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Hemophilia Ontario
Hémophilie Ontario

FALL 2014
VOLUME 5 • NUMBER 3

BLOOD matters

Help Stop the Bleeding

PM # 42837517

President's Message

by Julia Sek

Hello and welcome to our Fall edition. Once again, our summer passed quickly and we begin a new season. What a terrific summer it was! We had two very successful and fun camps, Wanakita and Pinecrest.

Thank you to the many staff and volunteers that helped to provide a safe and memorable experience for all our campers!

We will have experienced our Community Camp at Wanakita by the time you have this edition in your hands (or on your screen). This will have been our third community camp, a wonderful time to connect with old friends, make new friends and get to experience camp life as our children and youth do in the summer.

This edition of ***Blood Matters*** focuses on research. This brings to mind the Ontario Hemophilia Association mission statement. "Our mission is to strive to improve the health and quality of life for all people with inherited bleeding disorders, and to find a cure." Without research, we would not have the current excellent treatments and outcomes that we have.

Scientific research leads us to a greater understanding of the world as a whole, and much has been accomplished through and because of it. Some scientists approach research out of a sense of duty or maybe even a sense of spiritual need to further the knowledge of humanity, or simply to contribute by finding cures for various disease or at least ,improving outcomes for people and community.

Many of our clinics across the province (and country) participate in research. Ask your clinic about the latest research in Inherited Bleeding Disorders as we are among the highly respected researchers in this field!

In this season of Thanksgiving, I would like to express my GRATITUDE to all our Clinic staff, Hemophilia Ontario staff and volunteers; for all that you contribute to make our community better! ♦

Best regards,

Julia

Cover photo: Lisa Thibeault, Hemophilia Nurse helps Robbie C with his infusion

BLOOD matters
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Executive Director's Message

by Terri-Lee Higgins

How prevalent is the Canadian voice in research when it comes to inherited bleeding disorders? You may, or may not, be surprised to learn that Ontario and Canada are leaders. With approximately 4200 Canadians known to have an inherited bleeding disorder (Canadian Hemophilia Registry /Canadian Rare Inherited Bleeding Disorders Registry) research is a very important component of future care.

On their website, the Canadian Hemophilia Society says "CHS has a dream — a cure for hemophilia and other inherited bleeding disorders. That dream is not a fantasy. It may become reality within the next decade if we can hasten the pace of research. Gene therapy research is being conducted in Canada and elsewhere in the world. Trials with humans are already underway. The goal is to discover a way to help the body produce its own supply of clotting factor proteins. Research in other areas may lead to advances before a cure. Scientists are looking for ways to prevent children from developing inhibitors to clotting factors, a very serious complication. Others are hoping to find a technique to make clotting factor proteins last longer in the bloodstream, thereby reducing the 3-times-a-week infusions that make care so difficult. It is never easy to predict when the research breakthrough will occur. But we sense that it is close. And the CHS will not rest until that breakthrough comes… and a cure is found… making our dream a reality."

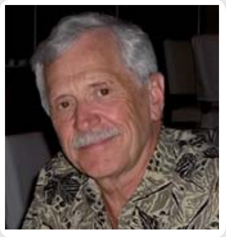
Throughout the year both the CHS and Hemophilia Ontario share opportunities with our members to have a voice in research by participating in interview based or survey based studies and the Hemophilia Treatment Centres engaged patients to become involved in clinical trials of medications. We, also, partner with different companies to assist with market research opportunities to provide feedback for future enhancements such as what individuals really want in app based technology.

The CHS directly supports research through Hemophilia Research Million Dollar Club (HRMDC). Ken Poyser led the creation of this endowment in 1984 with a goal of $1,000,000. In 2000, Frank Bott led a campaign to increase the capital to $1,600,000 which was achieved in 4 years. Today, the CHS is working to increase the capital to $2,500,000 by 2015. The capital of this endowment cannot be spent and this is why it is so important to continue to grow the endowment so that the earnings can be applied to research. The HRMDC, in partnership with the CHS, allocates money on a yearly basis to basic scientific research grants and studentships aimed at developing treatments for hemophilia A and B, von Willebrand disease, rare factor deficiencies, platelet function disorders and ultimately, to finding a cure.

In 2011 Dr. Paula James and Dr. David Lillicrap (Queens University, Kingston ON) were named Researchers of the Year by the National Hemophilia Foundation (USA) for their ongoing clinical, translational and basic studies of two inherited bleeding disorders, hemophilia and von Willebrand disease. Both conditions prevent the blood from clotting, causing abnormal bleeding.

Since 1990, the Hemophilia Research Million Dollar Club has funded more than 60 research projects, supported 50 Canadian researchers and invested close to three million dollars to improve treatment and to find a cure for inherited bleeding disorders. To find out more or to support HRMDC follow this link: http://www.hemophilia.ca/en/about-the-chs/to-support-us/hemophilia-research-million-dollar-club/

We hope that this issue gives you some insight into the research and studies that could have an impact in your future care currently happening in Ontario and around the country and encourage you to have a voice when the opportunity presents.



Editor's Message:

"Tis a puzzlement."

– The King and I

by Tom Beer

I've always loved that line from the musical, because it sums up a lot of life. It suggests that life is a constant search for answers. This issue of ***Blood Matters*** is based on the theme of RESEARCH; not only the "whats", but also the "whos" and the "hows".

A number of years ago my Federation sent me to UCLA for intensive training in how the brain works and how to implement "brain learning" in the classroom. The first thing the world renowned leader told us was that "There are NO absolutes". She went on to say that the questions we all have about how the brain works are constantly being studied, being researched, but there are few answers that fit all cases and all people.

This edition of ***Blood Matters*** examines the issues of research on blood disorders.

The puzzles and activities in this magazine use the visual and verbal skills of the brain, often relying on both to solve the problem. Scientists, doctors and researchers use these same skills in their efforts to deal with the puzzles of life. The puzzles section answers will be provided in the next edition of ***Blood Matters***.

I like the etymology of the word research, i.e. "to look again". It implies that one must continually go back to what is known and to challenge it, and, to apply new knowledge to previously held beliefs or practices. In England, residents once closed their shutters at night to keep out the diseases that came in the dark. How much nicer for those citizens to see the moon through the open window after that superstition was debunked. For many diseases, research has resulted in enlightened discoveries and, in some cases, cures. In medical and scientific labs, time is spent examining, literally, "under a microscope" those not yet understood well enough to conquer, and the battle continues.

Important to new discoveries is the creative scientific mind that inquires "outside the box."

If it had not been for Jenner's observation that milkmaids had less severe bouts of 'pox, we wouldn't have the knowledge that the use of live "antibodies" in serum has eliminated the threat of Smallpox in the world. Jonas Salk "found" a vaccine for Polio, using the "killed" virus that caused the terrible withering malady. Frederick Banting used reconstituted islets, insulin, from dead pancreatic ducts as a last desperate measure and saved a Diabetic young boy's life. All of these are evidence that research works. If Alexander Fleming had not re-examined a contaminated petri dish, he would have missed the "penicillin" mold, the powerful antibody that saved so many during WWII from infection.

Read the articles in this edition, and thank those doctors and clinicians, nurses and caregivers, researchers and lab workers, and those who live with blood disorders for their vigilance and diligence. Their feedback and observations provide much valuable data used in medical diagnoses and treatment regimens.

Our older readers realize how far interventions have come. Our younger readers and their parents and caregivers can take heart that the world of micro-medicine is coming closer to being able to answer the questions that we all have.

We're so fortunate to have a committed community of researchers, doctors, nurses, clinicians, caregivers, parents, and volunteers dedicated to relegation and elimination of blood disorders and their impacts on the lives of those affected.

Many of the articles in this edition deal with the 'puzzles' of identification and treatment; the challenges of research. ♦

Read on…

Hemophilia Ontario News

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.

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. protective helmets), in-hospital costs (e.g. telephone and TV) and other emergency funding. Hemophilia Ontario will pay for the first MedicAlert bracelet, first year of membership and a replacement bracelet if worn out. Lost bracelets are the responsibility of the family, except under exceptional circumstances.

Hemophilia Ontario is the payer of last resort and will, first of all, ask that members attempt to have these costs covered by other social agencies including medical plans and the government. 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. 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. ♦

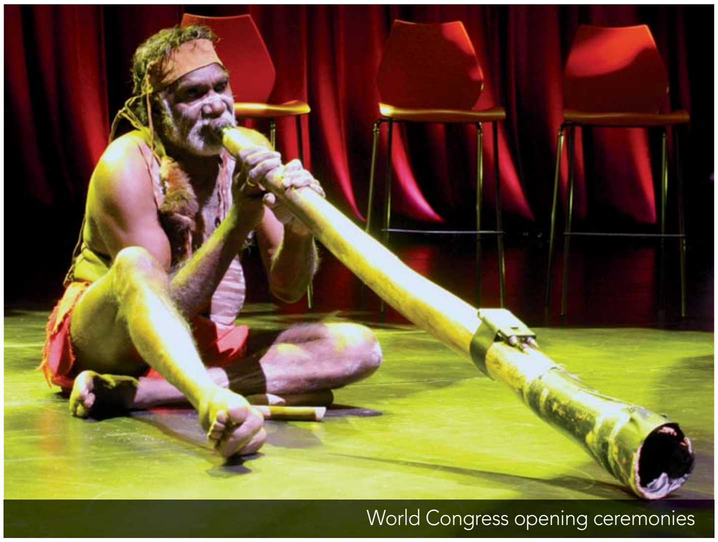
World Congress

by Terri-Lee Higgins

4 thousand individuals from around the world arrived in May in Melbourne Australia for the 2014 World Congress. This conference brings together individuals from developing and developed countries providing a forum to share their expertise and learn what's new, changing, challenging in the inherited bleeding disorders community.

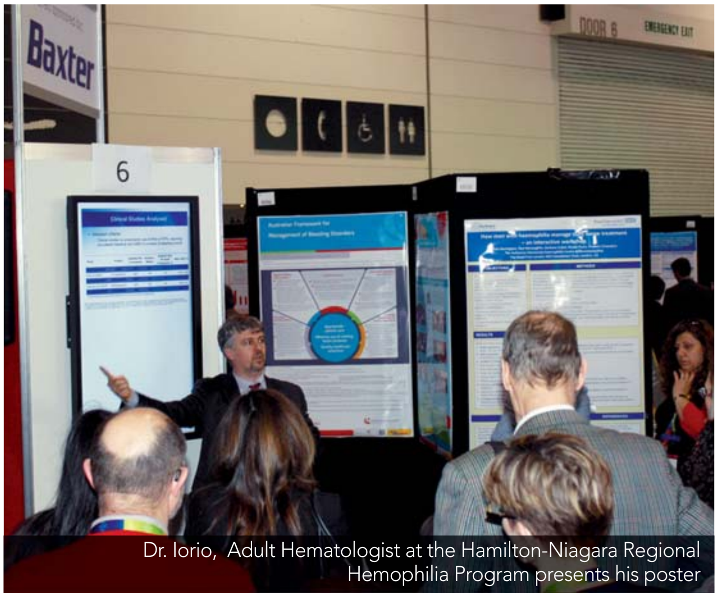
Ontario and Canada were well represented as presenters and through the submission of posters / abstracts. Our community has a strong history of collaboration and we have an ethical obligation to each other to accomplish tasks responsibly, with integrity and in a relevant and appropriate way. It's key that the medical and lay communities continue to find common objectives and purpose and agree on an action plan. When this is realised improvement in health care is the outcome. Dr. Alan Weil President of World Federation of Hemophilia was clear – bleeding disorders do not discriminate. We must innovate or stagnate.

It can be a difficult task to determine which of the many sessions to attend so I chose to focus on some of the areas of Hemophilia Ontario's organizational objectives. I was inspired by Megan Adediran of Nigeria and her efforts to bring care to her country. I was struck by the statement that females with low factor levels are not only carriers but should be recognized as having a bleeding disorder and be followed by their HTC. I was inspired by a Canadian prophylaxis study that found 1 in 4 children who infuse weekly have normal joints, reinforcing our belief that 100% adherence means healthy joints, and may mean future generations may live very different lives. Life expectancy is increasing for those living with an inherited bleeding disorder and those with mild and moderate levels must ensure their bleeding disorder needs remain front and centre as they age and that treatment is received as required before procedures. Therapeutic exercise improves muscle strength and balance and is an integral part of rehabilitation. Prophylaxis and resistance training helps decrease episodes of bleeding, diminishes pain, improves strength and promotes bone mineral density meaning it is safe and encouraged, and, that, as we age, we continue to find ways to keep our bodies strong. We have added years to our life, now let's add life to our years. 🩸



World Congress opening ceremonies

Lori Laudenbach, Hemophilia Nurse Coordinator and Terri-Lee Higgins, Executive Director with their poster for Pinecrest Camp



Dr. Iorio, Adult Hematologist at the Hamilton-Niagara Regional Hemophilia Program presents his poster

Zach Adams, Hannah Higgins, Terri-Lee Higgins of Hemophilia Ontario, Dominic Seye of the Haemophilia Society of Tanzania, and Helene Bourgaize of the Canadian Hemophilia Society at World Congress

Thank You Barbour Family!

by Alex McGillivray

Almost 10 years ago, the Barbours wanted to make a difference in the bleeding disorders community and continue to so today. While they have volunteered at the regional level, their hearts truly lie in planning and hosting the Annual Liam Barbour Charity Golf Classic each year in Guelph. A family run affair, this golf tournament began as a way to help raise funds for their region, and has since developed into an event that helps support sending 50 youth to YMCA Camp Wanakita each summer, and in essence, helps give 50 youth a chance at independence.

Proceeds from the tournament have also helped ease challenges for newly diagnosed families in the Central West Region by providing them with a new patient package that includes parking, a voucher for a helmet or padded clothing, and a variety of other items that connects new patients to Hemophilia Ontario. The Liam Barbour Scholarship also provides recognition to youth leaders and volunteers in Central West Ontario Region with an annual $500 post secondary scholarship for a first year student that meets the criteria.

It goes without saying that everyone at Hemophilia Ontario is truly grateful for all of the hard work and support the Barbour Family has provided our community. You are all champions and we sincerely thank you from the bottom of our hearts for all that you have and continue to do. 🩸

Just the Guys 2014

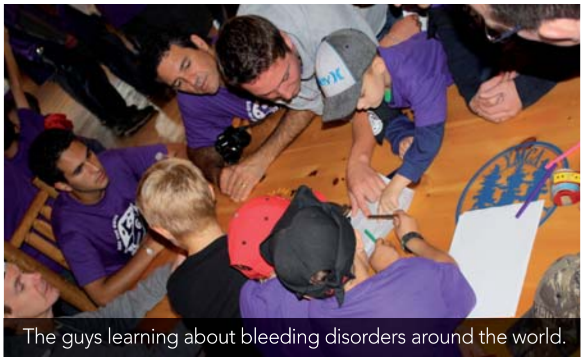
This year's edition of our *Just the Guys Weekend* – a program that focuses on fathers and male role models taking a more active role in the care of their boys – was out of this world! Participants worked together to build their own spaceships, and even completed a space-walk shuffle!

Many thanks to our sole sponsor, Bayer, for supporting this event and also for providing our phenomenal educational speakers from Winnipeg, Greig Blamey, Physiotherapist and John Schmitke. We received an overwhelming amount of positive feedback from our participants about how relatable and applicable the information was.

Many thanks to Zach Adams, our lead youth volunteer, for his involvement in the planning committee, his presentation on Bleeding Disorders Around the World, and, of course, his leadership during the weekend. Also, a huge thank you to our three other youth volunteers, Jordan Cabral, Paul Travaglini, and newcomer Marc Montminy – we know the participants really love having you around as role models for their children, and you all did a fantastic job!

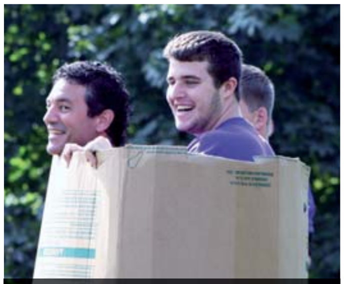
We'd also like to thank Vanessa Bouskill and Lisa Thibeault, our attending nurses for participating in this program. Your time and expertise is always appreciated by this community and this program is no exception. Lastly, thank you to the *Just the Guys* Planning Committee for all of your hard work and tremendous support of this program. It would not be as great as it is without your participation.

We can't wait to start planning for 2015! 🩸

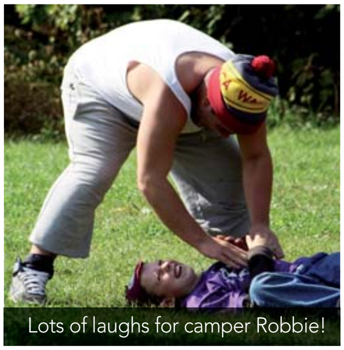


The guys learning about bleeding disorders around the world.

The JTG silly face group photo!



The JTG Out of this World Spacewalk Shuffle!



Lots of laughs for camper Robbie!

Hemophilia Ontario Camps and Youth

by Spencer Sterritt, Summer Student

Hemophilia Ontario is a vast organization, providing service to more than one thousand individuals across Ontario's million square miles. There are numerous programs in each of the regions, and many different ways to get involved.

Summer Camps are one of the biggest opportunities Hemophilia Ontario provides to affected youth. One camp is Pinecrest Adventures Camp run at Camp Menesetung in Goderich Ontario. Dedicated to the Southwest Region, Pinecrest Adventures Camp is a place for those with an inherited bleeding disorder and their sibling to enjoy the sunshine and all that camp provides in a safe and exciting setting. One of the biggest goals of Pinecrest is to make the youth feel like they do not have a bleeding disorder. If they don't bring it up, often other campers will not know who has a bleeding disorder and who does not. "Being able to make the youth feel safe," says Hannah Higgins who is an Arts & Crafts co-leader, "and giving them an opportunity to have safe fun is one of the best parts about camp." This year's theme was Disney versus Pixar.

Pinecrest is an absolutely fantastic place for youth to volunteer and be counsellors. Many campers mature through the Leadership-In-Training program at Pinecrest and become counsellors themselves. Ryan Kleefman, this year's Director of Pinecrest, started attending Pinecrest Adventures Camp when he was a Jr. and has been involved nearly every year. "The best thing about Pinecrest is to see the youth from the first day to the last," he said in a phone interview "and to see all of them excited and ready for next year before they even leave camp." One of the best aspects about being a camp counsellor, according to Julia Lepera, is to "be able to make a difference. Camp has given me so much, and it feels good to be able to give back."

Pinecrest isn't the only camp that Hemophilia Ontario is involved in. Further North there is YMCA Camp Wanakita, which supports all of Hemophilia Ontario's regions. It is a YMCA camp near Haliburton right on Koshlong Lake and boasts 1000 acres of land for every activity from mountain biking and sailing to arts and crafts and swimming. Camp Wanakita is also home to the Bayer Den, where many of the children learn to self-infuse under the excellent care of our HTC Nurses. The Bayer Den is where Waylon, a ten year old with Severe Hemophilia A, first learned to infuse by himself. "I actually missed the first time because I went into the wrong spot," he said "but then the nurses came over and they helped me find the vein. I was nervous once more after that, but now I'm not." The Bayer Den was created in 2004 with the purpose of providing a safe place for campers with inherited bleeding disorders to learn self-infusion and gain independence. "I think about camp all year," Waylon continued, "since my friends are always in my cabin and they come every year and this is when I get to see them." Several youth with inherited bleeding disorders have become counsellors at Camp Wanakita after attending as campers, and are some of the most diehard camp counsellors out there.

Attending camp is just one of the many things that youth with inherited bleeding disorders can do. One of Hemophilia Ontario's major initiatives is HOY (Hemophilia Ontario Youth) which is focused on engaging our youth members outside of a camp setting. One notable example of this was seen when the HOY group made a photo diary of their lives, and then the 10 best shots from each person were put on display during the James Street North Art Crawl in Hamilton. The outdoors do factor into HOY activities, such as canoe trips, but there are also events and activities such as spending a day at McMaster University. Shaun Bernstein has been involved with HOY in the past, and said that "we want people to engage at a level different from camp, and create an example of advocacy for a voice that wasn't really heard." 💧

YMCA Camp Wanakita 2014

by Laura Tomkins

YMCA Camp Wanakita, located near Haliburton Ontario, once again, this summer, welcomed over 50 campers aged 6-16, all who are affected by an inherited bleeding disorder. Camp Wanakita provides an opportunity, over 1 – 4 weeks to participate in fun activities such as kayaking, guitar lessons, sailing and archery. All activities take place in safe environments, and involve campers meeting other children with and without bleeding disorders. With the help of almost 10 hemophilia nurses from across the province, children with bleeding disorders learn to self-infuse at camp and successful first time infusers are provided with a video to show their parents. Thank you to all of the nurses who dedicate their time to be available to campers and to Camp Wanakita. 💧

In Remembrance

Enid M. Page (Gow)

July 14, 1924 - October 16, 2014

Hemophilia Ontario is deeply saddened by the passing of Enid Page. Born in Toronto in 1924, Enid moved to Montreal in 1930. She served in the Royal Canadian Air Force during World War II as a photographer. After the war she worked at Wm Notman & Son Photographic Studio and in the Meteorological Office of the Department of Transport at Dorval Airport where she met Doug, whom she married in 1949. They lived in Moncton, New Brunswick and Goose Bay, Labrador before settling permanently in Lachine in 1952. The next year, Enid became one of the founding members of the Canadian Hemophilia Society. Enid was a painter, an avid quilter and a lover of books. She was an active member of the Parish of St. Andrew and St. Mark in Dorval and sang in the choir until very recently. She spent her summers at the family cottage on Grand Lake, New Brunswick, where she welcomed as many friends and family as she possibly could. Enid will be remembered by all who knew her as one of the friendliest, most energetic and most positive people they have ever known. Hemophilia Ontario extends their deepest sympathies to David and the entire Page family.

Please visit:
http://rideaumemorial.sharingmemories.ca/site/EnidM-Gow.html?s=120

By Giving Blood

by Matthew Maynard

Giving blood is one of the ways you can help stop the bleeding – not just for those with bleeding disorders. "Approximately 52 per cent of Canadians say they, or a family member, have needed blood or blood products for surgery or for medical treatment. Every minute of every day someone in Canada needs blood. Public Service Announcement" – *Canadian Blood Services September 30, 2014*

I have been a volunteer throughout school and my work career and very much consider it a part of what I do and enjoy. Along the way I have even been a plasma donor not to the blood system but to a research study being completed by a researcher with then Canadian Red Cross. Fast forward to just two years ago and as I was leaving a meeting I was approached about possibly volunteering for a blood donor clinic just an evening every other month.

I showed up for my first clinic and to start the volunteer training "Ice Please" "Gauze Please". I also learned at that first clinic that they did not just need a volunteer, they needed a lead volunteer as there were no volunteers remaining at the clinic! I am pleased to say that we now have a full team of seven volunteers – two students who love to do the "jiggy" signs at the corner during the clinic, a retired school teacher and her husband , a factory worker and a nurse when shifts don't interfere. The clinic has moved to once per month Saturday mornings so we are gradually building a whole new group of donors.

Volunteering is a delightful way of getting to know your own community, giving back or paying forward maybe not directly to Hemophilia Ontario but for all of us who rely on a strong and safe blood system in this country, and it is rewarding to help other volunteers and donors.

So, if you are not able to give blood, you can volunteer, you can take someone to give on your behalf called an "ally" donation, or help promote the next blood donor clinic in your area.

BLOOD INVENTORY IN CRITICAL CONDITION – Canadian Blood Services launches urgent appeal for blood donors September 30, 2014 (CANADA) – Canadian Blood Services is appealing to all eligible donors to make a blood donation immediately to increase Canada's critically low blood inventory. All blood donors are needed, in particular those with type O and A blood.

You may have seen this appeal for blood donors in your local newspaper or heard it on the radio or television at the time it was released. The need continues today so please encourage everyone to donate now.

DONATE TODAY!

Canadian Blood Services
it's in you to give

To book an appointment, visit www.blood.ca – or to find the clinic closest to you, download the Canadian Blood Services GiveBlood app on your android or Apple device – or call 1 888 2 DONATE (1-888-236-6283)

Lessons Learned as an RSC

by Sarah Wood

My two years as a Regional Service Coordinator for Hemophilia Ontario was brief but it was most definitely impactful on me as a person and as a worker. My career, prior to this role, involved working with a wide variety of populations, with a wide range of barriers that they faced, in a wide range of settings. Despite this very diverse experience set, I came to see Hemophilia Ontario as a unique place, unlike any other I had ever worked for. The bleeding disorders population has been through so much and through this they have developed such an incredible sense of community and mutual support, in a way that I had never experienced. They know what they want, what they won't accept, and are amazingly capable of banding together to make it happen. In all of my time as an RSC, I never felt like I was working FOR our members, I felt like I was working WITH them. In my previous roles a lot of time was spent working to make members feel empowered to fight for their rights, but this population was already there and so it was a true gift to be able to work alongside them to assist in achieving their goals.

This community really set the stage for me for future roles as to the ideal that other populations should work towards. It laid out very clearly for me exactly what can happen when a community sticks together and I will use tips, lessons, and approaches that I witnessed and participated in as learning lessons for my work in the future.

Thank you for letting me be part of your intimate world and for showing me valuable lessons about advocacy, community, support, and how to endure in the face of adversity. This organization and its members are truly unique and I hope that you all recognize that and fight to hold on to that. Thank you for everything!

Honoured by Our Volunteers

Big congratulations to our volunteers, Victoria Kinniburgh and Zach Adams, for being recognized for all their time and effort to Hemophilia Ontario by being awarded Ontario Volunteer Service Awards by the Ministry of Citizenship and Immigration this past March. Zach was awarded a Youth Award while Victoria was awarded for being a volunteer for over 5 years. You are both very deserving of this honour and we are so happy to have you as a part of the Hemophilia Ontario team!

Women and Inherited Bleeding Disorders Webinar

Dr. Paula James, associate professor in the department of medicine, division of hematology, at Queen's University, presented a women's inherited bleeding disorders webinar on Thursday September 18th. Almost 20 people signed in to hear Dr. James speak. Thank you to Dr. James for her amazing presentation and taking the time to be a part of this webinar, and Octapharma Canada for sponsoring the event.

Canadian Hemophilia Society News & World Federation of Hemophilia News

CHS Research Initiatives

The CHS promotes and funds research within Canada to improve treatment and to, ultimately, find a cure. Approximately a little over 50% of funding towards research initiatives ends up in Ontario; however, this is a result of Ontario having the largest number of treatment centers in comparison to other provinces. As a result, more research proposals are received from Ontario which plays in the province's favour in receiving funding that is used towards research initiatives.

There are five programs that the CHS supports that are research focused, and they are as follows:

1. CHS Dream of a Cure Program
2. CHS-Pfizer Care Until Cure Program
3. CHS-Novo Nordisk Psychosocial Research Program
4. Hemostasis Fellowship Program
5. CHS-Baxter Fellowship Program

If you wish to learn more about any of these five research programs, you can visit the CHS website at **www.hemophilia.ca/en/research** and click on the corresponding program in the left hand navigation bar.

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

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

WFH Research Initiatives

The WFH also promotes and funds research initiatives but at an international level. Their Clinical Research Grant Program provides support for international clinical investigation relating to inherited bleeding disorders.

The aim is to help create better evidence for the clinical management of Hemophilia A and B, von Willebrand Disease, Rare Factor Deficiencies, and Inherited Platelet Disorders. The program is peer reviewed and is open to researchers globally.

The WFH Clinical Research Grant Program can award up to four grants (two in each category) per year for the best proposals that address critical clinical issues of broad international significance.

For more information on the WFH Clinical Research Grant, you can visit their website at: **http://www.wfh.org/en/our-work/wfh-clinical-research-grant-program**

Bleeding Disorders News

Research, What's it all About?

by Terri-Lee Higgins & Spencer Sterritt, Summer Student
with contributions from Dr. Paula James
reviewed by Vanessa Bouskill, Hemophilia Nurse Coordinator

The most commonly recognized inherited bleeding disorders are Hemophilia A (low level or absence of clotting factor VIII), Hemophilia B (low level or absence of clotting factor IX) and von Willebrand disease (a quantitative or qualitative defect in von Willebrand factor). These inherited bleeding disorders are the focus of local, national, and international research initiatives. Every new day brings new developments in the field of inherited bleeding disorder research and treatment. Pharmaceutical companies, including Bayer, Baxter, Biogen Idec, CSL Behring, Novo Nordisk, Octapharma and Pfizer, are constantly working to improve product safety profiles, efficacy and the impact of product use on quality of life. Additionally, clinical laboratory research at some of the top universities and Hemophilia Treatment Centres (HTC) are driving the field forward into exciting new areas. We had the opportunity to speak with a few pharmaceutical company medical liaisons and reviewed several published documents to provide a broad scope overview of experimental methods currently being investigated.

One of the more well-known research initiatives in the hemophilia industry is the extension of factor half-life. The half-life of a product is the amount of time it takes for the half of the clotting factor infused to be used and not available in the circulatory system. There are many factors that influence a half-life. Generally speaking, factor VIII has a half-life of 8-12 hours, while factor IX has a half-life of 18-24 hours. With a great deal of the focus on extending the half-life of future and existing products, longer half-life concentrates should become the "new standard of care" allowing for tailored, individualized care with a goal of improving quality of life. Gene therapy research trials (hoped to eventually help people with hemophilia begin producing their own clotting factor thus reducing or eliminating the need for weekly infusions) is being trialed with humans with mixed results. They proceed at a moderate pace.

We learned of a one of a kind non-factor panhemophilia product in pre-clinical trials which is hoped to provide new options for hemophilia care as it is not limited for use in only hemophilia A. Additionally, in the early stages of development is a Factor VII product which the company hopes will have "clearly enhanced potency and extended durational activity."

The development of inhibitors in patients has long been a concern not only of patients and medical staff but also researchers. Through our review, it appears that nearly every major company has research on inhibitors somewhere in their product and research pipelines. It is a safety concern that is a requirement and needs to be addressed prior to completing any clinical trial. In various stages of current clinical trials are products geared toward preventing the development of inhibitors including a porcine Factor 8 product.

Von Willebrand Disease (vWD) research is the focus of a number of companies with pipeline and clinical trials including a first of its kind recombinant von Willebrand factor. Many Ontario HTCs are actively engaged in vWD clinical research. Designed to enhance patient care, one study focuses on working toward clinical indications for surgical use hopefully yielding new methods of reducing surgical risks.

Not all studies are focused directly on enhancing factor treatment. There are, also, numerous studies being conducted by primary investigators in laboratory settings and on the clinical frontline across Canada looking at enhancing quality of life and healthy living. One interesting new study looks at the incidence of embolisms in patients with inherited bleeding disorders. A common misconception is that someone with a bleeding disorder is not at risk for a stroke or heart attack. Clotting factor concentrates have developed to the point where hemostasis is better controlled. This means individuals with inherited bleeding disorders could face the same risk factors that cause clot related insults as the general aging population. Factors such as smoking, high cholesterol and obesity may contribute to thrombosis in a hemophilia patient. Additional ongoing research focused on VWD patients includes studies evaluating Quality of Life and studies validating novel clinical assessment tools. The accurate assessment of bleeding symptoms is critically important in VWD, and both expert- and self-administered bleeding assessment tools are being studied to help standardize the way physicians inquire about, record and evaluate bleeding symptoms. The symptoms include heavy menstrual bleeding, nosebleeds and bleeding after childbirth, dental work or other invasive procedures.

Nurses, the forefront of hemophilia care, focus on patient issues and ways they can optimize care and quality of life. We found information on two current initiatives. One investigates treatment adherence in youth and common barriers that may be minimized with the findings from the study. The second is a national study focused on developing a greater knowledge of inherited bleeding disorders, rare factor deficiencies, and platelet disorders with desired outcomes of quicker diagnosis and more consistent care.

Did you know that currently in Ontario there are 100's of studies related in some way to inherited bleeding disorders? We believe this is a strong sign that inherited bleeding disorder research will provide new treatment and product options. Stay tuned!

Guide to Getting into Research

by Spencer Sterritt, Summer Student

The scientific side of inherited bleeding disorders is a vast and complicated field that will need as many new faces as possible over the next few decades. Numerous new avenues of research are being opened, many by Dr. David Lillicrap and his team at Queens University. Dr. Lillicrap is a Professor at the Department of Patholgy and Molecular Medicine at Queens, and was co-named Researcher of the Year with colleague Dr. Paula James by the National Hemophilia Foundation in 2011. For all of those with hemophilia who are interested in learning more about their disorder he had some words of advice. "The main things that make a good researcher are being bright, having lots of initiative, working hard, and being interested in asking questions. It's about being curious and asking questions which will lead to better treatment. 'I don't know' is an initially reasonable response but then trying to find out why beyond that is good."

Dr. Lillicrap also suggested that getting into blood disorder research is a very pragmatic way to enter the field, because "you can combine clinical and laboratory interests very easily." Gastroenterologists have to operate on the stomach to get their samples, and neurologists have the difficult task of drilling through the skull to access their samples, whereas hematologists simply have to insert a needle into a vein.

Though hematology may seem like an easy field due to how uncomplicated it is to get a sample, don't take that to mean that it's an easy field in every other aspect. One of the largest challenges that most young scientists do not factor into their plans is how difficult it is to receive funding for their research. It's a challenge that every field faces, and a "definite stress of the researcher." Dr. Jonathan Foley, who did his undergraduate work at Queens University and is now a Banting Fellow at the University of British Columbia, concurs with how stressful funding issues can be, and elaborated on the process. "You come up with a bunch of related ideas, possibly add letters from collaborators at different labs, and then write up your proposal. Your submission would be reviewed by a panel of experts. The biggest is government agencies like the Canadian Institute of Health Research (CHIR) or the National Council of Educational Research and Training (NCERT). There are also private or public organizations like CHS or Heart and Stroke, and the private donors. It's about a one year process from writing your grant to submitting again, with a funding rate of about 10%."

All that funding is going into some very interesting projects in the next little while. Dr. Lillicrap and his team are currently working on discovering more about Factor 8 inhibitors, which make treatment of bleeding disorders very difficult. They are also focused on where factor, once inserted into the bloodstream, goes. "We don't know much about how that happens," he says "[or] how the proteins are cleared, and where they're cleared. We know most of the clearance occurs in the liver and the spleen, but there are many different cell types in those organs, [and] we are not precisely sure which cells are responsible." In the broader spectrum, Dr. Foley also has some ideas. "Future research will, in part, focus on developing predictive tools that will tell us ahead of time which therapy is best for which patient… In the end, administering the best possible therapy at the appropriate time will reduce the number of complications that the patient suffers, while improving their health and decreasing the overall cost of treatment."

Research is always moving forward, always looking ahead to solutions for those with an inherited blood disorder. Pathways mentioned above are not the only focuses of research, and there is still much to learn. With this advice from Dr.'s Lillicrap and Foley, hopefully anyone planning to enter the field will be able to accomplish everything they want to, and make their own breakthroughs.

The Importance of Studies

by Vanessa Bouskill, Hemophilia Nurse Coordinator

Being involved in research is essential in order to advance care. In Ontario, many health care professionals participate in investigator initiated studies to better patient care and also are closely involved in clinical trials with industry partners particularly in testing new drugs/factor concentrates in patients with inherited bleeding disorders such as the hemophilias.

The Hospital for Sick Children (SickKids) in Toronto is a premier centre for research related to inherited bleeding disorders in children. The clinical/ research group at SickKids consists of a team of physicians, nurses, basic scientists and clinical research associates working on dozens of research initiatives in areas such as prophylaxis strategies in hemophilia, measuring long-term outcomes in patients with hemophilia, investigating new longer acting factor concentrates, devising tools to quantify bleeding and exploring the genetics and basic pathophysiology of platelet disorders.

A recent focus that the research team at SickKids has undertaken is to explore the role of exercise on hemostasis (i.e. clotting ability) in boys with hemophilia. Additionally, the research team is evaluating physical activity patterns in boys and young men with hemophilia and how the severity of their bleeding disorder impacts on the amount of physical activity they do. As exercise impacts on obesity and as increasing rates of obesity are having significant negative consequences in society, this area of research has important implications for boys with hemophilia.

Additionally, the team at SickKids collaborates widely with other centres in Canada and abroad. Members of the SickKids bleeding disorders research program have played prominent roles in collaborative, multicentre research undertaken through the Association of Hemophilia Clinic Directors of Canada, the Canadian Pediatric Hemostasis and Thrombosis Network and the Canadian

Association of Nurses in Hemophilia Care. Furthermore, the SickKids bleeding disorders program, and in particular Dr. Victor Blanchette, has spearheaded a number of international collaborations in Brazil, China, India and most recently in the Caribbean. All of these are done to ultimately improve the care of children with bleeding disorders on a global front.

This is a brief insight into only one of many Canadian centres doing national/ international research to advance the care of special populations. We are immensely grateful to the children with inherited bleeding disorders and their families for their participation in our research studies - without their help, and the support of the Canadian Hemophilia Society, the important studies that we and other hemophilia treatment centres in Canada conduct would not be possible.

Qualitative Research – Contributions in the Field of Hemophilia

by Shannon Lane, Research Coordinator
McMaster Transfusion Research Program

Research has dramatically improved hemophilia treatment and care over the past 40 years, leading to the development of safer and more effective treatment products and practices. Many of these advances were achieved through the application and techniques of basic and clinical medical research, which are underpinned primarily by 'quantitative' research methods. Quantitative approaches involve the collection of numerical data that are analyzed using statistical methods.

Increasingly another kind of research, known as applied 'qualitative' research is being conducted to investigate other kinds of issues in the field of hemophilia. The term 'qualitative' refers to a form of inquiry, stemming from the social sciences, that aims to try to explore, understand and describe social phenomena through the systematic collection and analysis of non-numerical data. Qualitative approaches try to learn about an issue from the perspectives of research participants, often using interview or focus group methods to collect data. 'Applied' research "strives to improve our understanding of a problem, with the intent of contributing to the solution of that problem"[1]. A brief review of some Canadian studies that have used qualitative techniques demonstrates the unique potential for these approaches to enhance knowledge and improve care in the field of hemophilia.

In one study, the Canadian Physiotherapists in Hemophilia Care used semi-structured telephone interviews to learn more about the attitudes and behaviours of young men with mild hemophilia[2]. Study results revealed sub optimal communication between the young adults and the health care team, with common reference to the ineffectiveness of lecture style education, and knowledge gaps in the areas of bleed identification and management were also identified. The conclusions of this study suggest that clinicians may benefit from listening to patients and developing a more collaborative relationship.

Another Canadian qualitative study germinated from the realization that the loss of many older members of the hemophilia community during the tainted blood era had resulted in a lack of understanding of the needs of aging men (>40) with hemophilia among health care providers[3]. In order to identify and better understand the needs of this population a qualitative study using focus groups was conducted to elicit the perspectives of men in this age group. The study identified three major themes which will be used to develop new programs at a comprehensive care centre: reflections on living an active lifestyle, normal versus disease specific impacts of aging, and the health system, and its ability to respond to the needs of ageing individuals. In addition to some anticipated findings, this study also identified issues that were not anticipated from the study outset.

One last example of how a qualitative approach has been used in the field of hemophilia is taken from a project I worked on with a research team from McMaster. The objective of this study was to identify the knowledge needed by men with hemophilia to achieve optimal self-management[4]. Focus groups with healthcare professionals were conducted in the first phase of this study to identify items for a survey that was administered to men with hemophilia in the second phase of this study. Mixed methods (qualitative followed by quantitative) were used to ensure that the survey was asking relevant questions. In addition to the anticipated findings participants also highlighted the challenges of assessing knowledge and the importance of providing information in the right format at the right time in order to ensure knowledge uptake and assimilation[4].

Many of the ideas for applied qualitative health research often stem from observations of issues that are not well understood by those practicing in the field. As the studies in this brief review demonstrate, by eliciting the perspectives of those who have experience with the issues or phenomena under investigation, unanticipated knowledge can be gleaned to advance treatment and care. The experiential knowledge that people have is valuable, and qualitative research approaches can be used to tap into this knowledge and learn from it.

To anyone who has ever participated in a qualitative study thank you for sharing your perspectives, and a broader thanks to anyone who has been a part of research in hemophilia. Research could not happen without your willingness to be involved.

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Hemophiliac Patients with HIV Show Increased Amount of Immune Cells Targeting HIV

Researchers from Germany have discovered "that people who have been infected with HIV for decades and also have hemophilia have an increased amount of immune cells in their blood that specifically target HIV. This protective immune response helps chronically infected hemophilia patients survive even throughout periods of HIV activity." "All of the patients (who were studied) were men infected with HIV at the end of the 1970s and early 1980s via virus-contaminated clotting factor products."

Article Source: http://www.hcplive.com/publications/contagion/2014/may2014/Hemophiliac-Patients-with-HIV-Show-Increased-Amount-of-Immune-Cells-Targeting-HIV-

Plant-based Research at Penn Prevents Complication of Hemophilia Treatment in Mice

A recent article on Penn State University's website has indicated that, "20 to 30 percent of people who get infusions (to deal with their severe hemophilia) develop antibodies, called inhibitors, against the clotting factor. Once these inhibitors develop, it can be very difficult to treat or prevent future bleeding episodes."

However, researchers from the United States have released a new study in which a "strategy to prevent these antibodies from forming" was developed. "Their approach, which uses plant cells to teach the immune system to tolerate, rather than attack the clotting factor protein, offers hope for preventing one of the most serious complications of hemophilia treatment."

"Henry Daniell, a professor in Penn Dental Medicine's departments of biochemistry and pathology and director of translational research, (who) was (also) the senior author on the research" states that "our technique, which uses plant-based capsules, has the potential to be a cost-effective and safe alternative."

University of Florida researcher Roland Herzog also stated "this could potentially be a way to prevent antibodies from forming or to lower the incidence of it… this is a major step forward." 💧

Article Source: http://www.upenn.edu/pennnews/news/plant-based-research-penn-prevents-complication-hemophilia-treatment-mice

HIV/AIDS and Hepatitis C News

Novel Drug Could Eliminate Hepatitis C in 15 Years

"A treatment estimated to cure chronic hepatitis C infection in up to 99% of cases when used in combination with other drugs has been launched in the UK. Described as 'an important step forward towards the holy grail of highly effective, short, tolerable and interferon-free therapy', daclatasvir is the third new treatment for hepatitis C virus (HCV) to be launched in 2014, following sofosbuvir and simprevir."

With no severe side effects linked to treatment, chief executive of the charity 'Hepatitis C Trust' Charles Gore has stated that daclatasvir "presents an opportunity to eliminate hepatitis C within no more than 15 years."

Article Source: http://www.pharmaceutical-journal.com/news-and-analysis/news/new-drug-could-eliminate-hepatitis-c-in-15-years/20066367.article

from Michel Long, CHS

As you may have seen in the August edition of the Canadian Hemophilia Society (CHS) news magazine *Hemophilia Today* on page 24, the CHS has started to communicate the fact that people who are approved claimants under the Hepatitis C January 1, 1986 - July 1, 1990 Class Actions Settlement may be reimbursed for their costs for treatments and generally accepted hepatitis C medications that are not recoverable under any public or private healthcare plan. This is a fact not well known by the claimants themselves nor their health care providers.

Moreover, thanks to a collaborative effort between the CHS and Gilead Health Sciences Canada, The Momentum Support Program can now provide upfront payments to those eligible for the high-cost treatment Sovaldi (sofosbuvir) while the claimants wait for a reimbursement from the 1986-1990 plan. In addition to Solvaldi, the upfront payment can cover the other drugs which would be part of the combined treatment regimen. The Momentum Support Program is Gilead Sciences Canada's patient support program that can put patients in touch with a case manager who can support patients to access therapy, help seek financial assistance to pay for treatment, and provide education and support throughout the treatment. Case managers at Momentum have been prepared to support the particular situation of the 1986-1990 claimants.

Given that many of the 86-90 claimants are hemophiliacs who were infected with HCV through blood products received in Canada between January 1, 1986 and June 30, 1990 and may still be in need of a treatment, we are trying to reach them and their health care providers to inform them about this opportunity to begin treatment now without having to wait for the Health Canada approved drugs to be on their provincial formulary. For those eligible to be treated with Sovaldi as part of their regimen, having to front large sums of money should no longer be an obstacle thanks to the new provisions made under Gilead's Momentum Program.

A webpage on the CHS website which you can consult and share: **www.hemophilia.ca/en/hcv-hiv/hcv-treatment-support-for-1986-1990-claimants**

Note that we are in discussion with Janssen which offers Galexos (simeprevir) to explore if a similar arrangement can be made with their patient support program. Once a decision is made, we will inform you. 💧

Physical Activity in Adults with Severe Hemophilia: A Feasibility Study

authors: Sandra Squire BScPT, Dr. Shannon Jackson, Dr. Pat. Camp 2 3 – Shannon and Sandra are from the Hemophilia Program of British Columbia (Adult Division) St. Paul's Hospital, Vancouver, British Columbia, Canada

Introduction and Objectives: Adults with severe hemophilia are reported to be less physically active than adults without hemophilia resulting in a sedentary lifestyle, which negatively impacts joint health. There is a paucity of studies evaluating objective measurements of physical activity in adults with hemophilia. The aim of the study was to assess the feasibility of using an objective, direct and continuous measurement of physical activity.

Materials and Methods: Consenting adults with severe Hemophilia A or B starting individualized prophylaxis were recruited. Activity was assessed using an accelerometer-based sensor system (SenseWear Pro Armband™) worn 24 hours/day for 7 days. Physical activity data was collected including steps per day, minute-by-minute energy expenditure (METS), amount of time sleeping and total daily calories. The patients were informally asked about the experience of wearing the accelerometer.

Results: 10 patients participated with a median age of 26 years (range 20-44). The data were compared with the normal average steps per day and METs for the general population. 90% of the adults with hemophilia were classified as "low daily activity" (less than 7,499 steps per day) and of these patients 60% were "sedentary" with less than 5,000 steps per day. For all the participants the average daily energy expenditure was less than 2 METs (light level of activity>3METs). Patient adherence was excellent with the majority of the patients wearing the accelerometer consistently for 7 days.

Conclusion: This pilot study indicates that an accelerometer is a practical and valuable tool to measure physical activity of adults with hemophilia. Patients with hemophilia are inactive compared with a general adult population. Future research will investigate the benefits of individualized prophylaxis on increasing physical activity in adult patients with hemophilia. 🩸

What Research Means to Me

by Zach Adams

What does a cure look like to you? This question, although seemingly straightforward, can encompass many layers. I was once asked this question during a program I attended with fifteen other young men from around the world who are also living with hemophilia, and it was interesting to take note of the variety of answers. The majority stated something along the lines of, "a cure would look like an injection or pill that could completely remove my hemophilia and allow my body to produce factor on its own". I believe that this answer and the ultimate goal it seeks to achieve, is the sentiment held by the majority of people, me included, and would encompass the complete definition of a cure for hemophilia.

Taking a step back, however, I came to the realization that this desired goal was not a task which could be achieved overnight. I decided to re-examine what the word 'cure' meant to me and began to recognize that every individual with hemophilia could define this term as something completely different. When I was younger I remember thinking about a cure and at the moment of discovering a bleed, the thought of taking a pill with my morning orange juice seemed like a 'cure', when faced with the alternative reality of having to worry about an intravenous infusion.

Remembering this idea of a 'cure' has made me realize that a cure should be considered as a continuous progression, and not solely regarded as the two extremes of either being cured or having a disease. I now look at each of the new accomplishments and breakthroughs in hemophilia care as part of this overall 'cure'. For example, those on prophylaxis infusing every other day may view the possibility of once a week or once a month infusions as a part of this continuum of a 'cure'. We should view these accomplishments in research and product development as just one of the bricks laid down towards achieving an ultimate cure. Embracing this thought of a cure as laying a continuum, it is possible to remain steadfast with positivity and excitement with each new breakthrough in hemophilia care.

Finally, it is important to keep in mind the blessing provided by living in Canada and being able to receive exceptional care. This is another aspect that can be considered along the continuum of a 'cure'. The treatment we are now offered provides those living with hemophilia the opportunity to live an energetic and healthy life, which is an aspect very much regarded by many as part of a 'cure'. I feel as though it is important to keep this positivity and thankfulness in mind as we progresses along this continuum towards our search for the ultimate cure. 🩸

Bright Future

by Ryan Kleefman

Research toward a cure means hope. Today's recombinant factor provides an extremely effective level of care. However, hemophilia still has effects on my life. Prophylactic injections can cause a hassle, especially when travelling. Ups and downs of factor levels mean I don't always have 100% protection and injuries happen to me more often than for others who are unaffected. Having hemophilia means thinking twice about everything physical. Whenever I do something active, I have to take extra precautions and pay much more attention to what my body is saying, rather than focusing on enjoying a game or activity like others. While hemophilia treatment today has provided me with all the opportunities that those unaffected have as well as many more they don't have, the hemophilia remains.

A cure, to me, would mean the final barriers could be overcome. A cure would mean no more worries. A cure would mean that the family I plan to have will never have to deal with the consequences of having a bleeding disorder. A cure would mean a brighter future. 🩸

Research & Resources for Women

by Amy Griffith

Speaking from experience, it's pretty easy to live unnoticed in this big world. But just because a girl can stay under the radar, doesn't mean she shouldn't try to be even the smallest part of the change she wishes to see in the world.

Bleeding disorders are still predominantly unknown to the majority of the population. This is particularly true if you are a woman with a bleeding disorder. We are vastly outnumbered, and until recently, research was geared chiefly towards our sons, fathers, and husbands. Medical advancements in bleeding disorder care, in any shape or form, are monumental victories for the bleeding disorder community; however I am thrilled to say that more recently, the diagnosis and care of women with bleeding disorders is now front and centre, and literature on the subject can be found through a simple Google search.

However, I find the most challenging aspect of being a woman with a bleeding disorder, or a woman acting as primary caregiver to someone affected by a bleeding disorder, is finding someone to relate to, an outlet of more casual, less medicinal support. Through my years involved in the society I have relied on my social networks just as much, if not more, than my medical caregivers, and I am grateful for them all.

I wanted to take this opportunity to share a few of my favourite resources and networking outlets, all accessible with simply an internet connection, where empowered women are available and eager to help others who may find themselves in similar circumstances, who once thought they were alone.

CODErouge
WHEN WOMEN
BLEED TOO MUCH

Infusing Love: A Mom's Blog

This blog, created and maintained by the Hemophilia Federation of American, is a platform where mothers freely and unapologetically discuss the daily triumphs, missteps, hiccups and victories that come hand in hand with caring for their children with inherited bleeding disorders.

http://www.hemophiliafed.org/news-stories/moms-blog/

Hemophilia is for Girls

Written by an inspirational and courageous young Canadian woman that I have had the pleasure of meeting personally, this blog is dedicated to raising awareness for young women with bleeding disorders, by shedding light on the daily struggles and adaptations necessary in order to live a healthy, happy and "normal" life with severe hemophilia, as a female.

http://hemophiliaisforgirls.blogspot.ca/

My Girls Blood

Though based out of the United States, this non-profit website has a strong international presence and prides itself on being a well-informed ambassador for women worldwide. Founded by Cheryl D'Ambrosio, step mom to two young women with factor V deficiency, she and her team believe in the importance of documenting the current happenings and history of women with bleeding disorders. This site has a plethora of resources, testimonials from women worldwide, and reportings from large meetings where the care and needs of women with IBDs is discussed, such as the World Congress.

http://mygirlsblood.org/

Bleeding in Hemophilia Carriers: An Unrecognized Problem

by Jane Young and Paula James

Hemophilia is a bleeding disorder that primarily affects men. It involves a mutation on the X-chromosome which causes a deficiency of factors that are required for normal blood clotting. Women who have one of two X-chromosomes carrying a hemophilia mutation, are called 'carriers' of the disease. Historically, carriers were not considered to have bleeding symptoms, but could pass the mutation on to their children. It is now known that approximately 30% of carriers of hemophilia (HC) have low clotting factor levels and can have abnormal bleeding symptoms. Currently, there is no standardized tool for the assessment of bleeding symptoms in HC, therefore we set out to validate our existing Self-BAT (self-administered bleeding assessment tool or bleeding questionnaire) in these women.

This is an international study involving researchers from Queen's University in Kingston, Canada, the University of Calgary in Calgary, Canada and the University of Witwatersrand in Johannesburg, South Africa. We are recruiting female carriers of Hemophilia A or B, > 18 years of age. To date, 18 HC have been enrolled in Kingston and 15 in Johannesburg. Of these 33, 32 have completed the questionnaire and had their clotting factor levels measured. All carriers with low clotting factor levels scored higher than normal (5) on the Self-BAT. Therefore, this questionnaire is able to correctly identify carriers who are suffering from excessive bleeding and may help them access the appropriate health care. We are delighted that our preliminary analysis suggests that the Self-BAT is a highly effective tool to incorporate into the clinical assessment of HCs. The Self-BAT allows the identification of HC who will benefit from treatment strategies aimed at controlling bleeding symptoms and will facilitate improvements in the management of these patients overall.

15th Annual TCOR Golf Tournament

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

The TCOR Golf Tournament, which took place on Friday September 12 at the Nobleton Lakes Golf Club, was a huge success! After a beautiful day on the course, over 70 golfers attended a fantastic dinner and were able to bid on great prizes, including tickets to several sporting events, autographed sports memorabilia, and performing arts tickets, as well to participate in a raffle. At the end of the day over $10,000 was raised for the society!

Big thanks to Nobleton Lakes Golf Club for hosting our event, to all of our amazing sponsors for their generosity, including Barrick, Pfizer, and Biogen Idec, Pine View Hyundai who donated the vehicle for the hole in one car giveaway, and to all of the participants. See you again next year!

Summer Fun!

The TCOR Families in Touch (FIT) event was held on Saturday June 21st at High Park in Toronto. With great weather and delicious food available, families were able to enjoy a picnic and bond with those new to the society and those who have been members for several years. The event also had a psychologist from SickKids hospital in Toronto talk with the parents, with the topic being "Mental Health of Children Living with a Bleeding Disorder and their families: the Challenges of Parenting", while the children were entertained by Baldini the magician!

A big thank you to the over 40 attendees, including the several volunteers who helped run the event. The next event will be happening in December and we hope to see you all there!

Don't Push Your Luck

On June 28, in Toronto, Bayer hosted a game day! A pizza lunch was followed by allowing families to play the new game "Don't Push Your Luck", a board game especially targeted for those living with inherited bleeding disorders! Families got to play and network with, and learn from, one another.

A big thank you to everyone who attended; the families, Vanessa Bouskill from SickKids, Dr. Andrea Pritchard Kennedy from Mount Royal University in Calgary and Bayer.

World Hepatitis Day

Over the last 2 weeks of July TCOR had tables set up at both SickKids and St. Michael's hospitals to hand out educational materials for World Hepatitis Day.

The tables were popular, with approximately 100 people visiting and educating themselves on Hepatitis and Inherited Bleeding Disorders.

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FIT Winter Celebration!

Mark your calendars, as the next Toronto and Central Ontario Region Families in Touch event, which will be taking place on Sunday December 7th, and will be a holiday party! For those interested in Camp Wanakita 2015 there will be registration forms available at this event.

More information about registration and location will be released closer to the event. Our most popular event of the year, make sure to be there for a fun time!

TCOR

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North Western Ontario Region

Fall and Spring Clinics

Fall clinics will be taking place on Monday November 10th, and Tuesday November 11th at the Thunder Bay Regional Health Sciences Centre. We hope to see you all at our Spring Clinic in 2015. Keep a lookout for dates on when this will be taking place.

NWOR

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Ottawa and Eastern Ontario Region

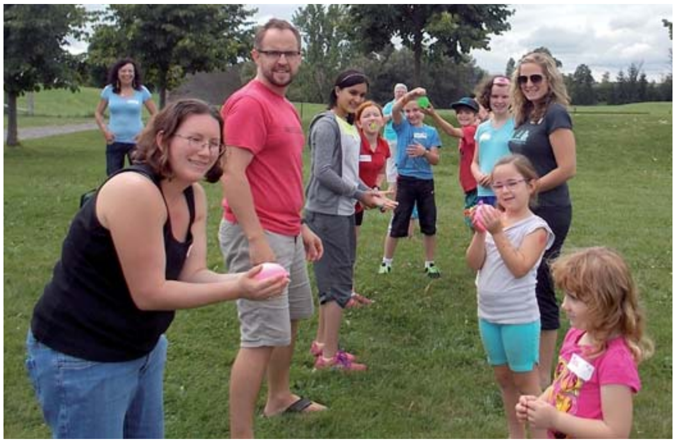
Ottawa Summer BBQ

All OEOR articles, unless otherwise noted, are by Amanda Grant

It was a beautiful day on August 24th at Millennium Park with lots of people out enjoying the remaining days of the summer. Participants enjoyed delicious burgers, as well as salads and tasty desserts. Kids loved the balloon toss and trivia prizes, and the event gave parents the opportunity to meet each other. Overall the event was a success and OEOR hopes to see some new faces next year.

Kingston Summer BBQ

This was the first outdoor event the Kingston area has had and attendees enjoyed a day at Grass Creek Park. It was overcast but that didn't stop members from coming out and kids playing in the park and the lake. The food that was brought by guests was delicious and the children loved the Ring Pops as well as the Cineplex gift cards they won. OEOR would like to thank Sherry Purcell and Lisa Thibeault for their help with bringing the families together for this event.



20th Annual Shawn Duford Hemophilia Golf Tournament

There were 88 registrants and all attended the 20th Annual Shawn Duford Golf Tournament on Saturday August 9th, 2014. The event fell on one of the warmest days of the year and it was the perfect day to enjoy it. Golfers enjoyed a BBQ prior to the event, and a delicious top sirloin buffet for dinner as well games with many prizes to be won. This year the tournament netted approximately $7800. OEOR thanks all of the volunteers that helped out with the tournament and many thanks to Pfizer and all sponsors for their donations.

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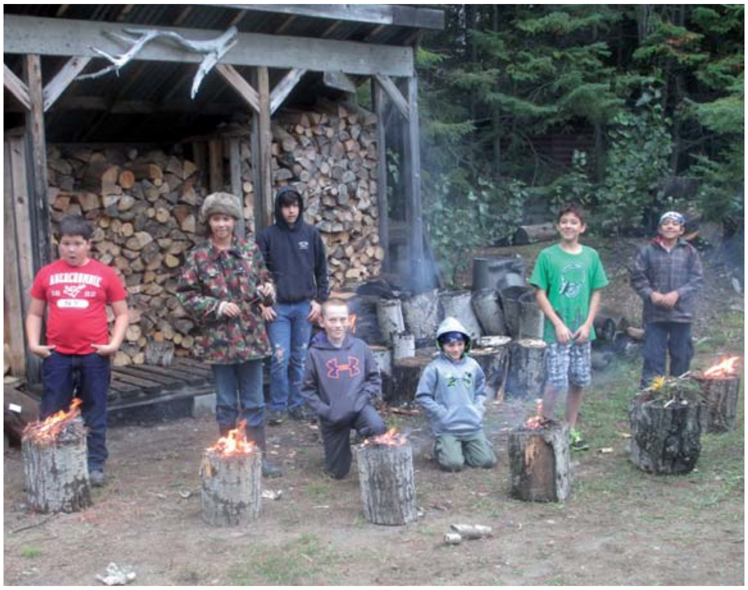
Just the Guys

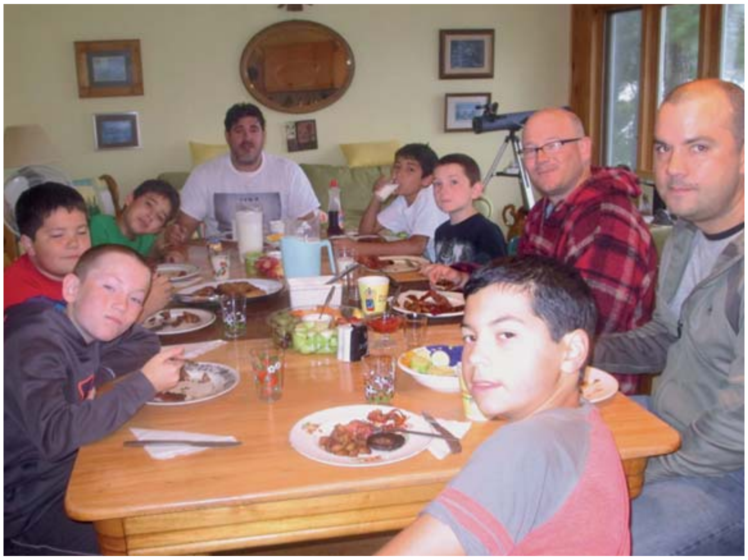
All NEOR articles, unless otherwise noted, are by Stephanie Morrison

This September fathers and sons spent a beautiful fall weekend on Lake Manitou. Northern dads' and their sons were invited to participate in the "Just the Guys Survivor Island Weekend" at Betty-Ann Paradis' cottage for the occasion. Betty-Ann is a nurse from the NEOR HTC.

The weekend focused on survival skills, such as knot tying, safe fire building, first aid in the wilderness, and how having hemophilia may present some challenges but that they can be overcome with proper preparation.

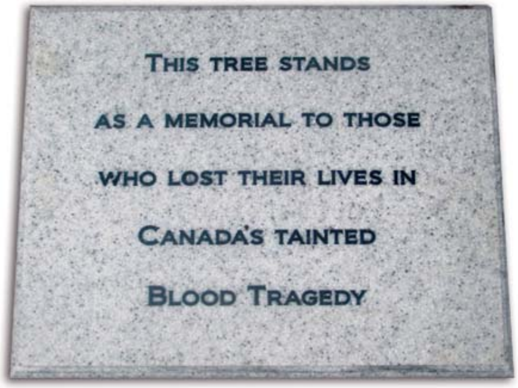
A big thank-you to Andre Paradis our cook, Adam Paradis our youth camp counsellor, and Tammy Bourque, NEOR HTC nurse. A special thank-you to Betty-Ann Paradis for her wonderful hospitality. ♦





Commemorative Tree Dedication Ceremony

During the closing ceremonies of the Just the Guys weekend, the fathers and sons took part in a commemorative tree planting dedication. The six young boys and their fathers attending the ceremony gained a valuable insight into the lives of individuals with hemophilia prior to the use of recombinant factor. They acknowledged that the tainted blood tragedy was tragic, however as a result of this tragedy, new and safer treatments were developed, making the lives of individuals living with hemophilia safer. The tree dedication ceremony also signified the importance of remembering those who were touched by the tainted blood tragedy and our commitment to ensure it never happens again. 🩸



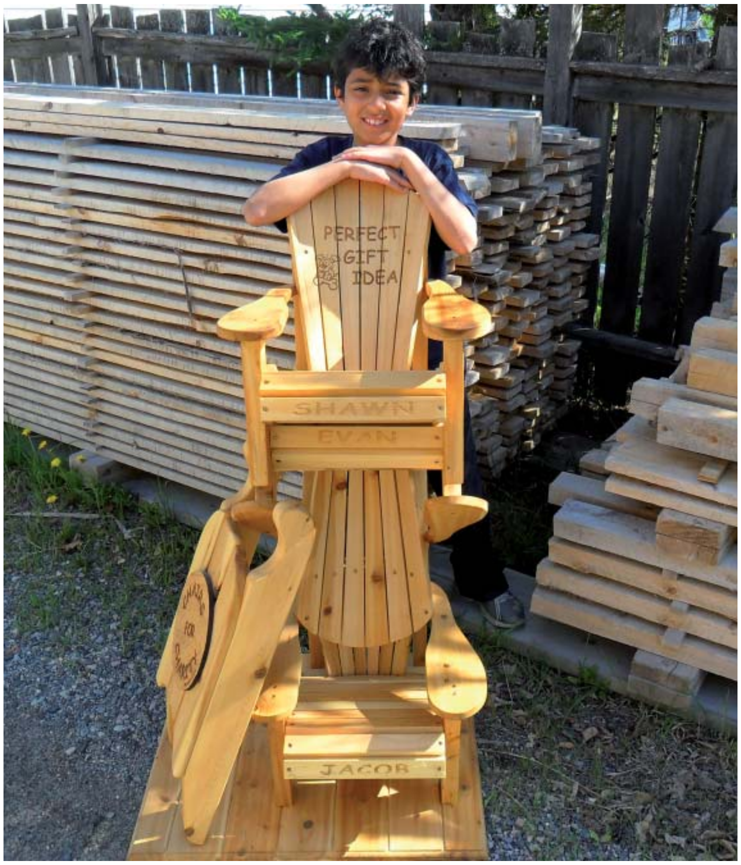
Cedar Chairs for Charity

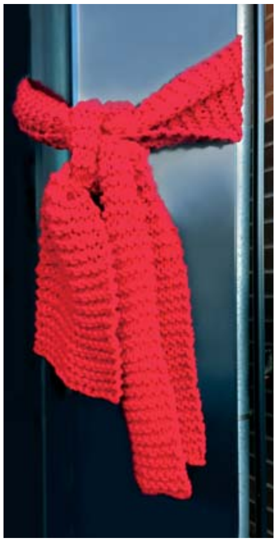
by Spencer Sterritt, Summer Student

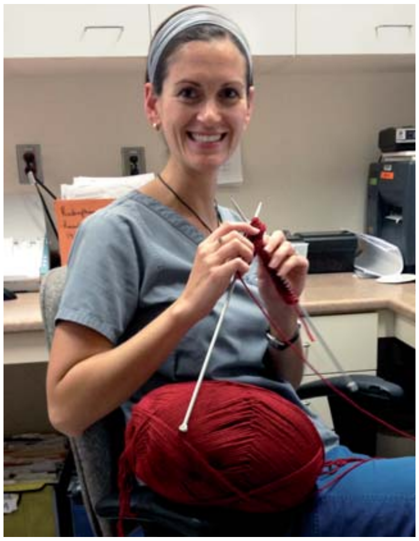
There are so many ways to donate to charity and non-for-profit organizations these days, which results in the fantastic feeling of doing your part and a thank you message in the mail. By donating to Cedar Chairs for Charity, you can enjoy that fantastic feeling while reclining in your new personalized Adirondack chair courtesy of Evan Morrison.

At only 10 years old, Evan Morrison is shining a light on all of the different ways that we can become involved in supporting those with inherited bleeding disorders. Afflicted with hemophilia himself, Evan had the great idea to make Adirondack chairs to then sell for charity. The cedar comes from Manitoulin Island, is provided by the Cedar Shack (where Evan's father works), and for every chair sold a tree is planted. Cedar Chairs for Charity has become a family affair, with Evan's older brother Jacob overseeing the website, and his younger sister Carly acting as a spokesperson on the site. His mother Stephanie commented "From a very early age Evan would often ask 'when is someone going to make a pill for me to take?' and I would always answer 'they're working on it.' I think his motivation for starting this charity is to help move his wish along, and what better way than to support the people trying to make it happen?"

The chairs can be bought for $70.00 each, with $20.00 going to the Northern Ontario Hemophilia Society. A personalized name plate can also be purchased for an additional $15.00 of which $2.00 would also be donated. 🩸







AIDs Awareness

The ultrasound department at Health Sciences North has volunteered their time and exceptional skills to the "Red Scarf Project".

Handmade knitted red scarfs are attached with information about AIDs and HIV, which are then tied around lamp posts in the city. The project targets homeless individuals providing them with valuable information and a warm scarf to help throughout the cold winter months. ♦

NEOR

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Central Western Ontario Region

Summer BBQ at Kinsmen Park

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

After a few years of canceling our annual event due to weather and poor turnout, we were thrilled to hold our potluck BBQ at Kinsmen Park in Caledonia for our community on Sunday July 6th. It was a hot, sunny day which was perfect for families to come out and enjoy each other's company as well as the free entrance to the Kinsmen Park Pool.

Thank you to the CWOR Council for all of their help and continued support in the planning of these events. Our region wouldn't be as great as it is without you! ♦

Big Sale on the Little Street!

September is always a busy month for fundraising in this region. On September 6th, the Big Sale on the Little Street took place just outside of the Locke Street Festival. Our regional volunteers came together to host the sale, and raised $400.00 for CWOR programs and services.

Many thanks to Mary Pedersen for organizing the sale, to all of the volunteers for helping with the set up, and to Jace Pedersen for helping with the take down. We'd also like to thank Jane Dinsdale and Tyler McGillivray for helping out during the day. ♦

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

Supercrawl was Super Awesome!

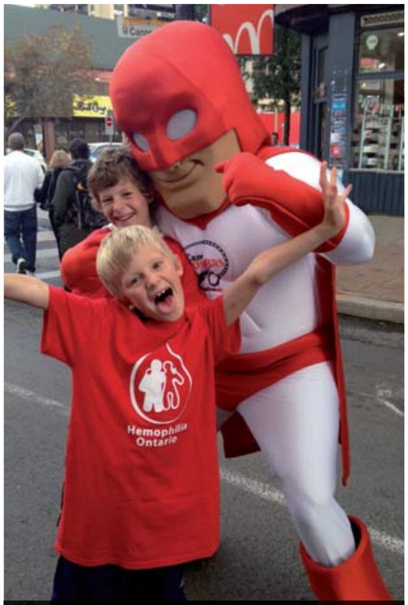
After the success we experienced in 2013, the CWOR Council decided it was best to move forward with creating a planning committee to participate in 2014's event. As expected, planning provided us with an opportunity to attract new volunteers to help run the event, and a fun way to raise awareness for the inherited bleeding disorders community. This year we had the added bonus of participating in Supercrawl for two days. From Saturday September 13th to Sunday September 14th, you would have found us at the corner of Cannon St. and James St. N slinging hot dogs and sausages to the masses.

This event was a great success with an estimated 160,000 people attending the festival, and the region raising just shy of $2000.00 to be used towards regional programs and services! Many thanks to all of the volunteers who helped make this event such a huge success: Paul Bordi for the use of his truck and for helping with both the set up and take down during the event, Mary and Jace Pedersen, Rob Dinsdale, Amy Griffith, Debbie and Meagan Bordi, Jenny Vasquez, Nola Plumb, Dannielle Hazaras, Vivienne Hazaras, Gabriella Hazaras, Nomvelo Nkomo, Megan Johnston, Anthony MacLeod, and Stephanie Vasquez. We'd also like to thank Marvin, Jesse, Michelle, Cohen and the two Elis for their amazing job directing the crowds to our tent. A tremendous thank you is sent out to our grillmasters, Tyler McGillivray, and Cale Mundt. We'd also like to thank those who generously sponsored items for the BBQ: Starsky's Fine Foods for the sausages, Highland Packers for the discounted hot dogs and Costco Wholesale for the $25 donation.

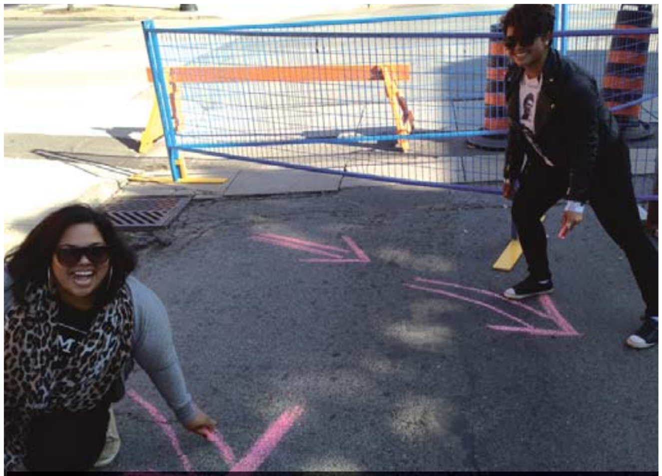
A special thank you is extended to the Supercrawl Organizing Committee for giving us the tent space at the festival. We truly appreciate being able to participate in this amazing event.

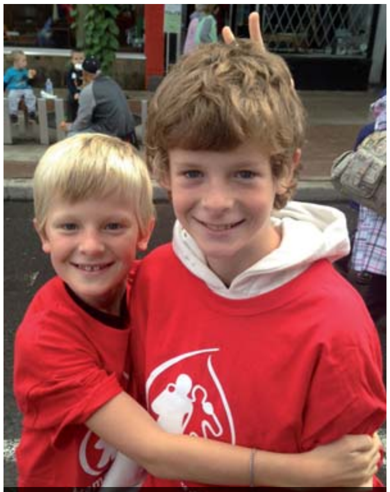
If this event sounds like fun to you and you're interested in volunteering, please contact Alex McGillivray, Regional Service Coordinator at **amcgillivray@hemophilia.on.ca** for more information.


Superstar volunteer Cohen M helping to direct people to the BBQ



Brothers Jesse and Eli B having a time with the Crime Stoppers Superhero


Sisters Clarissa and Jenny Vasquez happily adding some artistic touches to help out our cause!


Brothers Jesse and Eli B at it again and helping direct people to our BBQ

Our awesome night crew - Stephanie Vasquez, Gaby Hazaras, Tyler McGillivray, Vivi Hazaras, and Dannielle Hazaras

CWOR

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Meagan Bordi

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SWOR Goes to Western University

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

Participating in the volunteer fair at Western University over two days in September was an opportunity to tell the story of bleeding disorders in our community and to make new connections with students, professors and staff on campus. All the results for this growing participation of the campus community are not in but just one benefit was the opportunity to network during the following week with professional newcomers to Canada who are looking to get connected with the community as well as finding meaningful volunteer work.

Dine & Learn

SWOR held its first event as part of the Aging with a Bleeding Disorder series happening across Ontario. We thank our sponsors Bayer and Baxter for supporting this event.

With over 20 participants, we shared dinner and lots of conversation followed by Dr. Minuk, Medical Director of the Bleeding Disorders Program at the London Health Sciences Centre, who presented on the emerging concerns beyond joints, treatment protocols, and inhibitors for elderly patients. These were the results of a multi-center study which were presented at the World Hemophilia Congress in May. Darren Robbins, Coordinator with the South West Self-Management Program, provided very practical suggestions with his presentation, 'Getting the Most out of Your Healthcare Appointment.'

> *'I liked meeting new people and especially seeing old friends - never see enough of them! It was like our old get-togethers. The info was pertinent – we used to talk about getting through childhood with emphasis on the kids - new importance to aging.'*
>
> *— quote from event participant*

> *'Surprisingly good speakers. Could have been a rather dry affair, but Dr. Minuk and Mr. Robbins had good energy and were engaging.'*
>
> *— quote from event participant*

SWOR Council Learning and Volunteering Together

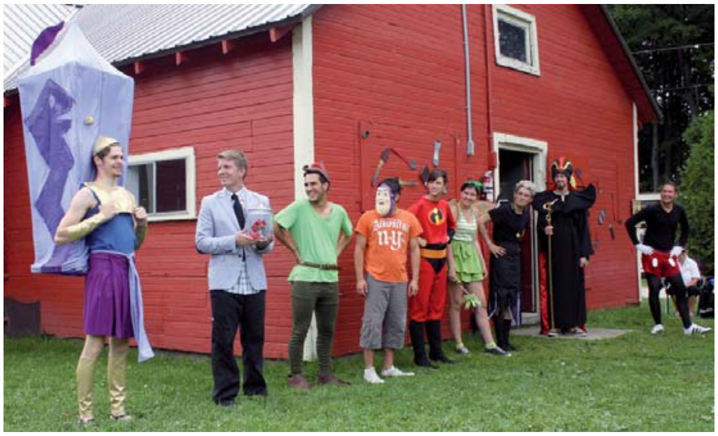
The SWOR Council has committed to their own development as part of each of their regular meetings with both presentations from members and invited speakers and leaders from the community. Some of these have resulted in discussions beyond the meeting like Sean Quigley of Emerging Leaders on engaging members through storytelling or Alison Graham, author, consultant, and speaker about building relationships. Our own members have presented on the budgeting process, outcomes programming, and soon to come gene therapies and health care politics. While it is often challenging to get through the agenda of each meeting the commitment to learn from each other and together has become an integral part of volunteering on the SWOR Council.

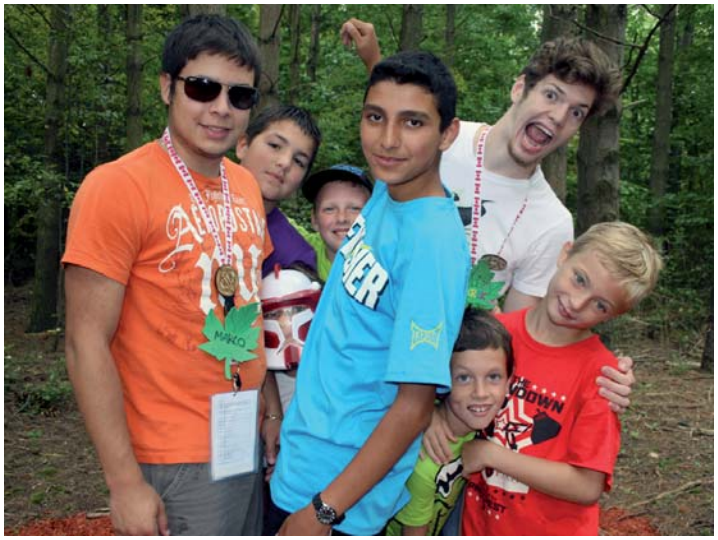
Saving Movie Magic

by Terri-Lee Higgins

The campers and staff proved that movie magic isn't lost in this year's Pinecrest Adventures Camp Disney vs. Pixar. Walt Disney and Mickey Mouse, robbed by Jafar and Ursula of their movie magic, sought help from Peter Pan, Tinkerbelle, Mrs. Incredible and Buzz Lightyear to save their movies. The campers and staff bravely faced many challenges, including an obstacle course, to ensure that both Disney and Pixar will continue to make movie magic.

Thank you to our amazing staff for their continued outstanding efforts to make every day of camp special and the overall camp experience exciting. You build a love of camp in them and as a result ensure campers want to come back year after year with many becoming future staff. From the crafts to the games to the many activities your enthusiasm was contagious. Thank you, Ryan, for your time and passion. We wish you the best of luck as you continue to pursue your medical career. To the Camp Committee and SWOR Council, thank you for making sure that Pinecrest remains a cornerstone program for the regions youth. Please join us on thanking Pfizer, Bayer, Baxter, Biogen and the employees of Cando Rail Services for their support of Pinecrest Camp 2014, without them camp magic could cease to exist.





Pinecrest Camp

by Terri-Lee Higgins

How important is beginning leadership development for some SWOR youth? If you read the following texting exchange with which I thought was a parent (to learn it was the camper) you'll know:

TEXT RECEIVED: Will N be an LIT this year? He's just been a senior for a really long time?

REPLY: unfortunately he is only 14 this year, LIT's are 15 and 16

TEXT RECEIVED: ☹

TEXT RECEIVED: he's sad

REPLY: he'll be an LIT next year

TEXT RECEIVED: Can we just say he is this year? ☹

TEXT RECEIVED: and by the way this is N

TEXT RECEIVED: LOLZ

REPLY: I wish we could and just think you have lots to look forward to next year

TEXT RECEIVED: ☺

SWOR

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Travis Hazelwood
Hannah Higgins
Julia Lepera
Michelle Lepera
Monica Mamut
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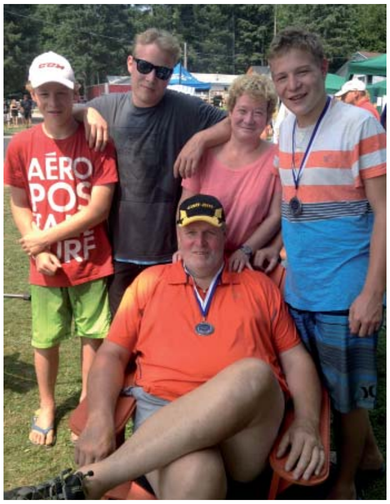
The Postma Family

by Heather Postma



I am a physiotherapist and mother of three sons – Cameron (17), Graeme (16) and Bryn (13). All three boys were born prematurely related to bleeding complications. All three boys are vibrant and healthy now. Both Cameron and Bryn have hypofibrinogenemia, which is a rare blood disorder involving a deficiency of fibrinogen and affects 1 in 10 million people.

Similar to most bleeding disorders, it affects the clotting of the blood. I like to explain it to people that we still clot, we just take Highway 7 when others take the 401 – just a little longer. I was diagnosed with hypofibrinogenemia at age 27 and had undergone 2 major neck surgeries as well as a wisdom teeth removal prior to diagnosis. I did require transfusion on the second surgery but most of my difficulties were during pre/post natal times.

Our biggest challenge has been to balance sport and recreation activities that Cameron and Bryn enjoy. Cameron has played football and Bryn non-contact hockey. Both boys have excelled. I have recently been referred to as "the coolest mom" by a physician co-worker for being able to find a life/play balance with our knowledge of the bleeding problem. I've also had a chance to reflect on how equipment and safety has progressed in sports and how I was allowed to live a "normal" sporting life prior to diagnosis. Therefore, despite our knowledge of hypofibrinogenemia, Cameron, Bryn and I enjoy a regular active lifestyle. We are very fortunate.

Web Resources

World Federation of Hemophilia
www.wfh.org

Canadian Hemophilia Society
www.hemophilia.ca

Hemophilia Ontario
www.hemophilia.on.ca

Living Beyond Hemophilia
This site was created especially for people with hemophilia who are searching for resources and practical information needed in today's world.
www.livingbeyondhemophilia.com

National Hemophilia Foundation (NHF)
The American organization dedicated to the inherited bleeding disorders community.
www.hemophilia.org

Step Up Reach Out (SURO)
An international youth leadership program designed to develop and train young adults with hemophilia in the bleeding disorders community who have the drive and ability to become leaders.
www.hemophilialead.net

HERO Study
HERO (Haemophilia Experiences, Results and Opportunities) is an international, multidisciplinary initiative guided by the HERO International Advisory Board and supported by Novo Nordisk.
www.herostudy.org

Hemophilia Village
Stay Informed. Be Inspired. An American website brought to you by Pfizer.
www.hemophiliavillage.com

Speaking Frankly
A daring, distinctive online magazine that aspires to serve as a candid, trusted resource on real issues of concern to teenagers and young adults with hemophilia worldwide. The magazine casts light on often taboo subjects such as sexuality, drugs and depression, and offers lively coverage of lifestyle topics including travel, entertainment, health and fitness. Sponsored by Bayer HealthCare, Frankly.net was established to help teens and young adults with mild to severe hemophilia make informed, confident decisions about life.
www.frankly.net

CODErouge
A website dedicated to women and inherited bleeding disorders provided by the Canadian Hemophilia Society.
www.coderougewomen.ca

Hamilton-Niagara Regional Hemophilia Program
Website for the hemophilia clinic located at McMaster Medical Centre in Hamilton, Ontario
www.hamiltonhealthsciences.ca

London Health Sciences - London, Ontario
Website for the bleeding disorders program.
www.lhsc.on.ca/About_Us/Bleeding_Disorders

Thunder Bay Regional Health Sciences Centre (TBRHSC) - Thunder Bay, Ontario
Website for the hemophilia clinic located at TBRHSC.
www.tbrhsc.net

Health Sciences North - Sudbury, Ontario
Website for the hemophilia program.
www.hsnsudbury.ca

St. Michael's Hospital - Toronto, Ontario
Website for the hemophilia comprehensive care program
www.stmichaelshospital.com/programs/hemophilia/

SickKids Hospital - Toronto, Ontario
Website for the hemophilia clinic.
www.sickkids.ca

Kingston General Hospital (KGH) - Kingston, Ontario
Website for the hemophilia clinic located at KGH.
www.kgh.on.ca

The Ottawa Hospital - Ottawa, Ontario
Website for the Ottawa Regional Adult Bleeding Disorders Program.
https://www.ottawahospital.on.ca/wps/portal/Base/TheHospital/ClinicalServices/DeptPgrmCS/Programs/BleedingDisordersProgram

Children's Hospital of Eastern Ontario (CHEO) - Ottawa, Ontario
Website for the hemophilia clinic at CHEO.
www.cheo.on.ca

Victory for Women with Blood Disorders (V4W)
An initiative by the National Hemophilia Foundation (NHF) to address the critical issues faced by women with bleeding disorders.
www.victoryforwomen.com

Biogen Idec's Press Release Site
A place where you can find the latest news releases from pharmaceutical company Biogen Idec.
www.biogenidec.ca/news

Infusesmart
A website with useful information about hemophilia and its treatment that is brought to you by Biogen Idec.
www.infusesmart.ca

CANADIAN PHARMACEUTICAL COMPANIES

Baxter Canada
www.baxter.ca

Bayer Healthcare
www.bayer.ca

Biogen Idec
www.biogenidec.ca

CSL Behring Canada
www.cslbehring.ca

Novo Nordisk
www.novonordisk.ca

Octapharma Canada
www.octapharma.ca

Pfizer Canada
www.pfizer.ca

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

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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.

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Hémophilie Ontario

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