

A publication of



Hemophilia Ontario
Hémophilie Ontario

BLOOD

matters

"We're all related by blood."

Volume 2 • Number 2

Summer 2011



Disclosure
Whom do you
tell, and when?

Hemophilia Ontario

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Hemophilia Ontario
Hémophilie Ontario

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What's in this issue?

Summer 2011 • Vol. 2, No. 2

Information from Hemophilia Ontario and its Regions

	Page
Hemophilia Ontario	3-13 21-28
Central Western Ontario Region	14
North Eastern Ontario Region	15
North Western Ontario Region	16
Ottawa and Eastern Ontario Region	17
South Western Ontario Region	18
Toronto and Central Ontario Region	19

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Leadership Messages

President's Message



OVER THE COURSE of the next year it is my hope that Hemophilia Ontario will work collaboratively with its members and partners to continue to “improve the health and quality of life for all people with inherited bleeding disorders and to find a cure.” This should begin with a review of our desired outcomes to ensure that we are contributing to research efforts and focusing enough on advocacy and awareness.

We need to work to rebuild our relationships with our partners. We should recognize that we are stronger working together than unilaterally. As an organization, we must recognize that the regions are where the passion of our organization lies, and where much of the work that makes a real difference in our members' lives gets done. The grassroots understands the needs of our members much better than our chapter board.

However, it is essential for the regions to realize that the provincial board is the incorporated entity and will need to take steps to protect the organization from liability and financial or reputational harm. Hemophilia Ontario should strive to work more cohesively with the national organization to ensure that we reduce redundancies of effort and capitalize on expertise. Hemophilia Ontario should have a global vision and ensure that we contribute what we can to the Canadian Hemophilia Society and the World Federation of Hemophilia efforts to improve the quality of care for people around the world with inherited bleeding disorders.

Hemophilia Ontario needs to consider volunteer development and succession planning as priorities. We also need to make sure that youth are included in the work of the organization. These steps will help ensure that a new crop of strong and informed leaders will emerge to advocate for people with inherited bleeding disorders.

Congratulations to the newly elected and re-elected board members for 2011-2012. As we move forward, the board will be looking to:

- Improve practices and develop board assessment tools
- Develop an effective orientation session, including updated job descriptions and ongoing comprehensive training for board members.

Don't be surprised if you are approached by a board member to help as we reach out to bring individuals with necessary skills to the table. We will search out expertise from within our community to help us focus on big picture issues.

Thank you to all of the retiring board members and volunteers for your benevolent efforts to move our cause forward. Thank you to the Hemophilia Ontario staff for your tremendous efforts for this organization. Thank you to David Page and the national office team for your support. I hope you all know how much your efforts are appreciated by the individuals Hemophilia Ontario serves.

I look forward to a positive year in which we work cohesively towards achieving our mission.

Paul Wilton, Hemophilia Ontario President ♦

*Hemophilia Ontario
needs to consider
volunteer development
and succession planning
as priorities.*

Message from the Editor

FIRST OF ALL, I want to welcome you to this edition of *Blood Matters*. I'm both honoured and humbled to be your new Editor.

Since I was diagnosed at birth, I think it's almost fair to say that I was born into this organization. In my earliest years, my mother, Susan Bernstein, played a major role as a dedicated TCOR volunteer. When I became active in the organization a few years back, I knew I had tremendous shoes to fill.

The biggest shoes of all though clearly belong to our previous Editor, Frank Bott. It's impossible to mention Frank's name in this organization without acknowledging his decades of tireless service in the same breath. Frank, I want to personally say it's the work of your generation that has granted me and my peers freedoms that were previously unimaginable. From the bottom of my heart, I can't thank you enough.

In this issue of *Blood Matters*, you'll read a lot about disclosure, and how people reveal that they're affected by a bleeding disorder. No matter what personal choice you make in how you disclose your illness, a great deal of it has to do with the posture you take. No matter what you tell someone, or even choose not to tell them, doing so with confidence and poise can make a huge difference.

The same can be said for Hemophilia Ontario. It's no secret that we've seen this organization through a great deal of change in recent months. I'm tremendously proud of how our staff and volunteers are handling those changes, with confidence and poise. Instead of looking backward, they're facing forward, and working impossibly hard to create a strong, dynamic Hemophilia Ontario for the 21st century. I'm just proud to be part of the team.

I also want to let you know that I'm completely accessible at any time for any comments, questions, or feedback you may have on the magazine. Feel free to drop me a line at shaunbernstein@gmail.com.

Have a pint on me!

Shaun Bernstein, Editor ♦



The Value of Volunteers

by Terri-Lee Higgins, Interim Provincial Program Manager

I OFTEN PERUSE THE INTERNET for information, facts and details that I can use in my day-to-day work. Recently I came across the following statement about volunteers:

"A volunteer is someone who gives time, energy and talents to others, expecting nothing in return. Volunteers must have an open mind, be willing to embrace wisdom learned from others and also let the experience of volunteering lead to personal inner growth. Volunteers realize the importance of time and kindness. With the wide range of opportunities, volunteers have the freedom to find an organization that best suits their needs. A volunteer is someone who is willing to learn. A volunteer is someone who has the freedom to choose."

The last sentence really hit home with me—volunteers have the freedom to choose the organization to which they dedicate their time and skills. We are a small society that has incredible wealth in our volunteers. I have interfaced with many Hemophilia Society volunteers across the province in recent months. They told me they volunteer because they

We'd love to hear from you!

Start thinking about these questions. We'd love to have you write for upcoming issues of Blood Matters, or our November direct mail appeal letter.

How do you explain your bleeding disorder to people who don't know anything about it?

How were you first diagnosed? What was the experience like?

How have you grown as person because of your bleeding disorder? What important things has it taught you? Have you learned something about yourself because of it?

How has Hemophilia Ontario and its regions helped you and your family?

Are you a mom or a caregiver to a young girl with a bleeding disorder?

Do you ever feel like an outsider in the bleeding disorders community?



benefit in many ways, including the opportunity to pursue an interest, gain new information, new skills or enhance existing knowledge, often gaining considerable expertise in the process. Many felt that they have reaped far greater rewards than a work promotion or good school grades.

Our volunteers serve in many capacities, contributing time, energy and talent to fulfil our organization's mission and create a positive community image. They extend and augment the work of paid staff, bringing new insights to the work. During a recent six-month timeframe, Hemophilia Society volunteers recorded a total of 2,465 volunteer hours across the province. It is estimated that each hour a volunteer works has a value of \$21.36. If this is true, then Hemophilia Ontario benefitted from over \$100,000 worth of volunteer time in the past year alone. Volunteers are the backbone and the true heart of the organization. Their time is a gift which they feel good about giving and we feel good about receiving—a win-win for everyone. I once heard there is no “I” in team but there is a “U” in volunteer. I can't imagine our community without them. ♦



Why Hemophilia Ontario needs to remain a strong grassroots organization

by David Page, Hemophilia Ontario Acting Executive Director

HEMOPHILIA ONTARIO has been a leader among chapters of the Canadian Hemophilia Society on key advocacy issues for the past generation. Whether the issue was responding to the risk of HIV in blood products, lobbying for compensation for blood-related injuries, or pushing for reform of the blood system and introduction of high-quality clotting factor concentrates, volunteers from Hemophilia Ontario have been at the centre of national efforts and instrumental in our collective success.

Times have changed; the battles of the last 25 years have largely been won. New challenges, however, have emerged; for example, increasing access to comprehensive care for new clientele including women with bleeding disorders and people with von Willebrand disease and rare bleeding disorders.

Other challenges remain below the horizon. These include continued access to an optimal supply of therapies for the full range of bleeding disorders to support high-quality, preventive care; and adequate human resources to staff all the disciplines in our comprehensive care centres. Taking these for granted would be a mistake.

In 2009, Hemophilia Ontario wisely adopted a four-year strategic plan, one of whose strategic goals called on the organization to act as a strong advocate on behalf of people with inherited bleeding disorders.

Strategies included:

- the identification of emerging public policy priorities
- mentoring for new and emerging leaders
- enhanced representation on key external boards and committees
- partnerships with other organizations and health care professionals to foster knowledge and understanding of relevant issues
- the development of Hemophilia Ontario position statements on issues that influence members' health.

While staff can provide support in this endeavour, it is truly the role of Hemophilia Ontario's volunteers to lead the organization through the challenges of the coming years. ♦



Blood Matters Summer 2011 /5

A Tribute to Frank Bott

REMARKABLE SERVICE OF MORE THAN 40 YEARS FROM A REMARKABLE MAN.

by Susan Turner, Marc LaPrise and the Plater Family



AS FRANK BOTT STEPS DOWN as the Editor of *Blood Matters* magazine, it's vitally important to thank him for the tremendous amount of effort he has put into the newsletter/magazine over many years with all levels of the organization. How do you possibly recognize Frank for all that he has done? It seems the best way would be to hear from a few of the community members who have benefitted so greatly from Frank as the driving force behind so many publications in Ontario. Here is what some of them had to say:

The Plater Family

Our family first met Frank Bott in 1968 at a Canadian Hemophilia Society Toronto Auxiliary Christmas party. Dr. Peter McClure from Sick Children's Hospital had put us in touch with the Society, and the party was our first contact with other families who were living through what for us was a nightmare. We knew very little about the disease and were ap-

prehensive as we ventured into the hall. What a surprise! People were talking and laughing, children were running around playing. In the midst of it all was the Bott family—Frank, Denise and their three boys. What a welcome they gave us! When we left that day we were part of a wonderful group who grew to be our “hemophilia family.”

Over the years we came to know Frank in social settings, and as a member of committees we sat on together.

He has always been a gentleman. At meetings he didn't raise his voice but quietly said what he had to say, and it was usually what everyone needed to hear. Any work he was asked to do was done right, and on time. Renowned for his knowledge of the history of the organization and its inner workings, Frank has become the unofficial historian of the Ontario Chapter and CHS as a whole. We owe him gratitude for having maintained and recorded our history to be passed down to future generations. It is always a powerful motivator to hear him reflect on his days as CHS President when the organization was “handed to him in a shoe box,” and then to scan through minute books and files to see how far we have come thanks to his hard work.

Frank has dedicated much of his life to educating people about hemophilia while championing a Society that responds to the everyday needs of people with bleeding disorders and their families. His early efforts in the movement for compensation in the tainted blood tragedy laid the groundwork for the huge accomplishments we made in that area. His legacy shines through in some of our key documents, thanks to his meticulous grammar and atten-

tion to detail. Yet he has never lost sight of the ultimate goal of finding a cure, and has devoted many years to re-energizing the research-focused Million Dollar Club.

Most importantly to us though, he has been a priceless friend and mentor to our family over the years. Frank, we thank you for your years of dedicated service as Editor of this fine newsletter [now a magazine], your friendship and devotion to making life better for hemophiliacs and their families. We wish you all the best.

Marc LaPrise

I had the pleasure of working with Frank Bott as Editor of the newsletter for about 10 years. I will never forget his handwritten notes arriving on my desk followed by a call about the deadline to have it all to press. We couldn't have asked for a better editor for so many years. Frank's attention to detail, impeccable grammar and English and “eagle eye” on the deadline provided the staff and other volunteers with a sense of direction and purpose. Thank you Frank for all your dedicated work on our newsletter/magazine. The next editor has a big set of shoes to fill! No pressure! ♦

Swan Song

In some ways this is a “sad event,” but more importantly, it represents more than 40 years of great satisfaction. When Denise and I first became involved with the CHS in Winnipeg, I was the Editor for the Manitoba Chapter newsletter. For years I was Editor of the national publication, *Hemophilia Today*. Then, as I became active at the Ontario level, I became the editor of the *TCOR Community News*, which subsequently became folded into *Blood Matters*. Recently I came to the realization that I wasn't “in touch” anymore and it was time for a new editor. Thank you for many years of satisfaction and enjoyment. Good luck and good writing!

Frank Bott

Ontario dynamos recognized at national Rendezvous conference

EVERY TWO YEARS, the Canadian Hemophilia Society's Rendezvous conference brings together representatives from its chapters across the country, along with doctors, nurses, physiotherapists and social workers involved in the bleeding disorders community. Rendezvous 2011, held in Calgary, provided an opportunity for learning, networking and future planning. The weekend included a scientific and medical symposium, strategic planning sessions, professional meetings and special sessions for older adults and youth.

Ontario has reason to be proud after two of its long-time members received awards at the banquet dinner.

Lucie Lacasse, RN, received an Award of Appreciation for her service over and above the responsibilities of a clinic team member in the care of people with inherited bleeding disorders. Not only has she provided outstanding care at the Regional Comprehensive Care Centre for Hemophilia and Hemostasis in Ottawa for over 20 years, but has contributed in countless ways to the bleeding disorders community. She has been a steadfast volunteer for the Ottawa and Eastern Ontario Region of Hemophilia Ontario; has developed many resources for hemophilia care, and is active on the CHS working group on aging, among many other contributions. Congratulations Lucie on your well-deserved award.

For her key role in the growth and development of the North Eastern Ontario Region over the last 50 years, **Helen Gibson** was given the Chapter Leadership Award. She dedicated her life to hemophilia, even after losing her son Robert. Mrs. Gibson was instrumental in creating the hemophilia clinic at the Sudbury hospital and was a founding member of the NEOR region. She and her husband Harry were also key players in the early campaign for compensation after the tainted blood tragedy. Mrs. Gibson, we can't thank you enough for your dedication to the cause. ♡

North Eastern Ontario Region revived and developing strongly

by David C. Bouffard

AFTER A GREAT DEAL of hard work, I can now announce with great privilege that on March 3, 2011 the Hemophilia Ontario Board of Directors unanimously approved the certification of the North Eastern Ontario Region. NEOR is once again as it should be!

Mrs. Helen Gibson was instrumental in developing and furthering the growth of NEOR from the very beginning and has seen it through many changes. I recently had the honour of meeting Mrs. Gibson, CHS 2011 Chapter Leadership Award recipient, and informing her that the NEOR had now been revived. Her eyes lit up and her smile gave me goosebumps. Thank you, Helen Gibson!

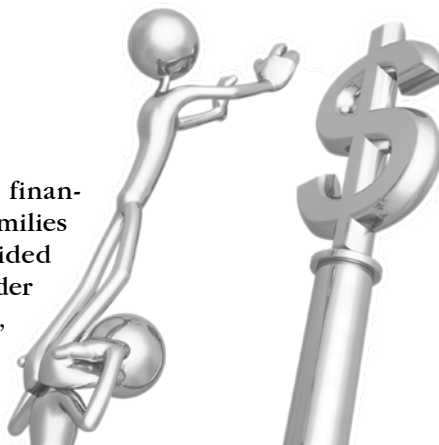
Redeveloping the NEOR is crucial to those with bleeding disorders and improves our ability to vigorously represent the best interests of those persons. Keeping in mind the infancy of this region, I am also pleased to state that it is within our vision that the NEOR territory will expand and strengthen with the consolidation of the NWOR with the NEOR to form the Northern Ontario Region (NOR). Application for this proposal is underway. Support from the national and provincial offices and the Ontario Board of Directors has been outstanding, especially in helping us to further our common mission. The experiences thus far have made our committee and board more confident and enthusiastic. I look forward to working together to achieve our goals. ♡

Financial assistance guidelines

by Terri-Lee Higgins

HEMOPHILIA ONTARIO provides financial assistance to individuals and families in need. Assistance could be provided for items related to a bleeding disorder including, but not limited to, tutoring, dental, medication, hospital parking/taxis, assistive devices, emergency funding and hospital funding for patients and/or equipment. 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 in that year. For information about the new guidelines or to receive the Financial Assistance Forms to complete and submit with receipts, please contact your local RSC. ♡



Hemophilia Families in Motion

by Robin Nobleman

► **HEMOPHILIA ONTARIO** brought together 31 people, the biggest team so far, to run in the GoodLife Fitness Toronto Marathon. All around, our team had a great race day—Matthew Travaglini from London won second place in the 5k run and his brothers Paul and Anthony and sister Laura all placed in the top 50 of their categories out of thousands of runners. We are very proud to have them representing the bleeding disorders community!

Team Hemophilia Ontario raised an amazing total of \$12,290 including \$5,595 in pledges raised by the runners. The proceeds support province-wide programs like Camp Wanakita and Just the Guys. Special congratulations to Darryl Gray and Victoria Kinniburgh who raised a spectacular \$2,090 and won the grand prize of a Nikon digital camera.

This event couldn't have run without the help of dedicated volunteers. Hemophilia Ontario had 15 volunteers operating a water station to rehydrate and cheer on runners. It ran very smoothly and our volunteers were congratulated on leaving the area spotless after the race. Volunteers at the information booth in Queen's Park raised awareness about inherited bleeding disorders and provided treats and encouragement for our team of terrific runners. Congratulations to all runners and volunteers on a job well done.

Our participation would not have been possible without the generous sponsorship of Pfizer Canada Inc. ◊



▲ Laura, Anthony, Paul and Matthew Travaglini after the race

Photo credit: Reid/Devereux

Youth Adventures

by Will Obm

D'MARC LEWIS invited me to join Hemophilia Ontario's Youth Adventures program. After a quick briefing at the McMaster campus, we split into smaller groups and drove to Dundas Valley, where we spent the next hour hiking up and down winding trails. The best part was getting to know the other group hikers. They were interesting and easy to talk to.

Back at the university over pizza, we turned our attention to the Photo-voice project. We had been asked to contribute photos related to our lives with hemophilia; now the collected pictures were distributed among smaller groups, who chose images they wanted to present at an upcoming art exhibit in Hamilton. We also discussed captions to add to the pictures.

A McMaster staff member took us out to McMaster's Alpine Tower II—the only one of its kind in Canada. At first sight, the 50-foot wooden climbing tower—decked with a bewildering array of single ropes, rope and log ladders, and massive dangling mace-like objects—looked intimidating. The higher I climbed, the less I tried to think about where I was and what I was doing; and it was such fun. Not everyone felt like climbing. Those who decided to

stay back or take a break enjoyed a friendly and fun atmosphere around a campfire.

After our climb (one member climbed all four sides, including the menacing mace-logs), we had a quick debriefing. As we walked away, I felt sorry to say goodbye. Thanks for a great day, everyone! ◊



Baxter





▲ D'Marc Lewis and Shaun Bernstein at the Photovoice show



▲ Photovoice gallery

The Photovoice Project

by Alex McGillivray

THE JAMES ST. NORTH ArtCrawl is a vibrant and bustling event held on the second Friday of every month in Hamilton's historic downtown core. On June 10, 2011 Loose Canon Gallery hosted the first ever Hemophilia Youth Photovoice show.

The Photovoice Project was designed to give youth ages 16-26 living with an inherited bleeding disorder a chance to share their experiences of living with a chronic illness. The youth were asked to choose a topic before embarking on their photographic journey, thus, the topic of "What Does Life Look Like with a Bleeding Disorder?" was born.

The photos were displayed for the enjoyment of the ArtCrawl crowd, and 50 percent of sales were donated towards continuing youth programs and initiatives for the future. This project was made possible by sponsorship from Bayer HealthCare.

Two of the pieces from the collection were sold at the gallery that night, but there are still 10 more up for sale. The photos are \$50 each with half the profits going toward future youth programs and initiatives and half going to the youth photographers. You can see them on display on Hemophilia Ontario's webpage: <http://www.hemophilia.ca/en/provincial-chapters/ontario/the-photovoice-project/> or search for Hemophilia Ontario or the Canadian Hemophilia Society on Facebook. ♡

JUST THE GUYS



Just the Guys registration now open

JOIN US for superhero-style fun and learning at Just the Guys, September 16-18. There are three easy ways to register:

1. By mail. Forms can be found at www.justtheguys.ca.
2. Register online at www.justtheguys.ca.
3. Contact your local RSC.

Can't wait to see YOU there!

Thank you to our title sponsor, Bayer HealthCare.

World Hemophilia Day around the province

Tasty treats in CWOR

by Alex McGillivray

FOR THE PAST FEW YEARS, the Central West Region (CWOR) has held their World Hemophilia Day Bake Sale in conjunction with the Hamilton-Niagara Regional Hemophilia Clinic at McMaster Medical Centre. This year CWOR celebrated World Hemophilia Day a little differently by holding their third Annual Bake Sale on Friday, June 10 during the James St. North ArtCrawl at Loose Canon Gallery in Hamilton.

The event provided a great opportunity for public awareness as hundreds of people stopped by the gallery and our table to connect as well as learn more about inherited bleeding disorders. Many thanks go out to Dane Pedersen for giving us a venue. I'd also like to extend a big thank you to Mary Pedersen, Robin Nobleman, Jeenetha Kulasingam, Tyler McGillivray, Carrie MacLeod and Rebecca Goldsmith who helped out by either donating their time at the event or by contributing baked goods. Your support is truly appreciated. ♡



▲ Paula Sapage, Andre and Carlos Linhares honour World Hemophilia Day with red tulips

Panel discussion for med students

by Robin Nobleman

► **THE TORONTO AND CENTRAL ONTARIO** Region tried a new approach to raising awareness this World Hemophilia Day by focusing on the doctors of the future. Two volunteers from TCOR, David S. who has VWD, and Dr. Maryam Naji, mother of a boy with hemophilia, spoke about their experiences with diagnosis, care and treatment to a packed room of first and second year medical students at the University of Toronto. Robin Nobleman, Regional Service Coordinator, provided basic information on inherited bleeding disorders and fielded the students' many questions. We hope this kind of awareness-raising will make things easier in the future for people with inherited bleeding disorders in the ER, at their GP's office and wherever they interact with non-specialists.

Generous donations from Bayer, Novo Nordisk and Paula Sapage enabled TCOR to give out tulips at the pharmaceutical companies and schools of two children with hemophilia. Baxter's Toronto office also held a lunch commemorating World Hemophilia Day where TCOR board member David Neal spoke about how improvements in factor treatments have changed his life for the better. ♡

Go Jump in a Lake!

by Paul Wilton

◀ “JUMP INTO LAKE ERIE on the most blustery day in April? Sure!” This is what approximately 25 members of our community said when they were asked to raise awareness of inherited bleeding disorders on World Hemophilia Day. On April 17 at Port Stanley’s Little Beach, SWOR held its second annual Polar Bear Dip awareness event. SWOR community members young and old braved the zero degree temperature, sleet and “gale force winds” to show their support for our community. Although this event is primarily intended to raise awareness, through the labours of our fearless dippers we were able to raise over \$5,000. Thank you to the participants, volunteers, donors, and Terri Lee for ensuring this event’s triumph. ♡



▲ The Catton family and friend Rob get psyched up for the tropical lake waters on World Hemophilia Day.

Walking for Hemophilia in NEOR

by Teresa Genereux

► **WORLD HEMOPHILIA DAY** was a cold, blustery one in Sudbury, Ontario. Many braved the wind, snow and rain to join us and Deputy Mayor Ron Dupuis as he proclaimed it World Hemophilia Day. I would like to take this time to thank two sponsors: OFSS Inc., and a private donor for their great financial support which allowed us to continue to meet our goals within the NEOR. A big thank you to our newest volunteer, Alana Brassard for hosting a third-party fundraiser in Sault Ste. Marie. Thank you to Lise Anne Lowe as well for selling fudge at our clinic. Thanks to the public and volunteers for all their support on this cold day. Our fundraising efforts were a great success. We have increased our volunteer base within our Northern communities who do not often get to attend such events in Sudbury due to long travel distances. ♡



▲ Chad Bizier and Christopher LeBlanc entertain fellow walkers on World Hemophilia Day



User Beware

OVER-THE-COUNTER PRODUCTS YOU SHOULD AVOID

by Betty Ann Paradis, Hemophilia Nurse (NEOR)

MANY OVER-THE-COUNTER medications contain aspirin or aspirin-like ingredients known as non-steroidal anti-inflammatories (NSAIDS) which can affect blood clotting. These medications are not recommended for persons with bleeding disorders. Before you use any over-the-counter medication, please check with your physician or nurse to be sure it is safe.

Acetaminophen is the aspirin substitute in Tylenol. It does not affect the platelets. If you need to use acetaminophen, please check with your doctor or nurse first.

On page 13 is a list of commonly used over-the-counter products that DO contain aspirin or Ibuprofen and SHOULD NOT BE USED unless approved by your doctor. Please read the labels of any other medicines you use to be sure that they are aspirin-free. For your safety, check with your doctor or nurse before taking any medicines or herbal supplements.

Topical Medications (medicines you rub on your skin)

Usually you can continue to use these products, but if you are taking a blood thinning drug (such as Coumadin) please ask your doctor or nurse before using any of these: Analgesic Balm, Arthrocare Lotion, Banalg, Ben Gay, Compound W, Deep-down pain relief, Freezezone, Icy Hot, Medioplast, Mentholatum Deep Heat, Whitfield's Ointment. ♂

Oral Medications (taken by mouth) THAT SHOULD NOT BE USED See article on p. 12

Acuprin	tablets	Nabumetone	Sulindac
Aches-N-Pain	Cosprin 325 and 650 tablets	Nalfon	Suspac tablets
Actron	Damason-P	Naproxen	Synalgos capsules and Synalgos DC capsules
Advil	Darvon Compound	Norgesic and Norgesic forte	Talwin compound tablets
Aleve	Darvon Compound 65	Nuprin	Tandearil
Alka-Seltzer (all preparations)	Dasin capsules	Nyquil	Tolectin and Tolectin DS
Effervescent tablets	Daypro	Nyquil	Tolmetin
Pain relief and Antacid	De Witt's pills	Orphenadrine	Toradol
Plus cold medicine	Diclofenac	Orudis	Trendar
Anacin analgesic	Diffunisal	Oruvail	Triaminicin tablets
Anacin maximum strength analgesic	Dipridamole	Os-cal-Gesic tablets	Tricosal
Anaprox and Anaprox DS	Disalcid	Oxaprozin	Trigesic
Anodynos	Doan's	Oxycodone and aspirin	Trilisate Compound tablets
Ansaid	Dolene	Oxyphenbutazone	Tusal
A.P.C.	Dolobid	Pabalate-SF tablets	Vanquish capsules
Argesic	Dolor	P-A-C	Voltaren
Artha-G	Doxaphene	Pamprin and Pamprin IB	Zorprin tablets
Arthritis pain tablets (all preparations)	Dristan (all preparations)	Panasal	
Arthropan	Duradyne	Pentusa	
ASA	Easpirin	Pepto Bismol liquid and tablets	
Asacol	Etodalac	Percodan and Percodan Demi	
Ascone tablets	Feldene	Persantine	
Ascriptin and Ascriptin A/D	Fenoprofen	Persistin	
Aspergum	Flurbiprofen	Phenaphen	
Aspirin , with or without codeine	Genpril	Phenergan Rhinex synalgos	
Asproject	Haltrin	Phenetron Compund	
Axotal tablets	IBU tablets	Phenylbutazone	
Azdone	Ibuprin	Piroxican	
B-A-C tablets	Ibuprofen	Plavix	
BC powder and tablets	Ibuprohm	Ponstel	
Bayer aspirin (all preparations)	Indocin and Indocin SR	Premysyn	
Children's chewable aspirin	Indomed	Propoxyhene compound 65	
Children's cold tablets	Indomethacin	Propoxyphene	
Bayer timed-release aspirin	Keterolac	Quiet World tablets	
Bexophene	Ketoprofen	Relafen	
Bufferin (all preparations)	Lodine	Resolve	
Extra strength tablets	Magan	Rexolate	
With codeine #3 tablets	Magsal	Robaxisal tablets	
Bultalbit	Measurine tablets	Robomol	
Butazolidin	Meclofenamate	Roxiprin	
Butazolidine	Medipren caplets & tablets	Rufen	
Butazone	Mefenamic	S-A-C	
Cataflam	Mementum muscular backache tablets	Saleto-200	
Cama In-Lay	Menadol	Salflex	
Cap-Profen	Mepor Compound	Salsalate	
Clinoril	Meprobamate/Aspirin	Salsitab	
Co-Advil	Meprogesic Q	Sine-aid	
Cogesic	Methocarbamol with aspirin tablets	Sine-Off medicine	
Congespirin chewable cold tablets	Micranin tablets	Sodium salicylate	
Cope tablets	Midol	Soma Compound	
Coricidin D decongestant	Mobidin tablets	Soprodol Compound	
	Mono-Gesic	Sominex	
	Motrin and Motrin IB	St. Joseph's cold tablets for children	

The Big Sale on the Little Street

COME OUT AND PARTICIPATE in our first community yard sale fundraiser! The sale will be held by a local volunteer on Saturday, September 10, on Fanning Street, located within the heart of the Locke Street district in Hamilton.

Come and help us out with this fundraiser, and also enjoy the treasures and gems of the Locke Street Festival (<http://www.lockestreetfestival.com>). Highlights of the festival include food, live music, and fun!

Ways you can help:

1. Donate typical yard sale items—no electrical items please. (If in doubt, please contact Mary Pedersen at dansker@cogeco.ca with questions.)
2. Come and volunteer for the day at one of our tables. (Contact Alex McGillivray at amcgillivray@hemophilia.on.ca.) ♡

Liam Barbour Scholarship Award

THE CENTRAL WEST REGION of Hemophilia Ontario is proud to present the Liam Barbour Scholarship Award, made possible through the generosity of the Barbour Family, and the proceeds from the Annual Liam Barbour Charity Golf Classic. The Liam Barbour Scholarship Award offers \$500 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 for as long as it exists.

Scholarship Requirements:

- To qualify for this award, the applicant must be residing in the Central West Region, be an active member of the Central West Region, and have a recognized bleeding disorder.
- The applicant must provide proof of their enrollment at a post secondary institution to the Central West Region.
- CWOR and its Board of Directors have been empowered with the disbursement of funds 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, 2011. Faxed or late applications will not be accepted. For more information, to obtain a Liam Barbour Scholarship Award application, or to mail your completed application, contact: Alex McGillivray, Regional Service Coordinator. ♡

Regional Board and Staff

Mary Pedersen
Igor Ristevski
Dane Pedersen
Justin Terpstra
Jace Pedersen

Alexandra McGillivray –
Regional Service Coordinator
10 George Street
4th Floor – Office #19
Hamilton, ON, L8P 1C8
905-522-2545
amcgillivray@hemophilia.on.ca

Comedy Night: The Sequel

THIS OCTOBER, Comedy Night returns. Tickets will soon be available for another amazing night of comedy at Club 54 in Burlington. Have a good laugh and raise money for CWOR at the same time. This is your special chance to see the hysterical Ben Guyatt, star of the Comedy at Club 54 commercials. For more information, contact Alex McGillivray, Regional Service Coordinator at amcgillivray@hemophilia.on.ca. ♡

Get Involved: Join us at our Community Meetings

CWOR IS ALWAYS looking for new volunteers and fresh ideas. We encourage you and your family to come out and join us at our monthly meetings to share your ideas on how we can serve you better.

In an effort to encourage more families to engage with the bleeding disorders community, CWOR will move its board meeting location to J. Edgar Davey School in September. We're hoping that the gym will be available for kids to get out and have some fun too!

For more information on our current list of programs, contact Alex McGillivray, Regional Service Coordinator at 905-522-2545 or amcgillivray@hemophilia.on.ca. ♡

All articles in this section, unless otherwise indicated, are by Alex McGillivray.

Events Calendar

DATE	WHAT AND WHERE?
July 23	Youth Adventures Canoeing
September 10	Big Sale on the Little Street
October TBA	Comedy Night
October TBA	Parents Education Day
November TBA	Winter/Holiday Event
November TBA	Wanakita Registration Event

Message from the Chair

IT IS MY GREAT HONOUR and privilege to assume the responsibility of NEOR Chair, delegated as Director to represent our Region to the Ontario Board and to have been bestowed the trust and confidence by my peers to represent Ontario and thereby participate with and support the Executive Committee and National Board of Directors.

Our trajectory is underway and I am very confident we will continue to build upon the foundation now in place and achieve our goals alongside Hemophilia Ontario and CHS. The youth committee has begun to develop its efforts and NEOR fundraising efforts are evolving. We are also presently attempting to consolidate the NWOR with the NEOR.

I recognize that in increasing our base, we must have the infrastructure to support our growing region and I remain confident that our constantly developing and dynamic team is up to the task. It is also my honour to thank the NEOR board and committee members for their commitment, support and dedicated hard work. Thank you Alana Brassard, Chad Bizier, Julie Comtoise, Carola DeBlasio, Tammi Deveau, Stephanie Gray, Cassie Green, Lise Ann Lowe, Gina Madahbee, Dylan Madahbee, Kaitlynn McDonald, Stephanie Morrison, Kristopher Onucky, Betty Ann Paradis, Brad Pearson, Bobbi Rushon, and Sylvie Veillette. And last but not least, a huge thank you to our amazing and dedicated Regional Service Coordinator, Teresa Genereux for all her hard work. It is because of all of you that our achievements have been possible.

David C. Bouffard ♡



Spring clinic day

OUR CLINIC DAYS are one of my biggest joys. We have two clinics a year, one in the spring and one in the fall. It is always nice to see our clients as well as meet and give comfort to the new families. I am always looking for new ways to keep the young children busy and happy for the long day ahead of them. This spring clinic we decorated flower pots and planted sunflowers. We started off our day around 8:30am with muffins, juice and coffee provided by Bayer. Our nurse, Betty-Ann Paradis, gave an informative presentation for all clinic attendees.

At lunch time we had a pizza lunch provided by Baxter with cake for dessert. It was a great day for everyone. ♡

I HAVE BEEN an RSC for the Sudbury area (North Eastern Ontario Region) for the past three years and recently, due to staffing changes, have been given the opportunity to be the RSC for the Thunder Bay area (North Western Ontario Region). An RSC represents both Hemophilia Ontario and the Canadian Hemophilia Society (CHS). They inform people affected by inherited bleeding disorders about Hemophilia Ontario's programs and services. They identify areas of need, develop programs and help members of the inherited bleeding disorders community connect with a variety of services. Any person with an inherited bleeding disorder and people infected with HIV and Hepatitis C, as well as family members and friends, can access the services of an RSC.

I am truly excited about this new adventure, and I look forward to providing the Thunder Bay area with programs and services that will benefit the inherited bleeding disorders community. I would love to hear from you, so should you have any questions, or would like to get in touch with me, please feel free to ask a clinic representative during your appointment, or contact me directly.

Teresa Genereux ♡

NEOR/NWOR STAFF

All articles in this section, unless otherwise indicated, are by Teresa Genereux.



Teresa Genereux

Events Calendar

DATE	WHAT AND WHERE?
July 28 (NEOR/NWOR)	World Hepatitis Day. Booth set up with information.
TBA (NWOR)	Tree planting to commemorate the Tainted Blood Tragedy
TBA (NWOR)	Clinic Date
October TBA (NEOR)	Clinic Date

NEOR Staff

Teresa Genereux, Regional Service Coordinator
705-966-3957
tgenereux@hemophilia.on.ca
50 Balsam St., Box 781
Levack, ON P0M 2C0

OEOR AGM

by Steve Van Dusen, OEOR Chair

THIS YEAR'S AGM had more than 50 attendees. Diane Bissonette from CHEO gave an excellent presentation on transition from CHEO (children's hospital) to OGH (adult hospital). Helene Bourgaize of CHS provided insight to their strategic plan and current plans for all chapters. We had another good show by Kids on the Block for the children. The children really enjoyed themselves, and so did most of the adults. New board members to join the group from last year are Kim Weir, Lyanne Cabral and her son Jordan Cabral. Members returning are Ashwani Kurichh, Raja Ammoury-Alami, Lori Kavanagh, Darlene Villeneuve, Nancy Sauvé, Brian Van Dusen and me. Jennifer Lelièvre returns as Past Chair. ◊



▲ Raja Ammoury-Alami and sons Omar and Yousef warm up after the sleigh ride

OEOR Bowlathon – Save the Date!

OEOR's Bowlathon Fundraiser will be held on October 28, 2011 from 6:00 to 9:00pm. Please contact Colin Patterson for more information and pledge sheets. Watch for details. ◊

17th Annual Shawn Duford Golf Tournament for Hemophilia

JOIN US for our 17th Shawn Duford Annual Golf Tournament for Hemophilia on Saturday, August 13, 2011, with a shot-gun start at 1:00pm at the Meadows Golf and Country Club, 4335 Hawthorne Rd., Ottawa. Registration will again be on a first-registered basis, so don't delay. Our golf tournament fosters friendships between our members, friends and business partners, and is our major fundraising event. Thank you to Pfizer Canada Inc., Baxter Corporation, CSL Behring, Novo Nordisk and Bayer HealthCare for making this fundraiser possible.

The cost of \$100 per person includes 18 holes of golf, golf cart, lunch prior to tee-off, and a succulent banquet dinner. In addition to the golf, we'll also have a lot of great gifts, contests, draws and a silent auction. Those not wishing to play golf may join us for the banquet for \$30. You will have opportunities to win extraordinary prizes while helping to support the Ottawa and Eastern Ontario Region of Hemophilia Ontario. This is a fun tournament for all to enjoy. Don't forget to bring your hat and sunscreen. Please complete a Registration Form and send it to us with your payment by mail or by fax to 613-739-3820. We accept cheques, MasterCard, Visa and cash. If you have any questions, please do not hesitate to call the office at 613-739-3845. We look forward to seeing you on August 13. Let's make the 17th year the best ever Shawn Duford Annual Golf Tournament for Hemophilia! ◊

Regional Board and Staff

Raja Ammoury-Alami
Jordan Cabral
Lyanne Cabral
Lori Kavanagh
Ashwani Kurichh
Jennifer Lelièvre
Nancy Sauvé
Brian Van Dusen
Steve Van Dusen
Darlene Villeneuve
Kim Weir

Colin Patterson, Regional
Service Coordinator
2445 Boul. St. Laurent
Ottawa, ON K1G 6G3
613-739-3845
cpatterson@hemophilia.on.ca

Events Calendar

DATE	WHAT AND WHERE?
August 13	17 th Annual Shawn Duford Golf Tournament for Hemophilia
September 20	Youth Webcast Pilot Project
November	OEOR Education/Information Event (Kingston)
December	OEOR Camp Wanakita Registration
December	OEOR Holiday Party

South Western Ontario Region



▲ *Prelude to Pinecrest— Special thanks to Charlie, Nick, Keira (Nurse), Lori (Nurse), Julia, Brittany, Denise, Holly and host family reps Kevin and Michelle; your time and commitment ensured the success of this new initiative as all youth attendees are registered as first time campers! Thank you Kevin, Michelle and Lori for the gift of your time helping me plan the weekend.*

Prelude to Pinecrest

SWOR'S FIRST-EVER Prelude to Pinecrest event provided the opportunity for potential new campers and their families to spend a weekend at camp living a day in the life of Pinecrest. With support from our amazing camp staff (Brittany, Charlie, Denise, Holly and Nick), camp nurses Lori and Keira, and the Cruse and Lepera mentor families, youth and their parents participated in gophers, noitacude, and horizontal time. They played jugs, participated in archery, made a craft and discovered we really do have no-hands meals. At the end of the weekend it appears we met our goal. We have many new campers who will join us for the first time this year. See you at camp! ♡

Celebrating our volunteers

DURING OUR REGIONAL general meeting we take the opportunity to thank our volunteers. The South Western Ontario Region is fortunate to have some of the best. Our Volunteer of the Year, Lori Laudenschick, brings her expertise and generosity to help the projects of the region in many ways. Lori is officially our Clinic Nurse Coordinator, but also helps during many regional events including the Prelude to Pinecrest Adventure Camp. Prelude is a family weekend for those new to camping and what camping offers to children. Lori does not just provide her nursing skills on her vacation time—she participates fully in planning and during the event. ♡



333 and the Rocker

WHO WOULDN'T like to own a Harley Davidson motorcycle? What would you say if it only cost a \$100? South Western Ontario Region is raffling a 2008 Harley Davidson Rocker on September 24, 2011. The best part is, it's only \$100 a ticket! There are just 333 tickets so contact us at 519-432-2365 or mmaynard@hemophilia.on.ca soon. This project led by Brendon Beer is in support of local programs and the Ride for the Record July 21, 2012 (www.ridefortherecord.ca).

Matthew Maynard ♡

SWOR

Regional Board and Staff

Paul Wilton, Chair
 Brendon Beer, Vice Chair
 Joyce Jeffreys, Treasurer
 Maureen Schaus, Secretary
 Adriana Balderas-Lopez, Director
 Travis Hazelwood, Director
 Marion Stolte, Director
 Sam Davis, Director
 Michelle Lepera, Director

Matthew Maynard, Regional Service Coordinator
 Terri-Lee Higgins, Acting Program Manager
 186 King St. E., Suite 30
 London, ON N6A 1C7
 519-432-2365
thiggins@hemophilia.on.ca

All articles in this section, unless otherwise indicated, are by Terri-Lee Higgins.



Events Calendar

DATE	WHAT AND WHERE?
August 24-28	Pinecrest Adventure Camp
September 24, 2:00pm	333 The Rocker Draw The Hilton, London, Ontario

Toronto and Central Ontario Region



▲ Benjamin Gray has no fear at the Creepy Critters show at the AGM

TCOR AGM

by Jeenetha Kulasingam

THE TCOR AGM brought roughly 40 participants to the Toronto Botanical Gardens on Sunday, March 6. The 15 children who attended were entertained with an arts and crafts workshop and a creepy critter show while the adults got down to business. Members were presented with programs and financial statements from the past year. Maury Drutz gave the President's report regarding the overall success and improvements of the organization. Shaun Bernstein offered updates regarding the youth committee and the new youth focused programs—Youth Adventures and Photovoice.

In addition to the reports, awards were given to several individuals for their valuable contributions to our society. TCOR acknowledged Victoria Kinniburgh, David Neal and Derrick and Venus Reid for their consistent commitment to the organization with Community Volunteer Awards. The James Kreppner Distinguished Volunteer Award went to Maury Drutz for going far and beyond his responsibilities as Hemophilia Ontario delegate and TCOR President. Karttik Shah's parents were given a President's award in recognition of their generous donations to this organization. Another President's Award went to Susan Turner, TCOR's Administration and Finance Assistant, for more than a decade of commitment to the organization. And last but not least, Ahmed Hassan received the Karttik Shah Award for his contributions as a TCOR board member and his significant assistance last year with the creation of the strategic plan.

Thank you to our sponsors Baxter Corporation, Bayer HealthCare, Pfizer Canada Inc. and Novo Nordisk Canada Inc. ♡

TCOR Board

Maury Drutz, President
David Neal
Mojtaba Khezry
Tim Jessop
Kiran Gopie
Mike Beck
Mark Lubinski
Shaun Silveira

Staff

Susan Turner, Administration
and Finance Assistant
Robin Nobleman, Regional
Service Coordinator
Jeenetha Kulasingam, Regional
Service Coordinator

Contact Information

Hemophilia Ontario - TCOR
501 - 65 Wellesley St. E.
Toronto, ON M4Y 1G7
416-972-0641
Toll free: 1-888-838-8846

Health Partners Speakers Bureau volunteers needed

ARE YOU LOOKING for a way to get involved and give back to the Hemophilia Society? TCOR is looking for volunteers for the HealthPartners Speakers Bureau to tell their story and help raise money to support the Canadian Hemophilia Society (CHS).

HealthPartners is a partnership of national health charities raising funds exclusively through workplace charitable giving programs. HealthPartners provides Canadians with the choice to direct their gifts towards improving the health of Canadians, through payroll deduction or cash donations. Donors can choose to direct their money to the health organizations of their choice, including the CHS.

Throughout September and October, HealthPartners will organize speaker sessions at locations in the GTA. All member charities are given an opportunity to send volunteers to speaking engagements. All training will occur in August.

If you are interested in joining the Speakers Bureau, please contact Robin Nobleman by August 1 at 416-972-0641 Ext. 12. ♡

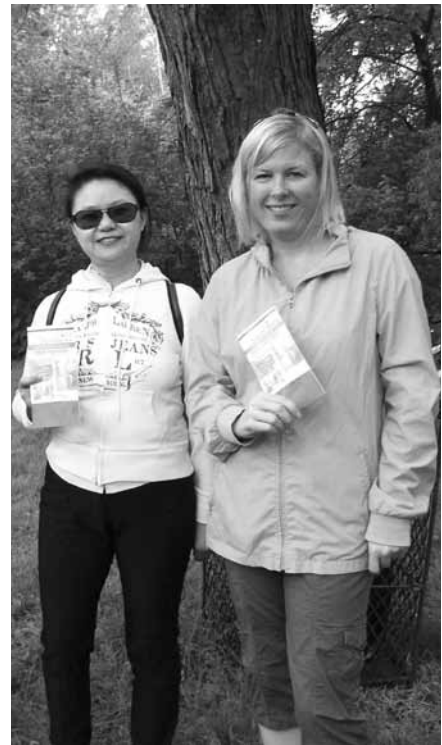
Families in Touch Summer Picnic

by Robin Nobleman

THE RAIN CLOUDS over Toronto Island held off just long enough for TCOR's summer Families in Touch picnic on June 11 to be a success. Families ranged from brand new members to those who have been coming for over 10 years. While we shared a deliciously diverse potluck lunch, parents chatted while their kids chased seagulls.

TCOR's Regional Service Coordinators, Jeenetha Kulasingam and Robin Nobleman led a Passport to Wellbeing session on traveling with a bleeding disorder. Parents shared their positive and negative travel experiences and learned some new tips to make their summer holidays go smoothly. They also tried out some possible problem situations with two role-playing scenarios. One had them negotiating with an airport security officer when bringing factor and needles in their carry-on and another included convincing a Fed-Ex agent to allow their factor into the US, though it was unlicensed there. Participants received useful materials such as a *Planning Your Travel* booklet, an emergency card with medical phrases in three languages and a copy of the *Passport to Wellbeing* booklet on traveling with a bleeding disorder. After successfully completing the workshop, parents and kids had their Canadian Hemophilia Society passports stamped. Everyone found the information useful and we look forward to facilitating another Passport to Wellbeing session soon.

A big thank you to Amina Agbons and Nadia Latifi who volunteered with the children while the parents participated in the workshop. The 15 children had a great time playing games, building kites and swinging in the nearby playground. ♡



▲ Jenny Sun and Victoria Kinniburgh learn about traveling with a bleeding disorder



◀ One of D'marc Lewis's pieces for the Photovoice Project. It represents the steps to healing from a bleed: R-I-C-E and time, which no one has enough of.

Events Calendar

DATE	WHAT AND WHERE?
July 23	Youth Adventures event with CWOR
July 28	World Hepatitis Day Health Fair, Yonge & Dundas Square in Toronto
September-October	HealthPartners Campaign speaking events
October	Commemorative Tree Planting

CHS News

HERO Study looks at psychosocial issues

THE CANADIAN HEMOPHILIA Society (CHS) invites you to participate in the HERO (Hemophilia Experiences Results Opportunities) survey. HERO is a study conducted in 12 different countries and will include about 1,200 patients and caregivers.

The aim of the study is to explore the psychosocial issues in hemophilia A and B and their impact on the various aspects of life, both for patients and their families and partners. The data collected will enhance the understanding of what it is like to live with hemophilia. Ultimately, HERO may inform strategies to improve hemophilia management.

The study findings will be made known to healthcare providers, patients, and patient advocacy organizations through presentations at hemophilia conferences, publications in scientific journals, leaflets and websites.

Upon completion of the survey a donation of \$50 would be made to your CHS chapter. The survey can only accept one respondent per household.

This is not a marketing study, but it could be very valuable in improving hemophilia care in the future. For more information and to complete the survey, go to www.hemophilia.ca/en/research/opportunities-to-participate-in-marketing-research-studies/. ◊

HIV/HCV News

People with HIV now eligible for organ transplants

by *Robin Nobleman*

UNTIL RECENTLY, HIV-positive people in Canada were not eligible for solid organ transplants, including liver and kidneys, despite their relatively high need for them. However, in Ontario, British Columbia and Quebec, HIV-positive people will now be considered for the waiting list for organ transplants. The Immunodeficiency Clinic at the Toronto General Hospital is now receiving referrals of these patients. The first successful liver transplant from a live donor to a person living with HIV was performed at TGH in May 2011; both the donor and recipient are doing well. Here are some things you should know if your doctor recommends considering an organ transplant now or in the future.

People with hemophilia and HIV or hepatitis C infection/co-infection should pay close attention to the news on organ transplants. Hepatitis C is a chronic infection that attacks the liver and in some people, at some point, may necessitate a transplant. HIV drugs may have long-term side effects that damage the liver and kidney, among other organs. In other words, in addition to people living with co-infection, HIV-positive individuals who do not have Hepatitis C may also require access to a transplant at some point. Coincidentally, a new liver is the only known cure for hemophilia because clotting factors are made in the liver. However, any organ transplant is risky and only considered as a last resort.

An organ transplant is still very difficult to get and carries many risks. Their availability for people living with HIV is a huge step forward, thanks to the advocacy work of the Solid Organ Transplant Group which includes members of Hemophilia Ontario, the Ontario Advisory Committee on HIV/AIDS (OACHA) working group, former staff of Hemophilia Ontario and others who passed away before seeing their efforts pay off in this important step forward.

This article is based on CATIE's Treatment Update 183, Vol 23, No. 2. You can find the full article at www.catie.ca/tu.nsf ◊

Direct antiviral agent therapy for hepatitis C – a promising prospect

by *Jeenetha Kulasingam*

THE CURRENT DRUGS used to treat the hepatitis C virus (HCV) have a 50 percent success rate in clearing the virus from the system, or achieving a “sustained virological response.” *The New England Journal of Medicine* published an article in March by researchers McCone et al. evaluating boceprevir, an oral HCV-protease inhibitor, as a potential treatment for untreated chronic HCV.

A double-blind study was conducted; untreated adults with HCV genotype one were assigned to three groups randomly. In all three groups, the current standard of care, peginterferon-ribavirin therapy, was administered for the first four weeks. For the following 44 weeks, group one received a placebo with standard care and group three received boceprevir with standard care. Group two received boceprevir plus standard care for only 24 weeks. However, those in group two with detectable HCV RNA levels between weeks 8-24

received a placebo with standard care for an additional 20 weeks. Results from the three groups have led to the conclusion that adding the antiviral agent boceprevir to the standard care significantly increased the rates of sustained virological response in both the short treatment and long treatment groups. Black patients had significantly lower success rates in all three groups than non-black patients.

It is evident from this source and others that direct antiviral agent therapy has delivered on its promise to improve efficacy. More details of the results can be found in the article referenced below. Telaprevir, another new direct antiviral agent therapy, may show even better results. Both were recently licensed in the US by the FDA and are expected to be approved by Health Canada later in 2011 and available soon thereafter.

Reference:

McCone J, Poordad F, and Bacon B, et al. Boceprevir for Untreated Chronic HCV Genotype 1 Infection. *The New England Journal of Medicine*. (2011). Vol. 364: 1195-1206. ♡

Pharmaceutical News



Bayer HealthCare

Bayer Hemophilia Awards Program recognizes researchers

THE BAYER HEMOPHILIA AWARDS Program (BHAP) contributes funds to support a broad range of programs including basic and clinical research in bleeding disorders, aims to encourage new physicians to enter the field, and supports the training and education of hemophilia caregivers and professionals.

In 2011, an Ontario researcher is being recognized by BHAP for her accomplishments. Dr. Christine Hough, Ph.D. and Assistant Professor of the Department of Pathology and Molecular Medicine at Queen's University in Kingston, Ontario was awarded the BHAP 2011 Special Project Award for her research on the regulation of factor VIII synthesis and its contributions to overall plasma factor VIII levels.

BHAP recognizes the prominent role played by Canadians in the global hemophilia community. Since the start of the Bayer Hemophilia Awards Program in 2003, about one in 10 grants have been awarded to Canadian healthcare professionals. BHAP has awarded 18 Canadians with funding totaling nearly \$2 million over the past eight years. ♡

Clinic Corner

All about anemia

by Robin Nobleman

ANEMIA IS ONE of the most common blood ailments, but you probably don't think about it as much as your bleeding disorder. However, it might be worth paying attention to. The symptoms can really drag you down and it's relatively easy to prevent and treat.

If you have anemia, your blood does not carry enough oxygen to the rest of your body. The most common cause of anemia is not having enough iron, the building block of red blood cells.¹ This can happen for many reasons, including blood loss due to bleeds or heavy menstrual periods. A diet that is low in iron can make it difficult for your body to get as much as it needs.

Some signs and symptoms of anemia include feeling tired and not having energy to do everyday things, shortness of breath, dizziness, pale skin, cold hands and feet and headaches.² These symptoms occur because the heart has trouble pumping enough oxygen-rich blood through your body. If left untreated, anemia can have several complications because your blood can't get enough oxygen to your vital organs. If you have experienced these symptoms and think you may have anemia, talk to your doctor. He or she will run some tests and do a physical exam.

The treatment of anemia depends on the cause, but treatment of iron-deficiency anemia requires increasing the amount of iron in your body through diet or supplements. Your doctor may also try to stop the source of anemia, for example by prescribing hormonal contraceptives to treat heavy menstrual bleeding. Here are some foods that can help increase

iron in your diet:

- Meats (especially red meats)
- Spinach and other dark green leafy vegetables
- Tofu
- Peas, lentils, beans and chickpeas
- Dried fruits such as prunes, apricots and raisins
- Iron fortified breads and cereals
- Vitamin C can help your body absorb iron, so eat foods high in vitamin C such as oranges, grapefruits, strawberries, broccoli and tomatoes.

Give yourself more energy and feel better by taking these easy steps to prevent and treat anemia. If you're concerned about anemia, talk to your doctor first. ♡

¹ Medline Plus, National Institutes of Health

² National Heart Lung and Blood Institute, NIH

Hemophilia News

Claiming Tax Advantages

HAVE YOU TAKEN ADVANTAGE OF TRAVEL COSTS AS A MEDICAL EXPENSE ON YOUR INCOME TAX RETURN?

by *Phyllis Gray, Certified General Accountant*

IF YOU HAVE TO TRAVEL to obtain medical treatment that is not available to you within 40 kilometres (one way) of your home, you may be able to claim travel (either vehicle or alternate transportation) costs as a medical expense when you file your income tax return.

If you are eligible, Canada Revenue Agency (CRA) provides for two different methods of calculating vehicle costs. One is to claim actual costs supported by receipts, the other is a simplified method, which allows you to claim 55 cents (for 2010) per kilometre without retaining receipts.

If you have to travel more than 80 kilometres (one way), you may also be able to claim the cost of your meals and accommodation. If someone is required to accompany you, that person's meals and accommodation may also be an eligible claim.

The following are a few things to consider when claiming travel as a medical expense.

1. A detailed log of trips should be kept to support your claim.
2. Receipts should be retained for detailed calculations, and for accommodations.
3. Medical expenses are reduced by a certain capped percentage of net income which may affect your claim, depending on your income.
4. If you are reimbursed for travel expenses, they are ineligible.

This information is not intended to be professional advice. As every claim is different, your accountant or tax preparer should be able to assist you in filing a claim that is appropriate and yields the best result for you. ♡



Genetics Breakthrough Promising for Hemophilia

DOCTORS HAVE RECENTLY treated hemophilia B in mice by repairing flaws in their genetic code, a major breakthrough in gene science. The new technique, called genome editing, holds promise for other genetic diseases as well.

To demonstrate the therapy, researchers treated mice that were bred to develop hemophilia B.

In a report in the journal *Nature*, a team led by Katherine High at the Children's Hospital of Philadelphia describes how genome editing reversed hemophilia B in mice, restoring their blood clotting times to near-normal without causing any apparent side effects.

In the first stage of the therapy, the mice were injected with enzymes hidden in harmless virus shells that find their way to the liver where blood clotting proteins are made.

Once there, the viruses smuggle the enzymes into liver cells, where they home in on the specific gene sequence that is defective in hemophilia B. Having arrived at their target, the enzymes slice through the faulty gene, causing the cell to launch an emergency repair effort.

At this point, the second stage of the therapy swings into action. Injected with the enzymes are DNA templates of the healthy blood clotting gene. These feed into the cell's repair machinery and, instead of simply fixing the sliced gene, a new working copy is created.

This technique raised the level of factor IX only marginally, to about 5 percent of normal levels, but this was enough to have a dramatic impact on the animals' health.

A similar technique has been used by scientists to make genetic changes to cells in a dish. In an ongoing clinical trial, the US company Sangamo, with whom High collaborates, is using a gene-slicing technique to alter immune cells in HIV patients, making them resistant to the virus.

This article was adapted from "Doctors make breakthrough in repairing genetic defects" by Ian Sample, The Guardian, June 26, 2011. ♡



▲ Hemophilia Ontario Board, L to R: Brendon Beer, Ashwani Kurichh, Steve Van Dusen, David C. Bouffard, Kristopher Onucky, Kiran Gopie, Mike Beck, Claire Cronier, Jace Pedersen, Mojtaba Khezry, Dane Pedersen, Maury Drutz. Seated: Raja Ammouy-Alami, David Neal and Paul Wilton

Spring is a time for new beginnings

by Paul Wilton

ON APRIL 16, Hemophilia Ontario held its Annual General Meeting (AGM) in London, Ontario. Dr. Castelloux of McMaster University spoke on “The Golden Age of Hemophilia” and Greg Schinkel provided “Motivational Strategies to Increase Volunteer Commitment.”

Thank you to those who attended the meeting, as well as our staff, volunteers, speakers and sponsors Baxter, Bayer, Pfizer and Novo Nordisk who contributed to the AGM. I would like to extend a special thank you to members of our community who courageously asked tough questions and gave feedback on the performance of the organization over the past year.

In the board meeting following the AGM, Hemophilia Ontario retained the management services of the Canadian Hemophilia Society for the next six months. The board looks forward to working collaboratively with our partners to further our mission of striving to improve the health and quality of life of all people with inherited bleeding disorders. ♦



◀ Hemophilia Ontario staff and volunteers at the Canadian Hemophilia Society's Rendezvous conference included L to R: Holly Valenta, Terri-Lee Higgins, David C. Bouffard, Paul Wilton, Robin Nobleman, Teresa Genreux, Maury Drutz, Shaun Bernstein, Alex McGillivray, Jeneetha Kulasingam and Colin Patterson



Attention future high school students!

Are you going into Grade 9 this year? Good news! You can now earn volunteer hours towards your required 40 hours of community involvement in the summer before Grade 9. Hemophilia Ontario has lots of great volunteer opportunities. If you want to get involved, contact your local Regional Service Coordinator.



Photo Credit: bigstockphoto.com 137264

To Tell or Not to Tell?

by Robin Nobleman and Shaun Bernstein

DISCLOSURE IS THE ACTION of making new or secret information known. When it comes to the world of bleeding disorders, it is telling someone else that you, or someone you care about, has one. But of course, it's never that simple.

There are as many approaches to disclosure as there are people with bleeding disorders. Each person must decide who they're going to tell, when they're going to tell them, and how exactly they're going to get that message across.

While disclosure may have changed somewhat in the years since the tainted blood tragedy, everyone affected by a bleeding disorder still has their own story to tell, and their own way of telling it. *Blood Matters* spoke with four different individuals in our own community to hear their strategies for telling their story.

Living a double life

MD—he chose not to use his full name—says growing up in the '60s meant disclosure wasn't always his choice.

"I experienced first-hand the stigma of labels such as 'fragile' or 'handicapped,'" he says. His peers were well-meaning, but their over-protective, overly-cautious interactions led to him feel different, and inferior to those around him. Relocating in his teens allowed him to rebuild his identity, but he was again faced with the choice of who to tell.

"I learned very quickly the value of picking and choosing my true confidantes, both male and female."

Now retired, MD opted not to disclose his illness to his employers during his successful career, which he says opened many doors for professional growth. However, he describes masking his illness at times as a "Herculean task." As a parent, MD has opted not to tell his child about his illness, concerned by any undesirable attention his family would receive in the shadow of the tainted blood tragedy.

MD stresses that disclosure is an individual choice, and he's made the choices that have been right for him and his family. He describes his existence as a sort of unavoidable double life, which he says has been the lesser of his personal evils. "Some things are not for all eyes to see," says MD, "and those that do should be ever so dear."

One mother's story

Venus Reid is the mother of a 12-year-old son who was initially diagnosed with moderate hemophilia, and then re-diagnosed with von Willebrand disease type 2N.

"Disclosing information about Trevor's bleeding disorder diagnosis was never an issue for us," says Reid.

"We informed various family members, friends, as well as the office staff and relevant teachers at our son's school, and from time to time we would encounter situations where we would tell some of his classmates' parents."

Reid says she sees now that there have been times in the past where Trevor was excluded from social activities because people knew about his bleeding disorder. She cites one incident where a teacher denied their parental permission form because the teacher felt cross-country running would be too risky for Trevor.

"It has been exhausting at times reassuring others that Trevor can be an active participant in everything the other kids his age participate in," says Reid. Reid says as Trevor grows older, he's learning to make his own choices of when and when not to participate in activities. She and her husband Derrick encourage Trevor to partake where possible, knowing that ensuing bumps and bruises may require treatment.

Reid says Trevor has endured negative labelling over the years as "the kid with the bleeding disorder." However, as he matures she's leaving the option to disclose in his hands. "We will leave it up to him to decide who he will tell as he meets new people around the neighbourhood, at school, or through new organized sports and activities."

"I bruise easily"

David S. (he chooses not to use his last name) spent his childhood trying to keep his von Willebrand disease type 2B a secret, although it wasn't always easy.

"Showing up with a conspicuous bruise made it difficult, but 'I bruise

easily' was my usual response," he says.

While David opted out of contact sports such as football and ice hockey, he also chose to reveal his status only to his closest friends.

"I didn't want to be treated differently, or thought of as weak or fragile."

David says he still prefers that people don't know about his status, but there are times it's important they do, like when he's travelling for business. Then, he'll only disclose to those he trusts. Recently, David had the opportunity to educate a group of medical students about bleeding disorders, and is willing to disclose his status in order to educate the community. While he's still selective about his disclosure, David says he'll often involve his own story when telling others about HCV, AIDS, and the tainted blood tragedy.

"It's a way of personalizing this tragedy," says David.

The next generation

Mike (not his real name) was born in the late 1980s, just after the tainted blood tragedy, and says it's something he's grateful for every day.

"It's never far from the back of my mind, that if I'd been born just months earlier, my life would be very, very different," he says.

Mike says that before each school year began, he and his mother would visit the school early, and speak with his teachers one-on-one about his bleeding disorder.

"They were always very accommodating," he says.

In university, Mike was resistant to using the campus disability services because he was always more comfortable disclosing to teachers one-on-one. Mike says he's totally open about disclosing to any of his friends or girlfriends because he sees it as an opportunity to educate and inform.

"I make sure they know that I'm fine, but when I'm not I'll have a support system in place," he says.

Mike says one of the hardest areas of disclosure has been in terms

of employment, because he worries about losing out on opportunities if people know his status.

"I just completed a six-week internship that was very important to me, and I only told my bosses at the end because I felt it would hurt my chances of getting hired on afterwards," he says.

Now that he's applying for jobs, Mike says he isn't sure how to fill out the box on the applications which ask if he has a disability.

"Most of the time I've just been leaving it blank."

How do you decide?

The complex decision of whether to disclose is different in every situation, but some considerations may be helpful across the board. You may want to consider why you want to tell someone and how you hope they will react. It's also important to think about what would happen if they do not keep it to themselves.

Sometimes, especially when it comes to HIV and HCV, the choice is not up to you. It is illegal in Canada to expose a sexual partner to a significant risk of HIV infection without disclosing your status. You also must tell insurance providers about pre-existing conditions if they ask.

However, when it comes to telling an employer about your bleeding disorder or HIV/HCV status, you are under no legal obligation to disclose (except in certain regulated occupations in the case of HIV). If you require certain accommodations, your doctor can write a letter explaining that you have a "chronic condition" without disclosing specifics.

The challenges and solutions these members highlight are common to many in the bleeding disorders community, but each person needs to weigh the options for him or herself in deciding whether to disclose. ♦

Youth Section

Whom do you tell?

YOUTH PERSPECTIVES ON DISCLOSURE

We asked Hemophilia Ontario youth about their experiences with telling friends, romantic partners and anyone else about their bleeding disorder.



Shake off the stigma!

ALTHOUGH THERE MAY be a stigma, I always make it a high-priority to let them [a partner] in on this as soon as possible. When you tell your significant other that you have “this...blood disorder,” you not only show respect for his/her right to know and to inform him/her but you also show confidence. Shake off the stigma and the ignorance!

However, the best way to do it from my expertise is to not let it *all* out at one time. You may throw him/her off and scare them away. It's best to do in small doses. Maybe along the journey you invite her to come along to clinic (on a non-assessment visit) to see the day-to-day issues.

Last but not least (for the guys out there), as much as you should respect the one you're with and treat them with honesty, love, compassion, tolerance and respect, it's still a life saver when you get cheeky and she remembers as she's clenching her fist to whack you that, “You're sooooo lucky you have hemophilia,” and pulls back the action. However, this only has a 50 percent success rate. The other 50 comes when you probably deserve it. So watch yourself, and be safe out there.

Keep the peace,

D'Marc Lewis

Special, not different

AS A CHILDREN'S EDUCATION and Development major, I have learned that children like to pretend they are just like everyone else. As I was once a kid myself, I know how much children hate being different. As a kid with a bleeding disorder, I know what it feels like to be different, and fear for the reactions of others. Peers alone have the power to bring you up on a bad day, or push you down when you feel you are most vulnerable. I am an only child, and though my family are my whole world, my friends are some of the most important and influential people in life. Therefore, growing up forming relationships with some of my now lifelong friends, I was apprehensive about revealing that I “wasn't quite like everyone else” for fear of rejection

*those who mind
don't matter, and
those who matter
don't mind*

and ignorance. Thankfully, I quickly learned that the cliché is in fact true: those who mind don't matter, and those who matter don't mind. My friends are my strongest support system today as I live with von Willebrand disease, especially when I encounter someone with a less-than-receptive response when discovering my disease. Today as an adult I am more open to discussing my disorder with those who show interest, and I am happy to report we live in a world largely made up of compassionate individuals with an eagerness to learn what is very special about who I am, not different.

Amy Griffith (von Willebrands, type IIA) ♦





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Hemophilia Ontario Calendar 2011

DATE	WHAT AND WHERE?
July 28	World Hepatitis Day
July 31 - August 13	Camp Wanakita
September 16-18	Just the Guys (registration now open)
October 22-23	Wellness for Women – W2 Conference (registration now open)
October	Tainted Blood Tragedy Awareness events



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

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