

A publication of



Hemophilia Ontario  
Hémophilie Ontario

# BLOOD

*matters*

"We're all related by blood."  
Volume 2 • Number 1

Spring 2011



**Options for young people**  
scholarships, education, career choices

## Hemophilia Ontario

### 2010- 2011 Hemophilia Ontario Board Members

Dane Pedersen, President  
 Cameron Peters, Vice President-Elect  
 Maury Drutz, Vice President  
 Paul Wilton, Vice President  
 Steve Van Dusen, Secretary  
 Mike Beck, Director  
 Brendon Beer, Director  
 Venanzio D'Addario, Member-at-Large  
 Ahmed Hassan, Director  
 Mark Lubinski, Director  
 David Neal, Director  
 Jace Pedersen, Director  
 Barb Peters, Member-at-Large  
 Sheldon Rose, Director  
 Justin Terpstra, Director  
 Brian Van Dusen, Director  
 Jaime Villeneuve, Director  
 Shaun Bernstein, Youth Chair

#### Editorial Staff

Frank Bott, Editor  
 David Page, Interim Executive Director  
 Susan Turner, Administrative Assistant  
 Robin Nobleman, Regional Service Coordinator  
 Alex McGillivray, Regional Service Coordinator

#### Youth Editor

Shaun Bernstein

#### Editorial Committee

Frank Bott  
 Alex McGillivray  
 Susan Turner  
 Robin Nobleman  
 Terri-Lee Higgins  
 Shaun Bernstein

#### Staff

David Page, Interim Executive Director  
 Terri-Lee Higgins, Acting Provincial Program Manager  
 Marina Seliverstova, Senior Accountant  
 Jialing Liang, Bookkeeper

#### Art Direction/Design & Printing

GEPM Group (www.gepmgroup.com)  
 Gustavo and Donna Lee Pancorvo

A publication of



**Hemophilia Ontario**  
**Hémophilie Ontario**

Hemophilia Ontario is a certified chapter  
 of the Canadian Hemophilia Society.

## What's in this issue?

Spring 2011 • Vol. 2, No. 1

Information from Hemophilia Ontario and its Regions.

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

Cover photo: NEOR – Kaylee (11), Kyle (9) and Kurtis (7)  
 Cadieux proudly display their water boiling awards. Story on p. 16.

Thank you to our Magazine Sponsors:



Bayer HealthCare

**Baxter**



novo nordisk®

**CSL Behring**

Biotherapies for Life™

Published by  
 Hemophilia Ontario  
 501 – 65 Wellesley St. E., Toronto, ON M4Y 1G7  
 416-972-0641 or 1-888-838-8846.  
 Fax: 416-972-0307 • www.hemophilia.on.ca

©2011, *Blood Matters*, the contents of which is subject to copy-  
 right, is published three times a year. Reproduction in whole or  
 in part, in written, electronic or any other format, without prior  
 written permission, is strictly prohibited. For more information,  
 please contact Terri-Lee Higgins, Acting Provincial Program  
 Manager at thiggins@hemophilia.on.ca or 1-888-838-8846.

# Spotlight on the Province

## President's Message

by Dane Pedersen,  
Hemophilia Ontario President,  
2009-11

AS WE APPROACH the 54<sup>th</sup> Hemophilia Ontario AGM, I find myself taking stock of what has transpired over the past year. When I was skipped ahead of the queue for the position of President, I was a bit overwhelmed. The expectation of being part of the traditional grooming process from my predecessor was removed through circumstances beyond our control. I would like to thank Julia Sek for being a great support for me while she was President and after she stepped aside. There was not much time to get acclimatized to my new role, but some background reading got me up to speed. The Executive Director, Heather Heagle, was a tremendous asset for me. Heather was able to give me any background I was missing and had my confidence in making sure the organization not only ran well but sought out improvements. While Heather is no longer with Hemophilia Ontario, I know, like Julia Sek, she is out there making a difference in the lives of people.

We have been travelling down a road towards a Hemophilia Ontario that is attempting to maintain the strength and drive of the grassroots passion and experience found at the regional level, with the need to increase and focus the Board level responsibilities and skill requirements necessary at the Hemophilia Ontario Board level. This road has been rough, full of delays and cul-de-sacs, but progress still continues. I believe the net result of this process will lead Hemophilia Ontario to become a much more nimble and responsive organization that will have the ability to adapt and adjust to the world of bleeding disorders. Most importantly, we will be able to better communicate how we achieve our

mission. Unfortunately, this effort to introspectively realign Hemophilia Ontario is diverting our attention from matters within which we have historically been active participants.

Hemophilia Ontario continues to be able to provide programming, primarily for families, with our camps and workshops. Additionally, we are providing many in the bleeding disorder community with financial assistance to make sure that people with bleeding disorders can live normal lives. In maintaining these activities, we are dangerously close to losing our voice in Ontario. We have a great legacy of individuals who have stood tall and represented Hemophilia Ontario, but many, including me, have remained on the sidelines. Representation of the bleeding disorder community on provincial governmental committees is not being sought. Hemophilia Ontario is making efforts to build this capacity but it will take time and require an infusion of new, energetic people. Now and in the years to come, advocacy will be the most important strategic goal as a direct result of the progress in care and treatment that has been achieved. The better the care, the more vigilant Hemophilia Ontario will have to become to ensure that it does not succumb to the budgetary whims of governments or hospitals. As a bleeding disorder community, we need to challenge and demand more from Hemophilia Ontario and its Board. As a Board member, I would greatly appreciate that demand for accountability from my community. With this legitimacy in hand, I believe Hemophilia Ontario could be successful.

In my mind, we have structure in place but work remains to be done.

We must reinforce the vision of Hemophilia Ontario as a strong advocate through an active community, and implement that spirit in our health partners, governmental representatives and the general public.

My term as President comes to an end in April and I feel as though for as many answers as I have found, I will leave with a vast amount of questions. I learned a lot about how not-for-profits work structurally and administratively. I learned that the varied and dynamic perspectives of people need to be taken in varied and sometimes dynamic ways. So, I take this two-and-a-half years as those I won't forget and fondly look back on. I would like to thank the Board for their help through the year. Specifically, I would like to thank Cam Peters for his wise words, Ahmed Hassan for his drive and expertise, Maury Drutz for compassion and listening, Mike Beck for his experience and dedication, and Jace Pedersen for his support, patience and time. I would also like to thank the staff for riding through a tough year. I would like to acknowledge the unsung members of our staff that you may not see out at events. Marina Seliverstova, our senior accountant who has helped to clean up and improve our financials, Jialing Liang, our bookkeeper who patiently revealed the nuts and bolts of how we operate and is a wealth of information about our activities, Susan Turner, whom I turn to and rely on without fail, and Stephanie Darroch, who left an indelible mark amongst her peers as a conscientious and hard-working person. Of course, my thanks go out to all the RSCs whose efforts you will be able to read about in this issue of *Blood Matters*. ♦

## Message from the Interim Executive Director

by David Page

READERS OF THE FALL 2010 issue of *Blood Matters* will know that Heather Heagle left the position of Executive Director of Hemophilia Ontario on November 1. Subsequently, the Canadian Hemophilia Society (CHS) offered its help as the Hemophilia Ontario and TCOR Boards of Directors considered their options with regard to staffing. In January, CHS, Hemophilia Ontario and TCOR signed a three-month agreement whereby the national office of the CHS will provide day-to-day management and operational support. The agreement took effect on February 1.

Hemophilia Ontario and TCOR retain their separate legal status, and remain responsible for all their contractual obligations. The Boards of Directors of Hemophilia Ontario and TCOR retain absolute authority with regard to setting policy, determining their strategic directions and orientations, and adopting positions on issues affecting their members.

While the CHS, Hemophilia Ontario and its regions have a long history of collaborating on programming, advocacy and fundraising initiatives, this closer working relationship is bound to build greater understanding and stronger bridges among the different levels of the organization.

As CHS National Executive Director, and on behalf of the entire staff of the national office, I look forward to this opportunity to work side by side with our Ontario counterparts in furthering our common mission to improve the quality of life of all people with inherited bleeding disorders, and ultimately to find a cure. ♦

## HIV/HCV Provincial Program Manager

by Terri-Lee Higgins, Acting HIV/HCV Provincial Program Manager

**INSPIRATION IS DEFINED** as the act or power of moving the intellect or emotions, the act of influencing or suggesting opinion, the quality or state of being inspired. Each and every day, we are all inspired—by a picture, a random act, a moving story or a recognized need. Hemophilia Ontario as an agency is inspired by our mission: improving the quality of life of people affected by hemophilia and related blood conditions and working towards a cure. Our vision is a world free of the pain of inherited bleeding disorders.

I recently had the opportunity to review the Strategic Plan (2009-2012) and found my inspiration—what drives me every day to ensure that what I do makes a difference. I was particularly struck by the Values statement:

*At Hemophilia Ontario, an important part of our current organizational identity and experience is based in the loss suffered by the hemophilia community, those with inherited bleeding disorders and others who were infected with HIV and/or Hepatitis C and their families, friends and communities; through blood or blood products they depended on for lifesaving treatment and therapy over the past two decades. With this principle at our core, Hemophilia Ontario is guided by the following values in the work we undertake;*

- **Ensuring accessibility** of product, information and treatments where and when required and the **hope** that effective treatments and support will be available for all until the day that cures will be found
- **Ensuring autonomy** so individuals are free to make choices regarding their own health, care and treatment and the **dignity** of compassionate care that supports and promotes self-respect. We aim to deliver supports and services with the firm belief that every person is deserving of compassion, care and inclusion
- **That we preserve trust through honest communication and accountability**
- **That commitment and passion** to improve the quality of life of those living with and affected by inherited bleeding disorders underlies all we do.

These statements are at the core of the work performed by the staff and volunteers across the province. *You* are the core. *You* are the inspiration. With your input and ideas, we strive to provide the requested programming and education. I invite you to share your ideas with me or your Regional Service Coordinator. Keep us inspired. ♦



Hemophilia Ontario

We're All Related By Blood

### HEMOPHILIA ONTARIO Annual General Meeting

Saturday, April 16, 2011  
The Hilton Hotel, 300 King St., London, ON  
10:00am-3:00pm

Educational sessions (10:00-12:00)

- The Golden Age of Hemophilia, Dr. Jean-Francois Castilloux
  - Psychology of Leadership Success: Motivational Strategies to Increase Volunteer Commitment & Accountability, Greg Schinkel
- Lunch will be provided for those participating in the Annual General Meeting at 1:00pm.

If you are interested in becoming a board member, would like to nominate someone for a volunteer award or wish to RSVP, contact Susan Turner at sturner@hemophilia.on.ca 1-888-838-8846 or 416-972-0641 Ext 21.

## Advocacy

### The Quiet Advocate

by Alex McGillivray, Regional Service Coordinator

**THIS PAST JANUARY**, I received a request from a member asking me to attend an appointment at the Infectious Diseases Clinic at McMaster Hospital. As a Regional Service Coordinator, I was happy to assist with this request. I saw this as an opportunity to learn more about what the process is like for those who are infected with HIV, HCV, or co-infected.

When we first arrived at the appointment, I admit that my mindset was strictly focused on learning, and asking as many questions as possible. My objective quickly changed. Instead of looking to the doctors, nurses, and other healthcare professionals to answer technical questions, my focus shifted to posing emotional questions to the member with whom I was attending the appointment. I perceived him as exuding a mix of uncertainty, empathy and inquisitiveness.

A bit of an explanation is required before I continue. This member is not just a member for me. We may not see each other much outside the working environment, but I would consider this person a friend based on experiences and memories shared while working at Hemophilia Ontario. As a result, my thoughts from here on out are a reflection of this member not just as a member, but as a friend.

My immediate reaction after the first round of the appointment came to an end was one of disbelief and fear. My thoughts were, *Oh my God! My friend is going to die! He is in his early 30s and may not live to see 35.* Then I looked at my friend and asked him how old he was when he was diagnosed with his co-infection, and followed that question with another about what his co-infection meant for his life expectancy—two very hard questions to ask, and two very hard questions to answer. Much like



a professional, he looked at me and calmly replied that he was five years old when he was diagnosed, that life expectancy in circumstances like his are often difficult to determine, and that it's best to live one day at a time. Upon hearing his response, I initially didn't feel any sense of relief. Instead I began thinking of his mother and the rest of his family on the day he was diagnosed and how they must have felt when they heard the news. I then thought about his girlfriend and how she copes with knowing that there is the potential that he may not make it to 35. I think I felt overwhelmed because I don't particularly associate this person with co-infection. He actively partakes in sports and enjoys his life. As a result, I view him as living a normal life—which is why attending his appointment with him was such a shock to my system.

I know that I am making this sound like the most depressing story, but the truth is, this story *is* depressing. There are countless others who have similar stories if not worse, and by worse, I mean stories of losing their loved ones. At the same time, however, I have such great respect for my friend and his entire family—respect because they have the courage to face their demons with grace. I also feel a great sense of pride for him. I feel proud because he deserves to be commended for tackling his co-infection for the last 26 years like a true champion. My heart also feels an overwhelming sense of hope. While some have lost their battle with

these terrible diseases, there are still many, like my friend, who continue to challenge their adversity every day. Their tenacious nature gives me hope because it is that raw spirit that ignites the creation of new ideas and ways to beat the odds.

I may have gone into that appointment thinking I was going to learn something tangible that I could give back to those constituents living with HIV, HCV and co-infection, but what I really learned was far more than that. I learned that you don't need worldly knowledge to be a good advocate; sometimes being a good advocate means supporting someone quietly in their fight. Sometimes it means asking questions with empathy and understanding, and sometimes it means just treating someone like the normal human being they really are. It's not that I wasn't sympathetic towards HIV, HCV or co-infection before this appointment, but my sympathy and compassion now are much stronger in my heart than they have ever been. The experience as a whole is one that I would recommend to any Regional Service Coordinator if they haven't had the opportunity to do so already. It truly provided me with a deeper understanding of the emotional components involved in living with one, or both of these horrible diseases. If anything, the experience will make me more confident in assisting members with facing their challenges as well as celebrating their victories. ♦

## What does the law say about HIV disclosure?

by Robin Nobleman

**UNDER CANADIAN CRIMINAL LAW**, people living with HIV have a legal duty to disclose their HIV status to their partner before engaging in sex that carries a significant risk of infection. A reasonable law, you might think. No one should be able to knowingly infect others. However, the law does not clearly define what counts as a significant risk of infection. For this reason, many people, including some hemophiliacs, have been charged, convicted and sent to prison for not disclosing their HIV status, even when their partner did not become infected.

The Canadian Hemophilia Society and Hemophilia Ontario support the position that HIV/AIDS is an individual and public health issue first and foremost, and should be addressed as such. Criminalization is not an effective way to deal with a complex social issue such as HIV disclosure.

There are many reasons why persons might not wish to disclose their HIV status. HIV/AIDS is still a stigmatized disease and disclosure can lead to loss of employment, housing, friends and family and certainly a loss of privacy. Criminalizing non-disclosure could have negative consequences for testing and prevention as well. Some people might avoid testing to avoid being held criminally responsible for transmission. Criminalizing non-disclosure also takes away the individual responsibility of every person to protect himself or herself against HIV and other sexually-transmitted infections.

The increasing criminalization of HIV non-disclosure happened without adequate public debate and critique. If you would like to make your voice heard on the matter, here are some things you can do. Endorse the campaign for prosecution guidelines



Photo credit: BigStockPhoto.com/614439

run by the Ontario Working Group on Criminal Law and HIV Exposure by visiting their website at <http://www.ontarioaidsnetwork.on.ca/clhe/>. The CHS is also very interested in hearing your views on this matter, answering questions and providing support to those who may be facing charges. You can contact Michel Long in confidentiality at [m-long@hemophilia.ca](mailto:m-long@hemophilia.ca) or 1-800-668-2686. ♦

## Canadian Hemophilia Society Blood Safety and Supply Committee – Chapter Update

by Paul Wilton



**IN JUNE 2002**, Canadian Blood Services received an anonymous e-mail from a man indicating he had provided false information during the donor-screening questionnaire before giving blood. In this e-mail the donor indicated his disagreement with Canadian Blood Services' policy prohibiting men who have sex with other men since 1977 from donating blood. Canadian Blood Services went to court to obtain the identity of this donor so that his donations could be traced to reduce potential risk to blood recipients. The anonymous donor was identified as Kyle Freeman. Mr. Freeman was sued by Canadian Blood Services based on his alleged misrepresentations during the donor-screening process. Mr. Freeman counter-sued the Attorney General of Canada (on behalf of Health Canada) and Canadian Blood Services for discrimination.

The Canadian Hemophilia Society (CHS) was granted Intervenor Status in the case and argued that the MSM policy should be kept in place because the science was not there to indicate that a change to the deferral policy was safe for blood recipients. On September 8, 2010 Justice Catherine Aiken delivered her verdict in the Freeman case. In her decision, Justice Aitken ruled that blood donation is not a right; that donors have a responsibility to answer donor-screening questions honestly, the Charter of Rights and Freedoms does not apply to Canadian Blood Services, and deferring on the basis of the MSM policy is not discriminatory. Mr. Freeman had until October 8, 2010 to file for Appeal. Mr. Freeman did initially file an appeal of the decision, but recently withdrew his appeal.

### Canadian Blood Services Board of Directors

Canadian Blood Services Board of Directors is appointed by the members of Canadian Blood Services who are the 12 provincial and territorial Ministers of Health. Two positions on the Board of Directors are designated to public representatives. These directors are chosen from individuals with knowledge of blood system issues and close ties to organizations representing recipients of blood and blood products. James Kreppner served in one of these positions from 2002-2009. Other public directors have included representatives from cancer, aplastic anemia and thalassemia.

CHS takes very seriously the recipient appointments to Canadian Blood Services Board of Directors. It is the position of CHS that the recent appointments to the recipient positions violate Canadian Blood Services' by-laws because these appointments, to CHS' knowledge, are not connected to "patient organizations representing persons consuming blood and blood products" (Canadian Blood Services by-laws). The Canadian Hemophilia Society explained:

*This exclusion constitutes a loss of expertise for the CBS Board and the entire blood system. For example, CBS Board representatives from CHS were supported by our own Blood Safety and Supply Committee which has over 300 years of collective experience in blood system issues and extensive international contacts.*

*The position of recipient representative on the CBS Board of Directors requires the ability to vigorously represent the best interests of recipients of blood and blood products and to maintain close communication links between CBS and blood user groups. That is why the positions were created on the recommendation of Justice Horace Krever.*

CHS was also concerned about what it considered to be a lack of transparency in the nomination process for these positions and the inability of patient organizations to propose candidates. CHS has pursued its argument with the provincial Ministers of Health and recommended that the members take action to ensure Board appointments respect Justice Krever's recommendations and Canadian Blood Services' by-laws.

Hemophilia Ontario has supported CHS' efforts by raising its objections to the Ontario Minister of Health. ♡



## Dental Care and Bleeding Disorders

by Teresa Genereux

**DENTAL CARE IS IMPORTANT** for everyone in their daily lives. If you have a bleeding disorder, however, it is very important to take the proper precautions. Something as simple as getting your teeth cleaned requires special treatment and care. It is important for you to talk to your doctor or nurse at your treatment centre so that they can provide you with the proper care, along with your dentist. Sometimes we do not think to tell our dentist that we have a condition that requires special attention. Things the dentist needs to be aware of include what kind of bleeding disorder you have and what medications you are taking. The nurses' association has created a simple form that they can fill out for you to bring to your dentist to ensure that you receive the proper care during dental appointments. This will also ensure you are taking the proper dosage of your medication to prevent bleeds during and after any dental work. ♡

---

## Clinic Corner

### Southeastern Ontario Bleeding Disorders Clinic

## Kingston General Hospital

by Sherry Purcell, Nurse Coordinator

**WE HAVE HAPPILY** welcomed a new half-time RN, Lisa Thibeault, to our clinic team. She will be practicing in both a clinical and research role.

Our clinic has also been accepted by the World Federation of Hemophilia as a twin for Managua, Nicaragua. This is a wonderful opportunity for a mutually beneficial experience. The preliminary visit will be made in early April by our Spanish-speaking pediatrician, Dr. Mariana Silva. I am happy to report that our monthly Women's Clinic is up and running with Dr. Mary Anne Jamieson attending as our obstetrics and gynecology physician.

All for now from my "frozen brain." We in this region are longing for spring and are sure the rest of you share that similar desire. ♡

## Hemophilia News

### Early Prophylaxis Effective for Children with Hemophilia

Summarized by Jeenetha Kulasingam

**THIS NEWS REPORT** was based on the journal article, "A Randomized Clinical Trial of Prophylaxis in Children with Hemophilia A (The ESPRIT Study)." This study, led by Dr. Alessandro Gringeri, MD, of the Angelo Bianchi Bonomi Hemophilia and Thrombosis Centre in Milan, was done in Italy, where not all children are on prophylaxis. The objective behind this study was to see the effectiveness of prophylaxis in the earlier stages of development. Forty-five children with severe hemophilia A between the ages of one and seven, with "negative clinical-radiologist joint score with at least one bleed within the previous six months" were submitted to randomized prophylaxis treatment or episodic therapy. Twenty-one children received prophylaxis and 19 children received episodic treatment. Researchers have stated that children that received prophylaxis had fewer hemarthroses (joint bleeds) compared to their counterparts. "Plain-film radiology showed signs of arthropathy (joint damage) in six patients on prophylaxis (29 percent) vs. 14 on episodic treatment (74 percent) ( $p < 0.05$ )." Researchers have confirmed that when prophylaxis is started early there are statistically fewer joint bleeds and less joint damage.

*References:*

Gringeri, A., et al. (2011). A Randomized Clinical Trial of Prophylaxis in Children with Hemophilia A (the ESPRIT Study). *Journal of Thrombosis and Haemostasis*. Abstract viewed on Wiley Online Library.

Source: Health Day News (Thurs, Feb 3, 2011) ♡

## Pharmaceutical News

### Canadian hemophilia researchers receive grant award from Baxter

by Robin Nobleman

**THREE CANADIAN** researchers have been awarded grants to conduct quality population-based clinical research in hereditary bleeding disorders in Canada. The grants are provided by the 2010 Baxter Canadian Hemophilia Epidemiological Research Program (B-CHERP), a partnership between Baxter Corporation and the Association of Hemophilia Clinic Directors of Canada (AHCDC).

Dr. Jean St-Louis, chair of the research committee of the AHCDC, announced that the following studies would be funded through the grants:

Dr. David Lillicrap has been awarded funding for the study, "Genetic Influences on the Pharmacokinetics (how the body acts on a drug, which can be affected by how and where it's administered and what amount is given) of Factor VIII." His co-investigators include Drs. Blanchette, Carcao and Rivard.

Dr. Paula James, grant recipient of the 2009 B-CHERP award, received an additional year of funding for the study titled, "A Genome Wide Association Study (GWAS) to Determine Factors that Contribute to Mucocutaneous Bleeding," comparing the DNA of many individuals with and without a certain disease or symptom (such as bleeding under the skin or in mucous membranes) to see how their genes vary, giving clues as to how a certain disease works at the molecular level.

Finally, funding for a study titled a "Multicentre Canadian Study of Prophylaxis in Older Adults with Severe Hemophilia" has been awarded to Dr. Shannon Jackson and co-investigators Drs. Warner, Brose, Webert, Card and Poon. Dr. Jackson is based at the University of British Columbia.

Grants that qualify for the funding include clinical, descriptive and epidemiological studies of hereditary bleeding disorders. Grants can reach \$75,000 annually with a total of up to \$225,000 for three years. ♡

# Baxter



**DAVE CROFT** of Novo Nordisk has recently retired after 30 years of service as Biopharmaceuticals Therapy Specialist – Hemophilia. We would like to express our gratitude to Dave for his hard work and wish him all the best in his retirement. It has been a pleasure working with him. ♡

# Thinking About Your Career

by Rob Dinsdale

**ONE OF THE MAJOR** and most important decisions that young people are faced with is a career choice. This can be especially true for youth with bleeding disorders as we face additional questions such as, what can I do safely? What are the long term physical effects of my choices?

I was born in 1954 and am a factor IX hemophiliac. I remember my family doctor saying to me at a fairly young age that it was important that I get an education that would enable me to work in a non-physical job as I got older. This was very important then because at the time there was very little available to treat bleeds, and we did not know the amazing advances in treatment that were coming that would so dramatically improve the quality of life for our community and open up a wider array of career options.

I was fortunate that even as a young person I was fascinated by the business world and was able to develop a career in that area. I studied business administration in college and was fortunate to be hired by an extremely good corporation in the chemical coatings field soon after graduation. I started as a sales trainee and worked my way up through the ranks until I was responsible for the Canadian division of the company. This was a job with a great deal of responsibility, long hours and quite a bit of travel. My job was a good fit for me; I like to compete, enjoyed the responsibility, and loved the business world. I think that my being a hemophiliac helped push me along as I always had a bit of an “I’ll show you” attitude when it came to work or sports.

Approximately 10 years ago I left my “corporate” job and began a career in the training and development field; I worked with companies training their personnel in various areas—leadership, sales, strategic planning and so on. This job too was a good fit for me. It enabled me to use my business skills, and also gave me an opportunity to do something else that I like to do: teach, coach, and mentor others.

Being a hemophiliac had little effect on me in the early part of my career but as I got older it has had an impact, to the point now of keeping me from working on a regular basis. My trouble joints are my hips; they began to fail when I was in my 30s due to arthritis caused by my hemophilia. This caused a great deal of pain especially when driving, sitting in meetings, or having to do a great deal of walking through airports. I had my first hip replaced

when I was in my early 40s. This was a great improvement and enabled me to continue my work schedule. I had my second hip replacement 10 years ago at about the same time I was changing jobs. The second hip replacement enabled me to be pain free again and I began to build a business in the training field. Unfortunately two and a half years ago I developed a serious hip infection and had to have a second replacement done on my first hip. This set me back physically and has kept me from working regularly. I mention my current situation because I feel that it is important to understand that my current health problems and their impact on my career are the result of injuries from activities that I did as a young person. My generation

Rob Dinsdale: rdinsdale@cogeco.ca  
905-825-1438



did not have the treatments that are available today, so be sure to use the treatments that are available to you. The untreated bruised knee, elbow or hip of today can come back to haunt you. Personally, I should be in the prime of my career, but instead I am working hard to get my health back. Please heed my message.

How do we go about making decisions about career choice? My job was a good “fit” for me in that I was able to work in an area that was suited to my interests and capabilities. This idea of fitting a job is important when making your decisions. Here are a few thoughts on how to discover what type of work might be a good fit for you.

Most importantly, understand yourself, particularly your strengths, talents, and interests—what really excites you and gets your attention. What are your hobbies and interests away from school? If you could get up every morning and do anything you want, what would you do? What courses at school do you enjoy, find interesting and do well at? (On a personal note, I did not like or do extremely well in high school. I thought it was because I was not a good student, but when I started to study business in college I suddenly became an A student. It was interesting, stimulating, and I was happy to work hard because it was a good fit for me.)

What about lifestyle? Do I want to do something with predictable hours, or am I willing to put in extra time as required? Do I like to travel, or am I happiest to come home to my family at the end of the day? How much money can I make? For some this is highly important; for others less so. Either way, the reality is that you need to make a living. Do I prefer to do physical work, do I like to work with my hands, or am I best suited for desk work? As people with bleeding disorders, we must consider the physical requirements of a career. The importance of this will vary from person to person and is something that you should discuss with the medical staff at your treatment centre. Consider what type of person you are. Are you highly social

and enjoy being with others, or are you happy being on your own? Do you like to compete? Do you like to be the centre of attention? Or are you happiest quietly helping others? To further help you understand yourself, ask your family, friends and teachers how they see you. Once you have an understanding of yourself you can look for careers that would enable you to use your strengths and talents in an area of interest.

Use the professional assessment tools that are available today through high schools, colleges, universities, placement centres, etc. and are mostly done online. These tools will help you find your interests and aptitudes and will suggest career areas to interest you. Many people are surprised at the results of these assessments and discover they have

---

*The most important thing to remember when looking at career options is that it is your career and it is your future.*

---

aptitudes for career possibilities that they had never considered. Sometimes it can be a real “Aha!” experience. Most businesses today will use them as part of their hiring process as they recognize the need to get the right people into jobs. If you have trouble getting access to this type of tool, please contact me and I would be happy to direct you to people that can help you. There are many books on career searching that contain useful tools for self assessment. (One of the best is a book called *What Colour is Your Parachute?*). These books can be found in your school or local library, as well as your local book store.

Once you have some ideas about what careers might interest you, be sure to research them. Go to the library, Google the industry, call companies or organizations in your field of interest and ask if you can meet with them. Many organizations will be happy to spend some time with you; in fact some will even offer co-op programs for high school

students. Be sure to ask what education and background are required for the career of interest. Your school guidance department can also help you, as can colleges and universities. When you have this information, you can plan the steps required to get you to your goal.

The world we live in today offers limitless career possibilities, and new career opportunities are becoming available every day in fields that were unheard of until recently. Unfortunately, some careers are disappearing as our economy evolves. Due to the never-ending evolution of society and its impact on jobs, it is important to understand that some flexibility is required, and that we need to have open minds as to the type of work we may have to do. In my experience the people that are most successful are the ones that accept and adapt to change. You may find that as you start your career you may have to do something other than your dream job at first just to get your foot in the door. Be open minded and willing to work toward your goal. The most important thing to remember when looking at career options is that it is *your* career and it is *your* future. You are the one who will live with the decisions that you make, so put the time and thought into it that you deserve.

As they say...the future is where you will spend your time. ◊



## *Challenges, Choices, Decisions: A Guide on Orthopedic Surgery for People with Hemophilia*

**ALMOST ALL ADULTS** with severe hemophilia in Canada suffer from joint damage in the knees, ankles and/or elbows because they grew up in a time when treatment was less advanced. Chronic joint damage causes pain and limits range of motion. When the pain is severe and interferes with the activities of daily living, orthopaedic surgery is an option.

This educational resource has been developed as a guide to help hemophilia patients not affected by an inhibitor, and their families understand what is involved in orthopaedic surgery. It has been adapted from the original booklet published in 2008 for people with hemophilia and inhibitors. It's available in PDF only. You can find this resource on the Canadian Hemophilia Society website at <http://www.hemophilia.ca/en/educational-material/printed-documents/>.

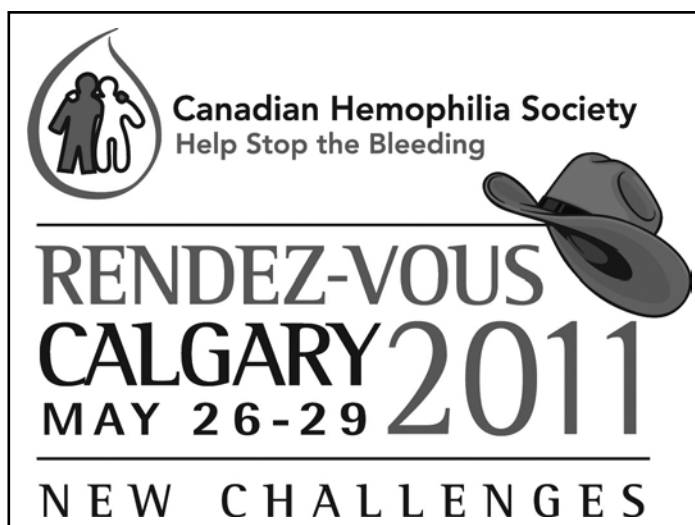
## **New resource for young carriers**

▲ **THE CANADIAN HEMOPHILIA SOCIETY (CHS)** is pleased to announce that a new resource about being a carrier of hemophilia is now available. *Me and My Genes* is an interactive animated video that provides potential pre-teen and teenage carriers with relevant and age-appropriate information about what it means to be a carrier of hemophilia A or B. It includes facts about hemophilia, inheritance of the hemophilia gene, carrier testing and the management of bleeding symptoms.

The resource also includes interactive buttons for viewers to test their knowledge and access tips, myths and fun facts of interest to young carriers.

To watch the video, visit <http://www.hemophilia.ca/genes/>. The resource is available in English and French. ♡

To register for the Canadian Hemophilia Society's national conference, visit [www.hemophilia.ca](http://www.hemophilia.ca). To apply for one of two sponsorships to attend, contact Terri-Lee Higgins at [thiggins@hemophilia.on.ca](mailto:thiggins@hemophilia.on.ca).



## Hemophilia Ontario Youth

### Career Choices

## Try your hand at golf

by Eddie Crosbie-Hirlehey

I AM 20 YEARS OLD and have severe hemophilia Type A (less than 1 percent). I have always been a huge sports fanatic, and after numerous injuries due to contact sports I was advised not to partake in, I was told to give golf a try. I figured it couldn't hurt and gave it a try. I loved the game and things took off from there. When I wasn't working at a golf course or teaching junior golf, I was out on the course trying to fit in as many holes as I could before dark.

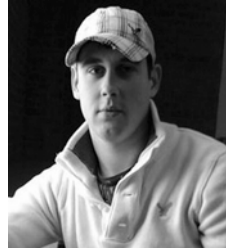
Doctors told me to choose golf over contact sports such as hockey or basketball because golf, although physically demanding, is very low-impact on your joints. The long-term result is that when I'm in my 40s I will not suffer major joint damage and repeat bleeds.

Those who have never played the game don't realize how physically demanding golf is. Walking 7,000 yards plus per round and taking 72-120 plus strokes to complete the course is physically and mentally exhausting and a great workout for your joints. Golf is one of the hardest sports to learn and even harder to master on a consistent basis. It is a continual challenge and can be played from the age of two all the way up into your 90s. To any who have not tried the game, I highly recommend it.

I had no idea what I wanted to do after high school. I knew that I did not want to be confined to a desk and that due to my hemophilia, trades were not a wise career choice. After looking through various college books, the Professional Golf Management Business Administration program immediately caught my eye. I applied and was accepted at Durham College for the PGM program. I have decided to pursue a professional golf career and on completion of turning professional next year my goal is, over time, to become a lead golf professional of a club. This entails giving lessons and running the golf operations. The job is very activity-oriented, but if I have a bleed I can still give lessons and perform office work, allowing me to work through bleeds.

To any sports enthusiast looking for a lifelong love and sport to follow, I highly recommend looking into golf. It is low impact on joints, a very good general workout and has both the competition and challenge of high contact sports such as hockey, football or basketball.

If you have any questions or are wanting to give golf a try and not sure where to get started, e-mail me at [eddie.crosbie.hirlehey@hotmail.com](mailto:eddie.crosbie.hirlehey@hotmail.com). ♡



## What do you want to do?

by Shaun Bernstein

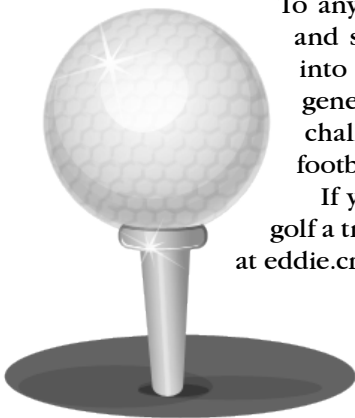
**ALL THIS LOOKING** at career choices has prompted me to re-examine my own. Actually, this month really marks my first real foray into my field outside of school, so it's the perfect time to talk about career choices.

I'm a redhead. I'm a hemophiliac. I'm a Torontonionian. But, I think above all else, I'm first and foremost a journalist. I've wanted to be a journalist since I was a kid. I've always been inquisitive, talking to everyone I meet and trying to figure out what makes them tick.

When it came to deciding what to do after high school, there wasn't a question in my mind that I was going to journalism school. I started in Carleton's journalism program, but due to some health challenges I returned home after a semester. I completed my undergrad degree at home for the next four years, in large part because of my health. I'd hit an age where I was a lot more conscious of my hemophilia as well as some of my other challenges, and I realized that I had to start preparing sensibly for the working world.

But when it came down to a career choice, I wasn't deterred. I was actually preparing to go to law school not that long ago, when it was wonderfully brought to my attention that that wasn't what I wanted to do. Finally someone was bold enough to ask me what I *wanted* to do, and my answer was simple: I wanted to go back to journalism school and finish what I'd started.

So two years later, here I am in the process of finishing what I consider one of the best programs in the province. As I write this, I'm sitting at my desk at CBC, where I'm completing my six-week internship through the



program. What's funny is that when I tell people I'm a journalist, they instantly ask who I write for. This is both right and wrong. It's wrong in the fact that I'm in radio, which is where my heart has wound up.

I'm a bit of a storyteller, and radio is still this amazing medium that lets you use your words to paint pictures. There's nothing quite like it.

On the other hand, all journalists are writers. Whether it's radio, television, or even the internet, there's always someone working to write the news. For the next few years, I'll probably be one of those folks, and I love doing it. Yet when it comes to my hemophilia, there are still certain considerations I have to waver. What's beautiful about journalism is that it's really something I can practice from anywhere, and believe it or not most of the jobs don't involve a lot of running around, which is easier on my joints.

On the other hand, I'm grateful I never had dreams of being a war correspondent. My dependence on factor alone will more than likely keep me in this beautiful country of ours, which I'm eternally grateful for, but it certainly changes my job prospects slightly.

My career choice was a complex road, and one that I'm nowhere near completing. But I know that I'm following my heart, and doing what I love. And I know that I'm doing it smartly by keeping my health in mind and making smart choices that are letting me do what I've always wanted. ♡



Shaun Bernstein

## Thinking Ahead – Bleeding Disorders Scholarships

**IF YOU'RE IN GRADE 12** or university, you're probably asking that big question. No, not "What am I going to do with my life?" but, "How am I going to pay for this?" There are several scholarships available for people affected by bleeding disorders. Here are two major scholarships you can apply for:

### CHS James Kreppner Memorial Scholarship and Bursary Program

In 2010, the Canadian Hemophilia Society website was pleased to award \$4,000 scholarships/bursaries to seven outstanding applicants. The awards are made possible by grants from CSL Behring and Pfizer. The award categories are as follows:

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

The 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.

More information and application forms can be found on the CHS website, [www.hemophilia.ca](http://www.hemophilia.ca) under Support and Education, then Scholarships. The deadline for submission of completed applications and supporting documents is April 30, 2011.

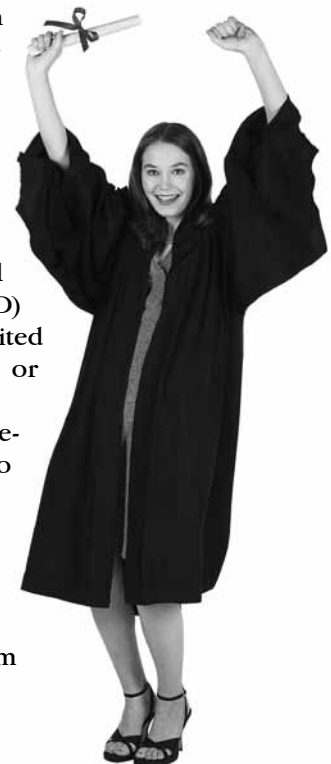
### Soozie Courter Scholarship from Pfizer Hemophilia

To be eligible for this scholarship, students must have either hemophilia A or hemophilia B and be a high school senior, have a high school diploma or general education development (GED) credential, or be currently enrolled in an accredited junior college, college (as an undergraduate or graduate student), or vocational school.

For the 2011-2012 academic year, Pfizer Hemophilia will award \$50,000 in scholarships to students in the hemophilia community:

- Five \$4,000 graduate school scholarships
- Twelve \$2,500 undergraduate college scholarships

Application forms are not yet available for this year, but check [www.hemophiliavillage.com](http://www.hemophiliavillage.com) for updates. ♡



# Central Western Ontario Region

## Events Calendar

DATE	WHAT AND WHERE?
Saturday, May 17	Youth Adventures & Photovoice
Saturday, June 25	Youth Adventures & Photovoice
Saturday, July 23	Youth Adventures
Saturday, September 24	Youth Adventures

### Get Involved!

CWOR is always looking for new volunteers and fresh ideas. We encourage you to share your ideas on speaker topics and programs. To share ideas, or for more information on our current list of programs, contact Alex McGillivray, Regional Service Coordinator at 905-522-2545 or [amcgillivray@hemophilia.on.ca](mailto:amcgillivray@hemophilia.on.ca). ☺

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

#### Regional Board and Staff

Jace Pedersen  
Dane Pedersen  
Mary Pedersen  
Justin Terpstra  
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](mailto:amcgillivray@hemophilia.on.ca)

## Liam Barbour Scholarship Award

THE CENTRAL WESTERN REGION of Hemophilia Ontario 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 offers 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, 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 Western Region, be an active member of the Central Western Region, and be recognized by their individual disorder.
- The applicant must provide proof of their enrollment at a post secondary institution to the Central Western 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, please contact Alex McGillivray, RSC, 10 George Street Office 19, 4<sup>th</sup> floor, Hamilton ON L8P 1C8 Tel: 905-522-2545; [amcgillivray@hemophilia.on.ca](mailto:amcgillivray@hemophilia.on.ca). ☺

## World Hemophilia Day Bake Sale

You're Invited!

Hemophilia Ontario – CWOR & the Hamilton-Niagara  
Regional Hemophilia Clinic present

### The 3<sup>rd</sup> Annual World Hemophilia Day Bake Sale

Join us on Wednesday, April 14, 8:30am-2:30pm at  
The Red Elevators on the 3<sup>rd</sup> Floor MUMC  
1200 Main Street West, Hamilton, ON

For more information, or to volunteer for this great event,  
please contact:

Alex McGillivray – Regional Service Coordinator  
905-522-2545 or [amcgillivray@hemophilia.on.ca](mailto:amcgillivray@hemophilia.on.ca)



# CWOR Holiday Event 2010

A TOTAL OF 80 participants in the Central Western Region came out on Sunday, November 14 to enjoy a fun-filled day at Mountsberg Conservation Area's Christmas-town. Families experienced a close community feel and took part in CHS' new Passport to Well-Being Module on Traveling with a Bleeding Disorder. The presentation was conducted by Kay Decker - Hemophilia Nurse Coordinator, Shannon MacKay - Nursing Student, Karen Strike - Physiotherapist, and Theresa Almonte - Hemophilia Program Secretary. Kay and the clinic team had the families take part in an interactive quiz based on the module's slide show presentation. All of the families were quite competitive as there was a \$25 surprise gift up for grabs for the family that had the most correct answers. There was a three-way tie for the win. Congratulations to Barb and Bill Kunkel for winning the prize after answering the tie-breaking question. The families also had a chance to enjoy a horse-drawn buggy ride, pancake lunch, snowflake craft and song time with Santa. For two of our families, this was their first time attending one of our events.

Thank you to all of the Mountsberg Staff for your hard work and for making our group feel welcome. Also, many thanks are extended to the clinic team for taking time out of their weekend to educate and socialize with the families at this great event. ♡



▲ L to R: Kay Decker - Nurse Coordinator, Karen Strike - Physiotherapist and Shannon MacKay - Nursing Student doing the Passport presentation.



► The Fruscella family works hard on their quiz.



► The Shivcharan family enjoys their time in Christmas-town.

# North Eastern Ontario Region

## NEOR-DAC Welcomes You

by David Bouffard

**WE ARE PLEASED** to introduce to you the North Eastern Ontario Region Development and Awareness Committee (NEOR-DAC), which was formally accepted and thus born on December 9, 2010. Fundraising, public education, and the formation of a new youth committee are key areas of focus. Currently it has grown to and consists of approximately 15 persons. We have members in Timmins, Sault Ste. Marie, Manitoulin Island and Sudbury.

NEOR-DAC will support HO and CHS long-term commitments by incorporating their Vision, Mission and Values, and is guided by a sense of duty that prioritizes the mutual respect, participation and the engagement of a broad range of members. In a novel manner for such a committee, it has considered and is incorporating English-French translations to be provided, to reflect the majority of various peoples of the 705 region. This integration will assist and reinforce the unity of the peoples of the region by incorporating a heightened sense of provincial perspective. Since NEOR-DAC is only a few months old, it is my hope that in the future, the Aborigines, a great people in the NEOR, will also have their language represented, as is the case for bilingual Canada. ♡



▲ Kaylee (11), Kyle (9) and Kurtis (7) Cadieux proudly display their water boiling awards.

### Regional Service Coordinator's Update

**ON FEBRUARY 5**, Hemophilia Ontario teamed up with the Old Timers hockey team for the third year in a row. Fun was had by all. The day began with a pancake breakfast. The fun and games began with curling, hockey, log sawing, water boiling, snowmachine rides, sleigh rides—the list goes on and on. The damp day did not stop these young people from winning the water boiling contest. ♡



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

#### NEOR Staff

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

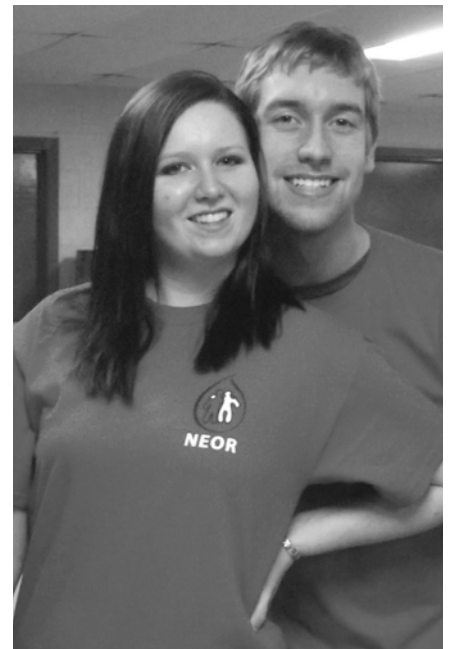
### Youth from the North

by Kristopher Onucky (mr.kristopher@botmail.com)

**WE ENCOURAGE** new youth to join us and participate in the NEOR Youth Committee. Fresh faces with new ideas will help us raise funds to let youth with bleeding disorders live a normal life and have fun.

With or without a bleeding disorder, everyone is welcome to join the committee. Our goal is to organize a camp with fun workshops and adventurous activities for those with bleeding disorders. If everyone else can do it, why can we not do it in the north?

All of the tools are here, all we need is the youth to do it. ♡



▲ Kaitlynn MacDonald and Kristopher Onucky

### Events Calendar

DATE	WHAT AND WHERE?
April 17	World Hemophilia Day Walk-a-thon in Sudbury, with Red, White and You days in surrounding areas.
May 7	Clinic Day with dinner and a talk with Betty Ann Paradis, Clinic Nurse, speaking on Hemophilia 101.
May 19	World Hepatitis Day

# North Western Ontario Region

## Thunder Bay Hemophilia Clinic



Thunder Bay Regional Health Sciences Centre

## World Hemophilia Day – Community Awareness

**THIS SPRING**, our Clinic at the Thunder Bay Regional Health Sciences Centre will be held on Monday, April 4 and Tuesday, April 5. We are always pleased to see our regular clients and happy to meet new ones. This year, Hemophilia Ontario is proud to be facilitating a Community Awareness Day in conjunction with AIDS Thunder Bay. World Hemophilia Day is on Sunday, April 17, and we will have a notice in the paper reminding everyone that we will be at Intercity on Tuesday, April 19 to give out information and answer questions. There is also a short questionnaire that you can fill out for a chance to win a small prize. Bob Manson and I will be at the tables that day, and we hope to see you there.

Hemophilia Ontario is pleased to bring the information to you. If you have a group or staff that you would like us to do a presentation for, simply call the number below and set a date. Hemophilia Ontario stays on top of the latest research and medical advances and is happy to share that information with the public in any way we can. ♡

*Sam Helfrich, RSC, Thunder Bay 807-622-9012*



### Volunteers Needed

**THERE HAVE BEEN** problems connecting with people for meetings, etc. To avoid that in the future, I have set regular monthly Volunteer Meetings that will always be held once a month on Mondays at 6:30pm at Tim Horton's on Memorial by Intercity. Dates are below. **If anyone** wants to talk to me, or help with any events, please come by and see me there.

- April 26
- May 30
- June 27
- July 25



Sam Helfrich

### NWOR Staff

Sam Helfrich, Regional  
Service Coordinator  
316 Robertson St.  
Thunder Bay, ON P7C 2N9  
sstorozuk@hemophilia.on.ca  
1-807-622-9012

NWOR



## Camp Wanakita Pizza Party

THE OTTAWA AND EASTERN ONTARIO Region in conjunction with the Children's Hospital of Eastern Ontario held a very successful Camp Wanakita Registration Pizza Party on November 27, 2010. Eight families attended to share information and fill in camp registration forms. Diane Bissonnette, our Clinic nurse did a presentation on camp and two of our more experienced campers, Jordon Cabral and Cameron MacNeil, answered questions and did commentary on the virtual tour slide show on Camp Wanakita. The day resulted in three new one-week campers, five two-week campers and three counsellors-in-training to attend camp this August. ☺



Colin Patterson

by Jennifer Lelièvre

EVERYONE HAD FUN at the Hemophilia Ontario (OEOR) Holiday Party on December 5, 2010. Children of all ages joined Board members of the OEOR at the Ottawa Police Association to play games, sing carols, do



crafts, eat, drink and be merry. This year's party was the best ever as guests were treated to a terrific puppet show by Kids on the Block. Each family decorated their very own gingerbread house to take home as a special souvenir. There were plenty of laughs and lots of good cheer as we shared the afternoon with several wonderful families in our community. A memorable visit from St. Nick completed the afternoon. ☺

## OEOR Fundraising & Programs Update

by Nancy Sauvé and Darlene Villeneuve

**WOW!** The year is going by so quickly. It was great to see so many families come out to the Holiday Party. It was nice to see families putting gingerbread houses together, interacting and enjoying crafts and snacks.

The puppet show was a great addition and Santa's visit with gifts made the children's day complete.

We are grateful to our community and the donations received. Special thanks to:

- Tim Hortons (Medhurst and Woodroffe) for the hot chocolate
- Costco (Merivale) for the \$50 gift certificate
- Walmart (Barrhaven) for the \$30 gift card
- Wrigleys (Ottawa) for the gum basket
- The Real Canadian Superstore (Kirkwood) for the gingerbread kits
- The Real Canadian Superstore (Kanata) for the cake
- Kids on the Block (Ottawa) for the puppet show

Thank you to the many volunteers. Your support helped to make this event possible and put a little magic in it.

Now is a good time to start thinking about how you can contribute - maybe join the Board or a committee or just share new ideas. ☺

### Regional Board and Staff

Raja Ammoury-Alami  
 Jordan Cabral  
 Lyanne Cabral  
 Lori Kavanagh  
 Ashwani Kurrichh  
 Jennifer Lelièvre, Past Chair  
 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?
April 17	World Hemophilia Day
August 13	17 <sup>th</sup> Annual Shawn Duford Golf Tournament for Hemophilia

## Regional General Meeting

**OUR REGIONAL GENERAL Meeting (RGM)** was held at the Hilton in London, ON on March 5, 2011. Prior to the meeting, education sessions were offered for adults and youth and Pinecrest Staff. It was with great excitement that we premiered our new Pinecrest Adventures Camp promotional video. ♡

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

### 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

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

## Toronto Marathon 2010

*by Sylvia Travaglini*

**LAST OCTOBER**, with the generous assistance of Hemophilia Ontario, the Travaglini kids—Laura (13), Paul (15), Matthew (17) and Anthony (19) participated (for the fourth time) in the GoodLife Fitness Toronto Marathon event. Paul, who has severe factor IX hemophilia, first noticed the marathon events five years ago. That year, he participated in the 5K run and had a great time. His best memory from that run was the spectators with the Hot Wheels radar speed guns clocking the runners. He enjoyed it so much that he managed to recruit his brothers and sister to join him in the marathon relay the following year. They were joined by other running volunteers from our region and from other regions to round out the relay team to eight runners. Anthony was in the pull position and Paul brought it home with the last 7K leg. The organizers suggest that each team have eight runners and they each take a 5K segment and the last runner makes up the additional 2K to round the total up to 42K.

The following year (2009) Paul began drumming up support early with his friends and his brothers' friends on the cross-country team. They managed to put in a very strong team and won the relay race. To this day all of the runners claim, "We won the Toronto Marathon!" As an aside, and under their breath: "The relay, that is."

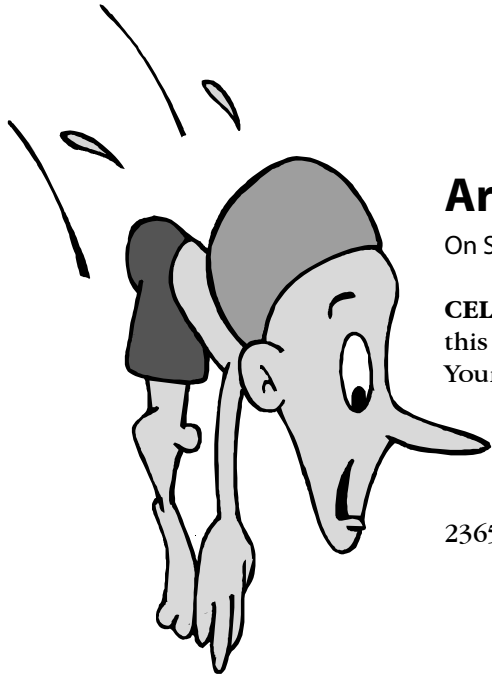
For this last race, they changed tactics and decided to participate in the 5K run instead. Matthew ran a very good race and finished fourth, being narrowly outpaced right at the finish line. Anthony and Paul were next in 11<sup>th</sup> and 12<sup>th</sup> places and Laura rounded out the pack at 90<sup>th</sup> with a time of 22:45. After the race, they went over to the Hemophilia tent. Pictures were taken, and relationships with the Toronto volunteers continue to develop. Thank you to the hemophilia community for making this event available to us. Regardless of the outcome, the awareness and camaraderie are priceless. This year, the Toronto marathon is being run in May. We'll definitely be there! ♡



## Pinecrest Adventure Camp 2011

*by Charlie Pangborn, Camp Director*

**IT'S GETTING TO BE THAT TIME OF YEAR** again. Pinecrest Adventure Camp will be held August 24-28 at Camp Menesetung in Goderich, Ontario. A theme has been chosen and staff members are already preparing for another safe and busy week of fun and games. Four Pinecrest staff members headed to NACCHO (North American Camping Conference for Hemophilia Organizations) in January and returned with loads of fantastic camp ideas from dozens of Hemophilia camps across North America. As the time nears, staff hopes that campers are getting just as excited to return to camp as they are. Whether it is your or your child's first time at camp or you are a camp veteran, we will be more than happy to see you there. August will be here before we know it. ♡



## Are you brave enough to take the plunge?

On Sunday, April 17, join us at Little Beach in Port Stanley, ON

**CELEBRATE WORLD HEMOPHILIA DAY** with us by jumping in a lake! Again this year, SWOR is recognizing World Hemophilia Day with a Polar Bear Dip. Your help raises 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.lhsc.on.ca/About\\_Us/Bleeding\\_Disorders/SWOR](http://www.lhsc.on.ca/About_Us/Bleeding_Disorders/SWOR). For more information or directions contact Terri-Lee at 519-432-2365 or [thiggins@hemophilia.on.ca](mailto:thiggins@hemophilia.on.ca). ♡

## Calling All Golfers

**HEMOPHILIA ONTARIO** South Western Ontario Region (SWOR) invites you to partner with us in the 4<sup>th</sup> Annual Golf Tournament for Hemophilia and Inherited Bleeding Disorders on Thursday, May 19, at the Highland Country Club ([www.highlandcountryclub.com](http://www.highlandcountryclub.com)). This scramble format event will foster friendships between members, friends and business partners and is our major fundraising event. The registration fee of \$175 per golfer includes 18 holes of golf, golf cart, lunch prior to tee-off, a banquet dinner, prizes and contests. In addition to the golf and prize table there will be draws and a silent auction. Those unable to play golf may join us for the banquet for \$45. Your participation will help support more than 300 children, youth and adults in our community with a bleeding disorder who rely on South Western Ontario Region (SWOR) of Hemophilia Ontario for training, education, financial and moral support. To provide support for this event, contact Terri-Lee at 519-432-2365 or [thiggins@hemophilia.on.ca](mailto:thiggins@hemophilia.on.ca). Register online at [www.sworgolftournament2011.com](http://www.sworgolftournament2011.com). You'll be glad you did! ♡

## Guinness Book of Records Attempt

**BECOME PART OF HISTORY!** SWOR invites you to participate in our attempt to set a *Guinness Book of World Records* record for the Longest Parade of Motorcycles. For full details, check out the website [www.ridefortherecord.ca](http://www.ridefortherecord.ca) or register online at [www.ridefortherecord.com](http://www.ridefortherecord.com). ♡



SWOR

# Toronto and Central Ontario Region



Maury Drutz

## President's Message

by Maury Drutz

**TCOR HAS HAD A BUSY** last few months organizing and producing various workshops and events. These workshops were run to enable both parents and children with bleeding disorders to develop a greater understanding of their condition and to facilitate a bright and optimistic lifestyle. They included the Inalex workshop on building strong relationships for parents, and the Women in Touch support group. The Community Carnation Memorial on World AIDS Day commemorated those we have lost to HIV/AIDS.

TCOR's AGM, just held, was a huge success. New board members were elected and volunteer awards were presented. Members were provided feedback and updates on programs and services while children enjoyed the Toronto Botanical Garden.

TCOR has also relocated to a new office. We are now located at Suite 501, 65 Wellesley St. E. We are settled in and enjoying the new setting.

These events could not be successful if it were not for the dedication and passion of all our staff and volunteers. ♡

## World AIDS Day – a time to remember

by Robin Nobleman with Antonia "Smudge" Swann

**DECEMBER 1** was World AIDS Day – a time to remember those who have passed away from HIV/AIDS and to raise awareness about the disease. TCOR participated in the annual Community Carnation Memorial organized by the 519 Community Centre. Several AIDS service organizations were represented by speakers who reflected on special people in their lives: someone who inspired them, someone remembered, someone forgotten and so on. Antonia "Smudge" Swann spoke about her late partner, James Kreppner, as "someone who made a positive difference." Below is an excerpt from her poignant and powerful speech.

*"James was an amazing person and he left an amazing legacy. I know I am biased but I also know that I'm not the only person who believes in how remarkable he was. He did so much in his 47 years that he lived more than most people do in an entire lifetime – I'd have to say James lived at least three lifetimes. Not only that, but I believe his ideas and his vision continue to thrive."*



James Kreppner

### TCOR Board

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

### 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

*He made a positive difference in many ways, too many to list here but I will touch on a few. He was a Director of the People with AIDS Foundation and the Canadian Treatment Action Council (CTAC), which he helped co-found. He advised the federal research funding body, CIHR, on issues related to patient care for those living with Hepatitis C; he was also a member of the Expert Panel, which in 2000, wrote the first Management Guidelines for HCV/HIV Co-Infected Adults (which was published in the Journal of Infectious Diseases). He also held a number of responsible positions at various levels of the Canadian Hemophilia Society (CHS); sat on various committees at all three levels of that organization, including committees (at both the national and regional levels), which helped force a \$14 million four-year Krever Inquiry into blood safety in Canada, which was spurred on by Canada's largest ever public health disaster...*

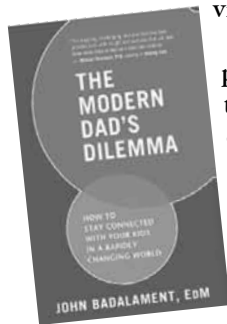
*What makes James's story so remarkable is not only that he accomplished so much in a life cut in half by AIDS and Hepatitis C, but that he accomplished so much despite facing overwhelming personal challenges... James was once asked by a reporter, "Why are you helping this cause when you have nothing personally to gain?" His answer was simply that these people needed help. That was James." ◊*

## Inalex Communications workshop helps build strong relationships

by Robin Nobleman

**THE STRESS OF CARING** for a sick child and the parenting gymnastics sometimes required to keep everyone happy can easily strain any relationship. Parents, uncles, grandparents and other caregivers attended a full day workshop run by an international expert on relationships and parenting to discuss how to deal with these challenges.

Drawing on his book, *The Modern Dad's Dilemma*, John Badalament used a variety of exercises to help participants reflect on how they and their partners can use their respective strengths to work towards a joint parenting vision for the future.



Aside from John's tailor-made exercises and discussions, participants enjoyed hearing how other people have faced the challenges of bleeding disorders. Parents of young children heard from adult men with hemophilia and grandparents benefited from hearing the younger generation's approach. The varied perspectives made for an interesting and informative day.

The workshop was made possible by a generous grant from Baxter Corporation who supports Inalex Communication's work. Inalex Communications is an American non-profit education and support organization dedicated to meeting the needs of all those living with a bleeding disorder. ◊

## World Hemophilia Day

**TO MARK** World Hemophilia Day, constituents will be selling red tulips to their family, friends and colleagues to raise awareness and to help fund TCOR's programs for 2011. If you would like to sell tulips, contact Robin Nobleman, TCOR Regional Service Coordinator, at 1-888-838-8846 ext 12 or [rnobleman@hemophilia.on.ca](mailto:rnobleman@hemophilia.on.ca). ◊

## Women in Touch



by Barb Peters

I have been involved with Women in Touch (WIT) for almost 10 years. I have two children, a son, 29, with classic hemophilia A and a daughter, 26. I am a carrier of classic hemophilia A and there is no known history of hemophilia in my family.

WIT is a support group for women who are part of the bleeding disorders community. We are mothers, sisters, grandmothers, spouses, mothers-in-law, aunts and friends of women who are affected by bleeding disorders.

We come together to know ourselves better and to get to know others who share similar circumstances. We open our hearts to supporting others and to receiving support from others. We call this part of our meeting "the sharing." We share about anything. WIT gives us the opportunity to share and be fully heard in a loving, confidential environment.

Some comments from women who attend:

*Thank you for letting me share my thoughts in a safe, non-judgmental environment.*

*I look forward to our meetings.*

*I feel empowered and energized.*

Our meetings include a potluck lunch. They are usually held on a Saturday and have been held in Toronto for the last five years or so. We travel great distances to come together. At our last event in November, 10 women attended; we find this small group ensures that everyone gets a chance to share.

If you would like to attend the next Women in Touch event, contact Robin Nobleman, TCOR Regional Service Coordinator at [rnobleman@hemophilia.on.ca](mailto:rnobleman@hemophilia.on.ca) or 1-888-838-8846, Ext. 12. ◊





▲ Robin Nobleman and Jeenetha Kulasingam dress for the superhero theme at the North American Camping Conference for Hemophilia Organizations.

## Adventures in a waiting room

by Robin Nobleman

**EVERY WEEK**, either Jeenetha Kulasingam, my fellow TCOR Regional Service Coordinator (RSC), or I sit in a waiting room for two and a half hours. We're not waiting to see a doctor or nurse, we are waiting for *you!* We attend the weekly Bleeding Disorders Clinic at St. Michael's Hospital.

Why are your RSCs in the clinic? We try to speak to every person that comes through the waiting room, either to check in with long-time members or to inform people unfamiliar with Hemophilia Ontario about what we do. If you are looking for informational resources about your disorder or want

to know about programs and services we offer, speak to us at clinic. If you have a sensitive matter to discuss, there is a private room available where we can speak confidentially. Of course, we're happy just to chat and get to know you. Clinic day is the time I count on to meet constituents face to face and gauge how well we're meeting your needs and how we can do better. If you come to St. Mike's on a non-clinic day, pick up one

of our business cards from the waiting room bulletin board and get in touch any time. We are here to serve you.

If you or your child attends the Sick Kids clinic, Jeenetha and I have also been approved by Sick Kids as volunteers, which allows us to work with the wonderful staff there to offer our services to you. Watch for more information and look forward to seeing our friendly faces. ♦

## Transitions Night – A Review

by Jeenetha Kulasingam

**TRANSITIONS NIGHT** occurred on February 23 with several staff from Sick Kids' and St. Michael's Hospital participating. Overall, the night was a success in helping patients and their parents through the switch from pediatric to adult care. Mojtaba Khezry (TCOR Board member) and Shaun Bernstein (Youth Committee Chair) talked about their transitioning experience in a very engaging manner that the transitioning patients could relate to. Robin Nobleman (TCOR Regional Service Coordinator) gave a presentation about the amazing youth programs that are in store for the upcoming year. Maury Drutz (TCOR president) reviewed the role of the organization and the great services and events that Hemophilia Ontario offers.

Georgina Floros, Nurse Coordinator at St. Michael's hemophilia clinic, was a wonderful host and along with Dr. Teitel, provided comfort and great insight about transitioning to their clinic. Dr. Blanchette, Dr. Carcao and nurse Ann Marie Stain from Sick Kids' bid farewell to their longtime patients and assured them that they were transitioning to equally excellent care.



Georgina Floros, Nurse Coordinator at St. Michael's bleeding disorders clinic, explains aspects of treatments.

Thank you to all of those transitioning patients who attended; we hope that you walked away from this night feeling more comfortable and more confident about attending clinic at St. Michael's Hospital and being responsible for your own care as young adults. ♦

## Events Calendar

PROGRAM	DATE	WHAT AND WHERE?
World Hemophilia Day	Sunday, April 17, 2011 (Tulip sales, Thursday, April 14, 2011)	Raising awareness and funds by selling red tulips to friends, family and colleagues.
World Hepatitis Day	Thursday, May 19, 2011	Expert lecture on living with hepatitis. Location TBA.
Families in Touch	Saturday, June 11, 2011	Connect with old friends and meet new families at a picnic on Toronto Island. Learn about travelling with a bleeding disorder through a Passport to Wellbeing workshop.
TCOR Golf Tournament	Monday, June 27, 2011	Fundraiser at Diamond Back Golf Club.
Youth Adventures Program & Photovoice	May 7, June 25, July 23, September 24, November 5	For youth 16-24. No Parents + No Nurses + You, your independence, your friends and an amazing time. At McMaster University, Hamilton.



# JUST THE GUYS 2011

**Save the date!**  
**Friday, September 16 – Sunday,**  
**September 18, 2011**



## TCOR's 12<sup>th</sup> Annual Hemophilia Golf Classic

Monday, June 27, 2011  
DiamondBack Golf Club



If you  
can't  
golf, you  
can join  
us for  
dinner at  
a special  
rate.

**Don't Miss The  
Early Bird Rate**

Toronto and Central Ontario  
Regional Hemophilia Society

Photo Credit: bigstockphoto.com/13749194



Hemophilia Ontario and TCOR have moved to a  
new office.

Our new address is:

**65 Wellesley Street East, Suite 501**

**Toronto, ON M4Y 1G7**

Our phone number is still:

**416-972-0641 or toll free 1-888-838-8846**

# Goodlife Fitness



# Toronto Marathon



**Sunday, May 15**

**Raise money for Hemophilia Ontario programs**

**Participate in the full marathon (40k), half marathon  
(20k) or 5k walk/run**

**Volunteer at the water station or information booth**

Contact Robin Nobleman at 1-888-838-8846 ext 12 or [rnobleman@hemophilia.on.ca](mailto:rnobleman@hemophilia.on.ca) or visit [www.hemophiliaontariotorontomarathon.ca](http://www.hemophiliaontariotorontomarathon.ca)



October 22 - 23, 2011

**This is YOUR time! This is YOUR weekend!**

**Wellness:** The quality, or state of being healthy in body and mind.

Being a woman living with and, or affected by an inherited bleeding disorder presents its own unique set of circumstances. Achieving wellness in today's world is a constant pursuit.

Hemophilia Ontario recognizes the importance of women's health, and thus, Wellness for Women-W2, was created in 2009.

W2 brings together dynamic guest speakers, provides practical tips, lessons, and advice. It also provides an opportunity to raise awareness about inherited bleeding disorders, family, spirituality, as well as health and wellness.

We invite ALL women living with and/or affected by an inherited bleeding disorder to engage in making wellness a priority.

***Please set aside October 22nd-23rd, 2011 in your schedule to take part!***

For more information please contact:

1-888-838-8846

Save the Date

## World Federation of Hemophilia Highlights



▲ Children attend a World Federation of Hemophilia program in Iran.

## Sharing Stories, Inspiring Lives - World Hemophilia Day 2011

*by Liane Cerminara, WFH Communications Manager*

**WHAT MOTIVATES PEOPLE** to strive to make a difference when the challenges they face seem insurmountable? What pushes them towards their goals? Find out at [www.wfh.org/whd](http://www.wfh.org/whd), where you can read profiles of remarkable people and post your own story on the World Federation of Hemophilia (WFH) “Share Your Story” forum. Every week from March through till World Hemophilia Day, get acquainted with a person who has made a positive difference in the bleeding disorders community—from an Olympic athlete to a filmmaker, to a man with severe hemophilia A who has made a significant impact in the availability of treatment and care for people with bleeding disorders in Russia.

On World Hemophilia Day 2011 “Be Inspired, Get Involved in Treatment for All.” This year’s theme celebrates supporting positive change for people with bleeding disorders and encouraging others to do the same. By working together and inspiring each other for a brighter future, we can achieve Treatment for All. ♦



**MARK  
THIS  
DATE**

# Hemophilia Ontario Calendar 2011

PROGRAM	DATE	WHAT AND WHERE?
Hemophilia Ontario AGM	Saturday, April 16	Annual General Meeting for all members in London
World Hemophilia Day	Sunday, April 17	Get involved in your regional event.
Toronto Marathon	Sunday, May 15	Run, walk or volunteer for this great fund-raiser beginning at Toronto's Queen's Park.
Camp Wanakita	July 31-August 13	Children ages 7-15 can attend for one or two weeks at beautiful Camp Wanakita, near Haliburton, ON.
Just the Guys	September 16-18	A fun camp weekend for boys with bleeding disorders and their male role models at Camp Ki-Wa-Y.
Wellness for Women	October 22-23	Conference for women affected by bleeding disorders and female support figures in Toronto.



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

**Hemophilia Ontario**  
**Hémophilie Ontario**

