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BLOOD matters

Help Stop the Bleeding

There is beauty
in change.

PM # 42837517

BLOOD matters
Hemophilia Ontario

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Hemophilia Ontario
501 - 65 Wellesley St. E.
Toronto, ON Canada M4Y 1G7
416.972.0641 or 1.888.838.8846
Fax: 1.888.958.0307
www.hemophilia.on.ca

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Hemophilia Ontario is a certified chapter of the Canadian Hemophilia Society

President's Message

by Julia Sek

"We must be the change we wish to see in the world"

This is one of my favourite quotes by Ghandi. Our world requires that we be ready for change and better yet, participate in the change.

We are so fortunate to have a very good standard of care for our people with inherited bleeding disorders, and at the same time we must remain vigilant in advocating for this continued standard of care.

While advocating we must also be mindful of competing priorities in our communities and healthcare systems. While being mindful of this, I ask that everyone think about how you might contribute to our community and keeping it healthy and active.

Healthcare dollars are decreasing and together we must be prepared for change and participate in our future. We have known for years that our funding support may change. Are we ready to step up and support the very programs that bring us together? I know I am.

I encourage you to look at how you might help your regional council, support a local, provincial or national program. Change can be a good opportunity to look at how we do things and what really matters to us. I know for certain that the Hemophilia Society has led and participated in many valuable programs and government initiatives and I look forward to us continuing on this journey!

Reach out to your local council, Regional Service Coordinator, Executive Director and Hemophilia Ontario Board; we are here to discuss our roles and future. We look to you for ideas and support with the work we are all doing.

On a lighter note, I look forward to our season's change and welcome spring.

I hope to see you at our AGM in London!

Best regards,

Julia

Cover photo: Terri-Lee Higgins, taken at YMCA Camp Wanakita

What's in this Issue?

Spring 2015 Volume 6, Number 1

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Executive Director's Message

by Terri-Lee Higgins

Every few days my mom forwards her 'Sunrise Inspiration' e-mail that has a positive quotation. As the dutiful daughter I read them, let her know I read them and then delete them. This has been going on for about a year. While cleaning up my 2014 e-mails at the start of this year, I realized that I had not deleted about 15 of them, so I went back and re-read them and found that they still resonate with me. Here are a few:

> Accept yourself, your strengths, your weaknesses, your truths, and know what tools you have to fulfil your purpose. ~ *Steve Maraboli*
>
> It is in your moments of decision that your destiny is shaped. ~ *Anthony Robbins*
>
> Values are not just words, values are what we live by. They're about the causes that we champion and the people we fight for. ~ *John Kerry*

As a personal mantra, I have always tried to maintain an overall positive attitude and be a positive person. I listen to music that I like; I read and re-read books that I enjoy; I can watch movies many times and I choose to surround myself with people who are important to me. Do I get caught in negativity around me? Yes. Do I always realize I am in the negative mindset? No. Do I sometimes wallow in self- pity? Again, yes. But somewhere in this head space I realize that I don't like being here, that things are not necessarily as bad as I am making them and I make a conscious decision to move forward. It can mean letting go of frustration, anger and pathos. It can mean not responding to another person's sarcasm or engaging with them in non-positive conversations. It can mean a cooking or cleaning frenzy. It can mean driving in total silence while I think or playing music and singing loudly as I drive. It looks like many things depending on when and where I make that decision to move forward.

So why does this matter? 2015 provides the opportunity for us all to 'write another story'. The year is new and yet, personally and professionally, I am already aware of some of the challenges I will face. It is up to me to determine how I choose to meet all the challenges, known and not. Every challenge will be a learning opportunity; every decision will make a difference in my life and the lives of those around me. While a bit daunting, I know that not every decision I make will be perfect and not everything I do will be smart. That's okay. It won't make me a bad person because I made a mistake; rather it reinforces my humanness and, in my books, that's totally fine. As we all move into this new year knowing we are human I share this final quotation:

> Success is not measured by what you accomplish, but by the opposition you have encountered, and the courage with which you have maintained the struggle against overwhelming odds. ~ *Orison Swett Marden* 💧

Editor's Message:

"… for the times they
are a-changin"
– *Bob Dylan*

by Tom Beer

The longer I'm around, the better I'm able to understand that NOTHING is permanent. For some, that's a very scary thought, because we like things the same. How often have you heard someone talk about accepting an uncomfortable position "because it's easier to deal with the devil we know, rather than the devil we don't know?"

Think about the following. Rank them in order of discomfort to you (1 – a little, 5 – a lot):

You decide to change courses/ schools/ cities.

You decide that your actions are going to have negative impacts on someone else.

You decide to get married.

You decide to have a family.

You decide to buy a house.

Your basement gets flooded.

You fail an important test.

You get a promotion.

You get a new job.

You get fired.

You are diagnosed with a life changing illness/ condition.

You decide to wear green instead of blue.

You decide to eat in instead of ordering in or going out.

Some of these are "just" decisions, but they suggest change. Some of them are very positive, so, the change is seen as a positive challenge. Some of them are threatening to our wellbeing.

Unrest, stress, or, of course, excitement and anticipation of the challenge are general reactions to change. And, the impact on the individual is the most stressful because change is personal. "What will it mean to me? How will it affect me? What are the costs and/ or benefits to me?"

Often, our reaction to change is governed by its suddenness, or that the changes have come in bursts, and all we can see is the wall and not the bricks it's built of. Many of us recognize missed or stretched deadlines… I didn't get this piece done on time and now something else is due. So, 2 bricks = beginning of the wall. Soon, you can't see around or over it.

What do you do? Stop trying to do it all. Sometimes NO! is a whole sentence. Sometimes, the best way to attack a large project is to break it into small pieces. We've all heard the truism "Don't sweat the small stuff! It's all small stuff!" And, your perception of the size of the change can alter your decision to take it on. For example, Michaelangelo said that all he did was release the statues that were already inside the marble blocks that he sculpted. It was Aristotle who gave this concept a name, the theory of "potency"; the possibility and capacity of being transformed, of being changed.

It's in us all. It's not change that changes us; it's our reaction to it and how we deal with it. Arvind Kalech stated,"If you don't like something, change it. If you can't change it, CHANGE THE WAY YOU THINK ABOUT IT!"

That idea has kept me sane for many years.

This edition of *Blood Matters* is centred on CHANGE. As you read the articles, you will see how much is being done around the province with and for those with inherited bleeding disorders. Read the article about how far Hemophilia Ontario has come and its plans for a dynamic, meaningful future. See how you can be a part of the future.

Read on …

Now Experience Wellness (NEW)

The NEW program provides funding for youth 17 years of age or younger living with an inherited bleeding disorder to participate in first time physical activities or quieter activities toward promoting healthy lifestyles. There are many things to consider when you choose a sport, please contact your physiotherapist for individual advice and guidance in activity selection. Hemophilia Ontario will provide a maximum of $250 per child, per year. Funding may be used for registration fees and / or safety equipment required for the sport or activity that includes instructions from a qualified individual. Forms are available through your HTC Physiotherapist or your RSC. Completed forms that have the signature of the Physiotherapist can be submitted to Hemophilia Ontario 65 Wellesley Street East, Suite 501, Toronto ON M4Y 1G7. Funding will be awarded after a complete application and supporting documents (invoice or original payment receipt) is received. Funding is subject to the availability of funds. Once allocated annual funds are exhausted no further funding will be available that year.

The Challenge of Change

As we begin a new year, there is one thing that we know will be true or constant – change. Change can be risky, there are many risks and there are also many rewards. Over the past few months, I have been reading a lot about change and came across an article called The Challenge of Change by Kerry Johnson and Maggie Walsh and found this section pertinent to our organization:

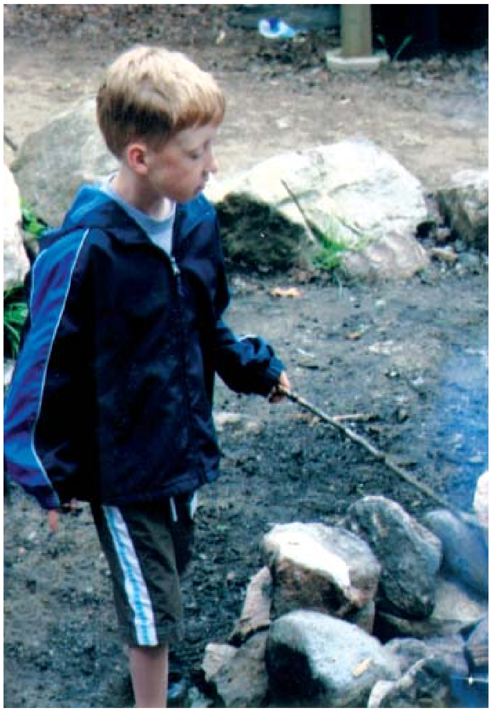
"People feel it: The constant pressure to do more, do faster, keep up. Technology, globalization, the demand for productivity and growth, competition, complexity, and pressures from stakeholders, shareholders, and employees drive an environment of continuous and constant change. And, significant technological breakthroughs and innovations – each of which often drives enormous change – are on the rise.

Today's market and competitive pressures require that organizations not only are ready to transform themselves, but also to continuously "tweak" themselves by improving individual performance, making service improvements, streamlining processes, implementing new systems and technologies, reducing costs, upgrading talent, and responding to changes in leadership. People feel it: When organizations change the pressure trickles down. Each change can take a toll on employees and members alike in terms of focus, productivity, satisfaction, and loyalty."

Hemophilia Ontario has been serving the inherited bleeding disorders community since 1956. Our first and foremost commitment has been, and continues to be, to provide members with the supports and services that meet their needs. As our history shows, our memberships' needs have – and continue to – evolve in response to advancements in research, healthcare and changes in the inherited bleeding disorders community. In reflection on these changes, what began as a volunteer-based organization has evolved into the immensely successful Hemophilia Ontario we know today: 5 provincially staffed offices, a provincial Board of Directors, regional councils and hundreds of volunteers committed to keeping the organization a successful leader to 1,100 individuals, and an advocate for those whom are not yet a part of our membership.

In reflecting on the continuing need to evolve and adapt to our environment, Hemophilia Ontario is taking a proactive approach to meeting a new challenge. We have been fortunate to have dedicated funding, the largest of that we receive from the Ministry of Health and Long-Term Care (MOHLTC) AIDS Bureau to provide supports for individuals infected through the tainted blood tragedy. As the number affected continues to decline, our organization is faced with a corresponding loss in this funding.

In pre-emptive response, Hemophilia Ontario Board of Directors initiated a dedicated Funding Review Task Force to analyze the organization and provide recommendations. In order to continue serving our membership in a manner that best suits their needs and endure as a strong organization, the Task Force recommended and received Board approval for focusing reductions on MOHLTC AIDS Bureau-subsidized areas in Hemophilia Ontario's operating budget.



If accepted by MOHLTCAIDS Bureau, these reductions would start April 1, 2015. Hemophilia Ontario will focus on building volunteer capacity to ensure continuity of our most vital services and take a measured and thoughtful approach in preparing for the forthcoming organizational change. Most importantly, Hemophilia Ontario will consult with stakeholders and develop a Communications Plan to keep the inherited bleeding disorders community informed of potential organizational changes.

Hemophilia Ontario is embracing this as our opportunity to completely evaluate who we are, what we do and how we do it: this is our time to adapt, evolve and, ultimately, improve. It has been many years since Hemophilia Ontario has undertaken a large scale review of the organization. Now that we are facing a loss of funding, we are looking inwards and outwards. It's a good time to streamline programs and services, to exact efficiencies, and to revisit our original purpose.

While significant changes are ahead for Hemophilia Ontario as both an organization and a vital programs and services provider to individuals with inherited bleeding disorders, hidden in this call to change is a call to action.

We will be engaging all our stakeholders for feedback, including members, volunteers, HTC staff, funders and other community partners. We'll keep what works well, know where there are issues and develop new opportunities and gain an understanding of what we need to do to move forward. The truth is that we don't know what changes are ahead. What we do know is that in order to remain a viable and key resource to our members, we must look at everything, listen to what we are told and proactively respond to be a stronger, more effective organization.

With these changes on the horizon we encourage you to ask your questions, share your concerns, let your voices be heard. The following individuals are our champions of this process and we invite you to connect with them OR speak with our Consultant. (We'll share all information by e-mail as soon as it's in place):

Terri-Lee Higgins, Executive Director | thiggins@hemophilia.on.ca 519-432-2365 OR 1-888-838-8846 ext.17

Julia Sek, President | juliatraceysek@gmail.com

Paul Wilton, Past President | pwilton3@gmail.com

Phyllis Gray, Treasurer | pgray@saybuck.com

Amy Griffith, Secretary | grif3170@mylaurier.ca

We hope you are as excited as we are with the possibilities that this opportunity presents, and we look forward to your feedback and help as we begin to plan our future. 🩸

Community Engagement

by Paul Wilton

Our quality of care will regress without community engagement. Things are good now. We've achieved a high quality of life for most bleeders. Some of our young people have never had a bleed. We have Hemophilia Treatment Centres, access to treatment, and blood safety practises. All of this progress has resulted from the engagement and work of our community.

These achievements are not set in stone. We're already seeing cracks. Our clinics are underfunded for data entry (to name only one aspect of the comprehensive care team) that is key to demonstrating to governments the cost benefit of funding preventative treatment. As patients have less bleeds the funding of our clinics will be less certain. That's a big deal. Have you been to a General Practitioner lately for a bleeding related issue? In recent trips to Emergency Rooms, I received a right-handed splint on my left hand and I always encounter doctors who want to check my factor levels before they give me factor. I have severe hemophilia! If I haven't had a treatment in two days, it doesn't take a psychic to predict my levels! We are seeing signs that access to extended half-life factor concentrates (a potential game changer in our treatment) will be a very difficult fight.

Quality of life is good for many but what about those not feeling the positive outcomes? Do the rest of us leave them behind? Inhibitors are still a critical issue for some. Women with bleeding disorders and people with rare bleeding disorders are sometimes undiagnosed until they're in a life-threatening situation. Members of our community still live with hepatitis C and HIV. Older bleeders have pain and restricted mobility that affect their quality of life and their ability to earn a livelihood. Patients have no factor products in some countries. And what happens when that 16-year-old who has never had a bleed enters that age when young men think they're invincible?

We need you to be involved to maintain our quality of care and improve it. We're going to reimagine the way Hemophilia Ontario engages with our members. We'll inform you of emerging issues in new ways. We'll be clearer about the small contributions of time you make to create a big difference. In the coming months, we'll engage you in a conversation about how we can best serve you and involve you in our work. 🩸

Hemophilia Ontario Annual General Meeting

Saturday, April 18, 2015 – London, Ontario

Hemophilia Ontario
Annual General Meeting

Saturday April 18, 2015
10:00 am

Ivey Spencer Conference Centre
551 Windermere Road
London, Ontario

Please RSVP your attendance to:

Susan Turner
sturner@hemophilia.on.ca
416-972-0641 ext. 21 or 1-888-838-8846

Dear Hemophilia Ontario Member,

Re: **HEMOPHILIA ONTARIO'S 59TH ANNUAL GENERAL MEETING**

This letter is to notify all Hemophilia Ontario Members that the 59th Annual General Meeting will be held in the Ballroom at the Ivey Spencer Conference Centre, 551 Windermere Road, London, Ontario on Saturday April 18, 2015 beginning at 10:00 am.

The affairs of Hemophilia Ontario are conducted by a Volunteer Board made up of not more than 18 Members. At the present time the Board of Directors are: Julia Sek, Paul Wilton, Zach Adams, Rob Dinsdale, Maury Drutz, Phyllis Gray, Amy Griffith, Shelley Hewett, Ashwani Kurichh, Samuel Leon, Monica Mamut, Maia Meier, David Neal, Mary Pedersen and Darlene Villeneuve. Each member has been elected for a one-year term – ending April 18, 2015.

If you are interested in being a Board Member or if you wish to nominate someone to stand for election, as a Board Member, please contact Susan Turner for a 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 Monday, April 13, 2015.

If you are unable to attend and wish to be provided a Proxy Form, please contact Susan Turner at sturner@hemophilia.on.ca 416-972-0641 ext 21 by Tuesday April 1, 2015. All forms to be returned no later than Monday April 13, 2015. In recognition of National Volunteer Week, Hemophilia Ontario will present The Volunteer Awards at the AGM. Nomination forms and Award details are available at www.hemophilia.on.ca

Sincerely,

Terri-Lee Higgins
Executive Director

Schedule of Events | 10:00 am - 3:00 pm

9:00 - 10:00 Registration and light breakfast

9:45 - 10:00 SWOR Business Meeting

10:00 - 11:00 Welcome and Annual General Meeting

AGM Agenda

1. Call to Order – Julia Sek
2. Approval of the Agenda
3. Approval of Minutes from Saturday, April 12, 2014 Annual General Meeting
4. Volunteer Recognition throughout meeting
5. President's Report – Julia Sek
6. Financial Report
   i. 2014 Audited Financial Statements
   ii. 2015 Membership Fees – Paul Wilton
7. Executive Director's Report – Terri-Lee Higgins
8. CHS Report – David Page
9. Appointment of the Auditor 2015

10:00 - 11:00

10. Submitted Reports
    i. Youth Committee
    ii. Hemophilia Provincial Coordinator – Sarah Crymble
11. Election of the 2015-2016 Hemophilia Ontario Board
12. Other Business
13. Adjournment

11:00 - 12:00 vonWillebrand Disease: Focusing on Iron Deficiency and Women
Dr. Michelle Scholzberg – St. Michael's Hospital, Toronto, Ontario

12:00 - 12:45 Lunch

12:45 - 1:45 Our Stories: Community and Care in the 21st Century

1:45 - 2:30 Round Table: A Community Conversation Where We Have Been and Where We Are Going

2:30 - 3:00 Wrap up and Closing Remarks

Community Camp 2014

by Susan Turner

Our third Community Camp was held October 3rd to 5th at Camp Wanakita in beautiful Haliburton. Despite the heavy rain during check in and registration one hundred community members plus staff from across the province enjoyed a weekend filled with great speakers. We heard from Dr. Karaguesian, the Emergency Room doctor at Haliburton Hospital who spoke on" How to prepare for that unexpected trip to the Emergency Room". Greig Blamey, a physiotherapist from Manitoba was our Keynote speaker and he discussed the importance of physical activity. Dr. Stephen de Wit a Relationship and Communication expert spoke to the adults on Relationship concerns and keeping communication lines open between partners. Betty Anne Paradis and Tammy Bourque spoke on preparing your school and daycare for children with bleeding disorders. Amy Griffith and Alex McGillivray held a session for the youth girls that focussed on periods, what to expect, and how to advocate for your needs when travelling with a bleeding disorder. Nick Higgins held an interactive session for the youth in attendance that included group discussion plus group and individual work to help participants identify their leadership style and develop ideas to build on their personal skills and abilities.

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

Reflections of Tanzania

by Dave Neal

When it was announced that Hemophilia Ontario was submitting a bid to the World Federation of Hemophilia (WFH) to participate in a Twinning initiative, I was interested and knew that we would be a great candidate to be paired with a developing country. I remember hearing stories from Mike Beck about how great a job TCOR did when they were matched with the Kingdom of Jordan about ten years ago, and thought that this would be a great opportunity for Hemophilia Ontario to take another leadership role on a global scale. When we were awarded our Twinning project with Tanzania, I signed up immediately.

I did have some reservations when I started to learn more about the country, and was nervous as our first official visit approached. The Ebola breakout in West Africa made me wonder if it could spread. The more I researched this region of Africa, I realized that Tanzania was on the East Coast, more than 7,000 kilometres away. Yes, the disease could spread, but there were measures in place to mitigate the risk of it spreading through Africa. I did learn some fast facts about Tanzania: its land mass is about the size of Ontario, with a population of 45 million (by contrast, Ontario's population is about 13 million). The capital is Dar es Salaam (the largest city in East Africa – 2,500,000 pop.), and the name means 'Haven of Peace' in Arabic. I was excited to get the opportunity to travel half way around the world (22 hours to get there including stop-overs) to meet with the people of Tanzania, knowing that we share the same issue – helping people with bleeding disorders in our respective countries. We left on Tuesday, November 11 and returned on Tuesday, November 18, so I knew it was going to be a whirlwind (Tanzania is 8 hours ahead of Toronto).

Candace and I arrived on Wednesday night and began Thursday morning with a trip to the Muhimbili hospital. We met with Richard Minja, the President of the Hemophilia Society of Tanzania (HST), and with the Hematologists and the nurses in the clinic (Dr. James, Dr. Stella and Nurse Happy). We learned about the healthcare system in Tanzania and the number of diagnosed individuals. I was amazed to learn that Hemophilia is not classified properly in Tanzania, so there is not proper funding for treatment. At the moment they use Fresh Frozen Plasma (FFP) to treat bleeding episodes, and the WFH has provided a donation of factor. At present, there are only about 70 patients identified as having hemophilia, and less than that have been officially diagnosed. Proper testing is not readily available, but they are hoping that this will expand in the near future. In the afternoon, we met with the Director of the Hemophilia program at Muhimbili University as well as a father and mother of a hemophiliac boy. They are very keen on moving the organization and the clinic forward to help the many undiagnosed people in the country. From speaking to our colleagues on this day, it made me realize that it was about 50 years ago that we, in Canada, were in a similar position as the people of Tanzania (no comprehensive care, no factor concentrate, damaged joints and muscles of hemophiliacs). We are very fortunate to have the care that we do in Canada today.


Medical Team at Muhumbili Hospital

Friday we were supposed to have a meeting with a government official, but that meeting was cancelled and Candace and I ended up working with Richard and a couple of members of the HST (Dominic Seye, a youth member and Stella Sinda, a mother of a young hemophiliac). We were explaining how important it is for all of the members of the HST to remain connected, and to gain as much knowledge as possible in order to work with the government agencies to advocate for their cause and for treatment. I kept repeating the same phrase to them – 'Knowledge is power!' We spent time in the markets in Dar with Richard, and he helped us to pick out items that we would use to raise money for them when we returned to Canada. Saturday was the first official AGM of the HST. Candace and I attended the meeting and were happy to meet families from Dar, as well as families from the upcountry (Tanzanians refer to the more rural areas of the country as 'upcountry'). I was very touched by the stories that families were telling us about their journeys to the AGM (how far they had to come), and what it is like in the rural areas. In the small villages, some families


Attendees at the AGM in Tanzania

think that the local medicine man can help cure their hemophiliac son (and stop bleeding). Others think that if they visit the clinic in Dar, the factor provided will cure their sons. Some are not willing to make the journey to the clinic because they don't believe it will do anything. Candace and I explained that they need to trust the clinic doctors, and that the factor provided is to treat the bleeding episode (not cure it). At the end of the AGM, there was an education session, and I demonstrated how I self-infuse with my factor. The members were amazed at this and at how healthy I looked. When speaking with Nurse Happy at the end of the day, she reminded me of my own nurses when I was younger – Anne Marie Stain at Sick Kids and Ann Harrington at St. Mike's. She is just as passionate as Anne Marie and Anne are. The one comment she told Candace and I, which will stick with me my whole life, is: "David, you are a God-send." Quite powerful…it makes me realize how fortunate I am and the difference we are making with this project.

There were no events planned on Sunday. However, Dominic took us to his home in one of the suburbs of Dar. He showed us his shop and where he and his wife live. The main highway was paved, but the roads off the highway were dirt roads, and were washed out in a few places. There was no infrastructure as we know it in Canada. Dominic's shop was about the size of a bedroom (about 8' x 8' at most), and his home is about that size. Dominic and his wife were expecting their first baby when we were there (their son, Benedict was born in December – Congratulations Dominic!)

Monday we had a meeting with another university, and I presented to a group of about 100 medical students to educate them about hemophilia. I mentioned my lifestyle and my treatment regimen, but I think the highlight was when I asked Dominic to come up on stage with me. We both lifted our pant legs above our knees, and the students were able to see the difference between healthy knees and 'knobby' knees. My knees are healthy (thankfully); however Dominic's knees were twice the size of mine due to constant bleeding and scar tissue in the joint. I emphasized the importance of treatment to these students so they can diagnose it in the future.

Overall, I enjoyed my experience. If not for Hemophilia Ontario, I don't think I would have taken a trip to Africa. As mentioned, I feel very fortunate that I live in Canada, and realize how much drive and determination those hemophiliacs and healthcare professionals in Canada had 50 years ago when advocating for comprehensive care and treatment for all. I believe that Tanzania could get to a level of treatment for all, but it will be a slow process and with the help of Hemophilia Ontario and the WFH, it can happen.

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 individuals 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 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. Requested submitted by December 31 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.

An Interview with Holly Reid

by Alex McGillivray

Recently I had a chance to sit down and interview Holly Reid, Partner at Blakes, Cassels and Graydon Law Firm.

1. In what ways do you support Hemophilia Ontario?

I am a partner in the Employment and Labour group at Blake, Cassels & Graydon LLP. I provide legal advice regarding all types of employment matters to HO, as part of Blakes' pro bono program. I have assisted in drafting employment policies and contracts for HO, and have advised on various personnel matters involving legal issues.

2. How long have you been assisting Hemophilia Ontario?

I started working for HO when I was an associate at Blakes, around 2010 I think. We have had a long association with the organization. I have also just started getting some of our junior associates involved in providing employment advice for HO, so that they have the same opportunities as I did. Our pro bono program provides non-profit organizations with sound legal advice, and also provides training and development opportunities for young lawyers. It is a win-win.

3. What do you enjoy most about helping non-profit organizations like Hemophilia Ontario?

Pro bono work is part of Blakes' culture and I consider it a professional obligation. It is also personally rewarding. Non-profit organizations like HO are always appreciative of our advice, and it is satisfying to help them prevent and solve problems.

4. How does your work with non-profit organizations differ from the work you do for other companies?

In most ways, the work itself is very similar. However, the individuals I deal with at non-profit organizations are often wearing many different hats at once, and are working with very limited resources. That can force us to come up with creative solutions to challenging problems.

5. If you could tell our readers anything about your work with Hemophilia Ontario, what would it be?

The work has been interesting and rewarding, but at the end of the day it is mostly about the people. I have been really impressed by the commitment and professionalism of the people I have interacted with at HO.

Webinar Series

by Laura Tomkins

In November, Hemophilia Ontario offered the third provincial webinar in a new series bringing patient education to members with computers in their own home. The final webinar of 2014 took place on Wednesday, November 26 from 7-8pm and was hosted by physiotherapist, Greig Blamey. The feedback from the presentation was outstanding, and stated that host Greig was "very knowledgeable", "organized," "engaging and a great speaker," and attendees enjoyed learning new tools and tips, including "the importance of exercise" and "how to think like a physiotherapist".

If you have any ideas for webinars for 2015 please contact Laura Tomkins at ltomkins@hemophilia.on.ca

HO is Going Green!

In 2015 Hemophilia Ontario is going green! At the present time it costs $4.00 to print and mail one copy of *Blood Matters* and we are charged another $3 should the mail be returned to the HO office. We are working to reduce expenses in all areas with this initiative being the first. By joining our e-mail list you'll be helping the environment as well as Hemophilia Ontario while still receiving your favourite magazine – *Blood Matters*. You'll also receive all of Hemophilia Ontario's program notifications.

If you are interested in switching exclusively to our e-mail list, please contact Susan Turner, Executive Assistant/Bookkeeper at 1-888-838-8846 ext. 21 or sturner@hemophilia.on.ca

Happy Retirement Didi !

by Betty Ann Paradis

LEFT TO RIGHT – Lori Laudenbach, Diane Bissonnette and Betty Ann Paradis at the Vancouver Club Awards Banquet

Diane Bissonnette, also known as "Didi" to the Hemophilia Community in the Ottawa and Eastern Ontario Region, has served that community as the Hemophilia Nurse for 28 years.

Diane's full caseload includes Hematology and Hemophilia, with a total of 350 clients. She spends half-time in each clinic. She received her Bachelor degree in Nursing in the early 1990's, doing it part-time while she worked in her clinic and was raising 3 young children!

In 2006, she won the Bayer Caregiver Award and this helped her develop the twinning with the hospital in Iqualuit. During her 28 years, Diane has served on the Regional board, participated in many regional educational events, and most notably, spearheaded the annual pizza party in order to ensure that the children from her clinic were registered for Camp Wanakita. Diane worked as camp nurse for one week each summer for 20 years, giving up her own vacation to do so.

Diane has also been an executive member of CANHC, imparting her wisdom and support to other members of CANHC. She has served on various committees of CANHC and CHS, and has helped develop many educational tools for patients and health care providers. She also helped launch the PEP[Parents Empowering Parents] in Ontario.

I feel very lucky to have spent so much time working with Diane at Camp Wanakita. I have watched her mentor the children as they came back year after year, then become young adults; role models for the younger children. Her patience while quietly teaching these children self-infusion is incredible!

We will miss Diane in our CANHC meetings but her friendship will always be there.

World Hemophilia Day 2015 Focuses on Building a Family of Support

Every year on April 17, World Hemophilia Day is observed around the world to increase awareness of hemophilia and other inherited bleeding disorders. This is a critical global effort with an ultimate goal of ensuring better diagnosis and access to care for the millions who have a rare bleeding disorder yet remain without treatment.

World Hemophilia Day in 2015 is focused on Building a Family of Support, embracing and promoting the idea that family, in all forms, is critical to the care and support of those with a bleeding disorder.

The family is easily extended beyond those who are related by blood. Family can include all of those who participate in care and support of a patient; caregivers, both institutional and individual, the global community of those with a bleeding disorder, and each individual who steps up to provide support and encouragement when needed. Most importantly, families all share the ability to encourage and advocate for those with a bleeding disorder. These varied families are an invaluable resource of strength and support for the community but these connections are also critical in raising awareness and encouraging proper access to care.

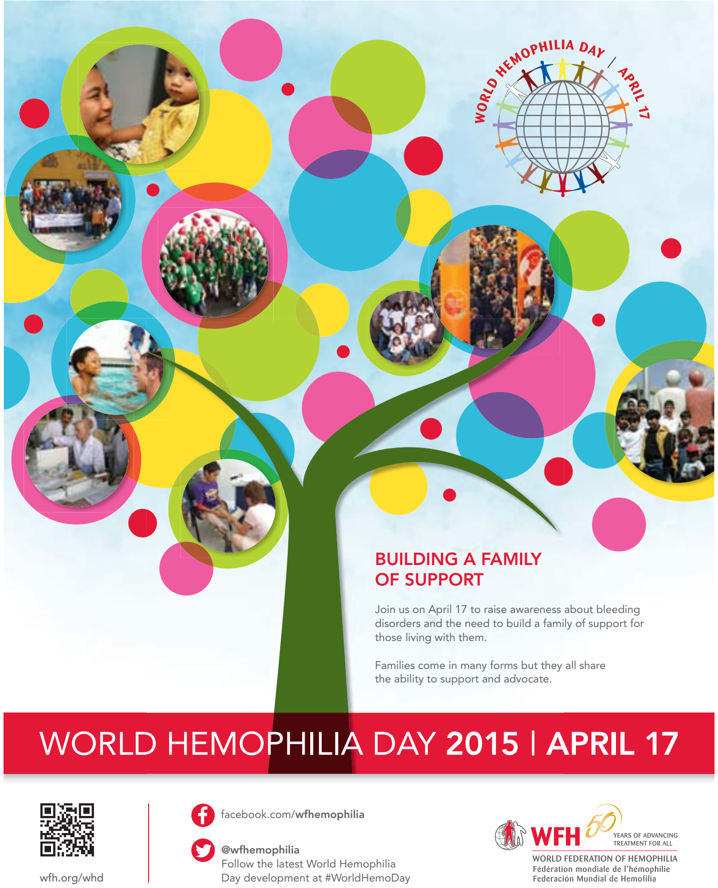
World Hemophilia Day provides an opportunity to talk to extended family, friends, colleagues, and caregivers to raise awareness and increase support. It also provides an opportunity to approach new communities with information about what it is to live with a bleeding disorder. It will be easier than ever to connect with the global bleeding disorder family on the World Federation of Hemophilia social media network this year and encourage your online community to join the global family.

World Hemophilia Day is also a good time to work with your children and relatives, to put together a family tree. It is a fun and educational process that encourages a discussion about the genetics of hemophilia and other bleeding disorders. The WFH has posted a guide on how to make a family tree at **www.wfh.org/whd**

This World Hemophilia Day, "We are all working together in this fight to raise awareness and improve care." said Alain Weill, WFH President. "Join the WFH family and be a part of the worldwide effort to improve the diagnosis and standards of treatment for those who need it." 🩸

WFH 50 YEARS OF ADVANCING TREATMENT FOR ALL
WORLD FEDERATION OF HEMOPHILIA
Fédération mondiale de l'hémophilie
Federación Mundial de Hemofilia

The World Federation of Hemophilia will be hosting online activities for our community on our website and social media accounts, to follow along like us at **www.facebook.com/wfhemophilia**



BUILDING A FAMILY
OF SUPPORT

Join us on April 17 to raise awareness about bleeding disorders and the need to build a family of support for those living with them.

Families come in many forms but they all share the ability to support and advocate.

WORLD HEMOPHILIA DAY **2015 | APRIL 17**

wfh.org/whd

facebook.com/**wfhemophilia**

@wfhemophilia
Follow the latest World Hemophilia Day development at #WorldHemoDay

WFH 50 YEARS OF ADVANCING TREATMENT FOR ALL
WORLD FEDERATION OF HEMOPHILIA
Fédération mondiale de l'hémophilie
Federación Mundial de Hemofilia

Products in the Pipeline – NEW Update

(December 16, 2014)

Canadian Hemophilia Society
Help Stop the Bleeding
Société canadienne de l'hémophilie
Arrêtons l'hémorragie

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, factor IX, inhibitor products, other coagulation products, and one for factor VIII and IX and inhibitors together, to help everyone stay informed of their progress through pre-clinical work, clinical trials and regulatory approval.

If you wish to learn more about any of these charts, you can visit the CHS website at **http://www.hemophilia.ca/en/safe--secure-blood-supply/products-in-the-pipeline/** for more detailed information. 🩸

HIV/AIDS and Hepatitis C News

Infectious Disease Care Program

The Infection Disease Care Program(IDCP) of St. Joseph's Health Care London has served the needs of people living with HIV/AIDS in Southwestern Ontario since 1990 (until 2006, the program was called the HIV Care Program). The program meets the outpatient needs of HIV-infected and affected populations across the region, providing medical, nursing, social work, pharmacy, and nutrition services.

In 2012, the Infectious Diseases Care Program moved from a stand-alone clinic into St. Joseph's Hospital, joining the ambulatory medicine clinics in a central outpatient area in Zone B, Level 3.The program has strong roots with the Hemophilia Program so those of you who have been followed by the IDCP would have made the change to receive care at the hospital.

In July 2014, the program welcomed a new Medical Director, Dr. Michael Silverman. He hails from Lakeridge Health in Oshawa where he had a long history of providing care to people living with HIV and Hepatitis C. Dr. Silverman brings a fresh new perspective on provision of care and a vision for how to expand services. We have begun going into the community to engage those people who may have been resistant or reluctant to engage otherwise. Enhancing accessibility is crucial for the best provision of care. Due to his keen interest and expertise, Dr. Silverman has expanded services to include treatment of Hepatitis B and C. He believes in individually tailoring treatment regimens to improve quality of life, which may include harm reduction strategies including pre-exposure prophylaxis.

Inflammation May Lead to Diabetes in People on HIV Meds

As found on the website **www.poz.com** – "there is a link between inflammation and the development of type 2 diabetes among HIV-positive people taking anti-retrovirals (ARVs)". The article goes on to state how "higher body mass index, older age, co-infection with hepatitis B or hepatitis C virus and the use of lipid-lowering medication were all linked with the diagnosis of diabetes. The study's authors concluded that low-grade systemic inflammation is an underlying factor in the development of type 2 diabetes among HIV-positive people taking ARVs".

Article Source: http://www.poz.com/rssredir/articles/diabetes_inflammation_761_26333.shtml

Plasma Company takes $400 Million Expansion out of Ontario

According to an article in *The Star,* Canadian Plasma Resources CEO, Dr. Barzin Bahardoust, says, "the company planned to open 10 plasma collection centres in Ontario, along with a plant that would separate plasma into component parts" but will now be taking the company, "to western Canada due to (Ontario's) intention to ban paid blood donations". While Bahardoust does have intentions to, "open the public on a volunteer donor basis, or paid donor for research purposes – he's still waiting for the go ahead from Health Canada, but says he fears the province will still block him from operating."

Article Source: http://www.thestar.com/news/queenspark/2014/11/24/plasma_company_takes_400_million_expansion_out_of_ontario.html

U.S. Panel Supports Lifting Ban on Blood Donations from Gay Men

According to **www.Time.com**, the Department of Health and Human Services panel in the United States voted 16-2 in November, "in support of allowing men who have had sex with other men to give blood after being abstinent for one year." While, "the FDA is not obliged to follow the panel's advice". Jennifer Rodriguez, a spokeswoman for the agency, said, "the meeting provided valuable information and perspectives that will help inform the FDA's deliberations".

The article goes on to state how this decision is similar to revised policies seen in the U.K., Australia, and Canada.

Article Source: http://time.com/3585329/fda-blood-donations-gay-bisexual-men/

Bleeding Disorders News

Hemophilia Injury Recognition Tool (HIRT?)

Now Available for Download

by JoAnn Nilson – Physiotherapist, Saskatchewan Bleeding Disorders Program

Officially launched on December 4, 2014 HIRT? is a joint media event between Winnipeg and Saskatoon and is now available for download. This app was developed following research with and feedback from young men age 18-35 with Mild Hemophilia. This research identified that young men with mild hemophilia often delay getting medical treatment because they cannot always determine the difference between 'mild' injuries and significant bleeds. The recently released CHS booklet *"Identifying Common Joint & Muscle Bleeds"* is included in the app to further assist with assessment.

This App will assist young men with mild hemophilia in self-management by:

- Helping them to identify signs and symptoms of a bleed.
- Encouraging the use of first aid.
- Reminding the young men to re-assess the injury (1 hour, 24 hours and 2 days) until the risk of re-bleed has passed.
- Providing Hemophilia treatment center contact information so they can access medical attention if the symptoms worsen.

Download information is available on the CHS website – see "Care and Treatment, Physiotherapy" **http://www.hemophilia.ca/en/care-and-treatment/physiotherapy/**. It is free and available from the Apple Store and Google Play. The app is adaptable to all screens (e.g., smartphones and tablets).

The development team: JoAnn Nilson, Kathy Mulder, Kristy Wittmeier, Candice Schachter, Richard Lomotey and Sarah Oosman. For any questions or if you are interested in participating in the evaluation contact: **joann.nilson@saskatoonhealthregion.ca**

Annual Holiday and Camp Wanakita Registration Event

All CWOR articles, unless otherwise noted, are by Alex McGillivray

Oh what fun! On Sunday December 14, families gathered for a potluck pool party at the Stoney Creek Rec Centre for the region's annual Holiday & Camp Wanakita Registration event. The children enjoyed a special visit from one of Santa's very own elves, played games, registered for camp, and enjoyed a swim in the pool complete with a few rides down the slide!

Thank you to CWOR volunteers Mary Pedersen, Megan Bordi, and Rob & Jane Dinsdale for their help running the day's events. Thank you to Zach Adams for his help running the games and for his help in the elf department. Lastly, thank you to all the families for the delicious treats! We look forward to seeing you all next year!

World AIDS Day Vigil

by Mary Pedersen

The vigil was held in Hamilton's beautiful Christ Church Cathedral on James Street North. It was a chance to honour those in our community living with HIV and AIDS and those we have lost. The service was planned by the church clergy and the AIDS Network with the participation of the Hamilton Gay Men's Chorus.

This was my first World AIDS Day Vigil. I remember those individuals I have known through the years that passed away of AIDS or complications related to it. In the early 1980's HIV and AIDS was just beginning to make an impact in the Canadian blood system. When HIV testing came to our community it became clear that a high percentage of our hemophiliacs were infected. My family and I remember them with great affection. They were young and old, always hopeful for a cure or a new treatment, but for some that treatment came too late. Some of those young ones are now a little older, taking the latest treatments and continuing their lives successfully along with its challenges. Many were hemophiliacs that I came to call friends and fellow society members in arms. Through my involvement with the AIDS community I met wonderful people who were very kind and helpful to me over the years. I think of them often at different times of my life and will never forget them. I sometimes cry when I think of my time with them and laugh at the times we had together. All their names and faces came to me as I sat in Christ's Church Cathedral and heard the reading from the Memorial Book. As I watched the participants walking to the front of the cathedral with their candles for those they lost and those who continue to live it felt for a moment like I was close to all of them again.

I took this from one part of the evening reading which I hope will be a tribute to all.

"What can we accomplish together? We will continue to mobilize our resources, our knowledge and our experience to finally defeat this epidemic. We, together, renew our commitment to this cause as well as to the memories and lives of those we honour. While there is not a cure, and while many still do not have access to treatment, our resolve continues to strengthen to stop HIV/AIDS."

I hope all came away from the vigil with the same resolve for a world without HIV and AIDS.

Liam Barbour Scholarship Award

The Central Western Region of Hemophilia Ontario (CWOR) is proud to present the Liam Barbour Scholarship Award.

This scholarship is made possible through the generosity of the Barbour Family. The Liam Barbour Scholarship Award will offer a $500 award to any affected member for their first year of post-secondary education. This amount is to be evaluated on an annual basis, and based on the amount of funds raised by the Liam Barbour Charity Golf Classic.

Scholarship Requirements:

- To qualify for this award, the applicant must reside in the Central Western Ontario Region, be an active member of CWOR, and have a bleeding disorder.
- The applicant must provide proof of their enrolment at a post-secondary institution to CWOR.
- CWOR has been empowered with the selection of the award on an annual basis. The award will be paid in/around the first week of October of the first year the student is enrolled in post-secondary education.

The deadline for receipt of scholarship applications is **August 1, 2015.** Faxed or late applications will not be accepted. For more information or to obtain a Liam Barbour Scholarship Award application, please contact Alex McGillivray – Regional Service Coordinator.

Applications can be mailed to Hemophilia Ontario CWOR, 101-King St. E, Hamilton, ON, L8N 1B2

Bleeding Disorders Awareness Month

This past November, CWOR had the opportunity to participate in The AIDS Network's annual Open House as part of their AIDS Awareness Week campaign. The region was able to set up an information booth alongside other partners in the community. An engaging event, the open house allowed us to share the work Hemophilia Ontario does within the community at large, raise awareness, and continue to foster our relationship with The AIDS Network.

CWOR would like to thank The AIDS Network for allowing us to be a part of the open house! 🩸

CWOR

Regional Council and Staff

Rob Dinsdale
Mary Pedersen
Debbie Bordi
Meagan Bordi

CONTACT
Alexsandra McGillivray
Regional Service Coordinator
amcgillivray@hemophilia.on.ca

101-140 King Street E.
Hamilton ON, L8N 1B2
905-522-2545

North Eastern Ontario Region

Fall Clinic

All NEOR articles, unless otherwise noted, are by Stephanie Morrison

On Saturday November 1, NEOR held their Fall Clinic at the Sudbury Regional Hospital. Members participated in the region's activities as they decorated and enjoyed some very delicious holiday treats! The region would like to thank Baxter, Bayer, Novo Nordisk, and Octapharma for sponsoring this great event. 🩸

Regional General Meeting

Make sure to keep your eyes peeled for information on our up-coming Regional General Meeting in March at Health Sciences North. There will also be details on how you can become more involved with Hemophilia Ontario NEOR!

All members are welcome. We hope to see you there! 🩸

NEOR

Regional Council and Staff

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

CONTACT
Stephanie Morrison
Regional Service Coordinator
smorrison@hemophilia.on.ca

501-65 Wellesley Street. E.
Toronto ON, M4Y 1G7
1-866-545-1647

North Western Ontario Region

Fall Clinic

NWOR RSC Laura Tomkins attended her first clinic as the NWOR Regional Service Coordinator on November 10th and 11th. It was a great opportunity to meet and speak to Hemophilia Ontario's northern members, new and old, and meet the HTC team. Below is a picture Laura took of the some of the staff she spent time with, RN Lori Hygaard and Dr. Laferriere.

Laura will returning to the Spring clinic (date TBD) and looks forward to seeing those people she has already met and meeting other members. Please make sure you say hi and find out what she and Hemophilia Ontario NWOR can do to support you.

NWOR

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

Regional Council and Staff
CONTACT
Laura Tomkins
Regional Service Coordinator
ltomkins@hemophilia.on.ca
501-65 Wellesley Street E.
Toronto ON, M4Y 1G7
1-866-920-2031

Ottawa and Eastern Ontario Region

OEOR Halloween Bowlathon

All OEOR articles, unless otherwise noted, are by Darlene Villeneuve

Our Bowlathon raised just over $2500.00. This year we had a silent auction which helped in raising much needed funds. The children wore costumes as well as some of the adults, and prizes were given out. Thanks to all who attended, your participation is so important.

Thank you to all of our sponsors for this event: Kids Kingdom, IDA Greenbank, Caribbean Exposure Tanning, Fitz Bar and Grill, Brass and Crafts, Walmart Portrait Studio Barrhaven, Shoppers Drug Mart Merivale Mall, Rexall Bells Corners, Shoppers Drug Mart Bells Corners, East Side Mario's Bells Corners, Amanda's Hair Studio, Funhaven, Sens Foundation, Viva Spa, Hilton Inn Airport, Skyzone, Tim Horton's Woodroffe/Medhurst, Loblaws Merivale Rd, Cineplex South Keys, Farmboy, Valleyview Farm, Walmart Baseline Rd, Boom 99.7, Jump 106.9, Hot 89.9, The Ottawa Fish Market, Days Inn Hunt Club, Loblaws Barrhaven, Bulk Barn, Novotel Ottawa, Toys on Fire Barrhaven, and Lyanne Cabral.

Annual Holiday and Camp Wanakita Registration Event

The annual Holiday event is always a great success, but this year seemed better than ever. There was plenty of food, awesome entertainment, more than enough door prizes and games that kept us laughing and sharing holiday cheer. It was awesome to see all the families come out and watch them building gingerbread houses together – building memories that will last forever.

The adults are always just as happy with this event as the children smile and their faces light up when they receive their gifts from Santa – a truly priceless moment. Many thanks to our wonderful city and their generous donations: Tim Horton's Woodroffe/Medhurst, Real Canadian Superstores, Lone Star Texas Grill, Walmart, Scores Restaurant, Loblaws, Fat Alberts, Wrigleys, European Hair, Ottawa 67's and Als Diner, Royal Oak, Ralphs, The Senate Sports Bar, and Laser Esthetique.

Mild Hemophilia Education Session

by Amanda Grant

The end of the year was busy for the Ottawa and Eastern Ontario Region (OEOR). Membership increased and so did attendance with the Mild Hemophilia Education Session, the Bowl-a-thon, and the Holiday Party. It was great to see members of all ages come out and support the inherited bleeding disorders community.

With the help of Diane Bissonnette and Lucie Lacasse, the Mild Hemophilia information session went off without a hitch this year at the Hintonburg Community Centre. Dr. Elianna Saidenberg started the session with the use of the new iClicker technology. This technology is a voting system that allow participants to vote based on a questions posed by Dr. Saidenberg. This platform opened up a frank discussion amongst attendees and debunked myths and common beliefs with hemophilia.

Physiotherapist, Brenda Elliot talked about the basics of recognizing joint and muscle bleeds along with first aid procedures. The Ottawa Hospital nurse, Lucie Lacasse had a presentation on navigating the ER and what to do outside of business hours. She emphasized the importance of good communication between parents and the triage nurse. CHEO nurse, Diane Bissonnette talked about navigating the world with a bleeding disorder while mentioning the importance of insurance and the Factor First card. She also discussed the Passport to Wellbeing program and the transportation of factor. Hemophilia Ontario thanks Bayer for sponsoring the event and Lonestar for providing the catering.

Thank you Amanda

We would like to thank Amanda for her work and support in the OEOR region during 2014. As the acting Regional Service Coordinator (RSC) it was her job to ensure that she was available as an information resource, an advocate and that OEOR continued to provide programs and fundraising. She worked with the volunteers of the OEOR Council and they accomplished just that. We wish Amanda success in her future endeavours.

OEOR

Regional Council and Staff

Ashwani Kurichh
Nancy Sauve
Anna Sicoli
Darlene Villeneuve

CONTACT
Alex McGillivray – Acting
Regional Service Coordinator
amcgillivray@hemophilia.on.ca

2445 Boul St. Laurent, Suite B151D
Ottawa ON, K1G 6C3
613-739-3845

South Western Ontario Region

SWOR AIDS Vigil

All SWOR articles, unless otherwise noted, are by Terri-Lee Higgins

SWOR participates in the World AIDS Day Vigil in collaboration with six other agencies. Each year we are asked to speak about a provided topic; this year we spoke about Honour:

For 30 years AIDS Vigils have provided the opportunity to highlight how human rights and diversity have played a role and influenced the struggles and response to HIV/AIDS around the world. Once a year we come together on World AIDS Day to honour the people who have died of AIDS or AIDS related illnesses, or who have given their lives in the fight against HIV/AIDS and to support others who live with this disease every day. Every year, thousands of candles are lit to honour and remember those who have died, and to encourage and support others who live with this disease every day.

AIDS appeared in the early 1980s and soon became an epidemic -an epidemic that began in illness, fear and death. June 5th, 1981 the Centre for Disease Control and prevention described what would come to be known as AIDS, and the next day they were flooded with reports from 100's of doctors of similar cases with 270 reported cases by year end.

Over the next years, HIV had a huge impact on the world, and was recognized in 1982 in the inherited bleeding disorders community I work in. More than 1,100 transfused Canadians were infected by HIV, of who 700 had hemophilia and other bleeding disorders, and 400 were transfusion recipients for other reasons (trauma, surgery, childbirth, cancer…). Between 700 and 800 of these people have passed away.

Defined in the dictionary, Honour says high respect esteem; fulfill an obligation or keep an agreement. Tonight we gather to Honour:

- The almost 25,000 Canadians who lost their lives to AIDS and AIDS related illnesses.
- The families and friends who supported and stood by those they loved.
- The communities that stepped forward to assist.
- The 6 researchers, health workers and activists on their way to the 2014 International AIDS Conference in Melbourne on the Malaysian airline that was shot down.
- The more than 71,000 Canadians and more than 30,000 Ontarians living with HIV.
- The 700 Canadians with hemophilia and other inherited bleeding disorders infected by tainted blood.

Do you know what your RSC and Program Council Does for You?

Every time you go to clinic you have the opportunity to speak with a Regional Service Coordinator (RSC). You might ask yourself "Why is this important? What can they offer?" Your RSC is not only your gateway to information about the supports and services Hemophilia Ontario offers every member but also what's happening in South Western Ontario Region (SWOR).

Every clinic, the RSC has the most up to date information about what's happening in the region and around the province. They have:

- Membership forms that get you on our email / mailing list so that you continue to receive pertinent information including *Blood Matters* magazine between clinic visits.
- Financial Assistance forms that will help you access a fund designed to assist with covering costs related to an individuals inherited bleeding disorder needs.
- For youth 17 and under, they have the NEW (Now Experience Wellness) program information that can reimburse some costs associated with trying new activities.
- Flyers on upcoming educational and fun programs as well as fundraisers which are key to helping us continue to provide members these opportunities. Money raised in SWOR is spent in SWOR. The calendar outlines what the SWOR council has planned for the year, we hope to see you at some of these events.

More importantly, perhaps, is that they are there to hear from you. Do you have concerns with something that happened, or didn't happen, during an emergency room visit or clinic appointment? Is there an educational opportunity that you think we should organize that would benefit our members? As your community advocate, the RSC brings your concerns and issues to not only the SWOR Council for forward planning but also to a unique program called SWOR Program Advisory Council that meets three times per year and is the only one of its kind in Canada. It provides the opportunity for SWOR members to have a voice in their care by representatives speaking directly with the medical team and hospital administrators to share / hear concerns and issues and praises. When you make your RSC aware of your issues, it's our responsibility to bring them to the comprehensive care team, without need to identify the source if that is your preference, in an effort to find ways to resolve the issue. Whether you are the only person experiencing the issue or there are a few people, every concern needs a voice – if we don't know it's a concern, we can't work to resolve it and to prevent it from happening again in the future.

We would encourage you to stop and say "Hi" to the RSC when you are at clinic and find out what SWOR can do for you. 🩸

TAINTED written by Kat Lanteigne

"It was meant to give them life"

by Marion Stolte

This past October some of us went to see this incredibly powerful reading of a family fighting to stay intact when the unimaginable happens. It was moving, thought-provoking, and unsettling. One of our friends said "Thank you for inviting me. I have a better understanding of what happened, and, oh, this should be seen by so many more people. We need to remember and not let things like this happen again." So true.

The play was inspired by true stories of families who endured the tainted blood crisis in the 1980's and 1990's – an extremely horrific public health disaster. HIV and Hepatitis C were blood-borne viruses that infected over 30,000 people through no fault of their own, with thousands dying. For both Eric and I, it was a reliving of the pain of the years in the 1990's when we listened, cared, wept and went to many funerals of dear friends who had contracted HIV/AIDS or Hepatitis C.

Yet, as we watched the play we, also, remembered the incredible courage, love and determination of each one. There was a lack of bitterness while pursuing justice. What an incredible community to be a part of. If you ever have a chance to see this play, I would highly recommend it and invite your friends. It's not easy, but it is oh so powerful.

Probably the one downside that I/we experienced was the significantly strong discussion that ensued with the audience after the play. This seemed to be a place where there was an effort to convince the audience that paid plasma collection should be prohibited. This is not the stance of the CHS. **http://www.hemophilia.ca/en/about-the-chs/public-affairs/chs-policy-on-paid-plasma-donations/**

It was unfortunate that the emotion and empathy of the audience for the suffering of those who went through this tainted blood crisis, would be used for this purpose. But this doesn't override the importance of the main message of the play – to remember the emotional and physical toll of the tragedy so as not to allow it to be repeated. 🩸

Wreaths, Patio Pots and Swags

by Maureen Schaus

SWOR had a very successful holiday fundraiser again this 2014 season. The sales were better than ever and a new product – a hanging basket, was a popular choice. As always we would not be able to run such a successful fundraiser without the help of our many volunteers. The weather was cold but that did not discourage our hardy volunteers. And we say a special thank you to Jennifer and Ross Crump for letting us invade their garage and for the warming Chili. We managed to sell 345 pieces of greenery and raised $3,900 for our region. 🩸

Pinecrest Adventures Camp

Planning is underway for 2015 Pinecrest Adventures Camp, which will take place August 26th – 30th 2015 at Camp Menesetung in Goderich, ON. All eligible campers will receive a mail out in early April with full details including this year's theme. Registration forms are due back by June 30th 2015, late registrations will be subject to a $50 late fee.

Watch your mail for further details or if you need any other information, please contact Terri-Lee at thiggins@hemophilia.on.ca

Hallowe'en Haunt

by Zakkary Young and Chantelle Mitchell

We had so much fun the night of the SWOR Kusterman's Halloween Haunt. It was a night of adventure, scary fun, and it was really nice to see SWOR friends!! Zakkary especially loved playing and seeing his friends from camp. Because of the bond they developed at camp, they found the courage to explore the haunted maze together... something Zakkary likely would not have done otherwise. It was a really wonderful night!!

SWOR 2015 Calendar of Events

March 28	Scrapbooking Event – London
April 12	Polar Bear Dip Fundraiser for World Hemophilia Day – Little Beach, Port Stanley
April TBA	CODErouge Participation in Wellness Fair
May	Commemorative Tree Planting and Women in Touch, Woodland Cemetery – London
May 9	Speakers Bureau –Telling Your Story
June 5-7	Pinecrest Staff Training – Camp Menesetung, Goderich
June 17	Evening of Adult Education
June 20	SWOR Summer Celebration
August 25-30	Pinecrest Adventures Camp – Camp Menesetung, Goderich
September 26	8th Annual Golf Tournament for Hemophilia and Inherited Bleeding Disorders – Ingersoll Golf Club, Ingersoll
October 23	November Appeal
November 27	Delivery of Festive Wreaths, Swags and Pots
December 6	SWOR Winter Celebration

Dates are tentative and may potentially change

SWOR

Regional Council and Staff

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

CONTACT
Matthew Maynard
Regional Service Coordinator
mmaynard@hemophilia.on.ca
186 King St. E, Suite 30
London ON, N6A 1C7
519-432-2365

Commemorative Tree Planting

All TCOR articles, unless otherwise noted, are by Laura Tomkins

On November 9, 2014, Hemophilia Ontario and TCOR partnered on this annual commemorative event at the Kortright Centre for Conservation. The event was held to remember those who were affected by and/or lost their lives due to the Tainted Blood Tragedy. This event included a tree dedication, refreshments and a discussion run by Yvette Perreault, Executive Director at the AIDS Bereavement and Resiliency Program.

For a donation of $20, individuals were able to purchase a stone to commemorate loved ones. All proceeds were invested in the Hunter Bishop Comfort Fund which provides financial assistance to members in the Toronto community. These stones were placed around the tree, and attendees were able to write a name(s) on the stones to remember, honour and celebrate loved ones.

Families in Touch Winter Celebration

The ever popular Families in Touch holiday party event took place on Sunday December 7 at Bathurst Bowlerama. Over 30 TCOR members gathered to bowl, fill out Camp Wanakita registration forms, have lunch, and listen to an educational session ran by Diana Cottingham, Social Worker at SickKids hospital.

Parents were given a family journal to use as a tool for communicating their feelings and personal thoughts. It can be used privately or used as a way to facilitate a dialogue with their child who has a bleeding disorder as well as the siblings. The child portion looks at things that" make me happy, sad, comfort me, make me angry, make me scared and worry me". Depending on the child's age the child can write in the journal or draw pictures or can have a discussion with their parent.

Women in Touch

The Women in Touch event, which occurs twice yearly, was held on November 1 at the Nottawasaga Resort in Alliston, Onatario. A program which has been going on for over 10 years, this event allows women who are mothers, sisters, aunts, friends, and partners of people with inherited bleeding disorders, or who are living with bleeding disorders themselves, to come together in an intimate and confidential group.

Keep an eye out for the next event happening in Spring 2015 or contact Laura for details of how to get involved ltomkins@hemophilia.on.ca

World AIDS Day

In celebration for World AIDS Day on December 1, 2014 – TCOR RSC Laura Tomkins developed a display board which was displayed on site all day at SickKids Hospital on November 28.

Throughout the day she shared information and handed out red ribbons in support of this national event.

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

CONTACTS
Laura Tomkins
Regional Service Coordinator
ltomkins@hemophilia.on.ca

Susan Turner
Executive Assistant/Bookkeeper
sturner@hemophilia.on.ca

501-65 Wellesley Street. E.
Toronto ON, M4Y 1G7
416-972-0641

Good Changes

by D'Marc Lewis

Hello everyone, long time! How's everyone been? I'll keep this short, so for the very few of you that have had the pleasure of learning, I recently acquired a new femme d'amour who, for this edition, we'll call Summa Lovin'. Growing together as a couple, she is engaged to be as aware as she can about learning about me and this hemophiliac extravaganza I live after I told her the complications, restrictions, responsibilities and a few stories along the way to give her an idea of what it's like. I asked Ms. Lovin' some questions during a phone call the other day ...

1. How did you feel when you first heard about it?

   ML: I didn't know what it was. Once I found out, I quickly looked it up.

She continues on ...

My concern for D'Marc is making him bleed; accidents that can be caused by me or other people. Smaller accidents by paper cuts or shaving. It's an everyday concern; when he comes and sees me, and when he leaves, I worry. But, then again, he's nearing his thirties (shhh, don't tell them!), he is yet to bleed to death (thanks, babe...) and he can handle himself and has shown to be independent in his care. I reassure myself that he'll be fine if things go wrong. It's not like he is prone to injuring himself like a teen (she's been informed that teens may read *Blood Matters*).

2. So when you hear of something like "hemophilia" after being given the info, doing your own research and having at least one's insight to the environment and the day-to-day life amongst other things, what goes through your mind?

   ML: It sucks, to be careful of everything you do, especially for the smallest things like paper cuts, to having needles all the time, watching everything you do every day. I wish there was a cure.

3. Biggest fear for you?

   ML: Not knowing what to do.

4. And what would be beneficial for you to overcome this fear?

   ML: Well, I would want to know what to do prior to the next time I see you, what to do in case of a bleed. And I would want to know now.

5. How in particular?

   ML: Who to call, emergency contacts, what to do until help arrives, closest health centre, etc.

6. Anything else?

   ML: I just want to say that I am happy to know that there is a society for people that have hemophilia. I think being in a relationship with someone that has hemophilia, that I need to become more aware of it and how to handle situations.

So, needless to say, everyone... I'll have my work cut out for me ahead. But I fail to see it as a chore at all. For the record (she just might read this), I see this as pure benefit for both of us, but for those of you gearing into long-term relationships: Once you get past the whole "divulging your medical condition to a loved one that was discussed on earlier editions because that's what D'Marc said on *Blood Matters* before" bit, to my opinion, it's far more beneficial for you, dear easy-bleeder, to educate yourself and be supportive of your loved one while learning of each other's values and giving the ABC's and the R.I.C.E's to them. The end results are that you do not leave them to feel helpless. They're more engaged and focused to care for you and follow any directions.

We hemophiliacs (and vWD's) are taught throughout our lives to live independently with this disorder. Our hearts and souls teach us (eventually) to live in harmony with someone who understands and who can stand by us. We need not need to be dependent, but we can enhance and better our lives with running beside our significant others to see our bleed episodes through. Trust me when I say it's a great feeling when you're on the down, that you have someone to peg you back up ...and call the Hemo Fellow.

Remember fellow youth, you call the shots when bleeds hit the fan. For those of you that are more the "help me" type, when you get your other to be well-versed in hemophilia or at least what to do, they can be super helpful to ensuring you're eventually a clotter! Just be sure to be as encouraging and supportive... and yeah, loving... you got me. 💧

Until next time, bleeders,
may your clot thicken.

Keep the Peace,
D'Marc

HOY & Hockey!

by Laura Tomkins

On Saturday December 13, twelve Hemophilia Ontario Youth members aged 13 to 26 and their friends and volunteers got together in Toronto to watch a Toronto Marlies hockey game from their own personal suite! The event was started with off with several rounds of icebreaking "Bleeding Disorders" charades, followed by loads of yummy food and a great game!

Hemophilia Ontario Youth, or HOY, is an opportunity for those aged 13-26 across the province to get together with others affected by inherited bleeding disorders to hang out and learn together, and be a part of the Hemophilia Ontario community. 💧

If you wish to be a part of HOY, and/or have any ideas for 2015 HOY programs, please contact Laura Tomkins at Ltomkins@hemophilia.on.ca

HOY Event to See the Marlies

by Shrey Patel

I had always wanted to see a 'real' hockey game, live and in person. On December 13, 2014, I got that opportunity. I was fortunate enough to attend a Hemophilia Ontario Youth (HOY) sponsored event to see the Toronto Marlies in action at the Ricoh Coliseum. They were going to play the St. John's IceCaps.

Sometime in October, Laura Tomkins contacted me to see if I was interested in seeing the Marlies play. Of course I was interested! And, as a bonus, I could even bring along a sibling or friend. I knew right away who I was going to invite. Now, I just had to figure out how to get there. I did some research and decided that taking the GO train was the most convenient option. Everything was set! It was going to be exciting, since I'd never taken the GO train by myself.

Game day had arrived! The game was going to start at 3:00 pm but we had to be there by 1:45 pm. We took the one o'clock train and arrived at Exhibition station by 1:30 pm. Laura met us at the station. I had spoken to Laura over the phone but had never met her, so I was happy to meet her because she was the one who organized the event and she, also, helps me with Camp Wanakita registration every year.

The event was a lot of fun. We got to the box reserved for our group where we started off by meeting the other kids and played charades. Charades was fun because we all had to act out difficult words in relation to hemophilia and other medical terms. Then, the food came and the game was about to start. We all got some food and sat down ready to watch the game. The game was fun to watch because both teams kept scoring and you didn't know who was going to win. In the end, the game went into overtime and the IceCaps won.

I thought that the event was educational and a lot of fun. My friend and I had a great time. 🩸

Change for Good

by Zach Adams

For better or worse, change is often an inevitable part of life. The hemophilia community offers a great example of how change can help our organization remain current and relevant to multiple generations; therefore, meeting the dynamic needs of those living with inherited bleeding disorders. Current advancements in technology have propelled us into new frontiers, and have allowed us to explore several new aspects of bleeding disorders that have only recently come to the forefront. This unique form of research and development into our use of everyday technology is being conducted and rolled out along with the novel treatment options becoming available with new products.

The daily use of a cellphone, which has become widespread among the majority of the population, is being studied as one of the possible tools used to deliver important and relevant information to the hemophilia community. One recent example is the release of a new iPhone and Android application termed "HIRT?" (The Hemophilia Injury Recognition Tool), developed in collaboration with several groups from Saskatchewan and written by PhD candidate Richard Lomotey of the University of Saskatchewan. This novel app can assist those with hemophilia by using self-reported symptoms to evaluate an injury, providing helpful treatment suggestions and scheduling alerts, which remind you to reassess the injury at a later time. Furthermore, the app contains contact information for every hemophilia treatment centre across Canada; conveniently accessible for those who travel. This app now provides an important first step in identifying the usefulness of making information available on mobile phones, which can instantly connect people with information related to their bleeding disorder.

Similarly, many people have already changed from pen and paper diary entries to several more technologically advanced methods, including Bayer's EZ-Log system. Serving this new generation requires the ability to provide quick, fast and easy access to the materials and resources an individual requires to manage their bleeding disorder. Collectively moving toward this change will promote the discovery of unique methods and opportunities to deliver useful, real-time information that is conveniently available in the palm of your hand. 🩸

"HIRT?" is available for free on Apple and Android devices in both English and French.

Information regarding HIRT? was retrieved from the article titled "Phone app can help with hemophilia" by Janet French.

BLEEDHers

Change

by Michelle Lepera

CODErouge
WHEN WOMEN
BLEED TOO MUCH

Ever since I was a little girl I knew what I wanted to be when I grew up. I wanted to be Mrs. Brady. I was going to be the Mom who worked from home. I was going to raise my 6 kids while my architect husband went to work. I was also going to do it without an Alice!

Until …

My life changed when my son was diagnosed with Hemophilia. In an instant the life I knew and the life I thought I was going to have changed. And to top it off I was also diagnosed as a symptomatic carrier; I also had a bleeding disorder.

There was no choice. I had to change the way I was going to raise my son. I had to change the furniture in my house to make sure he was safe. I had to change my career process, I had to change my thought process in life altogether. I even had to change the way I looked at myself.

These changes didn't come easy. But they had to happen. It's easier when you are looking for change. You know your need to change. Maybe you need a change of pace. The hard part is when things change in your life, when and how you least expect it. SO! Instead of hiding under my bed, which I wanted to do so many times, I took the lemons I was handed and made lemonade.

As life went on there were many changes in our family life, some regular changes some more difficult, but we adapted. I'm sure there will be many more change, that's just the way it is. The way you handle it is key to a happy acceptance of your situation. Today, the Lepera family are all heavily involved in volunteering with the Southwest Region of Hemophilia and CHS.

Our lives changed with a diagnosis of Hemophilia and now I can't imagine my life any different.

Healthy Living with a Bleeding Disorder

Making a Habit You Won't Want to Break

by Heather Gardner – Physical Education Teacher HWDSB & Ontario Health and Physical Education Curriculum Consultant with Ophea Canada
www.runsoulcycle.com

Start Small.

Take a close look at what it is you want to achieve and all the potential steps to get there. What is the first and simplest of those steps? That is where you will start! So if your goal is to go for a walk or run every day, the simplest step will be to put on your running shoes and head out that door. And once you're outside, well you might as well go! Break your habit into the simplest version of itself and start there.

Plan Ahead.

Examine your schedule and make time for you. Sure, once your shoes are on, going for the run becomes a straightforward task, but have you carved out the time for this to happen? Examine your day with a fine toothed comb, and just like you wouldn't cancel on that meeting with your coworker, or brunch with the girls, time to form your habit must be non-negotiable too!

Set a Reminder.

This behaviour is new, which means it might not always be on the top of your mind. So, consider leaving yourself some loving and gentle reminders throughout the day to help you make the right decisions. If your goal is to drink more water, then have a reusable water bottle ready to be filled at your desk. Want to sit less at work? Try setting an alarm to remind yourself to get up and move. Want to think happier thoughts? Why not change your phone background to someone you love, family or friend, whoever brings a smile to your face and heart. Setting up a visual reminder takes the thinking out of your goal making it much easier to remember.

Be Accountable.

Tell everyone you know about this awesome new habit you are forming. You'll be working hard to make these changes; the moral support will help you to keep at it and push through. Share your habit on social media, give daily updates which people will expect, and hey, you might inspire someone too!

Reward Yourself!

It's important to celebrate your successes every step of the way. Every time you remember your habit consider a little verbal "way to go!" After one week of success, how about an extra long bubble bath. One month, maybe you watch an extra episode of your favourite show. Rewards don't need to cost money, but they do need to make you feel good. Give yourself some praise and enjoy every success.

SAVE *the* DATE

Hemophilia Ontario Annual General Meeting - Saturday April 18, 2015 - London

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 1 year term. Each region elects a Regional Council at their Regional General Meeting.

For further information please contact:

Hemophilia Ontario, 65 Wellesley Street East, Suite 501, Toronto, ON M4Y 1G7

✉ info@hemophilia.on.ca	@HemoOntario	hemophiliaontario
/Hemophilia-Ontario	/HemophiliaON	HemophiliaOntario

How Can YOU 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 nine 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
65 Wellesley Street East, Suite 501, Toronto, Ontario M4Y 1G7

www.hemophilia.on.ca