

A publication of



Hemophilia Ontario
Hémophilie Ontario

BLOOD

matters

"We're all related by blood."

Volume 3 • Number 1

Spring 2012

**Women &
Bleeding Disorders:**
It's our turn!

Hemophilia Ontario

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Hemophilia Ontario
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of the Canadian Hemophilia Society.

Cover photo: Danielle Watson and her daughters Alexis and Marissa attend Pinecrest Adventures Camp for the first time and learn that there are other girls with bleeding disorders.

Photo credit: Terri-Lee Higgins

What's in this issue?

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Leadership Messages

Message from the EDITOR

by *Shaun Bernstein*



Shaun Bernstein



Paul Wilton

PRESIDENT'S Message

by *Paul Wilton*

GROWING UP, I honestly never knew much about women and bleeding disorders. With no ties to camp, I didn't grow up with any friends with von Willebrand disease. In fact, I remember the surprise I felt when I learned as a teenager about the experiences of women with hemophilia. In my world, very few men I knew had hemophilia, and certainly no women.

But women in the world of bleeding disorders aren't just limited to those affected. Every patient, male or female, seems to share an incredible woman in their lives—a strong, compassionate, determined mother who seeks to provide the best for their child. Permit me for a minute to talk about mine.

When I was born, my mother's introduction to hemophilia was startling and nerve-wracking. The community had just come through some impossibly frightening years, and while it looked like the problems had been solved, uncertainty lingered. My parents were visited in the hospital by a patient, who warned them of how difficult my life would be.

Both my parents are incredibly resolute individuals, but my mother really swung into action. She left a promising legal career because she realized I would need full time care. When she saw needs within TCOR, she swung into action once again, becoming one of their most promi-

nent fundraisers. When she didn't like advice she was given by experts, she questioned it, asked for second opinions, and made her own decisions. She made the brilliant decision to keep me on prophylaxis from an early age; a decision I'll be grateful for every day of my life. It was her strength, tenacity and constant love that turned me into the individual I am today. Of course that's true of any mother, but for the mother of someone with a bleeding disorder, that extra strength goes a long way.

Since I've become more involved with the various levels of the Society, I've been humbled and privileged to see such strength and devotion from countless women in the community, both mothers and patients. These are women committed to furthering their own health concerns, of course, but also improving the health of their entire community, while raising awareness of all bleeding disorders. Their passion for volunteerism in the community on the local, provincial and national levels never ceases to astound.

As a young man with a bleeding disorder, I'm personally grateful for the women so active in the community, and I'm pleased we're taking this opportunity to highlight some of their stories.

Have a pint on me. ♦

HEMOPHILIA ONTARIO is committed to improving the health and quality of life of all people with inherited bleeding disorders. So ladies, how are we doing so far?

In our own community, we have made significant changes, starting with our mission statement. We are more inclusive in our language, referring to "people with bleeding disorders." Our provincial camps now include girls, and Hemophilia Ontario has facilitated events to bring women together to learn more about the management of their bleeding disorder. That is a good start, but it is not enough.

To think that some Ontarians with bleeding disorders go undiagnosed and/or untreated for their bleeding disorders because of their gender is inexcusable. Despite the work that has been done to raise awareness of women with bleeding disorders among healthcare professionals, many still think of bleeders as being male. Imagine going to the emergency department with a major bleeding issue and not receiving the right care and treatment you need, simply because the physician doesn't know that women bleed too. Sound absurd? It happens in this province all too often. As a community we have a moral imperative to prioritize raising

awareness of women's bleeding disorders and increasing access to care.

Hemophilia Ontario can only become stronger by reaching out to and including more women with bleeding disorders. Since the very beginning, this organization has been fortunate to have strong women who have provided leadership and dedicated endless hours of volunteer time, most often to improve the lives of their sons, fathers, husbands and friends with hemophilia. Even though many were also carriers, little was ever mentioned of their own bleeding problems and potential risks. As care and treatment became better for the men in their lives, whispered stories of their own bleeding began to be shared. ("Whispered" because I'm guessing maybe the guys were a bit uncomfortable with those sorts of things.) That was probably the beginning of Hemophilia Ontario's paradigm shift. Today we do have more women with bleeding disorders, but we need to invite more women to our table who have von Willebrand disease, rare factor deficiencies, platelet disorders or who are symptomatic carriers. People with inherited bleeding disorders share many of the same challenges. We strive together for better health, access to care, better understanding and improved quality of life. We are all bleeders.

I was going to say that we are only half as strong without women, but I know better than that. The women in my life frequently remind me that they can accomplish twice as much as most men in a given day. Ladies, we have really come a long way, but we know that we have so much more to do to improve the health and quality of care of all people with bleeding disorders. ♦



Terri-Lee Higgins

PROVINCIAL PROGRAM MANAGER'S Report

by Terri-Lee Higgins

GROWING UP, I watched the Road Runner and Wile E. Coyote cartoons every Saturday morning. I always cheered for the Road Runner and couldn't understand why the Coyote kept doing the same thing time and again without success. In business today, being the Coyote means never thinking outside the box, taking a risk or trying new things. We have to be more agile and adaptive like the Road Runner and less like the tradition-bound Coyote.

There is an old cliché, "growth is painful." As I see it, *not growing* is what's painful. Growth is liberating—pain relieving. Growth means figuring out what's worth keeping and what needs to be thrown out. Growth results from action or personal motivation, which combines desire and energy. Influencing someone's motivation means getting them to want to do what you know must be done.

As we begin 2012, I wish to recognize and thank the Ontario staff team that has worked collaboratively among themselves and with our volunteers designing local and provincial programs and events that meet the unique needs of our population:

- Regional Service Coordinators Alex (CWOR), Teresa (NOR), Colin (OEOR), Matthew (SWOR) and Robin and Jeenetha (TCOR) for their continuing efforts to bring new and innovative programs and events to our members, based on your input.
- Hemophilia Ontario Head Office staff Susan and Marina for providing the necessary support to help us breathe life into this year.
- Interim Executive Director David Page who provided the opportunity for all staff to implement changes for positive impact with great results. Thank you for believing in our gifts and skills and allowing us to grow.

We are confident that the variety of programs and events planned for the upcoming year bring something for everyone. Check out our website at www.hemophilia.on.ca or talk to your RSC about the educational and fun opportunities that will be available to you this year. ♦



Hemophilia Ontario
Hémophilie Ontario

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HEMOPHILIA ONTARIO 56th Annual General Meeting Agenda

Saturday, April 21, 2012

10:00am - 4:00pm

CHIMO Hotel

1199 Joseph Cyr Street
Ottawa, Ontario
K1J 7T4
613-842-5622

Schedule of Events

- 9:00am - 10:00am - Registration and breakfast
- 10:00am - Welcome
- 10:10am - Dr. Robert Klaassen , *Updates in research, treatment and care*
- 11:00am - Dennis Garvin, Department of Patient Advocacy, Ottawa Hospital
- 12:00pm - Lunch (for those attending AGM)
- 1:00pm - Hemophilia Ontario Annual General Meeting
- 3:00pm - Hemophilia Ontario Board of Directors Meeting

Hemophilia Ontario

RSVP to: Susan Turner
888-838-8846
416-972-0461
sturner@hemophilia.on.ca
No later than: April 13, 2012

REGIONAL REPRESENTATIVES requiring overnight accommodations

Please contact Susan before
Friday, April 6, 2012 to make
arrangements.

Agenda

1. Call to Order
2. Approval of the Agenda
3. Approval of the Minutes of the Saturday, April 16, 2011 Annual General Meeting
4. President's Report
 - i. Volunteer Recognition
5. Treasurer's Report
 - i. 2011 Audited Financial Statements
 - ii. 2013 Membership Fees
6. Interim Executive Director's Report
7. Hemophilia Provincial Coordinator Report
8. Appointment of the Auditor 2012
9. Submitted Reports
 - i. Youth Committee
 - ii. Provincial Program Manager
10. Motion: That Hemophilia Ontario and the Toronto and Central Ontario-Hemophilia Society (TCOR) amalgamate by December 31, 2012
11. Election of the 2012-2013 Hemophilia Ontario Board
12. Other Business
13. Adjournment

The NACCHO experience

by Zachary Adams

AFTER SUCCESSFULLY navigating everything from an ice storm in Toronto, to almost running out of jet fuel while circling the airport, to missing my connecting flight in Detroit due to someone named Barack Obama taking off, I finally touched down in the warm and sunny south—that is Phoenix, Arizona. From January 27-29 I attended the North American Camping Conference for Hemophilia Organizations (NACCHO) for a weekend of listening, learning and collaborating on all of the aspects that are associated with being involved in a bleeding disorders camp. From the outset I felt



Pinecrest Adventures Camp Director Nick H, and counsellors Brittany S. and Shane N. receive the NACCHO cup from a Pfizer Rep in Tempe, AZ.



honoured to have been chosen to participate in this event and was extremely excited to learn as much information as I could.

The weekend was packed with fun and informative sessions from sun-up to sun-down, all containing valuable information which I look forward to sharing with the already phenomenal Hemophilia Ontario camps such as Just the Guys and Pinecrest. The weekend also allowed me to learn more about myself as a counsellor by teaching me how I can improve the camper experience as well as being able to work more efficiently with other staff. I was able to explore ways by which we can make bleeding disorder camps a place where a camper feels at ease, while still being able to participate in a wide variety of activities. I really enjoyed the opportunity to discuss issues and find solutions with other camp staff from all over the world, allowing me to gain a perspective I had not yet discovered.

The weekend would not have been the same had I not spent it with a wonderful group of people from Hemophilia regions across Ontario. I want to congratulate Terri-Lee along with Bret, Brittany, Shane and Nick who came in second place in the NACCHO Cup camps competition for the amazing job they do at Pinecrest. This trip was a one-of-a-kind event that will allow me to bring a wide variety of unique and interesting tools to the camp experience. ♦

Back Row from Left to Right: Bret R., Brittany S., Nick H., Zach A., and Shane N. / Front Row from Left to Right: Alex McGillivray – RSC, Teresa Genereux – RSC, and Terri-Lee Higgins – Provincial Program Manager @ the NACCHO Conference

Hemophilia Ontario updates **FINANCIAL ASSISTANCE POLICY**

by David Page

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, medication, hospital parking, taxis to hospital, gas to attend clinic, assistive devices (e.g. MedicAlert bracelets, crutches, brace), equipment (e.g. protective helmets), in-hospital costs (e.g. TV, telephone) 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 attempt to have these costs covered by other social agencies including 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 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 Regional Service Coordinator. ♠

Hemophilia Ontario **HONORARY LIFE MEMBER** Retrospective:

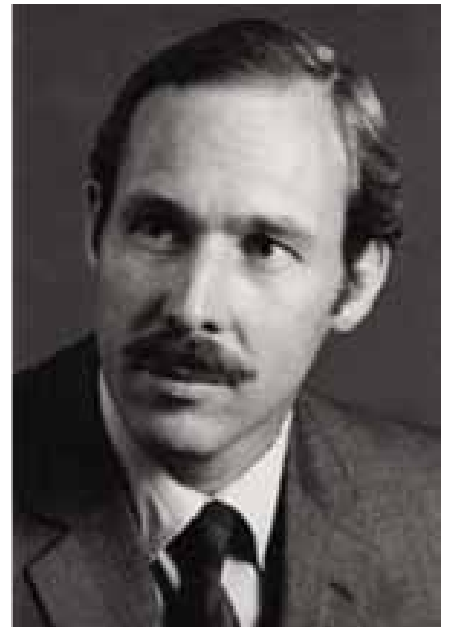
DR. MARTIN INWOOD

by Susan Turner

DR. MARTIN INWOOD, who retired almost 10 years ago, received an honorary life membership in 1990 to recognise his visionary leadership. A distinct group of members has been awarded an Honorary Life Membership for their efforts. We would like to tell the stories of these individuals in this *Blood Matters* series.

Dr. Martin Inwood, who retired almost 10 years ago, received an honorary life membership in 1990 to recognize his visionary leadership. Born in the UK, he was director for 25 years of the South Western Ontario Hemophilia Program, chair of the Canadian Hemophilia Society's Medical Advisory Committee, and held important positions at the World Federation of Hemophilia. As examples of his vision, he recognized the need for a systematic approach to hemophilia care; developed a practical database; directed a national conference on computerization; wrote a proposal for governmental recognition of hemophilia programs; initiated systematic approaches to HIV and hepatitis C infection; and strongly advocated for the introduction of recombinant concentrates. Committed to research, he gave numerous invited lectures around the world and was highly influential in promoting change.

Above all, Dr. Inwood was passionate about the hemophilia community. The community was part of his family and he continued to be passionately committed to providing the best care. Dr. Inwood and the Hemophilia Society are joined at the heart and he was very honoured by his Honorary Life Memberships from Hemophilia Ontario and the Canadian Hemophilia Society. ♠



Dr. Martin Inwood

This article was written using information from CHS' 50th Anniversary Book

WOMEN AND BLEEDING DISORDERS

The strong women of the bleeding disorders community

by Robin Nobleman, with special thanks to Teresa Genereux, Joan Kent, Victoria Kinniburgh and Amy Griffith for writing their stories



Joan Kent holds her new grandchild.

NOT SO LONG AGO, Hemophilia Ontario referred to its members as hemophiliacs, using only male pronouns to refer to people with bleeding disorders. Only fairly recently has Hemophilia Ontario recognized that women can have bleeding disorders too and play a major role in the lives of men and boys with bleeding disorders.

The Canadian Hemophilia Society's new program, CODErouge| When women bleed too much, aims to support women in our community and improve diagnosis and care for this underserved group. CODErouge will be launched nationally with the First Canadian Conference on Bleeding Disorders in Women in Toronto on May 25, 2012.

In advance of this groundbreaking conference, *Blood Matters* spoke to four women affected by bleeding disorders. Every woman's experience is different, but many women have faced and overcome similar challenges.

The diagnosis

Bleeding disorders are difficult to diagnose and not often suspected in women, even though one in 100 people carries an inherited bleeding disorder gene. The average time a woman waits before receiving a bleeding disorder diagnosis is 16 years. For Joan Kent, a long-time TCOR volunteer and former board member, it took double that time and a miscarriage to finally get a diagnosis

of von Willebrand disease. "Of course I had known for years that I bruised easily," says Kent. "Several short bleeding episodes had been passed off as my being "a bleeder" just as my mother and grandmother had been before me."

Similarly, Teresa Genereux, who was just diagnosed with VWD herself this year, never suspected that her two daughters had a bleeding disorder, despite nosebleeds and bruising. "By the time my older daughter Kaitlynn was four years old, she had her nose cauterized nine times," says Genereux, and still no one looked into the causes of her condition. Genereux felt very alone. The only advice she received from doctors

was that her daughters "needed to be more careful when playing." When her children were tested for VWD several years later after Kaitlynn had a severe hemorrhage, Genereux finally knew, "It was not just in my head. Something was wrong."

Victoria Kinniburgh experienced a similar sense of relief that her son's bruises had an explanation when Benjamin was diagnosed with severe hemophilia A at 14 months. Despite that relief, she and her husband Darryl were devastated and still in shock when the hemophilia team at The Hospital for Sick Children met with them for the first time to explain the diagnosis. "When our second son Nathan was born and diagnosed with



(L-R) Rachel, Amy Griffith, Alan, Kaylin, Robin and Cameron do a teambuilding exercise during the Youth Adventures Program.

severe hemophilia A we were not surprised. At least this time we knew what we were dealing with.”

Becoming your own advocate

After the shock of the diagnosis has passed, the next challenge for many women affected by bleeding disorders is learning to advocate for themselves and their children. With such a rare group of diseases, many doctors have never come across anyone with an inherited bleeding disorder before. It often falls to patients and parents to educate medical professionals, schools and daycares about their own or their child’s disorder.

This was especially difficult for Kinniburgh who describes herself as, “a quiet person who does not like to rock the boat.” She quickly realized that if she wanted her children to get the best care, that would have to change. “If this meant telling a doctor that they were wrong, I had to do it,” says Kinniburgh.

Advocacy was also required at the boys’ daycare, which was reluctant to care for Benjamin after his diagnosis. Kinniburgh put together a binder explaining hemophilia and how to care for bleeds. She and her husband encouraged the daycare to treat Benjamin like any other child and to ask as many questions as they liked. As a result, the daycare agreed to keep Benjamin in their facility and when it was time for Nathan to attend there were no issues.

Amy Griffith, a young woman with von Willebrand disease, has constantly found herself defending her diagnosis. “If I had a dollar for every time a triage nurse questioned the ‘medical conditions’ section on my emergency room form, or the blank stares from people who think bleeding disorder equals hemophilia equals male, let’s just say I’d be a millionaire.” At first, she found the questioning offensive, “as if I wanted to sit in the emergency room for four hours for a little attention.” As Griffith grew up, she came to realize that the problem was not ignorance, but innocent lack of knowledge, which she has worked to correct.

Kent’s advocacy was on a larger scale. At a time when cryoprecipitate was the only treatment available for VWD, the idea of establishing regional Comprehensive Care Units was starting to take hold. Kent made a financial contribution to help make this happen, and was thrilled to celebrate the inauguration of the Bleeding Disorders Clinic at St. Michael’s Hospital in Toronto in 1983. Three decades later, the clinic is now in the process of creating extra clinic time when Dr. Michelle Scholzberg, the new hematologist, will focus on women and bleeding disorders.

Treatment and care

Learning to treat a bleeding disorder can be a steep learning curve. For VWD, treatments range from infusions of von Willebrand factor, to pills and nasal sprays to help clots form and stay in place, to oral contraceptives to control heavy menstrual bleeding. Treatment can make an incredible difference in women’s health and quality of life.

For Kent, who is “well into her retirement years,” Desmopressin (DDAVP) has allowed her to undergo laser surgery to maintain good eyesight; a preventive-care endoscopy; removal of a small cyst; and so on.

“Suddenly I need this reliable product to help me through these events,” she says.

Fortunately, Genereux has been able to count on the constant support of hemophilia nurse coordinator Betty Ann Paradis. Paradis has taught her how to care for herself and her children, and how to teach Kaitlynn and Lorissa self-care. Genereux says, “Betty Ann gives me the strength to know we will be okay with proper treatment and care.”

Learning to care for oneself can be a huge step towards independence for both boys and girls with bleeding disorders. For Griffith, Camp Wanakita was where she learned the most about VWD from specialized on-site nurses. Throughout her 10 years as both a camper and a staff member, it was uncommon to find another affected female, but camp provided an opportunity to educate and “hang out with the boys and let them know there’s a place for us girls in the club as well!”

Giving back

The strong women of the bleeding disorders community have taken their challenges in stride and chosen to give back and support others with inherited bleeding disorders.



Victoria Kinniburgh with her sons Nathan and Benjamin Gray.

Whether through volunteering, fundraising, or sharing their story with other women, they have found many ways to contribute.

Kent was happy to see her efforts pay off when she recently made her first visit to the St. Michael's Bleeding Disorders Clinic as a patient. "You can imagine my surprise when I saw in the waiting room, a brass plaque with my name neatly engraved at the bottom. My von Willebrand years seem to have come full circle."

For some, giving back means providing the support they needed at the most difficult moments. Kinniburgh wishes that when Benjamin was diagnosed she could have talked to another mother of a child a bit older to see what life would be like in the future. As a result, she has offered to talk to mothers and/or fathers of a child recently diagnosed with hemophilia or an inhibitor in the hope that she can provide that crucial support and reassurance.



Teresa Generuex is currently the Regional Service Coordinator for the Northern Ontario Region.

Generuex has made a career of giving back to the bleeding disorders community. At the Sudbury Bleeding Disorders Clinic in 2008, she met with a Hemophilia Society representative doing a survey. Soon after, she was asked if she would like to represent Hemophilia Ontario as a Regional Service Coordinator. After

four years in the position, Generuex describes it as a journey in her life, using her experience to help others.

Hemophilia Ontario provides an opportunity for women to form a supportive community through its biennial Wellness for Women conference. Griffith has participated in the conference both as an attendee and a speaker. She values the opportunity to offer words of wisdom and ask personal questions in a safe and welcoming environment with women who have "been there."

In any challenging situation, it is comforting to know there are others like you. By providing opportunities for sharing and learning, the lives of women with bleeding disorders can be improved. It's up to women affected by bleeding disorders to reach out to others to both provide and receive assistance. Women in the bleeding disorders community have made huge strides, but still have a long way to go. ♡

My FIRST CLINIC VISIT at 50-something

by Laurie Maynard

I HAVE KNOWN FOR A LONG TIME that I am a carrier, and though it was mostly my brothers who had gone to the bleeding disorders clinic at least once year, I had taken extra precautions during surgery and accidents. It was not until I attended the Hemophilia Ontario Wellness for Women conference last fall that I decided to make my own appointment with the local Bleeding Disorders Program. I wanted to know if I should be wearing a MedicAlert bracelet, what I can do to be better prepared should I require surgery or have an injury, and what I can do to be healthier.

I recently had my first assessment with the clinic. Here are just a few things I can suggest. If you suspect you have a bleeding disorder or know you're a carrier, get a referral from your family doctor to the program now. You don't have to wait until you are 50-something!

- Go prepared with your questions and even your doctor's or dentist's questions. The bleeding disorder clinic staff are the experts.
- Take a list of all the medications and pills you take—even over-the-counter medications and vitamins, and a brief history of surgeries, medical conditions and dental work.
- Be prepared to be asked a lot of questions. At my stage in life I do not know how to answer some of the questions. How many bruises have I had? Lots! You may meet with a hematologist, nurse, physiotherapist, and social worker depending on the clinic, and each will do their own assessment.
- Be prepared to follow through on the clinic visit. This could be to ensure the information and results are available to your doctors—family physician, gynecologist and obstetrician, dentist, physiotherapist, massage therapist and others as need be. There may be information that you need to get back to the clinic with or more information that you need following the clinic visit.
- Be sure to keep your family doctor informed. My family doctor was happy to receive the Canadian Hemophilia Society pamphlet and local insert; it answers questions better than I can. I also gave my doctor a photocopy of the list of treatment medications, which is now with my medical chart.

The effects on my life of being a carrier are definitely different from those of the rest of my family. Yet it is comforting to have more knowledge, the support of the clinic team and Hemophilia Ontario's Regional Service Coordinator available to me. ♡

RESOURCES FOR WOMEN

affected by bleeding disorders

Canadian Hemophilia Society's CODERouge website

www.hemophilia.ca/en/women

This new website section is especially for women with bleeding disorders. It includes information about symptoms, diagnosis, treatment options, educational resources and stories from women and girls.

Hemophilia is for Girls Blog

hemophiliaisforgirls.blogspot.com

A blog written by RYANNE RADFORD, a young woman in Calgary with severe factor V deficiency. RYANNE shares her experiences as a woman with a bleeding disorder and has more than 90 readers around the world.

Hemophilia Moms Website*

www.hemophiliamoms.com/

A place for mothers of children with hemophilia to find resources, share stories and find comfort from others who understand what they're going through.

My Girls Blood Online Community

mygirlsblood.org

A place to share stories with other women with bleeding disorders from around the world.



Media Bakery MED0000187

HEMAWARE magazine website – Women's Section

www.hemaware.org/women

Find relevant articles for women with bleeding disorders and carriers. Topics range from genetic testing to participating in sports to intimacy issues.

Printed Resources from the Canadian Hemophilia Society

The CHS offers the following resources for women:

All About von Willebrand Disease

All About Carriers

All about Me (for young children with a bleeding disorder)

Cyklokapron - A Guide for Patients and their Caregivers

Desmopressin - A Guide for Patients and Caregivers

Diane Dino's Dilemma: A Story of von Willebrand Disease (a story book for children ages 8 and up)

Von Willebrand Disease: What School Personnel Should Know

Von Willebrand Disease - The Most Common Bleeding Disorder: Your Questions Answered

100 Questions & Answers About von Willebrand Disease

Resources for doctors caring for women with bleeding disorders

Guidelines Published by the Society of Obstetricians and Gynaecologists of Canada

*The Management of Women with Bleeding Disorders
Emergency Care for Patients with von Willebrand Disease*

Free copies of any resource can be ordered by phone, e-mail, fax or mail

Tel.: 514-848-0503

Toll-free: 1-800-668-2686

Fax: 514-848-9661

chs@hemophilia.ca

Canadian Hemophilia Society

400-1255 University Street

Montreal, Quebec H3B 3B6

* Hemophilia Ontario does not endorse any particular pharmaceutical company but shares all relevant resources with our constituents.

CHS launches CODerouge 2012

by Chantal Raymond and Clare Cecchini

IN 2011, THE CANADIAN HEMOPHILIA SOCIETY (CHS) initiated a new national awareness program: CODerouge | when women bleed too much. The goal of this new program, specifically targeted at healthcare providers and women in the general public, is to identify undiagnosed women with bleeding disorders and ensure that they have access to appropriate medical care from healthcare providers with expertise in bleeding disorders and the specific issues that relate to women.

On May 25, 2012, the CHS will officially launch this new program by hosting CODerouge 2012, the First Canadian Conference on Bleeding Disorders in Women. The one-day conference will be held in conjunction with the annual meetings of AHCDC, CANHC, CPHC and CSWHC in Toronto. In addition to hemophilia treatment centres healthcare providers, the conference will target obstetricians/gynecologists, emergency physicians, family physicians, trainees and affected women with VWD or other inherited bleeding disorders. The conference will feature sessions on VWD testing and diagnosis, quality of life, the management of menorrhagia, postpartum bleeding and other bleeding symptoms, the establishment of multidisciplinary clinics for women with bleeding disorders and an update on state-of-the-art research. Speakers will include world-renowned researcher Dr. Peter Kouides, as well as Canadian experts on bleeding disorders such as Dr. Rochelle Winikoff; Dr. Paula James; Sherry Purcell, RN; Dr. Diane Francoeur; Dr. Sue Robinson; Dr. Christine Demers and Nisa Renault, Ph.D.

Each of the 10 CHS chapters has identified a woman affected by bleeding disorders who will become the CODerouge ambassador for their province. Their role will be to assist with the implementation of CODerouge outreach efforts at the local level. Through funding support provided by CSL Behring, CODerouge ambassadors will be sponsored to attend the CODerouge 2012 conference. They will also participate in a training workshop on May 26 that will provide them with an opportunity to gain new skills and resources to assist with the implementation of CODerouge at the local level. We are confident that as a result of concerted efforts across the country, CODerouge will achieve its objectives and women will no longer have to suffer because of an undiagnosed bleeding disorder.

As part of the CODerouge outreach efforts, new hand-outs will be available for distribution on World Hemophilia Day. To obtain copies, contact your Regional Service Coordinator or call the national office at 1-800-668-2686.

And, don't forget to reserve May 25, 2012 in your agenda if you want to be part of history by attending the very first Canadian conference exclusively dedicated to bleeding disorders in women. There is no registration fee for the conference. To register for the conference, go to the CHS website at www.hemophilia.ca/en. ♡



Bleeding disorders SCHOLARSHIPS

by Robin Nobleman



ARE YOU IN GRADE 12 or post-secondary?

Here's some great news for you. The Canadian Hemophilia Society now offers even more awards with higher values to support your education. The CHS James Kreppner Memorial Scholarship and Bursary Program, sponsored by Pfizer, provides five scholarships/bursaries at a value of \$5,000 each to students affected by bleeding disorders.

The award categories are:

- Scholarship based on academic merit
- Bursary based on financial need
- Mature student bursary

Please note that the mature student bursary is for students age 30 and over in financial need that are returning to or beginning a course of studies at any post-secondary or vocational institution.

The scholarship program is open to Canadians with hemophilia (factor VIII or IX) or another inherited bleeding disorder (such as von Willebrand disease, a rare factor deficiency or platelet function disorder), carriers, and those who contracted HIV through a blood transfusion. Spouses and children of the above mentioned people may also apply. Those who have received a CHS scholarship or bursary are not eligible to reapply for continued support.

More information and application forms can be found on the CHS website, www.hemophilia.ca under Support and Education, Scholarships. The deadline for submission of completed applications and supporting documents is April 30, 2012. ♡

World Federation of Hemophilia News



GLOBAL FOCUS on Women with Bleeding Disorders

by Sarab Ford, WFH
Communications Manager

WHEN IT COMES TO INHERITED bleeding disorders, it's not just about men; women bleed too. As the World Federation of Hemophilia (WFH) president Mark Skinner stated during his plenary at the World Hemophilia 2010 Congress, "No matter where these women live or their cultural background, the keys to providing psychosocial and therapeutic support to them are the same: education and outreach." This extends beyond the women themselves to their families, medical practitioners and communities. Although a lot of progress has been made in diagnosis and care, women with bleeding disorders often have no idea that their symptoms are not normal, and lack of awareness among healthcare professionals often delays proper diagnosis and treatment.

According to the WFH's 2008 Global Survey, due to the bleeding challenges of menstruation and childbirth, von Willebrand disease (VWD) affects more women than men. It has been estimated that up to 1.3 percent of the population may have an abnormality in the blood protein that causes VWD, but the percentage of those with bleeding symptoms is much less. There has been an increase in diagnosis among females in developed countries, with the number of female patients treated at US hemophilia treatment centers growing by nearly 300 percent between 1991 and 2007. However, the

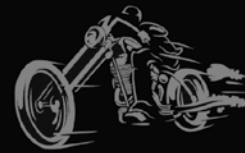
US Centers for Disease Control and Prevention found that women with VWD wait an average of 16 years from onset of symptoms to diagnosis. This means 16 years of significantly reduced quality of life that could include unnecessary surgical intervention, such as hysterectomy, due to lack of diagnosis or misdiagnosis. The situation is more serious in developing countries where proper testing is hard to come by and cultural norms can sometimes prevent women from talking about their symptoms.

While VWD is the most common bleeding disorder affecting women, they are just as likely as men to inherit rare clotting factor deficiencies and platelet disorders. Even hemophilia can affect women: carriers of the disease can have low levels of factor VIII or factor IX, meaning that they experience similar symptoms as men with hemophilia. These symptoms can manifest themselves in carriers especially during menstruation, childbirth and surgery. According to the World Health Organization, bleeding after childbirth (postpartum hemorrhage) is an important cause of maternal mortality, accounting for nearly one quarter of all maternal deaths worldwide. Given that women with bleeding disorders are at increased risk of postpartum hemorrhage, the need to identify these women and ensure they are properly managed is imperative.

The WFH's mission is to improve and sustain care for all people with inherited bleeding disorders. The organization has identified women as a keystone of its strategic plan, and is building a development program to identify women with VWD, rare factor deficiencies and inherited platelet disorders throughout the world. Pilot outreach projects are underway in Lebanon, Egypt and Peru, and the WFH has partnered with the World Health Organization to raise awareness of the risks of postpartum hemorrhage and maternal death.

An important goal of the WFH's global programs for women with

bleeding disorders is awareness-raising among frontline medical practitioners. Hematologists are experts in bleeding disorders, but women usually go to their family physician or gynecologist when first faced with symptoms. As Dr. Paula Bolton-Maggs, chair of the WFH's VWD and Rare Bleeding Disorders Committee said, "We need to educate those who are giving first-hand care to women with symptoms suggesting a bleeding disorder, and stress the importance of collaboration between the members of the healthcare team to ensure proper management of these disorders through various life stages." ♡



IMAGINE

The sound , vibration, and excitement to see nothing but bikes as far as the eye can see !

Well that is happening with 18, 000 or 32 kms of nothing but bikes. Come out and help Hemophila Ontario break the world record of the

LARGEST PARADE OF BIKES !

Saturday, July 21, 2012

Western Fair District, London, Ontario



REGISTRATION FEES: \$30.00 for bike and \$40.00 for bike with a passenger.

Fees include an official Guinness Ride T-shirt, secure motorcycle parking while you enjoy live entertainment (bands/comedians) contests and food. (Secure parking extends until 3 pm the following day.)

Early Bird Draw: July 1st 2012 (then the prices rise by \$10.00 per person)

ACCOMMODATIONS: Discounted accommodations for out of town riders available at the Hilton, London, Ontario. (For reservations please call: 1-800-210-9336).

For camping options see website for details.

ENTERTAINMENT: Comedians Al King and Paul McCullen then listen to the music of Pete Dorian, Murmur, Bender and Bonfire. Headliner TBA



REGISTER NOW: Call toll free: 1-888-838-8846 or register online at www.ridefortherecord.ca.

For more information, email Brendon at - recordride@gmail.com.

All proceeds from this Guinness World Record Event will go to Hemophilia Ontario, whose mission is to improve the health and quality of life for all people with inherited bleeding disorders, and to find a cure.



A great day of contests & prizes !

See Web Site for Sponsorship, Vendor Areas, Club Tables and Volunteer Opportunities

Web Site: <http://www.ridefortherecord.ca/>

Central Western Ontario Region

CWOR's Annual Holiday Event and **CAMP WANAKITA REGISTRATION PARTY**

CWOR HELD THEIR ANNUAL HOLIDAY PARTY and Camp Wanakita registration event on December 10, 2011 at Stoney Creek United Church. This year the region held their first potluck which was a great success!

More than 60 participants attended and enjoyed listening to our volunteer piano player, Ruth, playing Christmas carols. Families also enjoyed an indoor golf putting game as well as cooperative games. The event was closed with a visit from Santa.

Many thanks to Mary Pedersen for raising and donating the funds to hold this event. Also, thank you to all of the volunteers who assisted in the planning and running of the event: Mary Pedersen, Igor Ristevski, Rob and Jane Dinsdale, Leslie and Marvin Bauman, Courtney Lakin and Dane Pedersen.

A special thanks to Jace Pedersen for cooking the turkey. Many thanks to our young volunteers as well: Madeline Bauman, our volunteer photographer, Robin Pedersen and Anisha Hunter.

The region would also like to thank the Beamsville Sobey's and Nikki Unrau for their wonderful donation to our potluck. ♡



Kids enjoying some of the games led by volunteer Leslie Bauman

Regional Board/Council and Staff

Rob Dinsdale
Mary Pedersen
Jace Pedersen
Igor Ristevski

Alexsandra McGillivray –
Regional Service Coordinator
10 George Street
4th Floor – Office #19
Hamilton, ON, L8P 1C8
905-522-2545
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 join us at our monthly meetings to share your ideas on how we can serve you better. For more information on our current list of programs, contact Alex McGillivray, Regional Service Coordinator at 905-522-2545 or amcgillivray@hemophilia.on.ca. ♡

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, and the proceeds from the Annual Liam Barbour Charity Golf Classic.

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 be residing in the Central Western Ontario Region, be an active member of CWOR, and have a bleeding disorder.
- The applicant must provide proof to CWOR of their enrolment at a post-secondary institution.
- 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, 2012. Faxed or late applications will not be accepted. For more information, or to obtain a Liam Barbour Scholarship Award application, contact Alex McGillivray, Regional Service Coordinator. Applications can be mailed to Hemophilia Ontario CWOR, 10 George Street, 4th floor, Office 19, Hamilton, ON L8P 1C8. ♡

Events Calendar

DATE	WHAT AND WHERE?
April 17	World Hemophilia Day Bake Sale – location TBA
May 5	CWOR Women's Education Day - location TBA
June 2	CWOR Men's Education Day - location TBA
July 14	CWOR Annual Summer BBQ - location TBA

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

Northern Ontario Region



NOR Volunteers at the Winter Carnival

Dowling WINTER CARNIVAL

ON A COLD FEBRUARY 11, -30C with the wind chill, many families ventured out for the yearly Winter Carnival. Three volunteers and I, along with many others, enjoyed the pancake breakfast before setting up our booth.

The excitement of the children always warms my heart as they run from booth to booth playing games, winning prizes, getting faces painted and temporary tattoos—the list goes on. Even in the cold weather, they enjoyed the sleigh rides and the outdoor rink. The smell of the BBQ and popcorn brings me back to childhood years and memories of experiencing the same excitement and joy.

This annual carnival is held for all the communities within our Sudbury area. We made excellent connections with our schools and it was a great opportunity to bring awareness of bleeding disorders to the general public. ♡

Events Calendar

DATE	WHAT AND WHERE?
April 2-3	Thunder Bay Clinic (Lunch and Learn TBA) Tainted Blood Ceremony with Thunder Bay AIDS
May 12	Sudbury Clinic with Walk-a-thon following clinic

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

Happy Retirement to SUSAN HEIN

SUSAN HEIN, one of the two secretaries in the Haven/Hemophilia Program, retired on February 22, 2012. She has worked at Health Sciences North for many years, the last 10 years in these programs, bringing much joy to our clients. Her warmth and humour have provided her friends and co-workers with many moments of chuckles and laughter. We will surely miss her bubbly personality. Her family will certainly be very excited to spend more time with wife, mom, grandma, especially at “CAMP.”

Message to Mrs. Hein:

*If you have a quarter, Mrs. Hein,
Call us from time to time,
So we can have without confusion,
Our weekly “infusion,”
Of comedy by Susan. ♡*

Regional Board/Council and Staff

Paul McNeil – Chair
Kaitlynn McDonald – Vice Chair
Betty Ann Paradis – Treasurer
Cynthia Pulsifer – Secretary
Kris Onucky – Youth Chair

Fundraising Committee:

Tammi Deveau
Lorissa McDonald
Allan Ferdette

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

HAVEN PROGRAM

Sudbury celebrates 20 years

by Jeenetha Kulasingam

THE HIV AIDS Extended Network (HAVEN) is a diverse network of professionals including a medical director, social worker, pharmacist, dietitian, and a few registered nurses. The program’s focus is to provide interdisciplinary care to HIV patients across northeastern Ontario. Dr. Roger Sandre, the medical director, notes significant changes over the past two decades: patient numbers have increased three-fold, the demographic profile of patients has changed, and different treatments are being administered.

The increase in patients may be due to new cases of intravenous drug users, and the improved treatment has resulted in fewer deaths due to HIV-related problems. Twenty years ago most patients were “men having sex with men, but now it’s more women and Aboriginals.” This means that HIV is still spreading, but with new drugs now available, patients live longer and the development of AIDS has decreased. “At the beginning,” Sandre states, “we used only one drug—AZT. Now we have 20-25 highly effect drugs that are simple to use and less toxic.” The type of drug is chosen by measuring a patient’s CD4 cell count to gauge their immune system. In addition, the amount of virus in the blood is measured and patients are tested for drug resistance, tailoring the treatment to each individual patient. HAVEN performs HIV testing on all pregnancies, since the chance of spreading is under one percent when a mother goes on treatment during pregnancy.

With a growing team of professionals, enhanced treatment options and more knowledge acquired, HAVEN will have more success stories to share in the future. ♡

This article is based on “HAVEN program celebrates 20 years” by Norm Tollinsky in the Winter 2011 issue of The Northern Ontario Medical Journal.

Ottawa and Eastern Ontario Region



Kids and families enjoy a magician at OEOR's holiday party in 2011



From left to right, The Green Lantern – Colby Brown, Spiderman – Robbie Charbonneau, Princess – Amber Charbonneau dressed up for OEOR's Halloween Bowlathon Costume Contest. The event raised \$658.82. Thank you to the many sponsors that made this event possible.

A Memorable **HOLIDAY PARTY**

by *Aswani Kurichh*

HEMOPHILIA ONTARIO (OEOR) held its annual Holiday Party on December 12, 2011. Children of all ages joined regional council members at the Ottawa Police Association to build gingerbread houses, play games, sing carols and enjoy a delicious buffet.

Guests this year were treated to a wonderful show of magical illusions by Chris Pilsworth. Chris wowed the audience by performing an array of magical illusions that held the crowd breathless.

Each family got to take home a gingerbread house that they decorated at the event. All the children had a great time with a scavenger hunt and other games that kept them entertained.

St. Nick joined in the festivities by paying a friendly visit to the party and handing out gifts to each child, which put smiles on many young faces. ♡

Events Calendar

DATE	WHAT AND WHERE?
March 18	Regional Membership Meeting
March 30	Creation of Hemophilia Puppet, and Presentation Material
April 17	World Hemophilia Day Booth/Presentation
June	Youth Consultation Meeting

Regional Board/Council and Staff

Raja Ammoury-Alami
 Jordan Cabral
 Lyanne Cabral
 Lori Kavanagh
 Ashwani Kurrichh
 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

South Western Ontario Region

Ready to **SET A RECORD** on July 21, 2012

PLANNING IS MOVING QUICKLY to host up to 18,000 motorcycles in the Ride for the Record to set a new world record for the number of motorcycles in a parade. If you or someone you know would like to be part of the planning or volunteering during the event, we would like to hear from you.

If you are interested in helping with the planning or during the event, contact Brendon Beer at 519-630-7223, beerzie.ink@gmail.com or Matthew Maynard 519-432-2365, mmaynard@hemophilia.on.ca. ♡



Regional Board/Council and Staff

Dawn Harman
Kathleen Hazelwood
Travis Hazelwood
Ryan Kleefman
Michelle Lepera
Maureen Schaus
Marion Stolte
Holly Valenta
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All articles in this section, unless otherwise indicated, are by Matthew Maynard.

A **WIN-WIN** night at the **LONDON KNIGHTS** hockey game



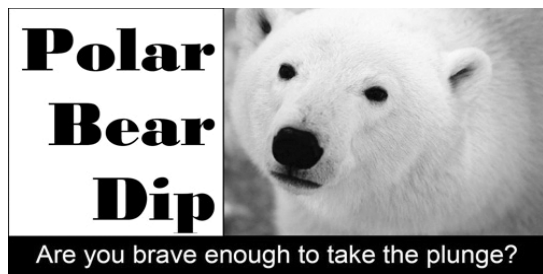
SWOR VOLUNTEERS had a great night on January 25 with so many volunteers coming out to help with the 50/50 Draw at the London Knights vs. Kitchener Rangers hockey game at the London John Labatt Centre.

We want to thank Brendon and the Ride for the Record for donating our shirts, Source Teamworks for lending us the money aprons, and Geoff Hare from the London Knights for making this opportunity available to us. Geoff's team supported us throughout our first time doing a 50/50 draw.

The Winner is ...

SWOR and Linda Wanamaker received \$2,667.50 each

Well done everyone! Lots of fun, lots of hollering "50/50 Tickets Here," to make a difference for those living with inherited bleeding disorders in South Western Ontario. ♡



TAKE THE PLUNGE in 2012

ON SUNDAY, April 15, join us at Little Beach in Port Stanley, and celebrate World Hemophilia Day with us by jumping in a lake! Again this year SWOR will recognize World Hemophilia Day with a Polar Bear Dip. Your help raises awareness and funds to support programs for the more than 300 people living with hemophilia, von Willebrand disease and other bleeding disorders and their families living in South Western Ontario.

Pledge Forms are available online at www.sworpolarbeardip.com. For more information or directions, contact Matthew at 519-432-2365 or mmaynard@hemophilia.on.ca. ♡

Events Calendar

DATE	WHAT AND WHERE?
April, 2012	Pinecrest Camper Applications will be mailed out to be completed and returned BY June 30
April 15, 2012	Polar Bear Dip Celebrating World Hemophilia Day, Port Stanley, ON
July 16, 2012	5th Annual Golf Tournament for Hemophilia and Inherited Bleeding Disorders, Highland Country Club, London, ON
July 21, 2012	Ride for the Record, London, ON
August 22-26	Pinecrest Adventure Camp, Goderich, ON

SWOR

Toronto and Central Ontario Region

Everything you want to know about **VON WILLEBRAND** disease

MAYBE YOU'RE STILL TRYING to remember how to spell it, or perhaps you know the ropes. TCOR's upcoming von Willebrand disease education session is a great learning opportunity for anyone affected by VWD. Dr. Paula James, an award-winning hematologist specializing in VWD, will speak about disease basics, new research and promising treatments.

Join us at the Northern District Library in Toronto (40 Orchard View Blvd.) on Saturday, March 31 from 1:00-2:30pm for an informal talk and plenty of time for questions. While you snack on some refreshments, take the opportunity to chat with other people with VWD and parents of affected children. You never know what you'll learn by comparing notes. Many resources on VWD will also be available at the session.

If you have questions already or have a topic in mind that you would like to hear more about or want to RSVP, contact Jeenetha Kulasingam at 416-972-0641, Ext. 14 before the event. ♡

TCOR membership votes to **AMALGAMATE**

At the Annual General Meeting on March 3, a strong majority of TCOR members voted to amalgamate with Hemophilia Ontario. If an amalgamation motion is also passed at the Hemophilia Ontario AGM on April 21, TCOR will cease to be a separately incorporated charity as of December 31, 2012. More information will follow by mail.



The Seanor/Hanneman family won an X-Box at the Holiday Party raffle.

Celebrating the holidays and **LOOKING FORWARD TO CAMP**

TCOR FAMILIES celebrated the holidays on December 3 at our Wanakita registration and holiday party. Amy Griffith talked about her experience as a counsellor and Trevor Reid spoke to parents and kids about how much he loves going to camp. By the end of the party even the most hesitant kids and parents had decided to register for Wanakita this summer. We know they'll have a great time.

Bleeding Disorders Jeopardy and a "Blood Snack" were enjoyed by all, and everyone learned something along the way. Thank you to the 519 Community Centre for hosting our party. ♡

Regional Board/Council and Staff

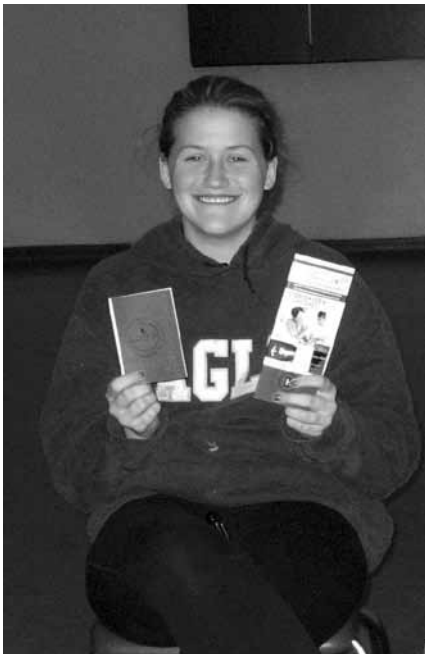
David Neal
Maury Drutz
Mike Beck
Mojtaba Khezry
Samuel Leon
Kristen Luszka
Victoria Kinniburgh
Kiran Gopie
Shaun Silveira

Staff

Susan Turner, Executive Assistant/Bookkeeper
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



Kaylin Murphy enjoyed a Passport to Well-Being education session on navigating the ER

Families in Touch MAKES A SPLASH

TCOR KIDS HAD A GREAT TIME at the Cummer Park Community Centre pool as parents shared experiences on the sidelines. The Regional Service Coordinators led a Passport to Wellbeing workshop on navigating the emergency department and families came away with helpful tips and strategies for their next ER visit. A special thank-you goes to Justin E. for his help with our skit. Join us at the next Families in Touch event in June for another educational workshop. ♡

Polar Bear Dip

Are you brave enough to take the plunge?

TAKE THE PLUNGE with TCOR

TCOR DOUBLE DARES YOU to put on your craziest costume and jump into chilly Lake Ontario for World Hemophilia Day. Collect pledges from your family and friends over the next month to support programs and services for people with inherited bleeding disorders in your area.

It's a simple way to raise awareness and funds for your community. You can register online at www.tcorpolarbeardip.com and collect pledges online or download the paper form. Just bring all your pledges on April 14 to Woodbine Beach at 1:30 pm and take the plunge. The more the merrier, so bring your family and friends. Everyone will enjoy snacks and hot chocolate to warm up afterwards.

As Hemophilia Ontario will not be participating in the Toronto Marathon this year, the Polar Bear Dip is now our major fundraising event. We'll be in friendly competition with the South Western Ontario Region who also hold a Polar Bear Dip for World Hemophilia Day, but all proceeds go towards supporting the same great cause in your region. Register today and start psyching yourself up! ♡

Events Calendar

DATE	WHAT AND WHERE?
March 31	von Willebrand Disease Education Session
April 14	Polar Bear Dip for World Hemophilia Day
April 17	Bleeding Disorders Panel Discussion for Medical Students
May 12	Men's Workshop
June 16	Families in Touch Summer Picnic

Clinic Corner

A ONE-STOP SHOP for women with bleeding disorders

by Sherry Purcell, Nurse Coordinator

OUR CLINIC AT THE KINGSTON General Hospital was established in 2005 following a site visit to the St. Justine Women's Clinic in Montreal, the first of such clinics in Canada. Our goal has been to improve the quality of life of girls and women with inherited bleeding disorders, by using an interdisciplinary team approach. Dr. James, our adult hematologist, Dr. Silva, our pediatric hematologist, Dr. Jamieson, our obstetrics/gynecology specialist, and a clinic nurse coordinator are in attendance monthly to provide their services.

The women who have attended this clinic since its inception report the experience as a great advantage for their ongoing care. The availability of both their hematologist and the expertise of an OB/GYN physician, when considering various therapeutic options for their menorrhagia is one prime example. Our clinic social worker is on call as well for counseling for family or financial issues, as required. This multidisciplinary clinic also offers the opportunity to discuss optimal care for women pre- and post-surgery. Although we do not follow women with bleeding disorders during pregnancy, we liaise with outlying general practitioners and obstetric physicians regarding the necessary precautions during delivery, and in the postpartum period, when there is a greatly increased risk of bleeding.

Our team believes that this "one-stop shopping" cooperative approach has greatly improved the quality of care we offer to women in this region with inherited bleeding disorders. ♡

Roles of the **SOCIAL WORKER** and **REGIONAL SERVICE COORDINATOR** at Clinic

by Linda Waterhouse, MSW, McMaster Hospital and Alex McGillivray, RSC

SOCIAL WORKERS at the various hemophilia treatment centres across the province are an essential part of the comprehensive care team. The social worker's role includes counseling, education, consultation, support, advocacy, resource finding, referral and participation in research. The role of the social worker is one that promotes and coordinates a systems-oriented assessment of the patient and family in an attempt to facilitate their optimum adjustment to living with an inherited bleeding disorder.

In addition, the social workers involved in hemophilia care often take part as volunteers on various committees associated with the Canadian Hemophilia Society (CHS), Hemophilia Ontario, and the Canadian Social Workers in Hemophilia Care group (CSWHC). As a result of their involvement with the CHS and Hemophilia Ontario, the social worker and Regional Service Coordinator (RSC) often work very closely with one another to provide services to the inherited bleeding disorders community in some clinics.

While the social worker provides a more systematic and clinical assessment, the RSC works closely with patients to provide information on educational services, programs, financial assistance, advocacy, peer support, and assistance with issues relating to HIV/AIDS and HCV with respect to both the CHS and Hemophilia Ontario. Together, the social worker and RSC are able to work collaboratively in an effort to provide enhanced services for patients and families.

Some of the services the social worker and RSC provide, but are not limited to, are:

Social Worker

- Adjustment to acute/chronic illness and disability (e.g. new diagnosis, recurrence of illness)
- Cultural or lifestyle barriers to receiving care
- Family conflict
- Relationship dynamics
- Quality of life issues and transitions in care
- Caregiver issues
- Family and parent/child relationship difficulties
- Compliance issues related to treatment recommendations
- Concrete needs such as finances, drug coverage, transportation, equipment, housing needs, activities of daily living
- Changes in employment/school/career status and income sources
- Referrals to other community resources (social, financial, legal, etc.)

Regional Service Coordinator

- Information on programs and services that Hemophilia Ontario and the Canadian Hemophilia Society provide
- Education, support, and care
- Peer support (e.g. making connections between families and individuals)
- Financial assistance
- Advocacy and practical support for issues relating to inherited bleeding disorders, HIV/AIDS and HCV
- Scholarship programs
- Access to educational materials on various inherited bleeding disorders
- Connections to other community resources ♡

What you NEED TO KNOW about your factor

by the Hemophilia Team at St. Michael's Hospital

IN THEIR NEW NEWSLETTER, *Clinic Notes*, the Hemophilia Team at St. Michael's Hospital defines some key terms about your factor treatments.

Recovery

Recovery is the highest level your factor reaches after you get an injection of factor concentrate. For most people this highest point will be between 15-30 minutes after completion of the factor infusion. This is why prior to surgery we will check your factor level to ensure that an adequate improvement in your factor level was reached.

The target recovery depends on what the factor is being infused for. Higher levels are required prior to surgery or in the case of a severe bleed. Lower levels are targeted for mild/moderate bleeding episodes and for prophylaxis. The dose of factor used in a particular situation is determined based on the desired recovery level.

Half-life

The other piece of information helpful when deciding frequency of factor administration is half-life. This is the time it takes for the clotting factor level to fall to half of its highest value just after infusion.

For factor VIII the average half-life is 8-12 hours, and for factor IX, 18-24 hours.

So what does recovery and half-life mean for you when treating at home? Using the information just provided, if you had a bleed one evening but you had infused factor that morning as prophylaxis, what should you do? Often patients will report that an additional treatment is not given because "I treated this morning." A new bleed usually requires a new dose of

factor. It is important to remember the factor's half-life. Maintaining the amount of factor in your blood will ensure that enough factor is present to assist in stopping the bleed.

Similarly, if you have a very bad bleed and inject your factor promptly—sometimes a slightly larger dose than you use for prophylaxis is required.

The hemophilia treatment centre should always be consulted to provide guidance on bleed treatment and dosing. A good reference is your wallet card or factor first card which provides dosage recommendations for mild, moderate and severe bleeds.

Finally, how much factor and how frequently you need to treat are also influenced by other principles such as consumption (more factor is used when a bleed is present) and the severity and location of the bleed. ♦



Dr. Paula James and Dr. David Lillicrap

Queen's HEMATOLOGISTS named Researchers of the Year

by Alex McGillivray

IN 2011, Dr. Paula James and Dr. David Lillicrap of the South Eastern Ontario Regional Inherited Bleeding Disorders Program at Kingston General Hospital received the distinguished honour of being named Researchers of the Year by the National Hemophilia Foundation in the United States.

The award was presented to the physicians for their continued research efforts towards improving the lives of patients with inherited bleeding disorders. On behalf of Hemophilia Ontario and all of its members, congratulations to both Dr. James and Dr. Lillicrap. ♦



Dr. Anthony Chan, Chair, McMaster Children's Hospital/Hamilton Health Sciences Foundation Pediatric Thrombosis and Hemostasis)

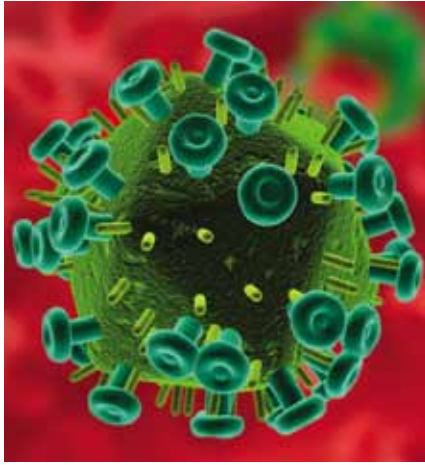
New Research Chair to FOCUS ON CHILD BLOOD DISORDERS at McMaster University

by Alex McGillivray

DR. ANTHONY CHAN, the Director and Pediatric Hematologist of the Hamilton-Niagara Regional Hemophilia Centre at McMaster Children's Hospital, has recently been appointed the chair of a newly established research initiative focusing on children's blood disorders.

The initiative is being supported by the Hamilton Health Sciences Foundation, McMaster Children's Hospital, and pharmaceutical company Bayer Inc. Congratulations, Dr. Chan. ♦

HIV/HCV News



The human immunodeficiency virus as seen through a microscope.

SLOWING THE PROGRESSION of HIV – the promise of elite controllers

by Natalie Chabrol, RPN

PROMISING NEW RESEARCH is being conducted on individuals who have been living with the human immunodeficiency virus (HIV) for many years. A group of people referred to as “elite controllers” may hold the key for slower progression from HIV to AIDS according to researchers. Elite controllers are a small group of people – about one in every 300 with HIV are considered to have this unique attribute. While they still have HIV and the possibility of transmitting the disease, these elite controllers can keep their viral loads down without medication and have not progressed to AIDS. Elite controllers, some of whom also have hemophilia, are being studied to find out why and how their viral load (how many copies of HIV in 1ml of blood) has decreased to undetectable amounts (less than 50 copies in 1ml of blood) without the use of antiretroviral medication.

The International HIV Controllers Study, which is based out of the Ragon Institute of Massachusetts

General Hospital, MIT and Harvard in Charlestown is requesting the participation of elite controllers internationally. Thus far, 1500 people have been recruited, 500 of whom are elite controllers and 1,000 viremic controllers (carrying less than 2,000 copies of HIV/1ml of blood). The continued hope is to find out why their immune systems handle the virus differently.

To better understand why this occurs, researchers are internationally investigating the genetic makeup of elite controllers. They have found five amino acids that seem to affect the viral load in the blood. These amino acids help the body’s immune system to recognize and destroy HIV infected cells earlier, preventing them from replicating and invading more cells.

The work of the amino acids make it possible for T-cells, which are part of the immune system, to be activated earlier therefore allowing more time for them to destroy the virus before its presence is too much for the immune system to handle. On average, elite controllers’ T-cells destroy 68% of infected HIV cells in one hour as opposed to 8.1% in non-controllers’ T-cells. This is done through the production of two other proteins which disrupt HIV cell membranes and cause them to self-destruct. Along with this, a protein called P21 was also found in elite controllers. This protein blocks the life cycle of HIV at two stages while it is within the CD4 helper cells (which are responsible for regulating immune responses), therefore inhibiting its further replication.

While there is still much to do in the way of isolating and somehow replicating the uniqueness of elite controllers, it is a positive step towards slowing the progression from HIV to AIDS, thereby increasing quality of life and life expectancy for those living with the virus.

This article is based on “HIV Under Control” in Hemaware Magazine. Sarah Aldridge, August 22, 2011. ♦

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I AM A SURVIVOR!

Survivor benefits for spouses and children of long-term survivors covered by the Multi-Provincial Territorial Assistance Program (“MPTAP”)

by Marc LaPrise

WERE YOU DIRECTLY INFECTED with HIV through the blood system? Are you covered under the MPTAP compensation plan? Did you marry or have children since September 15, 1993? If you answered yes to any of these questions we need to hear from you.

In the late 1980s the Multi-Provincial and Territorial Assistance Plan (MPTAP) was introduced which included survivor benefits for the spouse and dependants of the primarily-infected person. Spouse and children were defined as the spouse as of September 15, 1993, and dependant as a natural child as of September 15, 1994 or adopted child as of September 15, 1993. Following the death of the primarily-infected person the spouse as defined is entitled to \$20,000/year for five years. Dependants are entitled to \$4,000/year for five years for each child under 18 or between 18 and 25 and attending a secondary or post secondary educational institution full-time.

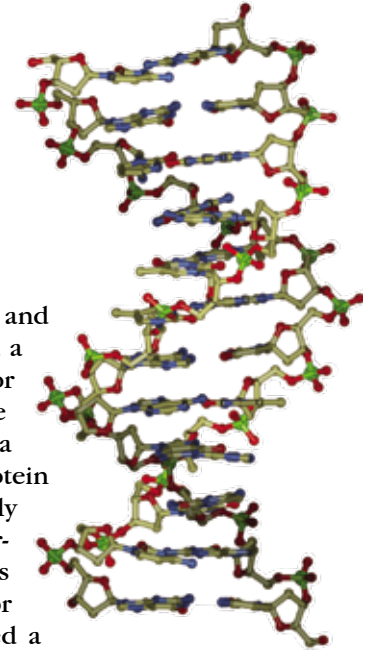
There are an unknown number of directly infected long-term survivors who may have married or entered a spousal relationship or had children since September 15, 1994. **We would like to find out how many of our members are in this situation.**

If you signed the MPTAP agreement and have subsequently married, your new spouse or any children born are not entitled to survivor benefits. The Canadian Hemophilia Society would like to hear from you if you are in this particular life situation. Some members have

Bleeding Disorders News

GENE THERAPY breakthrough promises a cure for HEMOPHILIA B

by Natalie Chabrol, RPN



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expressed a desire to seek modification to the MPTAP agreement for those long-term survivors who have decided to start a family.

If this applies to you, we want to help. The CHS is prepared to lobby provincial and territorial health ministers with a view to extending survivor benefits to all spouses and children of directly infected long-term survivors covered by the MPTAP, including spouses and children who were not part of the claimant's lives at the time of applying and being accepted under the plan. The advocacy work would be undertaken by a task force (small working group) and overseen by the CHS National HIV-Hepatitis committee.

We would like to hear from anyone in our membership who is in this situation—a 'head count' will be useful during the lobby process. Any information you provide to the CHS is kept in the strictest of confidence; no personal information will be divulged during the lobby process.

We are also looking for individuals who are prepared to join the working group and help bring this to fruition. One of our members, Marc LaPrise, will lead the working group that will help to advise the HIV-Hepatitis Committee as they coordinate the lobby effort. This is your chance to stand up for your rights as someone who was infected through the blood supply and wants to take responsibility for their new role in life as a mother or father or life partner.

Contact Michel Long at mlong@hemophilia.ca or 514-848-0503 ext. 225. ♦

RESEARCHERS FROM THE United Kingdom and the United States have developed and tested a treatment that has the potential to decrease or completely replace the medication otherwise normally required for those with hemophilia B. The multiple infusions of factor IX (a protein required for blood clotting) may be significantly decreased according to researchers at University College, London and St. Jude Children's Research Hospital in Memphis. In looking for a more permanent treatment, they modified a virus (adeno-associated virus eight, which can infect people without producing symptoms) to infect liver cells with the blueprint for making factor IX. Once the liver cells are infected with this genetic material, it will pass on to other liver cells which will then begin to create the protein independently.

According to the study, six patients were treated with the modified virus at different doses to test efficacy. Normally, severe hemophilia B patients have less than one percent of the necessary factor IX. After being given the modified virus, however, factor IX levels increased to between 2-12 percent. For the first patient treated, a two percent level was maintained for more than 16 months; for a patient given the highest dose of the virus, levels fluctuated between 8-12 percent for 20 weeks. This is promising, as Dr. Amit Nathwani from University College, London noted that patients who had factor IX levels of 12 percent no longer needed to be seen in the clinic.

If levels of factor IX remained high enough, those with hemophilia B would be able to maintain normal daily activities, and short of a serious accident, may not notice the effects of their condition. Of the patients in the study, even those who still required infusions benefited from the gene therapy because they needed fewer infusions. This goes along with the aim of the research, which is to reduce severe forms of hemophilia to mild ones with a stable and long-term level of factor IX, allowing patients to save both money and time and to have a better quality of life.

Before this research can benefit everyone with hemophilia B, further long-term testing will need to be conducted for safety and efficacy. During the research, an immune response against the altered liver cells occurred around the seventh to ninth week after injection of the virus. It was controlled with steroids, but doctors will want to prevent this from happening in future studies. While the modified virus still requires further testing, it has shown to be a promising start for a long-term treatment for those who have hemophilia B. Although hemophilia A (factor VIII deficiency) is the more common of the two bleeding disorders, the gene for factor IX is smaller and therefore easier to isolate and work with in a laboratory setting. Strides will continue to be made in hopes of discovering a treatment that will decrease the need and frequency of infusions for those with hemophilia A. ♦

Based on "Haemophilia gene therapy shows early success," by James Gallagher, health reporter, BBC News. December 10, 2011.

An **EXCITING TIME** for von Willebrand disease research

by Dr. Natalia Rydz

VON WILLEBRAND DISEASE (VWD) is caused by a deficiency or dysfunction of the von Willebrand factor protein, which is important for blood to clot normally. VWD is the most common inherited bleeding disorder, with as much as one percent of the population being affected. Each individual with VWD may have a different combination of bleeding symptoms, and some may only notice abnormal bleeding after a surgery or dental work. Others may complain of bruising without recognized trauma, prolonged and recurrent nosebleeds and bleeding from the gums after brushing the teeth. Females with VWD frequently experience heavy periods, and have abnormal bleeding after childbirth. The last several decades have seen much advancement in the understanding of VWD, and the ability to diagnose and to treat individuals with VWD. Nevertheless, we still have much to learn about this bleeding disorder. Researchers are continuing to explore several important areas: diagnosing VWD with bleeding assessment tools, the optimal use of drugs such as tranexamic acid (Cyklokapron®), the need for regular VWF replacement in severe VWD, and the development of new VWF products.

Diagnosing VWD can be difficult. Bleeding symptoms are common even in patients without bleeding disorders and the blood test results for VWD can fluctuate, at times looking normal in a patient who has VWD. For this reason, bleeding assessment tools (BATs) were first developed in 2005 to aid in differentiating normal from abnormal bleeding symptoms. BATs involve a list of questions covering each bleeding symptom, which is scored based on the most severe episode. This allows the quantification of bleeding symptoms. Much

work is ongoing to improve BATs. Versions of BATs are being developed that can be self-administered and are also available on the internet. These two advancements will be a useful tool for individuals who suspect that they may have a bleeding disorder and will aid in a prompt referral to a bleeding disorders specialist. BATs are also being created that will give an accurate assessment of day-to-day bleeding frequency and severity. Having such a tool is very important to accurately assess the success of certain treatments in decreasing bleeding symptoms.

Many researchers are focusing on improving the use of agents already used in VWD. One such example is the use of tranexamic acid (Cyklokapron®) in women with heavy periods. Tranexamic acid is effective in reducing menstrual flow, but up to 33 percent of women have side effects that limit its use. Researchers are exploring the lowest effective dose of tranexamic acid, which may be lower than what is currently prescribed. If this is true, tranexamic acid, at a lower dose and with fewer side effects, may be a good option for the treatment of heavy periods.

Another important study is looking closely at the optimal way of using VWF replacement in severe cases of VWD. Generally, individuals with severe VWD receive VWF replacement on-demand to treat a bleeding episode. On the other hand, in severe hemophilia, factor replacement is used regularly to prevent bleeding episodes, which has been shown to prevent long-term complications such as joint damage. This is known as prophylaxis. In an international, multicenter study known as the VIP (VWD International Prophylaxis) study, researchers are identifying which individuals with VWD may



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benefit from prophylaxis with VWF replacement, and the effect of prophylaxis on bleeding frequency. Also, they are establishing optimal treatment regimens for joint bleeding, nose bleeding, heavy periods and bleeding from the bowels.

To date, the VWF replacement products available for the treatment of individuals with VWD are produced from human blood products. New products, known as recombinant VWF, have been developed. These products do not contain blood-based additives. Multicenter clinical trials are underway which are assessing the safety and effectiveness of this new product in the prevention and treatment of bleeding episodes. This factor, which has no exposure to human blood products, may be an alternative treatment choice for VWD patients in the future.

This is a busy and exciting time for VWD-related research. With hopes in the near future to improve the identification of individuals with VWD, to more effectively treat or prevent bleeding symptoms with fewer side effects, and to have access to safer products, the ultimate goal is to improve the quality of life of those with VWD. ♦



JUST THE GUYS 2012

Save This Date!

Friday, September 21, - Sunday, September 23, 2012

The Just the Guys program is a weekend residential camp for boys ages 4-17 who are affected by an inherited bleeding disorder and an accompanying father/male role model ages 19 and above who is directly involved in the care of the child.

The weekend provides an opportunity for participants to gain a better understanding of the diagnoses, as well as to connect with other families through a series of education sessions, activities, and networking opportunities.

Note: 4 year olds will be given individual consideration for participation, and 17 year olds have the option of attending as a participant with their father/ accompanying male role model, or attending as a regional Just the Guys Youth Volunteer (one volunteer position per region).





**MARK
THIS
DATE**

Hemophilia Ontario Calendar 2012

DATE	WHAT AND WHERE?
March 30 - April 1	Hemophilia Ontario Youth Trip to Montreal
April 21	Hemophilia Ontario Annual General Meeting in Ottawa
May 25-26	The Canadian Hemophilia Society's CODerouge Conference
July 29- August 11	Camp Wanakita
September 21-23	Just the Guys
October 19-21	Celebrating Community Camp



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