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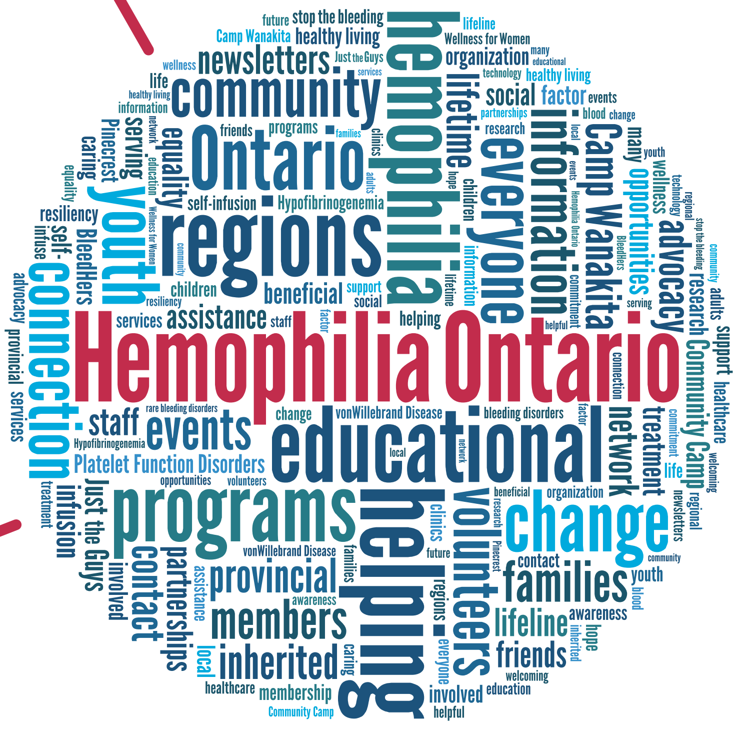
BLOOD matters

SUMMER 2015
VOLUME 6 • NUMBER 2

Help Stop the Bleeding



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Hemophilia Ontario

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Hemophilia Ontario is a certified chapter of the Canadian Hemophilia Society

President's Message

by Paul Wilton

When I was a kid I knew Julia Sek as the cool nurse from Hamilton. At Camp Wanakita she helped me learn how to self-infuse. In my teen years each summer she took a dozen bleeders on a week long canoe trip through Ontario's most remote and beautiful areas. She wouldn't judge the off colour stories or jokes teenagers sometimes tell. She seemed to like our music and we often sought her out for the most engaging, deep, and sometimes philosophical conversations. When I became involved with Hemophilia Ontario as an adult Julia was the President. I was struck by the way she worked to develop young board members and create a fun working environment.

In 2014, I was thrilled when Julia agreed to return for a year as President of Hemophilia Ontario. Her experience as a Nurse, Hemophilia Provincial Coordinator, hospital administrator and long-time volunteer made her, by far, the most qualified person for this role. Julia quickly opened the can of worms no one wanted to address, our increasingly uncertain funding environment.

Julia chose a skilled volunteer in Monica Mamut to facilitate the development of a Funding Review Strategy. Julia was thoroughly engaged in discussions often intervening to ensure the advocacy Hemophilia Ontario provides on issues of care and treatment and blood safety and supply, and research would continue to be our top priorities. Her experience as a manager helped identify areas where we could improve our performance. She has little patience for continuation of programs that do not address our goals or engage members. This was a very time consuming process and as President Julia led the way through treacherous terrain. In the end, she accomplished what no other President in the past fifteen years has been able to achieve: a strategy to address future funding and certainty about what the medium-term holds for the funding environment.

Working with Julia these past two years I have learned Julia is more than just a cool Nurse. She is a strong and resolute leader. Julia expects excellence from Hemophilia Ontario and sets high but achievable standards for all those who work with her. She's willing to lend a hand to help others perform their best. Two volunteers said of Julia:

> *"As President she was very approachable and kind. She always listened to everybody's point of view and was very appreciative of each person's contribution to the board."*
>
> *— Mom from NOR*

> *"I admire Julia's leadership. She took control completely and sought the full opinion of each Board member before making any final conclusions. She educated herself along the way and remained adaptable to the many roadblocks and uncertainties we were faced with this year."*
>
> *— Woman with a Bleeding Disorder*

I think Julia demands the best because she believes the people she has devoted her life to in this community deserve the best. Julia knows the issues facing our community because of her engagement. She strives to ensure those issues are understood by our members and that Hemophilia Ontario continues to advocate for the best care and treatment possible. Thank you to Julia for her work as President this past year. We're very happy she will be continuing on as Past-President helping to mentor our next generation of leaders and to be the voice of experience and wisdom in guiding our work.

What's in this Issue?

Summer 2015 Volume 6, Number 2

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Executive Director's Message

by Terri-Lee Higgins

Spending time with family, friends, business colleagues and acquaintances can be exhausting, exhilarating, invasive, annoying, and invigorating or any combination of emotions depending on what happens during that time frame. We can choose to break, step away from or continue connections once we determine what is best for us and we hope that in the end it is the right choice. Bottom line is we do what we need to do in order to help us find ways to stay healthy - mentally, emotionally and physically.

We all want to be healthy so we can be as active as possible. To do this we need to have the opportunity or tools and information to make the best choices and know how to prevent illness where possible. This may include:

- Staying in touch with family and friends – social media keeps us way more connected than when I was growing up.
- Eating healthy foods in healthy portions – and yes the occasional cheat can keep you on the right path the rest of the week.
- Finding ways to be physically active every day – stretching, walking, running, gardening, exercising, vacuuming can all be a benefit (yes its true cleaning the house and all the twisting and turning can contribute to physical wellbeing).
- Being sun smart – don't get too much and wear sunscreen, hats and protective clothing as appropriate.
- Making sure our medical (whether traditional or alternative) needs are met.

I recently overheard a conversation between two friends talking about visiting their doctors – they kept saying they know their bodies, how they feel when they are well and unwell. When they go see their various medical professionals they go prepared with written out questions, medication lists and copies of health records as back up so that they can provide as much information as possible to afford the most complete 'picture' to begin resolving the issue. Pretty sound advice from where I was sitting.

It got me to thinking, am I as connected to my health resources as I should be? My medical care team are all people I am comfortable with and can talk openly about my concerns. I have regular dental check-ups, see the Doctor when needed, appreciate massage and acupuncture when I can get in. I need to have my eyes checked – probably about 2 years ago would have been smart. I am fortunate that at this stage of my life I don't require accommodations such as those my in-law do but as I age I know this will be a consideration in my future care. We attend their medical appointments with them so that we understand changes in medications or level of health or the reason for pending medical tests - it has strengthened our ability to support them and make sure that everyone in the family has the same information for consistency in care.

Many members of the inherited bleeding disorders community that I know work to maintain their necessary connections with the underlying thought that when they need enhanced care they will be able to receive it because those who need to know, do know. Others have told me that what works for them is to share what they think is important and provide any other information when it proves necessary. I don't believe support and care should be a 'one size fits all' approach meaning that you have to decide for yourself the approach that works best for you at your stage of life. If you need help or have medical concerns, talk with your health care professional whether GP or Hematologist or other practitioners as need arises. If your family or friends can help or provide the support or assistance you need, call or connect with them in whatever way you usually do. Whether in person or through social media a caring ear is always within reach – the more connected we are to our supports the better chance we have for life success.

Editor's Message:

Drop a pebble …

by Tom Beer

This edition of *Blood Matters*, had me thinking of the Grade 6 science experiment when I asked children to drop a pebble in a puddle and observe closely what happened.

Pebble in the Puddle Experiment – Part 1

It always amazes me that little things/ events in our lives can have a large impact. For example, "the pebble in the puddle" sets off a series of multiple rings (mini waves) that move out to the edge.

A case in point, referenced in the article by Zack Adams, no one could have known or recognized the immensity of the impact that the Tainted Blood Scandal would have on Canadians, not just those with inherited bleeding disorders. How could they?

As a result, directly or not, extensive research followed and many related research initiatives are being undertaken today. We must acknowledge the importance and strengthening of those individuals and organizations that advocate for those with blood disorders. We must acknowledge the universal recognition of a worldwide need to address the struggles of those in developing countries in uniting in finding treatments and, indeed, cures, for those inherited bleeding disorders which are being dealt with daily. The widening rings after the pebble was dropped.

Now, look, personally, at the "pebble in the puddle" analogy.

Imagine you are the pebble. Look at your impact on those around you. How does what's happening to you affect those closest to you – your family and friends? How does what is happening to you influence your decisions about your future, or, their decisions about their futures?

Not long ago, for those with an inherited bleeding disorder, the idea of more than limited activity was looked on with skepticism. Read the article by Ryan Kleefman on page 14, where the bar is raised not by foolhardiness but by self- knowledge. He has not only learned his limits, but also, with his knowledge of his body, he can and does manage a more active lifestyle than could have ever been believed possible only a few short years ago.

If you are the pebble, you may not appreciate the impact of your strength and courage in facing your situation and advocating for others. Mary Pedersen's tribute article to John Hunter is a touching reminder that those with/ dealing with inherited bleeding disorders are not alone, and no longer advocate only for themselves.

Pebble in the Puddle Experiment – Part 2

Now, observe what happens when the rings reach the edge of the puddle. They make waves AND they reflect back into the puddle, creating rings which return to the centre.

That returning to the centre is fascinating for me.

We are, often, very aware of someone who is affected by a condition or behaviour, BUT, often, we are NOT aware of the community and the connections within that community that come together, focussing on the wellbeing of that individual. Think HO, HOY, SWOR, NOR, JTG weekends, Bleedhers, camps, clinics, doctors, nurses, friends, moms, dads, and you. I know I've left many out – you fill in your spot on the rings because you belong there. In the article by Michelle Lepera we realize the level of care, advocacy, and concern for her child, and her willingness to lead others in their search for help. The first ring from the pebble, closest to the impact, most affected.

So, as you think of the "pebble in the puddle", think of those things you did and the things others did to help you be who you are, where you are, today. Think of those who have given you guidance, and helped you to be who you are and have been an influential part of your planning for your future.

Lastly, in appreciating those who are the "pebbles" and those who are the "rings" in your life, ask yourself the following:

Who, besides you, made today a good day?

Who, besides you, tried to make your day better?

- Family
- Friends
- Doctors
- Those you served
- Those who served you
- Add your own here…

Did you thank them? Don't leave it. Do it.

Make their day by acknowledging their importance to you.

In this edition of *Blood Matters*, think of the "pebble in the puddle" as an analogy for life.

Read on …

Liam Barbour Charity Golf Classic

Thank You for Your Support!

The Liam Barbour Golf Tournament was initiated by Brad and Jen Barbour in August, 2006 to honour their son Liam who has a bleeding disorder as their way of making a difference. The intent of this fund is to help deliver better support and services to those who need it while raising awareness of living with an inherited bleeding disorder. Since its inception, this tournament has generated $83,000. Hemophilia Ontario is proud to be the primary recipient of the proceeds.

The proceeds from this tournament have supported CWOR regional and provincial programs, supported members in need, provided post-secondary scholarships and ensured the participation of youth with inherited bleeding disorders at YMCA Camp Wanakita. It also provided funds to the Hamilton Niagara Regional Hemophilia Centre to purchase educational materials and tools for use in the clinic. Their energy and enthusiasm to help others extends into many areas. Their genuine desire to help others has allowed us to make a difference in many ways.

Thank you to the Barbour Family for their continued efforts and to the golfers for their continued support and participation.

Brad Barbour presents Executive Director Terri-Lee Higgins with a cheque for the 2014 proceeds

Hemophilia Ontario's 59th Annual General Meeting – Volunteer Awards and Years of Service Recognition

The Ivey Spencer Conference Centre in London, Ontario hosted the 59th Hemophilia Ontario Annual General Meeting. We gathered to learn, network, govern and recognize our outstanding volunteers and long-time Hemophilia Treatment Centre (HTC) staff partners.

Keynote speaker Dr. Michelle Scholzberg, presented on the challenges women with inherited bleeding disorders face particularly around iron deficiency. Her comprehensive presentation reinforced the importance of self-care and why we continue to raise awareness of CODErouge in the community at large. This was followed by a member panel speaking about their experiences of community and care in the 21st century. Paul, Mike, Zach, Amy, Josh and Matthew generated conversations that lasted well after the meeting. Thank you all for your contributions to a very engaging day.

As part of the Annual General Meeting, we recognized the following individuals for their outstanding contributions to the Hemophilia Ontario and inherited bleeding disorders community:

President's Award

Monica Mamut

Ann Harrington Award

Nursing – Dianne Bissionette
Physiotherapy – Karen Strike

James Kreppner Distinguished Leadership Award

Paul Wilton

Shawn Duford Grassroots Leadership Award

Ash Kurichh
Nick Higgins

Youth Leaders of Tomorrow

Emily McCormack
Johnny Lepera
Kody Portelli

15 years Staffing

Susan Turner
Colin Patterson

Staff Leadership Award

Terri-Lee Higgins

HTC Staff Years of Service – we are pleased to recognize the following members of our Hemophilia Treatment Centres for their ongoing commitment with our community:

1 year	Lori Hygaard
5 years	Lisa Thibeault
10 years	Dr. James; Dr. Laferriere; Karen Strike; Simon Bougi
20 years	Cindy Milne-Wren; Brenda Elliott;
30 years	Dr. Rachel Schupak

Keynote Speaker – Dr. Michelle Scholzberg

An engaging panel discussion

Monica Mamut receiving her award

Paul Wilton receiving his award

Dr. James and Lisa Thibeault

Hemophilia Ontario
Hémophilie Ontario

Next year, Hemophilia Ontario will be celebrating 60 years of advocacy and support. We are beginning to develop what we hope will be an exciting program and look forward to seeing you at our AGM next April.

Pamela Wilton was recognized with an ***Honorary Lifetime Membership*** bestowed to a small but distinguished group of individuals who have been recognized for providing significant continuous and extraordinary service to Hemophilia Ontario. Pam's ongoing commitment to the IBD community is well documented and recognized. She became involved in projects that embody all the objectives for which this award was created, working towards better treatment for all and improved educational and support services for people in the bleeding disorder community. We have accomplished much and achieved much more as a result of Pam's involvement.


Pam with her family
from left – husband Brock, daughter Brooke and son Paul

Surprised and Speechless

Pamela Wilton, RN
Volunteer, SWOR

Lost for words is not something that happens to me often, but it happened (sort of) on Saturday April 18 in front of my family, many of my best friends and several new acquaintances. Three months have passed and I am still embarrassed by my lack of meaningful communication.

This is how it happened. "Pam, can you join a panel, at the AGM, and talk about what volunteering means to you?" Of course I could do that – happy to help. My angst increased when I saw that there were three excellent speakers ahead of me. They would talk about all the positive things related to volunteering and share hilarious anecdotes about their experiences. What could I say that would be different? I dug deeper, to honestly reflect on my many (almost 30 years) of volunteering with Hemophilia Ontario.

It turned out that there was a big surprise for me. I was asked to participate on the panel just so that I would attend the event. (As if I would ever miss a Hemophilia Ontario AGM in my home town!) There was a panel, but I was never supposed to be on it. The problem was that I never clued into that.

Soon after lunch, one of my heroes, Jennifer Crump (who was the Nurse Coordinator of the SWOR Hemophilia Comprehensive Care Program, when our son was diagnosed in 1985), began to tell us about a mom and what happened immediately, when Jennifer delivered the news that her baby had severe hemophilia, and how that mom eventually responded to the news. I totally related. My own experience was just like that. Jennifer was saying my name. It was my story. Then Jeff Beck said crazy, exaggerated things about my volunteer role. He was handing me a plaque and shaking my hand. Suddenly, I became an Honorary Life Member of Hemophilia Ontario!

That's when it happened. I was babbling on. I could hear myself talking but saying nothing. Those present must have thought I was lost for words, but I wasn't. I had the words, but I was still saving them for the panel. I am clueless! The following is what I wanted to tell you.

My volunteer work with Hemophilia Ontario has been some of the hardest work that I have ever done. Our community was trying to make it through a dreadful, cruel time, when I started. The Board of Directors had to make impossible decisions. We did not always agree on priorities. We did not always agree on strategies. We sometimes hurt each other without ever meaning to, but out of passion and/or fear. I was pushed to do things over and over again that I was not certain I had the ability to do (like present our case for recombinant factor to the Deputy Ministers of Health in Ottawa). When I was advocating for the integrity of the SWOR clinic through a hospital transfer, I got a call from my own boss, telling me to back off. I was criticized by another volunteer for being a woman, not a hemophiliac and told I therefore had no right to an opinion about a policy. I was warned, minutes before going into a meeting with government officials, that if I "blew it", I alone would be responsible for a negative outcome. Did I quit? I often wanted to.

Then there was all the good stuff. There was so much good stuff that it sustained me and kept me moving forward.

Volunteering for Hemophilia Ontario changed me. It made me a critical thinker. It showed me what perseverance and hard, hard work can accomplish. It made me expect more from myself and from the others around me. It highlighted the importance of community. It challenged me to do things I was afraid of. It shifted my values. It prepared me for national and international volunteer opportunities. It filled up my life with interesting people, experiences, stories, sadness, joy and some of the most loyal and caring best friends any person could have.

Jeff alluded to something important. You all know the names of the heroes who led us through the tainted blood tragedy, but you probably do not know the names of the volunteers who picked up the everyday-living-with hemophilia-and-keeping-an-organization-running work that had to be done. I do know those people. I am grateful to each of those volunteers and to the staff who allowed me to work with them, doing something to give back to a community that helped my family so much. I was truly surprised by this award. I am deeply moved and honoured to be an Honorary Life Member of Hemophilia Ontario.

Thank you

59th Annual General Meeting

Our members accepted the first revision to our By-laws allowing for a down- sizing of the Board of Directors to 9 with a 10th 'emergency' person.

The new Ontario Board has 1 representative from each region as well as Directors at Large.

The 2015-2016 Board of Directors was elected as follows:

President
Paul Wilton

Vice Presidents
Amy Griffith
Maia Meier

Vice President Finance
Phyllis Gray

Secretary
Zachary Adams

Past President
Julia Sek

CHS Delegate
Maia Meier

Nominating Committee Chair
Rob Dinsdale

Directors at Large
Shelley Hewett
Ashwani Kurichh
Monica Mamut

Thank you to everyone who attended the AGM, our pharmaceutical sponsors and our volunteers. 🩸

POSTERS INTRODUCED AT THE 59th ANNUAL GENERAL MEETING

W2- Wellness for Women

The Only Women's Conference on Inherited Bleeding Disorders in Ontario

Created for women, by women

Open to women ages 12 and up affected by inherited bleeding disorders, including carriers, caregivers, partners, and women living with inherited bleeding disorders

This Ontario based event changes location per event. The 2015 event will be taking place at McMaster University in Hamilton

W2 started in 2009 and occurs every other year. 2015 is the fourth year

W2 allows women affected by inherited bleeding disorders to come together for an interactive weekend. Dynamic speakers lead informative workshops and individual breakout sessions, which are designed to fit the needs of women throughout various stages of their life. During this weekend attendees are encouraged to share experiences, and engage and network with other women.

HEMOPHILIA ONTARIO

COMMUNITY CAMP

Community Camp is a biennial program held by Hemophilia Ontario. It is a 2 night, 2 day residential camp opportunity for individuals living with an inherited bleeding disorder and their families. It offers a chance to experience camp and participate in educational sessions such as "The Power of Exercise" and "How to Prepare for an Unexpected Trip to the ER".

Some Statistics:

Community Camp started in 2009

Community Camp has always been held at YMCA Camp Wanakita

Community Camp's member participation has increased 24% since 2009

Regional Breakdown

Central West Ontario Region	23%
Ottawa & Eastern Ontario Region	18%
Northern Ontario Regions	19%
South Western Ontario Region	2%
Toronto & Central Ontario Region	27%

Camp Wanakita Update

YMCA Camp Wanakita 2015 will be taking place during August and this year we are sending over 55 campers to spend 1-4 weeks in Haliburton to participate in activities such as kayaking, swimming, and canoeing, with hematology nurses from around the province on site to help campers learn how to self-infuse. ♦

Just the Guys 2015

Kamp Kragle where the ordinary is extraordinary.

Join Hemophilia Ontario for Kamp Kragle where everything can be awesome! Our Lego theme this year will be your chance to experience the ordinary being extraordinary as the 2015 Just the Guys Weekend.

Attention CWOR, OEOR, SWOR & TCOR members! Please save the date of September 18 - 20, 2015 for our Just the Guys Weekend at Camp Ki-Wa-Y, St. Clemens, Ontario.

If you are between the ages of 4 and 17, enjoy being in the outdoors with your Dad, Grandpa, Uncle, or other male role model and have an inherited bleeding disorder then the Just the Guys weekend is for YOU!

The Just the Guys program is a weekend residential camp for boys ages 4-17 who are affected by an inherited bleeding disorder and their accompanying father/male role model ages 19 and above. The weekend provides a unique opportunity for participants to gain a better understanding of the diagnosis, and connect with other families through a series of education sessions, activities, and group events.

At Just the Guys there are insulated cabins with bunk beds, washrooms with showers, a fridge for your medication, and a fully staffed dining hall that serves hot meals. The weekend is all about fun in a camp setting, where you can spend time swimming or canoeing on the lake, jump on the water trampoline, participating in activities, enjoy games, challenges, campfires, and much, much more! There are lots of things to do, lots of things to learn, and lots of new friends to meet!

The generous support of Bayer Pharmaceutical makes this weekend possible.

Join us this year for this AWESOME program in Ontario!

We hope to see you there. ♦

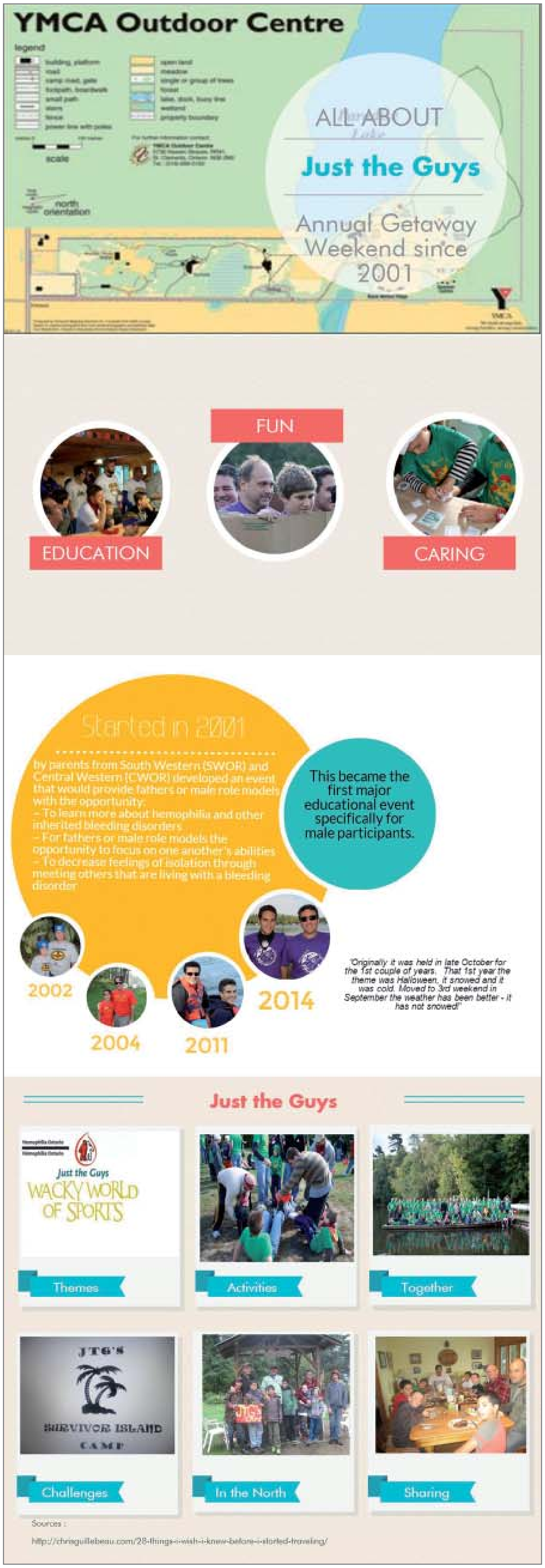
You can register online before August 17 **www.justtheguys.ca**
Or contact your Regional Service Coordinator for a registration form.

For any further information, please contact: Matthew Maynard at 519-432-2365 or mmaynard@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



by parents from South Western (SWOR) and Central Western (CWOR) developed an event that would provide fathers or main role models with the opportunity:
- To learn more about hemophilia and other inherited bleeding disorders
- For fathers or male role models the opportunity to focus on one another's abilities
- To decrease feelings of isolation through meeting others that are living with a bleeding disorder

This became the first major educational event specifically for male participants.

"Originally it was held in late October for the 1st couple of years. That 1st year the theme was Halloween, it snowed and it was cold. Moved to 3rd weekend in September the weather has been better - it has not snowed!"

Sources :
http://chrisguillebeau.com/28-things-i-wish-i-knew-before-i-started-traveling/

Wellness for Women: W2

by Laura Tompkins

The Wellness for Women, or W2, Conference was held May 23-24 at McMaster University in Hamilton. Over 40 women got together to participate in fun activities including outdoor yoga, nature walks, and a campfire, and to hear amazing speakers from across the province, including hematologist Dr. Michelle Sholzberg, motivational speaker Paula Morand, and child specialist Nate Seroski. Feedback from the participants included that they were empowering, engaging, enjoyable, and inspirational.

Attendees were able to attend breakout sessions of their choosing, which included talks on aging with a bleeding disorder, effective estate strategies, and the TCOR *Women in Touch* program. Feedback from the breakout sessions included that they were comfortable, informative, educational, and helpful.

Something new that was implemented this year was lowering the age requirements for participants from 16 to 12 years of age, to put more of a focus on youth and their needs during the weekend. This youth focus included youth-oriented breakout sessions. Feedback from these sessions included that is was "well informed" a "great discussion!!", and "awesome!! Best breakout session."

Additional feedback from the weekend included that it was "very positive… informative and empowering" and "an excellent 2 days of valuable information to take away." The strategies and tools women gained from this weekend that they can apply to daily life included "relaxation, communication, and self-understanding", knowing "that I am not alone… keep doing what I am doing". The women walked away with practical skills such as learning "the effects iron has on women and their bleeding disorders, how to cope with stress and be resilient, knowing when to let your stress out and say I'm not okay", and "how to explain bleeding disorders to different age groups, as well as allowing the person to be frustrated/mad about their bleeding disorder." ♦

Financial Assistance Policy

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

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

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

Each year, Hemophilia Ontario allocates a set amount of money for this fund and once these funds are exhausted, no further claims will be processed that year. Requests submitted by December 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.

HOY Heads to a Jay's Game!

by Laura Tomkins

Hemophilia Ontario Youth (HOY) had this first event of 2015 on Saturday May 9th. 15 youth, 1 volunteer, and 1 staff member came together to talk about and share bleeding disorders stories at the Hemophilia Ontario head office, followed by lunch. We then went down to the Rogers Centre to watch the Toronto Blue Jays play. HOY, previously exclusively open to those aged 18-26, was opened up to those aged 13-26 living with an inherited bleeding disorder, or those very involved as volunteers with Hemophilia Ontario, with each attendee able to bring one sibling or friend. This age range modification was a successful endeavor with 10 of the attendees under 18 years old.

If you have any ideas for or want to be involved in future HOY events, make sure to contact Laura Tomkins at ltomkins@hemophilia.on.ca.

A Great Day at the Ballpark!

by Michael Bosompra

The recent Hemophilia Ontario Youth (HOY) event could not have happened on a more perfect day; the sun was beaming, birds were chirping and smiles could be seen for miles! Our afternoon of adventure started at the office where 18 of the most incredible people in the GTA and Ottawa region met for lunch. We had a diversity of people, male and female ranging from 13 to 28 years old which made for very interesting (if not unpredictable) conversation. We talked about everything! We talked about the sports we participated in - fencing took the prize for most surprising. We shared stories about our experiences at various clinics and what it's like to transition to the adult clinic. We even talked about the *Fast And Furious* movie series and how surprised we were by the ending.

The afternoon truly was a time to form new friendships and strengthen old ones. We made our way down to the SkyDome (and yes, I called it the SkyDome!) after eating enough Greek food for two Big Fat Greek Weddings☺. The Jays were playing the Red Sox and we arrived at the bottom of the first inning. For the next 8 innings the Blue Jays put on quite the show smashing the Red Sox 6 to 1 or maybe it was 7 to 1… I lost count after a while!

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

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

Pennywise, Pound Foolish

The National Clinic Assessment – May 28, 2015

In 2013 - 2014, the Canadian Hemophilia Society (CHS) conducted an assessment of the human and physical resources in the network of 25 Inherited Bleeding Disorder Comprehensive Care Centres (IBDCCCs) across Canada. The staff, in these Centres, care for the vast majority of Canadians with inherited bleeding disorders. Our goal was to evaluate their capacity to respect current national Standards of Care. Individual reports were provided to each Program's Centre Director.

A national report was presented on May 28, 2015, at Rendezvous 2015, in Halifax. You can read the report online at: **http://www.hemophilia.ca/files/Penny%20wise%20pound%20foolish.pdf**

Tips for Travelers from the World Federation of Hemophilia

Summer is a season of travelling and adventures! Check out these tips from the WFH on how to travel safely with an inherited bleeding disorder.

TIPS FOR TRAVELERS

ALWAYS WEAR YOUR MEDICAL ID

BRING YOUR OWN TREATMENT

AVOID A SHORTAGE OF PRODUCT

Products abroad could be different from what you are used to and potentially very expensive.

HAVE A LETTER FROM YOUR DOCTOR

Explaining to security why you are carrying treatment products. Include the serious implications of not having them immediately to hand.

HAVE A LETTER IN THE LOCAL LANGUAGE

Outlining your condition and the treatment you need.

GET YOUR MEDICAL INSURANCE IN ADVANCE

Be able to deal with any issues that might come from having an existing medical condition.

FIND LOCAL TREATMENT CENTRES OR NATIONAL HEMOPHILIA ORGANIZATIONS

DO YOUR RESEARCH!

KEEP THEIR CONTACT INFORMATION AT HAND

See the WFH website for our worldwide Treatment Centre directory.

CONTACT THEM IN ADVANCE

Learn about the availability and cost of treatment products.

TRAVEL WITH FRIENDS!

Ease any stress that arises from travelling somewhere new and have someone nearby in case something goes wrong.

WORLD HEMOPHILIA DAY / APRIL 17

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

HCV Treatment Support

for 1986-1990 Claimants

As seen on the Canadian Hemophilia Society website, “recently, new HCV therapies have been approved by Health Canada that shorten the duration of treatment, achieve a cure rate of more than 90%, minimize side effects compared to past treatments, and are interferon free.”

While these medications may be costly, many of the companies that make and sell these medications have developed programs which “offer assistance by providing drugs upfront to the 86-90 claimants through their specialty pharmacy. Once the 86-90 plan issues the reimbursement cheques to the patients for their treatment, they, in turn, must reimburse the pharmacy directly.”

In addition, these programs “are designed to provide a wide range of customized services including reimbursement assistance, education and ongoing disease management support.”

“Whether or not you are a claimant, the CHS advises you to speak to your specialist about the current evolution in hepatitis C therapy.”

For more information, please visit **www.hemophilia.ca/en/hcv-hiv/hcv-treatment-support-for-1986-1990-claimants**

Transgender Healthcare in Southwestern Ontario

Transgender healthcare services in Guelph and the surrounding area are now available at ARCH (HIV/AIDS Resources and Community Health). Focusing on a “safe, non-stigmatizing atmosphere,” preventative and general healthcare for “temporary and chronic health issues for Transgender individuals” will be available, along with supervised hormonal therapy treatments.

For more information please visit **http://archguelph.ca/transgender-health-care** ; call 519-780-5298; or email at coordinator@archguelph.ca

Bleeding Disorders News

Staying in Touch

by Zach Adams

Staying in touch with your body and health often involves maintaining your awareness for relevant health and safety issues. For example, the tainted blood tragedy that started in the 1980’s is an event that is often discussed by those with an inherited bleeding disorder or those who care for an individual with an inherited bleeding disorder. Several decades ago, thousands of Canadians relying on blood products, including those with hemophilia, received tainted blood and were unknowingly infected with Hepatitis C and HIV. Although changes to the way factor products are manufactured and improvements in oversight have improved safety considerably, this tragedy should continue to guide us and remind us of the continued role we must play in holding individuals and organizations accountable for a safe and secure blood supply.

Earlier this month, *The Agenda* on TVO featured an episode titled “Bad Blood” in which four individuals, either directly affected or knowledgeable on the topic, took part in a roundtable discussion. Antonia “Smudge” Swann, who lost her husband, James Kreppner, to tainted blood, was one of those individuals. During the discussion, she described an occasion where an individual had mispronounced the name Krever. Now, for many in the bleeding disorders community and beyond, the name Krever is usually well known and frequently mentioned in a variety of conversations. Following the tainted blood tragedy, Justice Horace Krever was tasked with leading a formal inquiry into every aspect of the event. In my opinion, I believe it is vital to the inherited bleeding disorders community that people are familiar with the history and significance of this inquiry, which is now used as a guideline by blood collection organizations worldwide.

To provide a basic understanding, I would like to provide a brief outline of just one of the fifty recommendations put forward by Justice Krever. Overall, this one recommendation outlines how the Canadian blood supply system should be governed by five basic principles. First, blood is a public resource and a national operator should function as a trustee who will utilize it for the benefit of all Canadians, without regard for profit. Second, blood and plasma should be collected solely from unpaid donors, based on the idea that those donating altruistically will choose not to if there is potential to do harm. Third, Canada should strive to be self-sufficient, focusing on collecting the necessary donations of whole blood, plasma and platelets through domestic collection. Fourth, all Canadians should have free, universal access to blood components and blood products both inside and outside of a hospital setting. Lastly, the safety of Canada’s blood system should be of paramount concern.

I believe that staying in touch with our past can afford us the strength and knowledge to demand the highest standard of vigilance and accountability during any future decisions concerning our blood supply system.

Information in this article was obtained from the “Commission of Inquiry on the Blood System in Canada”

The full report can be found at the following link: **http://publications.gc.ca/site/eng/9.698032/publication.html**

Keeping in Touch

by Ryan Kleefman

The phrase 'keeping in touch' means so much more than just staying connected to friends or family. Especially for those affected by hemophilia or other inherited bleeding disorders, keeping in touch is a very important part of staying healthy and informed. Three major topics come to mind: keeping in touch with your body, your treatment, and your healthcare team.

In order to ensure a healthy and active life, it is important to keep in touch with your body. Listening to what it tells you is important to avoid injuries and, if injuries do happen, regaining health and preventing further damage. When I go out and exercise (biking and baseball being two favourite past times), I pay attention to what my body is telling me. After throwing the ball for a while, my arm will get tired. If it gets to the point of being sore, it's time to pack things up and call it a day. By paying attention to the signals my body sends to my brain, I can tell when my joints and muscles are getting tired and are likely to become more susceptible to injury.

Working hard and playing hard are just fine, but I work and play smart as well. After being on my feet all day, I pay close attention to my ankles, because what they tell me decides if I need to rest or if a joint requires more care. This leads me to my second aspect of staying connected: treatment.

Keeping in touch with treatment has application to both future and present care. Many companies are currently developing long-acting factor and there is research into gene therapy as well. Staying informed about the development of novel therapies is part of keeping in touch with treatment. Having discussions with the professionals at your hemophilia treatment centre will help to answer any questions you have about what kinds of new treatments may be available. Doing your own research about what companies are doing, can also help you stay connected with the many opportunities that are arising for safer, more effective, and more efficient bleeding disorder therapies. Many companies (Baxter, Bayer, Pfizer, Novo Nordisk, Octapharma, Biogen Idec and too many more for me to remember) are directing funds toward research, development, and ongoing improvement of current and future treatment options.

Hemophilia treatment is a daily task, even if you don't need an injection that day. For hemophilia and other inherited bleeding disorders, knowing when to treat and how much to treat are vitally important to avoiding injury and promoting healing of bleeds which do occur. Different people have various treatment schedules. Some treat prophylactically several times a week, while others only treat if an injury actually occurs. Whether you are mild, moderate, or severe, it is important to keep in touch with your treatment. Paying attention to when the last injection was and what your body needs are key to avoiding bleeds. If I know I am going to have a very busy day or I have to do something more physically demanding than usual (an extra long hike, for example), I plan my treatment so that my factor levels are as high as possible right before and during the activity. By keeping in touch with your treatment (knowing when to treat and how much you need), you can help to keep your joints and muscles as strong and healthy as possible. Of course, future and current treatments always require advice and guidance from the third aspect we want to keep in touch with.

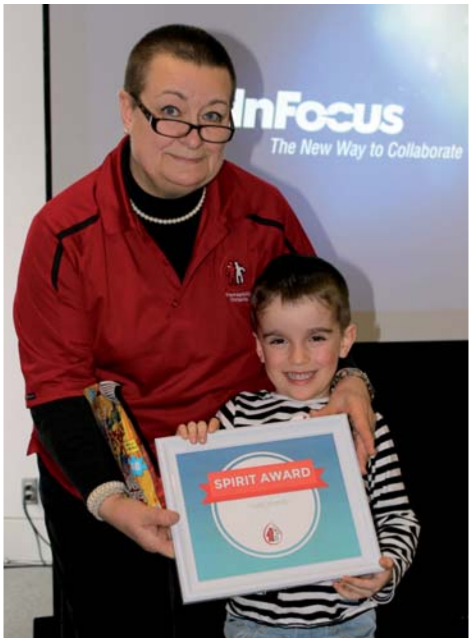
Keeping in touch with your HTC and healthcare professionals is vitally important. It is important that they are kept up-to-date on what is happening with your inherited bleeding disorders treatment. One of the ways this is done is with infusion diaries. While we may not always want to fill out our infusion logs, they are necessary to providing us with the care we need. By tracking our past infusions and, more importantly our past injuries, we keep a record of how well our treatment is working and whether or not certain joints/muscles may need extra care. Filling out prophylaxis diaries and infusion logs gives our bleeding disorder team all the information they need to asses our care and talk about any concerns there may be.

Keeping in touch with our bodies, treatment, and healthcare teams ensures that our needs are being met and concerns are being dealt with. Listening to signals from joints and muscles, staying connected with treatment, and keeping healthcare teams updated are all important aspects of keeping in touch and will help promote an active, healthy, and informed lifestyle.

Stay Connected

Regional General Meeting

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



CWOR's RGM took place at the Hamilton Art Gallery on Saturday March 7th. We had two fantastic presentations sponsored generously by CSL Behring. The first was an interactive session on "Connecting Physical & Mental Health" by Heather Gardner, Physical Education Teacher and Ontario Health & Physical Education Curriculum Consultant with OPHEA Canada, and our second was on "Joint Health Scores & What They Mean" by Karen Strike, Physiotherapist at the Hamilton-Niagara Regional Hemophilia Clinic. The children enjoyed a special tour of the gallery as well as participating in an arts and crafts session.

In addition to the presentations, the region's general meeting took place and we'd like to welcome two new volunteers to our group, the two Michelles – Michelle Markowski and Michelle Mundt. We are so happy to have you join us!

We also celebrated the region's volunteers and clinic staff by holding an awards ceremony.

This year's award recipients are:

CWOR Honour Roll

Rebecca Goldsmith

Dane Pedersen

Volunteers of the Year

Debbie Bordi

Tyler McGillivray

Spirit Awards

Coen Mundt

Eli Mundt

Jesse Bauman

Eli Bauman

In Remembrance

John Hunter

by Mary Pedersen

In 1981, I met a man of character and cheeriness. It was a time when Bob and I were uncomfortable with how much we faced with seemingly little support. Meeting John Hunter, along with John and Janet Moser, gave us a confidence that people and their children were leading strong and full lives.

John Hunter, in spite of chairing the Central West Auxiliary (now CWOR), always said he was a worker not a leader. John – for many of us, you were the very best kind of leader. Bob and I often spoke of who you were with more admiration than the many things you did. You were the "go to" guy for flyers, fundraising, programs and contacts. You were also kind, generous and open hearted. You were slow to criticize, quick to praise, and always made us feel better in your presence. I hope in some small way we have been able to carry your legacy forward.

Through the years I was privileged that John stayed in touch, reading '*Blood Matters*' and visiting me at my workplace. Sadly we no longer enjoy John being with us in body as he passed on April 9, 2015 due to cancer. His wife Jane was a constant by his side. All his family members will miss this man of great character. There will be a memorial service to remember John sometime this summer. I know that I will spend that time with many others thanking John Hunter for his gifts to all our lives.

John, though you may have known times of darkness, we know you will walk in the light. May peace and love be your resting place.

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

CWOR Upcoming Events

Annual Summer BBQ

- Saturday, August 29th at Bronte Creek Park

Supercrawl BBQ Fundraiser

- September 12th & 13th

CWOR

Regional Council and Staff

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

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North Western Ontario Region

Laura Tomkins
Regional Service Coordinator

Spring Clinic

NWOR RSC Laura Tomkins attended the Thunder Bay Clinic on April 20-21, 2015 where she enjoyed getting to meet and speak to patients as well as signing them up to become Hemophilia Ontario members!

Laura is looking forward to seeing everyone again at the Fall Clinic – date to be announced!

NWOR

Regional Council and Staff

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Joanne Beaulieu
Julia Fortunato
Tim Hewett
Shawn Morrison

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Downtown Sudbury Sidewalk Sale

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

Rain or shine… well, unfortunately, the rain came but the volunteers still showed up to help at the Downtown Sudbury Sidewalk Sale. Books were generously donated by Berri Books and die hard buyers showed up when the rain 'finally' took a small hiatus. All things considered, the fundraiser was a success raising funds for the NEOR region and educating the public about inherited bleeding disorders.

We're sending a big thank you to Paula Newman, Shawn, Jacob, Evan, and Carly Morrison for helping out. Thank you to Michael from Berri Books who donated a beautiful selection of books for us to sell.

Camp Wanakita

Kids from the north are looking forward to Camp Wanakita! This year four boys will get to take part in the fun and excitement of camping in the Haliburton area and we can't wait to hear the wonderful stories!

Spring Clinic

Spring Clinic was held on May 2, 2015 and members were treated to snack and a lunch from Subway. Thank you to the pharma reps for their continued support and generosity in covering the costs of the snacks and lunch.

Fall Clinic

Fall Clinic will be taking place on Saturday, October 24. A gala dinner is being planned to celebrate 35 years of the clinic serving the bleeding disorders community. Stay tuned for more updates on this event!

NEOR

Regional Council and Staff

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Julia Fortunato
Tim Hewett
Shawn Morrison

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Queen's Hemophilia Society

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

This past May Terri-Lee Higgins, Executive Director, and Stephen Perry, OEOR Council Member met with a group of students from Queen's University to begin working towards the creation of a university hemophilia society. The hope is that OEOR's partnership with QHS will bring more awareness and programs to the Kingston area for those living with inherited bleeding disorders. QHS and OEOR hope to work with the Kingston General Hospital Treatment team on campus educational opportunities and awareness programs.

OEOR Regional General Meeting

OEOR's Regional General Meeting took place at the Canterbury Recreation Complex in Ottawa on Sunday March 8, 2015. It was a very well attended event with new and old faces alike, with some members travelling all the way from Brighton, Ontario! The region held its first ever a CODErouge presentation done by Ambassador Amy Griffith which highlighted important information on women with inherited bleeding disorders.

This event also included a special retirement celebration for Diane Bissonnette, Hemophilia Nurse Coordinator. Many people, including several mothers, youth that have since transitioned from her care, current patients, and others shared their heartfelt wishes with Didi as she embarks on this new chapter of her life. Additionally, the OEOR Council presented Didi with a plaque for her tremendous efforts and dedication to the inherited bleeding disorders community. While her role as nurse coordinator has ended, she will continue to provide insight through her volunteering as an OEOR Council Member.

Special thanks to Ash, Darlene, and Nancy for helping prepare the day's events and arranging the delicious lunch.

Many thanks to the volunteers who assisted in making this day a great success, and a warm welcome to all new and returning council volunteers!

OEOR

Regional Council and Staff

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

CONTACT
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Scrapilicious Carnival Style

All SWOR articles, unless otherwise noted, are by Matthew Maynard

It was a wonderful day on March 28th! Thank you to ALL who came, donated, and encouraged at this year's Scrapilicious. This event keeps growing each year as the word of mouth spreads. It becomes a more creative, more fun, and a more productive scrapbooking retreat for a day. Hannah and Julia not only volunteered but shared a craft and stories about Pinecrest Adventure Camp. Including the cake walk, garage sale and raffle. This was a great day!

Special thanks to our organizers Kathleen, Marion, Heather, volunteers Julia and Hannah and our setup help from Ruby and the cleanup help from Eric and the Wiltons.

World Hemophilia Day Polar Bear Dip

Where can you see the three little pigs, birds, a gorilla, and polar bears all at once? Well - a zoo of course or the SWOR Polar Bear Dip! This fundraising event took place in Port Stanley on April 12th where the theme was "Animals". Mother Nature was kind to these brave dippers and gave them decent weather, even with a few small icebergs moved out of the way and the waters still icy cold! Thanks so much to everyone who took the plunge at the 2015 SWOR Polar Bear Dip. You raised over $7000.00 that will directly support programs and services in the region.

There were some great costumes and everyone got some fantastic sponsorship. The winner of most sponsorship was Hannah Higgins of London and a special shout out for Adam and the convoy from the Windsor area. The winners of the animal costumes were the three little pigs with props of straw, bricks and twigs.

Join us next year if you dare – our costume theme next year is Food!

Upcoming Events

SWOR Summer 2015

July 28

World Hepatitis Day – Join us in London to learn more about testing, treatment and enjoy the BBQ with us and Regional HIV/AIDS Connection

August 25 – 30

Pinecrest Adventures Camp – Camp Menesetung, Goderich, Ontario. This five day residential camping experience for children with a bleeding disorder and their siblings aged 5-15 years, offers knowledgeable and specially trained volunteer staff (medical and counselors) on site 24 hours per day. August 25th will be a staff training and preparation day on site

September 26

8th Annual Golf Tournament for Hemophilia and Inherited Bleeding Disorders – Ingersoll Golf Club, Ingersoll, Ontario

SWOR

Regional Council and Staff

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

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Recent Events

TCOR Spring 2015

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

In lead up to World Hemophilia Day, April 17, TCOR had display boards at both SickKids and St. Michael's hospitals. These popular displays allowed TCOR to spread the word about bleeding disorders to over 150 people.

TCOR's Regional General Meeting took place on Sunday March 1st at the North York Central Library. TCOR members came out to socialize, discuss Hemophilia Ontario and Toronto related topics and issues, and to hear a discussion on financial planning from Kat Downey. Thank you to all who came out. 🩸

Upcoming Events

TCOR Fall 2015

Comedy Night Fundraiser

This summer our popular event will be taking place once again! This event sold out last year, so make sure to keep an eye out for a date and how to purchase tickets!

TCOR's 16th Annual Golf Tournament - September 11

For Hemophilia and Inherited Bleeding Disorders The event will once again take place at the beautiful Nobleton Lakes Golf Club in Nobleton, just north of Toronto. For more details or to register please contact Susan Turner at sturner@hemophilia.on.ca or 416-972-0641 ext. 21.

Annual Commemorative Event – November 8

This event is held to remember those affected by the tainted blood tragedy.

Winter Families in Touch Event – November 29

One of the most popular events of the year, stay tuned to hear where this free event will be taking place!

Other events to look forward to in TCOR this Fall:

- Aging with a Bleeding Disorder event
- Men's Event
- Women in Touch Support Program
- Volunteer Appreciation Event

Make sure to read the next issue of *Blood Matters* for pictures and a summary of the following events:

- The Families in Touch summer event and walk fundraiser which took place on Sunday June 14th at the Toronto Zoo!
- The TCOR Council social get together at a Toronto Blue Jays game on Thursday June 18.
- The Toronto AIDS Candlelight Vigil, which Hemophilia Ontario participated in and took place on June 23.

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

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CODErouge
WHEN WOMEN BLEED TOO MUCH

Staying In Touch

by Michelle Lepera

As a parent of a son with an inherited bleeding disorder I have a perspective to give when it comes to caring for our children and staying in touch. Let me speak for a lot of us.

When our child with a bleeding disorder has to go for their annual and semi – annual assessments at our local treatments centers, we, of course, accompany them. We prepare them at home as they grow. They know they are going to be poked, but we are there to comfort them. We are their security. We make the appointments; we call the school, drive them, and take time off work. We want to see how they are progressing and discuss any issues with the medical team. We walk in as a family, and are greeted by the nurse co-ordinator, who oversees the whole appointment and we ask her questions. The doctor comes in and we ask more questions. We continue the day by having good discussions with the social worker and, maybe, the child life specialist if needed. We can't forget the ever so important physiotherapist who comes in and measures their arms and leg joints and we talk about what sports or activities they are engaging in and again good discussion on their physical well - being.

Year after year, we continue this tradition. Some appointments are better than others. Some years are better than others and somehow we always make it through. Thanks to our wonderful bleeding disorders team! Then, one year, the team start to prepare you for what is coming. Your child is getting older and pretty soon they will transition to the adult clinic where (it seems like) you will have no part in their care.

This is the most crucial time to stay in touch with our child. They are now teenagers. It will, frankly, be more difficult to communicate with them, especially when their heads are always stuck in social media! Now is the time to instill in our children how important it is to stay in touch with the bleeding disorder community. Let them start making the phone calls to order product. Give them more responsibility and explain the importance of self-advocating for their care. When they go to their annual appointments give them reminders on what questions they should be asking the medical team. Encourage them to start volunteering at member events and give back to a community that has given them so much. Make them a continuance of you. You will no longer be able to go in and ask questions, but you can guide them in the right direction so they can continue staying in touch with their own bleeding disorder care. 💧

More is More

by Amy Griffith

When it comes to VWD, I've learned to adopt the philosophy "more is more". More education, more exposure, more risk, more opportunity, more questions – the list, literally, goes on. In fostering this mantra in my life, I am constantly readjusting and adapting my lifestyle and expectations of myself, based on my experiences. I push my limits, just to see what I can accomplish. Truthfully, sometimes I push too far. But that begs that question:

How far can you go?

In my experience, there is nothing more valuable than being in touch with yourself. Balancing what you want to do versus what is beneficial for your health. As a woman with a bleeding disorder, asking questions and testing the limits is crucial. There is, yet, a benchmark to be set for the infamous "normal period" and it seems we will be forever seeking it, like the Holy Grail.

Proactive care is all about listening to your body, and going with your gut. For women, in particular, our needs are different and, often, less obvious;the silent threats being iron deficiency and anaemia caused by menorrhagia. There are serious life affects to women suffering from low iron stores due to excessive monthly bleeding (and I do not use the word "suffering" without intention), including:

- Inability to work or go to school during excessive bleeding
- Constant fatigue
- Loss of appetite
- Sensation of "pica" (the inexplicable urge to eat innutritious items, such as ice)

I, myself, have experienced all of the above, and the even sadder truth is that had I been more in touch with myself in my youth, I could have avoided them all. If I had stopped and asked myself "how am I feeling today?", the answer would have been, "pretty terrible". Then, that phone call from my hematologist with my bottomed out iron scores may not have been such a shock, and I wouldn't have had to hit the reset button on my life.

In closing, ladies do yourself a favour:

1. Listen to your body
2. Go with your gut 💧

Charting Your Way to Better Health

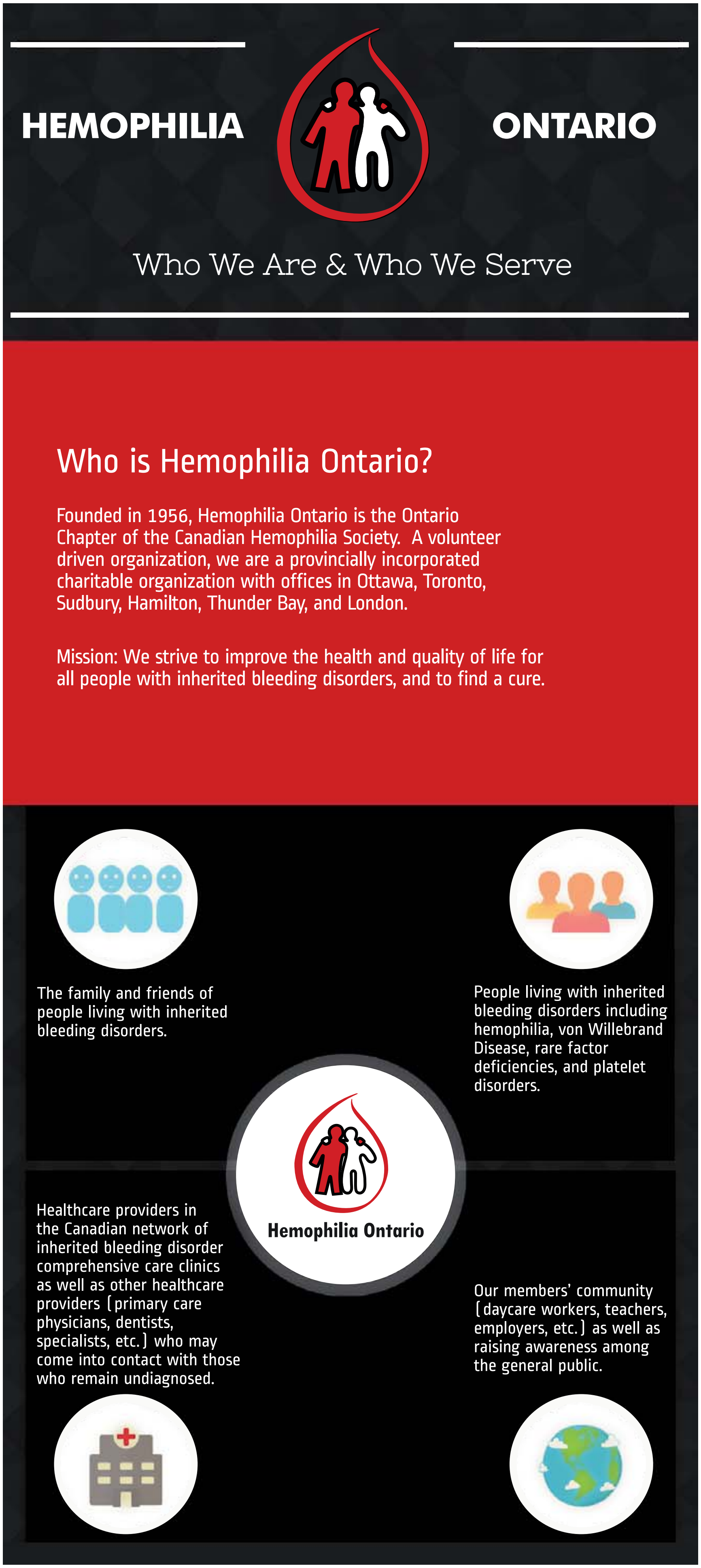
Up until 1970, patients with a bleeding disorder had to go to the hospital for transfusion of cryoprecipitate or plasma. When treated, the ER or when admitted the floor staff, recorded the transfusion information within the hospitals tracking systems and patients charts. With the evolution of home care, patients were given more responsibility for treating and storing product in the home as well as providing usage details around in-home infusions. Accurate tracking from manufacturer to patient became a new challenge. While the HTC places the order, not all hospitals track the product they disperse to patients and it is assumed by your pick up location, the HTC and Ministry of Health that you are tracking use – without your logs no one is tracking the product to its full accuracy. Good record keeping helps patients and health care providers:

- Chart the clinical course
- Prevent the development of a target joint
- Identify the development of an inhibitor
- Accurately monitor product usage and home inventory
- Find out about and report adverse reactions
- Address recalls

Not sure what you should be tracking? Ask your HTC team!

Infusion records allow you to remember your past years utilization, any injuries and on demand treatments. This will provide you and your HTC a yearly or semi-annual clinical health picture. Your records may be able to illustrate an under usage of product if you are having break through bleeding. If an over/under usage is illustrated, your HTC will tailor your treatment plan based on your pharmacokintics, annual bleeding rate, and your activities of daily living. With the introduction of the new Canadian Bleeding Disorders Registry (CBDR) and the individualized MyCBDR tracking is easier than ever. The new registry is rolling out across the country so if it's not available to you yet, it should be in the near future.

We encourage you to take advantage of this opportunity as you track your way to maintained or maybe even better health. 💧



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.

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

✉ 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

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