stand strong. Every region still has volunteers, will fundraise (and we guarantee those funds will continue to be spent in that region) and will still offer educational programs and member events. One of our challenges was how to communicate that the regions are still operating when we no longer have regional offices. We want to ensure that when we correspond by direct mail that we have something in place that should returned mail happen we will have 1 location for it to be received and followed-up on as required. Each region will continue to have its own letterhead which will be used when sharing information about your region. All letterhead and return envelopes will have the return address listed as the Head office (c/o 4711 Yonge Street) – In this way we can ensure that we don't miss any return mail from any member across the province. But, when you receive something from Hemophilia Ontario or one of the regions, we ask that you read the flyer / letter because whoever is responsible for the program or event will identify how they want you to respond. For example, if we are advertising an Aging program for CWOR / SWOR and TCOR, Matthew will ask you to reply to him. If we are promoting NOR's Just the Guys / Community Camp weekend, Stephanie will ask you to reply to her. As we have basically followed this process for the past many years, we believed it would be the easiest way to help ensure our members still have someone to connect with directly, when needed, about regional programs.

Provincial staff will interact with the Regions in a new way to ensure the implementation of regional educational programs continues. Where multiple regions are interested in similar topics we will be looking into collaborative sessions hosted by multiple regions. By combining smaller regional budgets, programs will provide a more comprehensive education program benefitting attending members.

Over the past two years webinars were introduced as a new platform for program delivery with solid results so we will look to continue these learning opportunities. If you have any ideas for topics or information that would be of interest, please contact one of the provincial staff who will be working with Regional Councils to deliver top notch programs.

Staff attendance at clinics enables member acquisition, coaching and health care navigation for affected individuals and their families, and relationship building with Hemophilia Ontario's stakeholders. Each staff will be attending clinics across the province at a minimum of once per month. Should you need to connect with any staff at any time all contact information is provided a little further in this article. Financial Assistance can still be submitted through any Hemophilia Ontario staff, a member of any HTC or directly to Terri-Lee by email or FAX. Further details on our Financial Assistance policy are detailed in another article in this edition.

It is recognized that Member Events provide the very important opportunity for our members to meet face to face, share stories, and develop important support networks that only those who live with an inherited bleeding disorder can appreciate. With the shifting of staff responsibilities from regional to provincial focus it is necessary to re-develop the processes around implementing these activities. Without the direct involvement of volunteers in the regions we will face significant challenges in continuing to offer these important member events. Each region will have a designated Resource Staff to assist with the planning of these events so be watching your email for upcoming events.

We have worked hard to develop the new job descriptions and role responsibilities in an effort to provide a consistent level of service and supports across the province. Over the next year we will continue to revisit the roles and responsibilities and, where needed, we will adjust to meet identified gaps.

The following is a breakdown of the basics of the new staffing structure and who is working each role:

Executive Director
Terri-Lee Higgins
thiggins@hemophilia.on.ca
or call 226-926-8028, toll free 1-888-838-8846 ext 17

- Organizational day to day operations
- Main point of contact: NEW program, Financial Assistance, World Congress, NACCHO, Twinning and Pinecrest Adventures Camp
- Contribute to *Blood Matters* and online presence
- Resource for SWOR youth and member events
- Clinic Support – London Bleeding Disorders Program - Pediatrics

Administration and Program Coordinator
Susan Turner
sturner@hemophilia.on.ca
or call 416-972-0641, toll free 1-888-838-8846 ext 11

Responsible for the day to day management of all financial and accounting requirements of the organization. Additionally, this person is responsible for the delivery of two provincial programs.

- Administration and Executive Assistant to the Executive Director
- Bookkeeping
- Submission of existing funding applications
- Lead program staff Community Camp & Wellness for Women
- Resource TCOR Member events (Families in Touch)
- Contribute to *Blood Matters* and online presence

Provincial Coordinator Northern Services
Stephanie Morrison
smorrison@hemophilia.on.ca
or call 1-705-561-5055, toll free 1-888-838-8846 ext 16

Responsible for the delivery of programs, communications, support and services to individuals living with / affected by inherited bleeding disorders residing in northern Ontario

- NOR education programs (Just the Guys, Community Weekend)
- Clinic Support – Sudbury, Thunder Bay
- Contribute to *Blood Matters*, online presence
- Resource NOR member events and Regional General Meeting

Provincial Coordinator Programs and Communications
Alexsandra McGillivray
amcgillivray@hemophilia.on.ca
or call 905-522-2545, toll free 1-888-838-8846 ext 14

Responsible for the delivery of programs, communications, supports and services.

- Implementation of provincial programs including Just the Guys, Hemophilia Ontario Youth (HOY), YMCA Camp Wanankita,
- *Blood Matters* / monthly information email / online presence / social media / awareness campaigns
- Resource TCOR, OEOR, CWOR member events and Regional General Meetings
- Clinic Support – McMaster, SickKids, Children's Hospital of Eastern Ontario (CHEO), Kingston

Provincial Coordinator Adult Services
Matthew Maynard
mmaynard@hemophilia.on.ca
or call 519-432-2365, toll free 1-888-838-8846 ext 15

Responsible for the delivery of programs, supports and services to individuals infected and affected by infectious diseases such as HIV/AIDS and / or Hepatitis C after receipt of tainted blood or blood products and adults living with an inherited bleeding disorder.

- Adult and aging programs and services
- HIV/ AIDS and Hepatitis C information and supports to infected and affected members
- Advocacy for any aspects for settlements (pre-86, post 90, 86-90, MPTAP, etc)
- SWOR Regional General Meeting
- Contribute to *Blood Matters* and online presence
- Resource for provincial volunteer events and Council building
- Clinic Support to The Ottawa Hospital, St. Michaels, Bleeding Disorders Program Adults and will work collaboratively with HO staff in any of the other 6 Hemophilia Treatment Centers around the province
- Establish working relationships with provincial HIV Clinics and provide assistance as requested

Alex, Matthew and Stephanie will collaborate on the delivery of programs that are identified by more than one region as an education topic. This will include webinars, Men's/Adult/ Aging education sessions, World Hemophilia Day - April 17 and November's Bleeding Disorders Awareness Month campaigns.

"In any moment of decision the best thing you can do is the right thing, the next best thing is the wrong thing, and the worst thing you can do is nothing." Theodore Roosevelt had this wisdom to share about making decisions. We ask you to bear with us through this process. We anticipate speed bumps. We will continue to be forthcoming and provide you with updates as they are available whether through *Blood Matters*, monthly emails or on social media. We are all working to make the transitions as seamless as possible and appreciate your support as we move forward.

If you have any questions or concerns do not hesitate to contact me at 226-926-8028 (toll free: 1-888-838-8846 ext 17)
or by email thiggins@hemophilia.on.ca

Financial Assistance Policy

The goal of the financial assistance policy is to provide exceptional financial support to people with bleeding disorders and their families to reduce the burden caused by their condition. To be eligible for financial assistance, these individuals must be members of Hemophilia Ontario or, if not, clients of one of the province's hemophilia treatment centres, and in financial need. Please note that submitted requests must directly reflect the individual's bleeding disorder related needs. Hemophilia Ontario reserves the right to contact medical personnel for addition information as necessary when considering submitted requests.

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

Hemophilia Ontario is the payer of last resort. Members are required to attempt to have these costs covered by other social agencies including medical plans and the government. Hemophilia Ontario reserves the right to request copies of such documentation in support of the submitted request. When an individual's costs are to be reimbursed by a social agency at a later date, Hemophilia Ontario can enter into an agreement whereby the funds are advanced and then later recovered.

Each year, Hemophilia Ontario allocates a set amount of money for this fund and once these funds are exhausted, no further claims will be processed that year. Requests submitted by December 31st will be considered pending availability of funds. We are unable to carry claims over into the following year.

For information about the guidelines or to receive the Financial Assistance Forms to complete and submit with receipts, please contact a Hemophilia Ontario staff for more information.

The Standards of Care

As a member or patient of the inherited bleeding disorders community, you may be familiar with the Canadian Comprehensive Standards of Care, but just in case you aren't, or need a refresher, we're here to help! The Canadian Comprehensive Standards of Care are used by your Hemophilia Treatment Team, and guide best practices for the treatment of your inherited bleeding disorder. They specifically outline who your core team members are, and who your extended team members are. The standards also highlight the services available and responsibilities of each treatment centre. These are all really important features for the optimization of your own inherited bleeding disorders care.

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

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

60 Years and Going Strong

2016 is the start of an amazing milestone as we enter our 60th year so let the celebration begin! This is a significant accomplishment and we owe this to the people who have put the 'heart' into the Chapters work. It is their determination and humanity that has enabled us to come so far in 60 short years. Starting with our Annual General Meeting in Toronto on Saturday April 16th 2016 and ending in spring 2017 as we co-host the Canadian Hemophilia Society's Rendezvous Conference in Toronto, we will be taking a look back at where we have been and where we are going and we hope, bring smiles and surprises.

HO is Going Green!

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

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

The SIPPET Study

The SIPPET (Survey of Inhibitors in Plasma-Products Exposed Toddlers) study was a global study managed by Sintesi Research. You can find out more about the study at www.sippet.org and can find the research abstract by visiting, http://bit.ly/1Xdc24U.

The Journal of Haemophilia Practice has published an article on the study's results titled, "The SIPPET Study: what impact will it have on hemophilia care?".

The article reviews the findings of the study as presented during a plenary session at the American Society of Hematology (ASH) conference in December of 2015. To read the article, please visit, http://bit.ly/1UftKoU and click on the download button at the bottom of the page.

Products in the Pipeline – NEW UPDATE

February 29, 2016

Never have so many clotting factor concentrates been in development or "in the pipeline". So many, in fact, that it has become difficult to keep track of them all. So the CHS is publishing five charts, one each for factor VIII and von Willebrand factor, factor IX, inhibitor products, other coagulation products, and gene therapy, to help everyone stay informed of their progress through preclinical work, clinical trials and regulatory approval.

We have currently identified 28 new therapies in development or soon to be marketed, including ten for hemophilia A and VWD, five for hemophilia B, four bypassing therapies to treat patients with inhibitors, three other coagulation products and six gene therapies. While some of these are still at the preclinical stage, when the research is conducted on mice and other animals, many are in, or have completed, Phase III trials with patients, the final stage before an application is made to market the product commercially.

Health Canada has recently approved six of these products: Alprolix™, an extended half-life factor IX manufactured by Biogen in March 2014; Eloctate® an extended half-life factor VIII manufactured by Biogen in August 2014; Rixubis™, a traditional half-life factor IX manufactured by Baxalta in September 2014; Nuwiq® a recombinant FVIII product manufactured by Octapharma using a human cell line in November 2014; Zonovate®, a traditional half-life factor VIII manufactured by Novo Nordisk in January 2015; and Kovaltry™, a traditional half-life factor VIII manufactured by Bayer in January 2016.

Extended half-life products: The development of extended half-life products could be the first major improvement in care for hemophilia since the advent of virally safe concentrates and prophylaxis in the late 1980s.While claims need to be confirmed by clinical trials and post-marketing experience, it is possible that the half-life of factor IX could be extended three- to five-fold, factor VIII one and a half times and recombinant factor VIIa eight-fold. This has the potential to reduce the frequency of infusions, an advance in convenience, or increase the trough levels in prophylaxis, a clear therapeutic advance. Currently, prophylaxis aims to maintain at least a 1% factor level at all times. Should physicians and patients be content with 1% or is a higher trough level desirable to prevent bleeding?

More potent products/Novel mechanisms of action: Some of the products in development are designed to be more potent and more effective in stopping bleeding or to be based on entirely novel mechanisms of action. This is critically important for patients with inhibitors, for whom current treatments are not nearly as effective as conventional treatments for patients with hemophilia A and B without inhibitors.

Broader portfolios for companies: The pipeline sees the development of broader portfolios for companies so that they can market products in all three major areas—hemophilia A, hemophilia B and inhibitors—and not just one or two, as is the case today. This has the potential to increase world supply and competition. In a worldwide market growing by 8% a year, this is a good thing.

While not all of these products will make it to market, many are very promising. We will update these charts periodically. We invite you to consult this page regularly to follow progress.

More details on these clinical trials are available on the Web site of the U.S. National Institutes of Health. Go to www.clinicaltrials.gov and type 'hemophilia' in the search box.

Source: www.hemophilia.ca

Me – The App that Could End Years of Suffering for Thousands of Women

MONTREAL, March 8, 2016 – Sixteen Years

That is the average time a woman can suffer before receiving a proper diagnosis of a bleeding disorder, and, moreover, receiving the proper treatment that will change her life forever. With the new app ***Me***, the CHS provides women concerned with their frequent and heavy menstrual bleeding with a practical and reliable tool to help them evaluate their menstrual flow and present their doctor with quantified evidence. This very simple assessment may allow them to finally put a name on what has been upsetting their lives for so many years.

To find out more about the ***Me*** app, please visit www.hemophilia.ca or http://bit.ly/1Yyg4pG

Just Need to Talk?

If it changes it seems to also stay the same. There are new treatments, new services and new supports for those with HIV and/or hepatitis. So whether you prefer to use the phone, visit your clinic, get your information from the internet or would like to just talk with someone – it takes effort to stay informed and feel confident that you are taking care of yourself or those you care about in the best way possible.

If you just need to speak with someone in confidence please reach out to Hemophilia Ontario. You can speak directly to Matthew Maynard at 519-432-2365 (call or text message) or toll free 1-888-838-8846 ext 15. Your information that you share with us will be held in the strictest confidence.

Telephone:

The Ontario Sexual Health Line	1-800-668-2437

Internet:

HIV and Hepatitis Resources	http://catie.ca
Ontario Public Health	http://sexualhealthontario.ca/
Health Services	http://www.connexontario.ca/

Our Community Partners in Ontario:

We are not only part of the bleeding disorders community in Ontario we are also part of our local communities and other communities. If there is an organization or community you think we should be partnering with please let us know. Here are some of the communities we are working with or will be working with:

African & Caribbean Council on HIV/AIDS in Ontario	www.accho.ca
Ontario Aboriginal HIV/AIDS Strategy	http://www.oahas.org
Women and HIV/AIDS Initiative	www.whai.ca
Gay Men's Sexual Health Alliance	www.gmsh.ca

HEMOPHILIA ONTARIO

Who We Are & Who We Serve

Who is Hemophilia Ontario?

Founded in 1956, Hemophilia Ontario is the Ontario Chapter of the Canadian Hemophilia Society. A volunteer driven organization, we are a provincially incorporated charitable organization with offices in Ottawa, Toronto, Sudbury, Hamilton, Thunder Bay, and London.

Mission: We strive to improve the health and quality of life for all people with inherited bleeding disorders, and to find a cure.

Hemophilia Ontario

The family and friends of people living with inherited bleeding disorders.

People living with inherited bleeding disorders including hemophilia, von Willebrand Disease, rare factor deficiencies, and platelet disorders.

Healthcare providers in the Canadian network of inherited bleeding disorder comprehensive care clinics as well as other healthcare providers (primary care physicians, dentists, specialists, etc.) who may come into contact with those who remain undiagnosed.

Our members' community (daycare workers, teachers, employers, etc.) as well as raising awareness among the general public.

Regional Highlights

Central Western Ontario Region

by Alex McGillivray

2015 was a year focused on continuing work within our community. We held 3 educational programs focused on engaging members and encouraging them to take control of their health. We held 2 social events that brought families together for some fun, and we even managed to host our very first webinar on keeping your feet and ankles happy in collaboration with the Orthopedic Team from Hamilton Health Sciences.

2015 was also our third year hosting our charity BBQ at Supercrawl in September. While it wasn't the nicest of weather, it was a ton of fun!

Thank you to all of our members for your continued support and to the volunteers who continue to work tirelessly towards the mission of the organization and making this community great.

CWOR

Regional Council and Staff

Rob Dinsdale
Mary Pedersen
Debbie Bordi
Meagan Bordi
Michelle Markowski
Michelle Mundt

CONTACT
Alexsandra McGillivray
Provincial Coordinator
Programs and Communications
amcgillivray@hemophilia.on.ca

c/o 4711 Yonge Street
10th Floor, Suite 10100
Toronto, ON M2N 6K8
905-522-2545 or 1-888-838-8846 ext 14

Regional Highlights

Northern Ontario Region

News from the North!

by Stephanie Morrison

The spring HTC for Sudbury will be Saturday May 7th. Pharma representatives will be onsite talking about the latest advances in the treatment of bleeding disorders.

- The spring HTC for Thunder bay will be announced shortly.

A quick 2015 year in review:

- RGM
- Spring Clinic Crafts
- JTG's and Member Weekend Getaway!
- Fundraising Book Sale
- NEOR 35 Year Gala Celebration

What will 2016 have in store?
Join in on the change! Participate! Volunteer! Fundraise!

NOR

Regional Council and Staff

Shelley Hewett
Betty-Anne Paradis
Joanne Beaulieu
Julia Fortunato
Tim Hewett
Shawn Morrison

CONTACT
Stephanie Morrison
Provincial Coordinator
Northern Services
smorrison@hemophilia.on.ca

c/o 4711 Yonge Street
10th Floor, Suite 10100
Toronto, ON M2N 6K8
705-561-5055 or 1-888-838-8846 ext 16

Regional Highlights

Ottawa and Eastern Ontario Region

by Alex McGillivray

2015 was a busy year for OEOR. We kicked our year off with our RGM last March, held Summer BBQ's in both the Ottawa and Kingston regions, joined in a Parents Education Day with CWOR, hosted our very first webinar with Dr. Manuel Carcao presenting on new factor concentrates, and ended our year with a fun filled holiday event at Upper Canada Village.

Many thanks to all the members for their continued support and to the volunteers who continue to work on providing these programs and events.

OEOR

Diane Bissonnette
Lyanne Cabral
Raminder Kaur Kurichh
Ashwani Kurichh
Stephen Perry
Nancy Sauve
Anna Sicoli
Darlene Villeneuve

Regional Council and Staff

CONTACT

Alexsandra McGillivray
Provincial Coordinator
Programs and Communications
amcgillivray@hemophilia.on.ca

c/o 4711 Yonge Street
10th Floor, Suite 10100
Toronto, ON M2N 6K8
905-522-2545 or 1-888-838-8846 ext 14

Regional Highlights

South Western Ontario Region

by Matthew Maynard

So many members, our health care team, our volunteers and donors/supports came together in the past year to ensure the success of our programs and progress throughout the region. A successful Pinecrest camp, educational events, and member events were just the start.

The support of fundraising – polar bear dip, scrapilicious, golf tournament, appeal and pots and wreaths ensure that we have the resources and support to continue to meet the needs of the families and individuals in our South Western Ontario communities.

So as a region we are reaching out to say thank you 2015 and here is to next year's progress.

SWOR

Sue Culliton
Kathleen Hazelwood
Travis Hazelwood
Hannah Higgins
Julia Lepera
Michelle Lepera
Monica Mamut
Leigh McFadden
Paul Wilton

Regional Council and Staff

CONTACT

Matthew Maynard
Provincial Coordinator
Adult Services
mmaynard@hemophilia.on.ca

c/o 4711 Yonge Street
10th Floor, Suite 10100
Toronto, ON M2N 6K8
519-432-2365 or 1-888-838-8846 ext 15

Regional Highlights

by Susan Turner

The fall months were quite the busy ones for TCOR. We had 4 programs take place between the months of October to December! We hosted a youth golf clinic for kids ages 12 and under, our annual Women's in Touch event, our Men's event, and our Winter Families in Touch event.

As always, participants had the chance to connect with other members and learn from a variety of guest speakers/HTC team members. The Youth Golf Clinic saw Karen Strike, Physiotherapist teaching the kids proper stretching techniques; Jordan Lewis, Social Worker facilitated a discussion at our Men's Event, and Georgina Floros, Nurse Coordinator provided a presentation on transitioning care from SickKids to St. Michael's Hospital.

Thanks to our Bingo Crew! Thank you to the special group of TCOR members who volunteer at our bingo! This year because of their commitment and dedication to the bingo program we were able to help many TCOR members with expenses related to their health care and send lots of kids to Camp Wanakita!

In 2015 our bingo funds paid for:

- Camp Wanakita Fees $12,500 & Camp Nursing Fees $4,000
- Hospital parking and travel $1800
- Medic Alert Bracelets $1000
- Orthotics $800
- Educational Events $1000
- Equipment purchase for St. Michaels Hospital $1700
- Equipment purchase for Sick Kids Hospital $1200

Huge thank you to our volunteers: Gloria Allain, David Neal, Renee Laviolette, Phyllis Gray, Joan & Murray Kinniburgh, Derrick & Venus Reid, Susan Bernstein, Maury Drutz, Pia Khaghani, Catherine Sanchez, Randy Neal and Carolynn Chasse!

Ava's Love for Jack Shines Through with an Act of Kindness! TCOR would like to recognize the kind and generous act of one of our youngest fundraisers! Ava O. had a 6th birthday party planned and she decided she would like to donate half of the money given by her guests to Hemophilia Ontario because she wanted to help her younger brother Jack who has hemophilia.

Ava, thank you so much for your donation of $90 to help support the programs and services that help Hemophilia Ontario improve the health and quality of life for all people with inherited bleeding disorders!

TCOR

Regional Council and Staff

Zachary Adams
Michael Bosompra
Sheila Coad
Maury Drutz
Ayeh Hamidian
Samuel Leon
D'Marc Lewis
Neil Mentuch
Maryam Naji
David Neal
Corrine Van Dusen

CONTACT

Susan Turner
Administration and
Program Coordinator
sturner@hemophilia.on.ca

c/o 4711 Yonge Street
10th Floor, Suite 10100
Toronto, ON M2N 6K8
416-972-0641 or 1-888-838-8846 ext 11

NACCHO

Hemophilia Ontario, through the support of Pfizer, provides the opportunity for up to four individuals to attend the North American Camp Conference for Hemophilia Organizations (NACCHO). This conference brings together individuals from around the world to share their best practices, successes and challenges as a means of helping those involved in camp type programs keep their programs vibrant and engaging. This year's attendees represented Community Camp, Just the Guys and Pinecrest Adventures Camp. We are thrilled to share that Pinecrest finished fourth in the NACCHO Cup earning $750 for their program this summer! We asked each attendee to share their overview of the conference, here are their stories:

Emily M.

This year I had the amazing opportunity to attend NACCHO. When applying to NACCHO my goals were to be able to continue to develop as a staff member so I can help make camp an even better experience for the children attending. By attending NACCHO I gained new skills and information that will help me do just that. At NACCHO I attended sessions on "Songs, Skits and Other Silly Things" and "Story Warriors". In these sessions I learned new songs to bring to camp and the art of telling stories. I can't wait to bring the information I gained from these sessions to the position of Spirit Leader. In other sessions I learned the importance of validating emotions, how to explain the importance of camp to others, and the importance of positive behavior in supporting campers. This was all mixed in with exciting ice breakers, a next level game of Simon Says and a mind teaser using two corks. One of the things I enjoyed most from NACCHO was meeting new people who have a similar passion in working at camps and planning activities for those with bleeding disorders. But most of all I enjoyed spending time and becoming closer with my fellow staff members. I can't wait till Pinecrest 2016!

Johnny L.

This year was my second year at NACCHO, and it did not fail to meet my expectations for the second year in a row. NACCHO has given me the opportunity to share aspects from my volunteering experience, as well as learn from everyone else who attended the conference. Being that I went on behalf of Just The Guys, it was enlightening for me to share what Just The Guys is all about. One group was so fascinated by the concept that they were going to propose the idea to their Hemophilia community! NACCHO is a great experience because you get to learn about other communities, ideas, and programs that they have been a part of. It is the perfect place to learn, and personally, I have grown substantially as a leader and a person from attending the conference and learning ways to make my community that much better. NACCHO is an experience that I will never forget, and I look forward to bringing back what I learned to Camp Pinecrest, Just the Guys, and anywhere else that I volunteer in.

Hannah H.

As I continue to expand my volunteer involvement with 2016's Community Camp (a family camp that occurs every other year and is scheduled for October 14-16, 2016) I focused my NACCHO session on finding ways to engage new families that are not sure how to take the leap into camp. What I found most enjoyable about NACCHO this year was that it was a refreshing look on how the present is affecting the future of our camps. Taking this approach through the theme of Tomorrowland, the sessions provided us the tools to build strong programs today that will carry on into the future and strengthen the legacy of our camps and organization. One of the messages that stuck with me the most was from Travis Jon Allison. In both his breakout and key note session, Travis inspired us to use our own personal camp stories as a method to demonstrate just how important and transformative camp can be for a child, their siblings, or a family as a whole. Story telling allows you to give families a taste of what opportunities and memories camp can provide for them by sharing your own experiences. If you are a volunteer, I would strongly encourage you to apply for the opportunity to attend NACCHO – it's an amazing weekend.

Tyse B.

Being a camp staff for a while now, I've heard stories about NACCHO, and on countless occasions, ideas that came from it. I remember stories from there, but couldn't fully grasp how a bunch of bleeding disorders camps would run a conference. I now understand; NACCHO was an unbelievable and unforgettable experience. It was really hard to comprehend a community of that size all committed to bleeding disorders camps, but I can safely say every single person there was after the same goal as me. As the director of Pinecrest, I've taken away so many ideas to help with staff and leadership training, program development and working with children to name a few. This was a great opportunity to look at how we can improve our camp and as the theme "Tomorrowland" suggests, plan for the future. That weekend is something I will not soon (if ever) forget.

‘BE’ Job Shadow Program

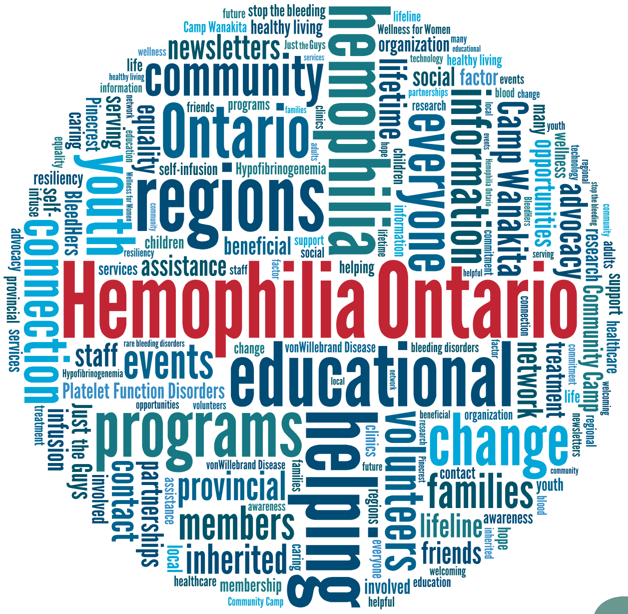
Assists Youth with Hemophilia in Choosing Careers

The **BE** Job Shadow Program offers youth, **aged 16-18 years with hemophilia**, an opportunity to understand what is entailed in various careers with up to 3 arranged job shadow experiences. Spending time with people who work in various fields is enlightening and can help students decide if this career or job is what they would like to pursue. They can make more informed choices with respect to the courses to choose in completing secondary school and beyond.

The **BE** Job Shadow Program was launched as a pilot in 2014, under the guidance of the Canadian HERO Advisory Board comprised of health care practitioners working in hemophilia treatment. In 2014, 25 job shadows were arranged in the fields of architecture, paleontology, engineering, filming/editing, medicine, laboratory technician, food preparation, actuarial work, and sports training, to mention a few. The **BE** pilot program was deemed a success and expanded in 2015 to more hemophilia treatment centers in Canada.

For 2016, interested participants with hemophilia are required to fill out application forms, and undergo a telephone interview with consultants to clarify their interests and to prioritize their wish lists for up to 3 job shadow experiences. Complete the application form online at BEjobshadow.ca. and build a résumé there if you don’t already have one. Email your completed application, résumé and signed consent form to admin@BEjobshadow.ca. The program coordinators will match you with employers to offer you your desired experience.

The **BE** Job Shadow Program is sponsored by Novo Nordisk Canada located in Mississauga, Ontario. **BE** stems from the global initiative called **HERO (Hemophilia Experiences, Results and Opportunities)** guided by the HERO International Advisory Board and supported by Novo Nordisk. The HERO study was the largest ever multinational, multi-method psychosocial study of 1386 people in 11 countries. Several themes emerged and in the area of vocation over 50% of respondents noted that hemophilia has had a large or moderate impact on their working life. HERO aims to build a comprehensive understanding of life with hemophilia as seen from the perspective of people with hemophilia, their families and their healthcare provider.



Hemophilia Ontario Calendar

APRIL 2016
SATURDAY
16
HEMOPHILIA ONTARIO ANNUAL GENERAL MEETING

SEPTEMBER 2016
FRIDAY • SATURDAY • SUNDAY
16-18
JUST THE GUYS WEEKEND

OCTOBER 2016
FRIDAY • SATURDAY • SUNDAY
14-16
COMMUNITY CAMP

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
@HemoOntario
/Hemophilia-Ontario
/HemophiliaON
HemophiliaOntario
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