A publication of

Hemophilia Ontario
Hémophilie Ontario

BLOOD matters

FALL 2016
VOLUME 7 • NUMBER 2

Help Stop the Bleeding

PM # 42837517

BLOOD matters

Hemophilia Ontario

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

Hemophilia Ontario
Hémophilie Ontario

Hemophilia Ontario is a certified chapter of the Canadian Hemophilia Society

President's Message

by Paul Wilton

“Our goal should be not to exist” the red-bearded intellectual boomed. Our goal is not to exist? I was puzzled. The man with the red-beard as some of you have probably already concluded is the late John Plater. The scene was a meeting room in downtown Toronto. The Board had brought in a facilitator to do some training. John was no longer a Board Member but agreed to my pleading with him to participate. The facilitator was trying to summarize her teachings in one simple phrase. She said “your most important responsibility is to ensure the survival of the organization”. John didn't miss a beat. “No, our most important responsibility is to accomplish our mission; actually our goal should be not to exist.” If we accomplish our mission, there is no need for us to exist. As we move into a new year let us all maintain focus on working together to accomplish our mission.

How will we improve the health and quality of life of all people with inherited bleeding disorders and find cures? We need to ensure everyone with an inherited bleeding disorder has access to comprehensive care. Over the past two years we have cooperated with Ontario clinics on assessments to identify gaps in services. In 2017 we will work with the clinics to develop an action plan to address these gaps. It is also time to update the Canadian Comprehensive Care Standards. These standards identify the basic level of care individuals with inherited bleeding disorders can expect. Ensuring women have access to the treatment they need for their bleeding should be a key focus in the development of these standards. Once these standards are updated we will work with clinics on another round of assessments.

We must continue to develop knowledge on blood safety, supply and availability issues. We need to continue to have strong representation on provincial and national blood committees to ensure that safe and innovative are available to people with inherited bleeding disorders. The collection of data through programs like the Canadian Bleeding Disorders Registry (My CBDR) can help us make the case to decision-makers that investments in the best available preventative therapies will result in better outcomes and lower costs. Hemophilia Ontario will continue to provide services to those affected by HIV/AIDS and Hepatitis C.

Developing community is central to our mission. We know that being part of a community improves quality of life. Our programs offer an opportunity for members to bond and learn from each other. When we have opportunities to come together as a community we need to make sure that we are learning about key advocacy issues. Aligning our programs with our goals empowers our community to contribute to our mission.

For all the work to ensure future sustainability, we are simply in a race against the clock. New developments in longer lasting products and gene therapy offer us all hope. If we discover cures and make them available to all, we will have accomplished our mission.

As we look forward to 2017, I am pleased to introduce Maia Meier as the new President of Hemophilia Ontario. Maia is a person with von Willebrand Disease and a mother to a son with vWD. As a past-president of Hemophilia Saskatchewan she has proven herself to be a skilled leader and consensus builder. She has been an active grassroots volunteer within the community for the past fifteen years.

I would like to thank all staff and volunteers for all of their hard work this year and for their service to the community. ♦

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.

Desired Outcomes

Care and Treatment for All

Goal: Achieve standards and evidence-based comprehensive care for all people with inherited bleeding disorders throughout their lifespans.

1.1 An action plan will be developed and implemented to address gaps in care identified through the most recent Ontario Comprehensive Care Assessments.

1.2 One-third of the Comprehensive Care Clinics in Ontario will be evaluated for accreditation each year using updated Comprehensive Care standards beginning in 2019.

1.3 Hemophilia Ontario will maintain strong representation on all key national/provincial/territorial blood committees to ensure safe, innovative therapies that have been shown to improve health outcomes or quality of life are accessible to users no more than six months after their approval.

1.4 The number of people who use clotting factor therapies at home and use MyCBDR in Ontario will increase from 80 at the end of 2015 to 300 by the end of 2018.

1.5 Women with bleeding disorders will have the opportunity to attend a women's bleeding disorder clinic either at their own centre or at a neighbouring one.

1.6 Hemophilia Ontario will continue to provide services to those affected by HIV and Hepatitis C.

1.7 All people registered in an Ontario Comprehensive Care Clinic infected with Hepatitis C will be offered the opportunity to undergo therapy with direct-acting antiviral therapy by the end of 2017.

1.8 Hemophilia Ontario will be involved in at least one active twinning partnership over the 2016-2020 period to help ensure care and treatment for all.

Education and Support

Goal: Deliver evidence-based information and support to patients, their families, health care providers and the general public across Ontario

2.1 Hemophilia Ontario will provide support programs and activities to people with bleeding disorders and their families throughout the lifespan to help them cope with their chronic conditions and reach their full potential.

2.2 In collaboration with inherited bleeding disorder programs, 100% of people registered in these centres will be informed of Hemophilia Ontario and CHS programs and services every two years, starting in 2018.

Research

Goal: Promote, fund, facilitate and conduct fundamental, clinical and quality of life research to improve health and quality of life and ultimately find cures

3.1 Hemophilia Ontario will regularly advertise opportunities for members to donate to the Hemophilia Research Million Dollar Club.

3.2 Hemophilia Ontario will increase member participation in the Patient Reported Outcomes Burden and

Experience Study (PROBE) each year it the study is conducted by 10%.

3.3 Hemophilia Ontario will publicize opportunities for patients to participate in research and clinical trials of innovative therapies.

A Strong and Cohesive Organization

Goal: Build a cohesive organization through good governance, member engagement, effective communications, and fundraising to support our strategic goals.

4.1 Membership will increase from 1230 in 2016 to 1420 by 2020.

4.2 Hemophilia Ontario will have its governance evaluated by participating in a recognized governance process by the end of 2017.

4.3 Two individuals aged 18-25 will sit on each regional council. One individual aged 18-25 will sit on each operational committee to ensure Hemophilia Ontario is developing future leaders and that youth are included in the operations of the organization.

4.4 In collaboration with the other Chapters, Hemophilia Ontario will develop a fundraising strategy which will be established to develop an internal case for support and increase fundraising capacity by June 2017.

4.5 Hemophilia Ontario will develop a communication framework to improve communication between the Board, Staff, Members and Key Partners by June 2017.

President's Message

by Maia Meier

It's with great excitement and anticipation to be serving our bleeding disorders community as I step into this new role as President of Hemophilia Ontario. We have set out many goals going into 2017. I would encourage each of you to read through our plans detailing our programs and organizational changes in the remainder of this issue.

I am pleased to be able to introduce Jenna Foley as our new Executive Director. Jenna is thrilled to be joining the team at Hemophilia Ontario. After receiving her Master of Library and Information Science degree from the University of Western Ontario, she began her career working at the Hamilton Health Sciences Foundation. From there, she joined the Windsor Symphony Orchestra as Development Manager, before moving on to the Executive Director role at Access County Community Support Services, where she has been for the past seven years.

Throughout her career, Jenna has been a passionate advocate for person-centred services, equal access, and respecting unique community needs. She is very eager to learn about Hemophilia Ontario's regions and how to support them individually, as well as growing and strengthening Hemophilia Ontario overall.

In addition to her MLIS degree, Jenna has completed a French as a Second Language diploma from Collège Boréal and the Charity and Not-for-Profit and Charity Finance Leadership certificate from CPA Ontario. Though she recognizes the challenges facing Hemophilia Ontario as it adjusts to the Ministry of Health and Long-Term Care (MOHLTC) funding reductions, she is optimistic about the opportunity to launch new programs, diversify revenue streams, and work together to take the organization to its next level.

More personally, Jenna has a family connection to the tainted blood tragedy and hopes to support continued advancement in care. Jenna lives in Essex County with her husband and two children, and she looks forward to meeting the staff, volunteers, and families of Hemophilia Ontario very soon.

I would like to take this opportunity to thank Matthew Maynard for all of his extraordinary efforts as Interim Executive Director over the last several months. As Interim Executive Director Matthew has brought knowledge, experience and relationships developed through a lifetime of dedication to Hemophilia Ontario. I would also like to commend and thank all of our volunteers and staff for their work over the past year. It is greatly appreciated and the work we do could not be done without you!

As this year is coming to a close, I wish you all a wonderful holiday season and look forward to meeting as many of you as possible through this year's upcoming events! Please feel free to contact me if I can be of assistance in any way.

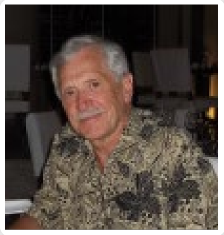
Sincerely,
Maia Meier, President - Hemophilia Ontario
maialmeier@gmail.com

Interim Executive Director's Message

by Matthew Maynard

As Hemophilia Ontario has continued to transform and transition over this past year, it is the contributions of each of you that has made it possible to stay focused on the care and well being of all those with a bleeding disorder in Ontario. Collective Enoughness: Together we have everything we need; it is only on our own that we experience scarcity. Hildy Gottlieb of Creating the Future.

We have collectively faced many challenges and facing them together has made it possible to work through these and continue to look forward to a better future. Your contributions and support have made this possible – whether providing your input to the Board of Directors or staff, you may have been one of the many individuals willing to share your story with the judges in the 86-90 Settlement that shaped the outcome and their decisions, a nurse or a volunteer that went to camp, a company representative that helped inform those faced with product changes, a member of medical team reaching out to provide additional support to a family, or a staff member making sure that you got the most out of your program participation. You get the idea – I am grateful for whatever contribution you have made and will make in the future!



Editor's Message

by Tom Beer

> *"..Do what you can."*
> "Start where you are. Use what you have. Do what you can."
> ~ Arthur Ashe, Professional Tennis Star

This time of year is particularly exciting for many of us –end of the old year –beginning of another. We are encouraged by those around us, by what we read, see, and hear to evaluate what we experienced and to use what we've learned to approach the future.

The last issue of Blood Matters focused on the many challenges to staff, programs and services of Hemophilia Ontario in part because of decreasing financial support by the Ontario Government. This perceived threat to the programs and people served by CHA and HO ignited a need to examine, revise, rebuild and innovate in an attempt to minimize the impacts and to try to anticipate potential gaps in programs, personnel, and in the care and well-being of anyone with an inherited bleeding disorder.

Under the leadership of President Maia, and building on the strengths of our past, there are new hopes, new ideals, and new goals, as expressed at the end of President Paul's message. These goals are achievable if we keep in mind Ashe's first statement, "Start where you are." The looking back, contemplation of what happened, examination, resolution, is not where we are –NOW- and that realization is vital to move forward.

The hardest part about growing older is the inability to predict what is going to happen. My Uncle Roy used to say, with a sly smile,"I woke up this morning. It's a good day." Take each day as a new challenge. What will happen, will happen. So, look ahead, create a "to do" list and, a "what to do" list for eventualities. Give life a purpose. These thoughts apply to the goals that outline the future of HO. Ashe's second idea is to "Use what you have." The articles in this edition of ***Blood Matters*** articulate the power of the programs, people, and services currently in place which work very successfully, and are the bases for the future of the revitalized HO.

One of my favorite memories of teaching in London is the graduation class of grade eight students from Mildred Barons P.S. Superintendent John Townshend was the guest speaker, whose topic was to "Use your talent!" He told the Parable of the Talents, where even the least successful servant was given one talent to invest, suggesting that all have something of value to bring to the world.

The call for new council members by CWOR asks you to bring your "talent", your ability to organize a yard sale or a weekend trip, to make phone calls, to encourage volunteers, to fundraise, to share your experiences with new members of your community. Whatever talent you can bring is welcome. Just make the call.

This emphasizes Ashe's last comment, "Do what you can." He doesn't say that you must be heroic, or wealthy, or marvellously physically talented. He says, "Do what you can." Don't stand back and think that someone better than you will step up. If you've paused while reading this, you're the one this article is speaking to. Help the council in your area become the best it can be by bringing your "talent" to the group. Hemophilia Ontario has ambitious goals. It's asking each of us to embrace them and to invest in its' future.

"In three words I can sum up everything I've learned about life; it goes on." ~ Robert Frost

Hemophilia Ontario is ready to go on. Come with us. Read on...

Just the Guys

What an awesome weekend celebrating our Back to the Future theme and 15 years of this very special weekend.

Participants traveled back in time through a panel discussion led by past participants and looked to the future as they "slingshot" their team towards the date they thought a cure would be found.

Special thanks to Lisa Thibeault, nurse coordinator and Terri Landine, ER nurse for driving all the way from Kingston to support the families at this weekend. Thank you to our incredible speakers, John Lepera, Gary Burrows, Tyse Burrows, Emrik Burrows, Derrick Reid and Karen Strike for their time and expertise.

Big thanks to our 4 youth volunteers, Trevor Reid, Matthew Devereaux, Luke Chasse, and Johnny Lepera as well as to Jordan Cabral for stepping up into our youth mentorship role. Each year the kids and dads tell us how much they look up to you and love the energy you bring to this weekend. We are truly grateful for your participation.

As always, thank you to Bayer for their continued support of this fantastic weekend, and of course to our awesome planning committee of John Lepera, Travis Hazelwood, Vanessa Bouskill, Lisa Thibeault, Raman Saini, Derrick Reid, Stephen Perry, Mike Charbonneau, and Zach Adams.

In the words of first time participants:
"This was an amazing weekend for us. I am so happy I got to experience this with my boys. We will see you next year for sure!"

We can't wait to see you in 2017!

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/

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

Hemophilia Ontario's Financial Assistance Policy

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

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

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

Each year, Hemophilia Ontario allocates a set amount of money for this fund and once these funds are exhausted, no further claims will be processed that year. Requests submitted by December 31st will be considered pending availability of funds. We are unable to carry claims over into the following year. For information about the guidelines or to receive the Financial Assistance Forms to complete and submit with receipts, please contact your local Regional Service Coordinator. 🩸

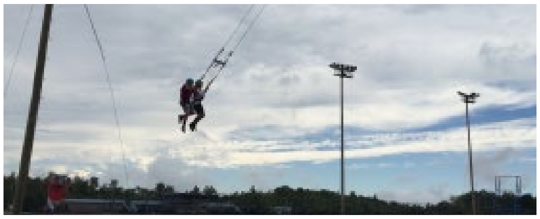
Just the Guys...*and Maybe a Few Gals*

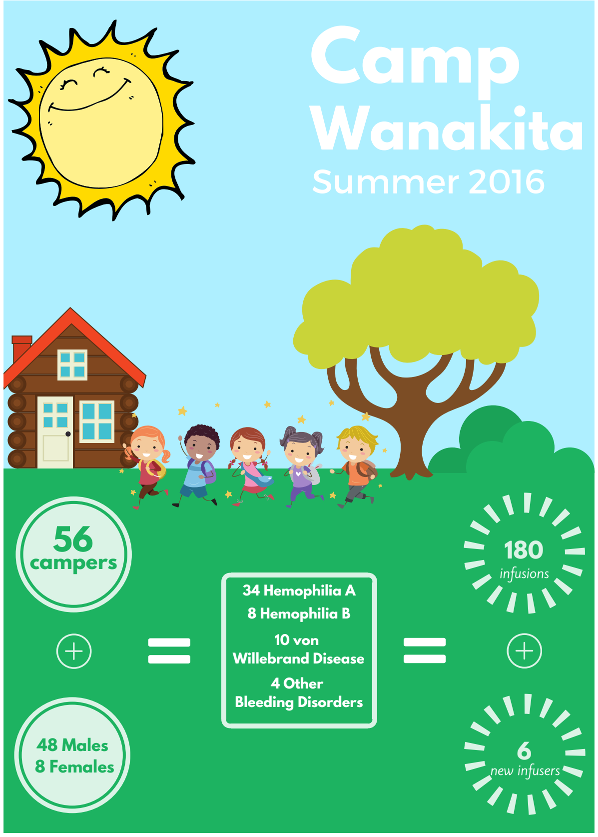
Northern Ontario Region

The excitement and fun continues in our 3rd annual Just the Guys and combined Members Weekend Getaway! Mary Sabo, physiotherapist at Health Sciences North provided the group with a great overview on physical activity, how to make choices to keep you physically fit and safe at the same time. She got everyone's blood pumping with an impromptu exercise and stretching element to get us ready for the afternoons activities.

"Climb over what challenges you" was our theme this year and we definitely climbed! All members geared up and climbed the Tango Tower wall at Laurentian University. Fantastic team building with cheers and encouragement for everyone. Hard hats were needed for the high rise zip line swing. Screams and laughs could be heard throughout the campus when the pull cord was yanked! Even our nursing staff joined in! The afternoon ended with a scenic tour of Nepahwin lake by canoe with some of us staying drier than others. Attending members had a fantastic educational and fun filled weekend and are already talking about next year!

A big thank you to our very supportive nursing staff, Betty-Ann Paradis and Tammy Bourque who encouraged members to become active and volunteer for Hemophilia Ontario. Also for gearing up and joining in on the fun! 🩸





Community Camp 2016

Our fourth Community Camp took place October 14 to 16th at the beautiful Camp Wanakita in Haliburton. One hundred community members attended from across Ontario! Our keynote speaker was John Schmitke, Vice President CHS Manitoba Chapter. John spoke on engaging in your own health care and maintaining an active lifestyle. Vanessa Bouskill MN, RN, provided us with an excellent update on the advances in treatment over the next 10 years. Samantha Stuart, a child life specialist at Sick Kids Hospital spoke on the stages of coping for parents and patients with chronic conditions. Theresa Almonte, Program Assistant at the Hamilton-Niagara Regional Hemophilia Program presented on the MyCBDR app, a new app which is to be used on a daily basis by members of the bleeding disorders community. Ann Marie Stain & Liz Sagerman provided the group with information on the BE Program, which aims to increase workplace engagement by introducing participants to potential careers before they embark on post-secondary education. The panel discussion was led by a diverse group of adults including those living with HIV and hepatitis, new to Canada, a couple, and a Board member. The conversation and candid discussion ranged from care to advocacy to the needs now and in the future. While the adults were participating in the educational workshops, the children and youth were participating in lots of outdoor activities with the YMCA staff!

There was lots of positive feedback at the end of the weekend and the community really appreciated the opportunity to spend time with their families and other members of the community in the beautiful fall setting of Camp Wanakita.

Thank you to our sponsors for making this weekend possible: Bayer, Biogen, Octapharma and Pfizer! A special thank you to our planning committee for helping plan and guide this weekend: Betty Ann Paradis, Tammy Bourque, Diane Bissonnette, Stephen Perry, Matthew Maynard, Alex McGillivray, Stephanie Morrison and Susan Turner. ♦

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.

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.

Hemophilia Ontario

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.

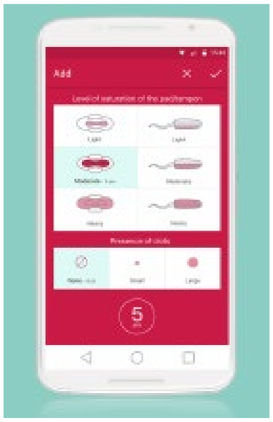
CHS Support to Research & Market Studies

Several times in the past, the CHS has invited the bleeding disorder community to participate in research and market studies. Once again, we wish to reinforce the importance of these projects and the benefit for our community to participate. Research and market studies are crucial to the advancement of care and treatment. This is your chance to voice your concerns and priorities when it comes time to your care and treatment or those of your child. At many levels, these studies are often one step closer towards a better quality of life. These studies, however, need our community to gather sufficient data to be relevant.
Please take the time to see what is presently happening with regards to research and market studies and to see if you could take an active part in them.

You can find more details on the **RESEARCH** studies here:
http://www.hemophilia.ca/en/research/opportunities-to-participate-in-research/

You can find more details on the **MARKET** studies here:
http://www.hemophilia.ca/en/research/opportunities-to-participate-in-marketing-research-studies/

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

HIV/HCV News

MyCBDR

The Promotional Video now on YouTube

The CHS just launched a promotional video showing how easy and fast it is to report bleeds and treatments to your treatment centre via MyCBDR. You can find the video on YouTube at the following link:

https://www.youtube.com/watch?v=PzTPMI8bk9Y&feature=youtu.be

Experience to be Shared

In the early part of 2017 Hemophilia Ontario will provide new opportunities to share your lived experience with your bleeding disorder, HIV or hepatitis. This will form the foundation of network for adults having the intention of providing mutual support to each other whether for mental health, burn out, or PTSD like symptoms, while creating a space for individual and collective action.

Matthew, Marc and Ian will be sharing in the planning so contact us with your interests and thoughts:
Marc Laprise **marclaprise@yahoo.ca** or Matthew Maynard **mmaynard@hemophilia.on.ca**
Want to know more about the results

Central Western Ontario Region

Regional Highlights

by Alex McGillivray

CWOR is having a very good year and our members have participated in a number of events. We partnered with TCOR for the Toronto Zoo Walk Fundraiser and had 13 CWOR families participate. 4 of our youth attended Camp Wanakita this past summer, 22 people from CWOR attended the Just the Guys weekend, and 4 families attended Community Camp. It is terrific to see so many members participate in events. Other activities included hosting an information and fundraising booth at the Locke Street Festival in Hamilton and Mary Pedersen held her 5th annual fundraiser "The Big Sale on the Little Street." We have also welcomed Christine Smith to our council as a new volunteer. As we look toward 2017, we plan to continue our focus on fundraising events and supporting programs that are aligned with the CHS Strategic Plan.

We feel as a council that we, CWOR, would greatly benefit by having new council members, particularly from these centres and their surrounding areas:

Kitchener/Waterloo
Guelph
Milton
Mississauga
Oakville
Burlington
Niagara

If you feel able to help, please contact us, and remember that if you don't have time to be a council member we would appreciate any time and help you could offer. If you are interested in learning more, please contact
Alex McGillivray at 905-522-2545.

CWOR

Regional Council and Staff

Rob Dinsdale
Mary Pedersen
Debbie Bordi
Meagan Bordi
Christine Smith
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

Northern Ontario Region

Regional Highlights

News from the North!

by Stephanie Morrison

Monday October 31st – NWOR (Thunder Bay and district) Hemophilia Treatment Clinic Day
Thunder Bay clinic is embarking on an exciting new journey to open a pediatric clinic for the bleeding disorders community.

Saturday October 29th – NEOR (Sudbury and District) Hemophilia Treatment Clinic Day
Health Sciences North held their clinic day where pharmaceutical representatives were on site to answer questions by members.

Members were treated to a surprise Halloween party, complete with masks, fake mustaches and a chance to pop balloons stuffed with Halloween treats.

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

Ottawa and Eastern Ontario Region

Regional Highlights

by Alex McGillivray

This year OEOR held their annual Summer BBQ at Mont Cascade Waterpark in Cantley, Quebec. There were a total of 21 members that came out to enjoy the waterpark while enjoying the shade of the covered area that was reserved for OEOR members. All the members enjoyed sliding down the waterslides or lounging around the pool while enjoying the sunny warm weather.

Members were treated to a cool treat / snack from the restaurant, at the waterpark, to help cool off from the heat.

A special thanks to all the OEOR Council for their role in planning and hosting the event and all the members for attending. Hope to see you all again next year. ♦

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

South Western Ontario Region

Regional Highlights

Superheroes Academy!

by Matthew Maynard

Talents shared, acts of kindness around every corner, and capes of wonder were everywhere! Pinecrest was led by superheroes (volunteers staff and nurses) and brought out the superhero in every camper. Each staff member brought their best to make sure every camper had their best camp experience. This staff team brought the songs, leadership, and wits to make sure the camp was worth coming back for year after year.

Thank you Pfizer, Shire, Novo and Bayer for the support of this camp program in South Western Ontario. Special thanks must also go to the Camp Committee who made many extra efforts to ensure a safe and well-planned camp for each and every camper and youth leader. ♦

SWOR

Thanks to all who served as part of the SWOR Council in 2016.

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

Toronto and Central Ontario Region

Regional Highlights

TCOR Hemophilia Golf Classic!

by Susan Turner

TCOR's 17th Annual Golf Tournament took place on September 9, 2016 and was held at the beautiful Nobleton Lakes Golf Club. Over 60 people participated raising $13,000 for TCOR programs and services! Our sponsors were: Barrick, Biogen, Martine Celej, Strype Injury Lawyers, Neal and Smith Barristers & Solicitors, Fitzpatrick Electrical, May Pierre, Fidelity Investments, Hogg Shain & Scheck, MacKenzie Investments, Ev Spence, the MacDonald Family and Friends of the Oulahen Family! Thank you to Trevor Reid for speaking on behalf of the TCOR community at dinner!

TCOR

Regional Council and Staff

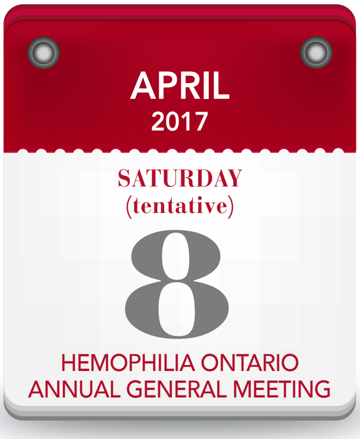
- Zachary Adams
- Michael Bosompra
- Sheila Coad
- Maury Drutz
- Ayeh Hamidian
- Samuel Leon
- D'Marc Lewis
- Neil Mentuch
- Maryam Naji
- David Neal
- Corrine Van Dusen

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

Hemophilia Ontario Calendar



APRIL
2017
SATURDAY
(tentative)
8
HEMOPHILIA ONTARIO
ANNUAL GENERAL MEETING

OCTOBER
2017
FRIDAY•SATURDAY•SUNDAY
TBD
WOMEN'S WELLNESS:
W2 WEEKEND

Dates are tentative and may be subject to change.

How to Get Involved …

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

For further information please contact:

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

✉ info@hemophilia.on.ca

@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