

A publication of



Hemophilia Ontario

Hémophilie Ontario

BLOOD *matters*

"We're all related by blood."

Volume 1 • Number 2

Summer 2010



**Summer camps for kids
and families**

A stress-free camping experience

**Travel tips for a worry-
free vacation**

Hemophilia Ontario

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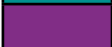



Hemophilia Ontario
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Message from the President

IT WAS GREAT TO RECEIVE my copy of *Blood Matters* and see the complete package. After leafing through the pages, it became clear why we received so much positive feedback. What you hold in your hands is the continued effort to engage you, a person with a bleeding disorder. We want to make sure we can communicate what we accomplish as an organization across the province so that you can ensure that Hemophilia Ontario can continue to meet its mission.

Blood Matters is a tool that can initiate a dialogue but it really is at the programming level where the best exchanges take place. The warm weather brings on Hemophilia Ontario's most large-scale social programming of the year. The summer is full of golf tournaments, kids' camps and barbeques where people with bleeding disorders are able to come together and create strong community bonds.

Having children with hemophilia sent my parents looking for that community in their local region. With two boys in tow, they were looking to get information from other parents and even other hemophiliacs. In our case, Christmas parties and barbeques gave the best opportunity for this to happen. While many of the events have changed packaging over the years, the core of these events continues to help families across the province.

This June, I was fortunate enough to attend the barbeque of my local region, CWOR. I had not attended a Hemophilia barbeque in years but the memories came quickly flooding back. I saw parents chatting at different picnic tables with nervous eyes cautious to the sweaty kids running around. I saw the conversations lead to a more relaxed time for all. Before the meal I was able to walk around and introduce the region and myself to the various families. I realized then that I had become that hemophiliac my parents had looked to for some answers. This situation is hardly unique and I'm sure it happens in other regions. As a volunteer and a board member it is easy to forget these moments

So, as Hemophilia Ontario moves to implement our new Strategic Plan—our guiding document—and tailors programming accordingly, I believe these barbeque moments are amazing reminders of how significant this organization can be in the ongoing lives of people with bleeding disorders. I hope that together we can ensure that this tradition continues and new opportunities are created. ♦

*Sincerely,
Dane Pedersen
President, Hemophilia Ontario*



Dr. Norm Buckley

Hemophilia Ontario AGM Address on Pain Management

THE AGM on April 24 was well attended by members from across the province. As guest speaker, Dr. Norm Buckley's particular focus was on pain, both acute and chronic. He is the Director of the Pain Management Centre at the Hamilton General Hospital. In addition, he has been involved extensively in the development and organization of the acute post-operative pain service for adult and paediatric patients, and the paediatric sedation services. His clinical practice is divided between chronic pain management and anaesthesia at McMaster University Medical Centre, with an interest in paediatric practice. Within the Michael G. DeGroot Pain Institute, Dr. Buckley is establishing a centre for the development and distribution of guidelines for pain management. Prior to his appointment as Chair, he also held hospital administrative positions as Operating Room Director, Chief of Anesthesia (Chedoke McMaster) and Deputy Chief (Hamilton Health Sciences Corporation). ♦

AGM - Volunteer Recognition Awards

During Hemophilia Ontario's 54th Annual General Meeting on April 24, the following three Board Members were recognized for their participation, support and dedication to the bleeding disorder community.



Alan Sutton

President's Award - Alan Sutton

ALAN BEGAN HIS VOLUNTEER career path with CWOR when he participated in the first VWD Conference in Hamilton with Bob Pedersen and Caroline Mulder-Sutton.

He joined the CWOR BOD in 2001 and became regional treasurer for CWOR in 2002. In 2003, he was appointed as a member of the Hemophilia Ontario Administration and Finance Committee, then joined the Hemophilia Ontario Board in 2006 and became chapter treasurer in 2008. Alan maintained the financial records for CWOR until it was centralized at the chapter level in 2008. He was involved in many other areas of the region, including writing articles such as "Emergency Room Experience – Be Prepared." His favourite CWOR event was the Grand River Boat Tour and Dinner and his favourite chapter event was a team building retreat (the one with the elephant in the room). At a "Just the Guys Event" he became the living pin cushion for Venanzio D'Addario's first needle attempts. Alan enjoyed developing relationships with so many people at both the regional and chapter level. He worked with the following chairs throughout his years of service: Dane Pedersen, Susan Feere, Linda D'Addario, Venanzio D'Addario, Brad Barbour and Justin Terpstra. In 2010 Alan chose to participate in a sabbatical of undetermined duration.



Jennifer Lelièvre

Ann Harrington Award – Jennifer Lelièvre

JENNIFER JOINED OEOR in 2002 and became very involved with OEOR's annual golf fundraiser, and was involved for many years in the mechanics of the Region's Bingo operations.

In 2003 Jennifer became chair of OEOR and served in that capacity for six consecutive terms. She became a Hemophilia Ontario board member for four years and for the last two years became secretary to the board on the Executive Committee.

Jennifer is a pharmacist by profession and a devoted mother of two. Her son has hemophilia and she was very active on all related medical issues. She is a dedicated individual who lends her easy-going and mild-mannered approach to the OEOR board and has provided guidance and support during her tenure. Jennifer will continue to assist in OEOR's Shawn Duford Golf Tournament and is available for advice and counsel. In the very near future, Jennifer will become a grandmother; we wish her every success in the future.



Volunteer award winner Ahmed Hassan receives award from Antonia Swann, widow of James Kreppner

James Kreppner - Distinguished Volunteer Award – Ahmed Hassan

AHMED HAS HAD NUMEROUS volunteer positions over the years, namely as a social support worker with CAMH and a volunteer probation officer with the Ministry of Corrections. His professional experience over the past four years has centered on project management in the financial services sector. Ahmed is currently completing his MBA and is volunteering as an Engagement Manager with Endeavour Volunteer Consulting for Non-profits. He joined TCOR in 2009 through Board Match and has served on several committees including A&F, Communications and Programs. In late 2009, Ahmed became a Hemophilia Ontario delegate and joined the Strategic Planning Committee where he has worked closely with many individuals across the organization in putting together a comprehensive and detailed strategic work plan spanning all aspects of the organization. Ahmed looks forward to continuing his volunteer work with Hemophilia Ontario and serving as a board director for many years to come. ♦

Programs



Founding Members Maria Vandelaar (forefront-left, blue jacket) and Cathy Stutz (forefront-left, white shirt)

Biking to Stop the Bleeding

HEMOPHILIA ONTARIO'S 5th Annual Biking-To-Stop-The-Bleeding had three magnificent bike routes in the Niagara Peninsula area. There were 29 cyclists in total who participated. The first route for experienced riders was 150 kilometres in length and began at 6:30am at the end of Thorold Road in Welland. The second Family Biking Route was 25 kilometres long and began in the same location at 11:00am. The Intermediate Biking Route began at Kingsbridge Park, Chippawa at 10:30am. Many thanks to the continued generosity of committee members, volunteers, participants, staff and local media who raised funds and helped build awareness about bleeding disorders. This year's event was a great success!

Please join us for next year's event on Saturday, June 4, 2011. ♦

Just the Guys Weekend

September 18 – 20, 2010

HELD AT BEAUTIFUL CAMP KI-WA-Y, this weekend retreat is a time for male children to bond with their father (or other male role model). Teams compete throughout the weekend, testing knowledge, ingenuity, dexterity and deduction. There are plenty of activities, from climbing and archery to swimming and boating. Fathers are also treated to educational seminars that help to expand knowledge of their child's condition and/or treatment.

Watch your e-mails and/or mail, or contact Eli Bennett (416-972-0641, Ext. 12; or ebennett@hemophilia.on.ca) for more information. ♦

2010 Toronto Marathon

Sunday, October 17

THE TORONTO MARATHON travels through 42.2 km of Toronto's finest scenery, beginning at Mel Lastman Square, passing by Casa Loma, and through the Martin Goodman Trail and Rosedale Valley to Queen's Park. Each year the weather cooperates and runners and volunteers are met with sunshine and mild temperatures. Last year 13 runners/walkers and 26 volunteers from the Hemophilia Ontario Community participated in this great event.

You too can become involved by participating in the full or half marathon, by being a member of a relay team, or by participating in the 5K run/walk. The 5K event welcomes families wishing to collect pledges and spend quality time together.



Or, you can volunteer to assist with the water station located on the Rosedale Valley Road route. Hemophilia Ontario has manned this station for many years. Volunteers' responsibilities at the water station include distributing water and Gatorade to marathon participants, assisting with set-up and take-down, and providing high energy encouragement to passing marathon runners.

In 2009, funds raised at this event supported many great initiatives such as Camp Wanakita.

Come and join us for a great day. Contact Stephanie Darroch at 416-972-0641 Ext. 20 to learn more about being a runner/walker or volunteer. ♦

Bott-Harrington Fellowship

ANDY CUMMING—a hemophiliac—and his wife Hillary, have generously offered \$250,000 over five years as “seed money” to train two persons in this important nursing specialization. Their donation to the St. Michael's Hospital Foundation and matching grants by other donors will enable attainment of this goal. To this end the Foundation is establishing the Bott-Harrington Fellowship in honour of Denise Orioux and Frank Bott, who have lost two sons to the tainted blood tragedy. Ann Harrington, a retired nurse-coordinator from St. Michael's Hospital, who is also being honoured, provided invaluable lead-

ership and dedication during this crisis. Her commitment to her patients never wavered and she knows how great is the need for more trained staff. Ann Harrington, Frank Bott and Denise Orioux exemplify the contribution thousands have made to help persons with hemophilia.

The goal is to establish this fellowship by September, 2010. A variety of materials and visual aids are being developed to support the Doubling Up campaign, as it is being called, to facilitate matching donations at least equal to the grants made by the Cummings. Once the main campaign

site is launched, it will be opened to non-matching donations by the general public and members of the Hemophilia Society. Any contributions to the Fellowship will be recognized by the Foundation in a manner consistent with its policies, which are in the process of being updated. Donations can be made to the St. Michael's Hospital Foundation.

St. Michael's Hospital Foundation (Bott-Harrington Fellowship) will be recognized in the hospital's publication *In Touch* and in the Foundation's newsletter, as well as in *Blood Matters*, Hemophilia Ontario's magazine. ♦

Healthy Families Camp Weekend October 22-24

HEALTHY FAMILIES CAMP WEEKEND, 2010 is designed to assist individuals and families within the bleeding disorders community by providing some insights and training for adults, parents, youth and families in the relaxing and replenishing spectacular setting of Camp Wanakita in the Haliburton Highlands. All participants will be engaged in a full range of activities including recreations for individuals, children and families as well as group sessions for adults, parents and youth on a variety of topics.

Joe Rich, MSW, a social worker best known for his ongoing role as regular guest therapist on City TV's *Cityline* for the past 15 years, will be the main facilitator for the adult programs. Joe joins us with a wealth of experience in camping and programming and is sure to offer some great insights and a fun experience in his workshops on relationships, self-care and management, and parenting. Joe will be joined by other facilitators for workshops over the weekend and the support of the Camp Wanakita staff will give adults on the weekend plenty of time to attend sessions and to enjoy the setting.

If you wish to register early, please contact Stephanie Darroch at 1-888-838-8846 - Toronto: 416-972-0641, or e-mail sdarroch@hemophilia.on.ca. ♦



Camp Wanakita August 1 – 14, 2010

CAMP WANAKITA offers youth 7-16 years of age living with a bleeding disorder in Ontario the opportunity to participate in a summer residential camp program. Participants engage in a variety of stimulating activities in a safe environment. In addition, six Hemophilia Treatment Centre nurses from across the province help supervise and guide children as young as 7 years old in learning proper self-infusion techniques. Successful first-time infusers are videotaped and given the recording to take home. This year 48 campers will enjoy this wonderful opportunity. Camp registration begins in September 2010 for 2011.

Contact Susan Turner (TCOR) sturner@hemophilia.on.ca or Stephanie Darroch (Hemophilia Ontario) sdarroch@hemophilia.on.ca to have your camp registration/information packages mailed to you for 2011. ♦

**October 22 – 24, 2010
Registration: \$25/Family**

Draft Weekend Program

Friday Night Welcome
Dinner with Program Activities

Saturday Morning Breakfast
Sessions for Adults and Youth
Children in Recreational Programs
Saturday Afternoon Lunch
Elective Sessions for Adults
and Youth
Children in Recreational Programs
Saturday Night Dinner
Family Recreational Programs

Sunday Morning Closing Session
Children's Recreational Program
Sunday Afternoon Lunch - Closing



Needleless Transfer Device for FEIBAVH Therapy

ON MAY 1, 2010 Baxter announced the launch of BAXJECT II Hi-Flow, a needleless transfer device designed to make the reconstitution of FEIBA (Anti-inhibitor Coagulant Complex) bypassing therapy easier, faster and safer than needles alone. BAXJECT II Hi-Flow represents the latest enhancement for reconstitution of FEIBAVH therapy, an integral part of inhibitor management for people with hemophilia. ♦



Baxter Goes Green

LOOK AT THE BAG your clinic or blood bank uses when you make your next factor pick up. Baxter has recently donated “Green Bags” to Hemophilia Treatment Clinics and blood banks across Canada. Making it more convenient for you to pick up your product, these reusable bags will replace the clear plastic bags used at many sites. Made from 85 percent post-consumer recycled plastic bottles, these green bags will help you make a positive difference in our environment. The photo shows our summer intern Greg holding one of bags.



Ann Marie Stain, hemophilia nurse coordinator at the Hospital for Sick Children, was involved in the choice of bags. “These bags will enable our families to transport their factor in a discreet way. The bags are great as they blend in with all other environmentally friendly bags and are sturdy enough to be used whenever factor or any other items have to be carried home.”

If your factor pick-up point does not have the bags on hand, ask them to contact their local Baxter representative to ensure they have them for your next visit. ♦

NiaStase RT® available soon

NIASTASE RT® is a new formulation that is stable at room temperature (from 2°C to 30°C) and will replace the current NiaStase® formulation.

The new formulation has been introduced to help:

- Storage at room temperature (from 2 °C to 30 °C) means you can keep the product close at hand;
- Round-number vial sizes to simplify dose calculations (1 mg, 2 mg and 5 mg vials);
- Higher concentration of the reconstituted solution means 40 percent less volume to infuse. (NiaStase RT at 1 mg/ml compared to NiaStase at 0.6 mg/ml);
- A pre-measured diluent is now included in each package of NiaStase RT. The solvent solution contains histidine (10 mM) and should be used to reconstitute each vial of NiaStase RT.

Your Novo Nordisk representative is available to answer any questions you may have in preparation for the introduction of NiaStase RT. ♦



Ask an Expert

Do you have any outstanding questions about your health issues, medication, research, programs, services, or other topics pertaining to bleeding disorders? Your questions may help others who are less willing to voice their concerns. Questions will be printed anonymously and answered by the appropriate professional who has expertise in those areas in question.

Submit your question to hheagle@hemophilia.on.ca.

News

1-800 Line Helps Kids with Blood Clots



THE HAMILTON SPECTATOR, MAY 26, 2010

PHYSICIANS WORLDWIDE, from a US army base in Japan to Sweden's Nobel-prize-awarding Karolinska Institute, call Dr. Anthony Chan's 1-800 line in Hamilton to tap into his expertise in blood clots in children.

Chan received 1,200 calls on the line last year alone, which averages out to 3.2 calls a day. And Chan, who runs both the pediatric thrombosis clinic and the hemophilia clinic at McMaster Children's Hospital, volunteers all of the time he spends on these calls.

"I'm using my best skills to volunteer," he said when asked why.

He also considers the line a way to continue the work of his mentor, the late Dr. Maureen Andrew, who started the 1-800 line in 1994.

With more children getting blood clots, the phone line is helpful for doctors who don't know how best to help these young patients. In the thrombosis clinic, Chan saw about 75 new patients in 2008 and about 100 in 2009.

Chan attributes the increase in childhood thrombosis (a blood clot formed in a blood vessel) in part to more doctors now recognizing the problem, and to childhood obesity and treatments that can induce blood clots, such as chemotherapy.

The 1-800 line has also been valuable to Chan, giving him yet more expertise through the feedback he gets, he said. The 1-800 line is strictly for doctors treating children. Most of the calls are from the US, but doctors from Australia, the UK and Argentina have also called.

The call from Sweden's Karolinska Institute during Christmas Eve dinner a few years ago led to some good-natured ribbing from Chan's brother, who jokingly asked if he was up for a Nobel Prize.

There was also a call from a US army base in Japan, where the doctor told Chan the base would airlift the child to US soil if he thought it was necessary. It wasn't and the child recovered.

The line also helps locally. For example, Chan recently got a call from Oakville while he was on his way into a Wendy's with his children. It was about a 17-year-old boy with a pulmonary embolism or blockage—a case Chan had already discussed with the boy's doctor earlier in the day. But this call was from the boy's mother, and under normal circumstances Chan wouldn't take it.

"She was almost in tears and wanted to be assured I'd see her son," he said. "I said, 'I will make sure to see your son in the next 24 hours.' "

Chan is now following the boy through the clinic at McMaster and says he is doing quite well.

by *Carmela Fragomeni* (cfragomeni@thespec.com)

Reprinted with permission from *The Hamilton Spectator* (www.thespec.ca/article/775774) ♦

Chicken Pox Vaccine Leads to HIV Breakthrough

CANFAR funded-researcher reveals new HIV vaccine candidate

RESEARCHERS FUNDED by the Canadian Foundation for AIDS Research (CANFAR) have unveiled a new HIV vaccine candidate that can reduce—and in some cases, prevent—HIV progression by triggering the body’s natural immune defences.

This scientific breakthrough is the work of Dr. Kelly MacDonald, Microbiologist at Mount Sinai Hospital, and her research team, in collaboration with Dr. Mark Wainberg at McGill University, another CANFAR-funded researcher.

The study investigated two vaccine candidates: Delta 5 and Delta 6 simian immunodeficiency virus (SIV), both of which are a weakened form of the HIV virus used in primates. The study showed that control of and protection from HIV depended on initial exposure to the Delta 5 vaccine, which primed immune responses to the virus.

The research team discovered that by using the chicken pox vaccine, which provides the body long-term protection by triggering the immune system intermittently, they could adapt a delivery system for an HIV vaccine. By inserting HIV genes into the chicken pox virus, they created a vaccine that is non-toxic and incapable of causing disease.

The study highlighted the importance of controlling the virus before it enters the gut, because 70 percent of the body’s immune system is found in the digestive tract, and the memory of the immune system resides there. If the HIV virus reaches this area, it eliminates immune memory, leaving the person vulnerable to the virus.

“Now we need to test a practical vaccine delivery system that will intermittently tickle the immune system to ensure the natural immunity is properly primed,” said MacDonald. “This way, if HIV exposure does occur, the system can respond quickly when it enters the body and before it reaches the lymph nodes in the gut.”



A trial for the new vaccine candidate will begin this spring. A successful vaccine will generate immunity to both chicken pox and HIV.

CANFAR remains committed to ending the HIV/AIDS pandemic through funding research initiatives such as Dr. MacDonald’s vaccine candidate.

For more on CANFAR-funded research and how to donate to Canadian HIV/AIDS research, visit www.CANFAR.com. ♦



Credit: BigStockPhoto.com/2364347

Looking for a Family Physician?

THE MINISTRY of Health and Long-Term Care has a provincial initiative to try and find a health care provider for every Ontarian. If anyone you know does not have a health care provider, please direct them to the MOHLTC website and click on “health care options.” There they will find Health Care Connect and they can register either by phone or online at <http://www.health.gov.on.ca/en/ms/healthcareconnect/public/default.aspx>. ♦

Youth Speak

Did You Know?

Ontario youth are required to complete 40 hours of community volunteer time to graduate from high school. By participating in our various community events, you can earn hourly credits toward completion. Contact your Regional Service Coordinator to find out how easy it is to get involved.

Amy Griffith



ADVOCACY. As defined by the Webster's dictionary, this word represents the act of supporting a cause or proposal. Though this seems a simple enough definition, what I find truly interesting and critical in understanding this term, is that advocacy means something different to each and every individual that has ever needed it. Each and every person has, at some point or another, need to advocate for themselves, and in some cases,

advocate for others. In the case of the bleeding disorder community, I am confident that this is a well-exercised principle for all.

To me, advocacy is knowledge. It is understanding and it is listening. It is support and empowerment. I am so fortunate to have a supportive and loving network of family and friends that have always been there for me. My two best friends from middle school would sit and stay with me through my horrific 5+hour nosebleeds at school, and do everything they could on my behalf, like calling my mother and letting my teachers know I would not be attending class that day. My family has advocated for my health from the day I was born, before I was diagnosed with von Willebrand type II/A disease. When I was young it was they who did all the talking, made all the decisions and fought all of my battles, and for that I am eternally grateful. However, I am an adult now, and I have started to see just how much of a battle advocacy can be.

I want to state first that all doctors, nurses and interns I have ever had contact with in clinic—both at the Hospital for Sick Children and St. Michael's Hospital—are and have been absolutely wonderful. They have made me and my family feel safe and saved my life more times than one. When I was too young to understand, they gave my likely very frightened parents support and peace of mind that their little girl would be just fine. I have no amount of words to string together to express how appreciative and thankful I am to each and every one of them, because anything I say would be less than they deserve.

This said, in the event of an emergency, these are not the only doctors we have come into contact with, and unfortunately, my condition and I have not always been as well received. At 18 years of age I was well into my first year at Wilfrid Laurier University and enjoying my new, independent life away from home. I soon realized how much my family had always done for me when I started making my own decisions and living on my own. However, I came to the peak of this realization when I was admitted into hospital that February for an intense nosebleed. This bleed was a lot of firsts. It was the first bleed I had ever had away from my family. It was the first bleed I had ever had away from my own clinic and doctors. But most importantly, it was the first bleed I had ever had to deal with by myself. However, I knew the ropes and my condition better than ever at this point, and was confident about my own treatment plan and I had never expected that my knowledge and experience as a patient would ever be questioned. Upon entering Brantford General Hospital emergency, I felt totally invisible. Nobody seemed to listen to me, my needs, and my condition. The doctors and nurses—though I was certain were very capable—were convinced that they had things under control and therefore didn't have to

Youth Editorial Committee

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listen to me, vetoing everything I had to say, and all of my protests against a new treatment plan. I was panicked and uncomfortable, and though my distraught roommate attempted to speak on my behalf, she was herself uneducated on what I needed. As I attempted to advocate for my own treatment plan and my own health care, I was ignored. Therefore, I was given an unsuccessful treatment of painful packing of my nose without administration of Humate-P and forced to come back to the hospital the next day after another bleed, just as bad if not worse.

I was shocked. I had never had to advocate for myself and expressed my anger to my mother who came straight to Brantford General from work when my roommate called her, as I was not allowed to make the call myself. Turns out, this is something she had been dealing with while I was too young to notice. I did not always get the priority in the waiting room that I needed. My parents expressed what had happened and what I needed, and it had fallen on deaf ears as doctors did what they “saw fit” for me. I will say again, I do not doubt that these unfamiliar doctors (just as unfamiliar to me as I am to them) are fully qualified; however, who knows my condition better than me and my family? I believe living with this bleeding disorder every day for the rest of my life and knowing when I need help and what that help is, merits some sort of respect in the medical field.

I was fortunate enough to be a guest panel speaker at this year’s Hemophilia Ontario’s Women’s Weekend in Kingston, and I expressed my frustrations about advocacy with my audience. When the panel opened up for a question/answer session, I was overwhelmed by how many women felt the same way I did. So many women advocate for their hemophiliac sons and even themselves as carriers, and often they ultimately get frustrated by how little they are heard. They

all expressed how they give home treatment to their sons, and have since day one of diagnoses, and yet how this merits nothing upon entering a hospital and lending expertise to exhausted and often exasperated triage nurses. No matter what they say regarding the treatment of their sons or themselves, quite often it is just as effective as if they had said nothing at all.

Though I have no solution to this concern, I will say again what I said that weekend. Never stop advocating for yourself, but remember to pick your battles. My mother picked her battles with nurses that made me sit for hours on end, bleeding into a towel,

who refused to have me be bumped up in the priority line, but never for one second believed that she was more superior than a doctor. She advocated for me like I now advocate for myself. I know what I am talking about, please listen to me. I may live with this disease and it is a part of my everyday life, but this is scary for me; please listen to what I have to say. My treatment plan has been made for me and I have become accustomed to it. I am not helpless, I am strong, and though you may not understand that and I may get frustrated at you for not listening, I will still always thank you for your help. ♦

D’Marc Lewis

107 IS THE NUMBER OF TIMES I reach the clinic in a year on average. Nine of them will be on a Tuesday. Seven is the number of years come September I have been in this adult program at St. Mike’s. I have seen nine nurses come and go as a regular here. Only one of them retired... then came out of retirement. I think it’s safe to say that all of them have seen how difficult it can be to juggle around a number of people nearing 1,000 on their own. I can’t help but feel (only sometimes) a little guilty to be as much of a burden... well just being only one. Then there’s the countless numbers of them teaching a few things to students, emergency staff and other members willing to learn.

When you hear the term *transitioning*, many of you may think that all it entails is a brisk autumn night, listening to your former (or still current) and future faculty at both Sick Kids and St. Mike’s (respectively) over some sandwiches. Well, lucky you. Many of us didn’t have that. Not that we didn’t come out of it independent or needed sandwiches. But it would have been nice. You see, transition for me wasn’t that much of a smooth ride. There would be the visit to the clinic. And the Emerge... Oh God! (I’ll get to that in a moment). There



was a big learning curve for me and the operations around me. I had to keep myself constantly adapting to the changes that occur around me. Let me share something.

In the Sick Kids days, I was a “treat on demand” hemophiliac. Many times, I was able to avoid the treatment completely. Sometimes it was just going in for the attack, realizing what the consequences could be if the orders aren’t adhered to. Often it was simply just a matter of R.I.C.E. Sometimes, maybe just delay it? “Hmm, I think it would dissipate a bit...” But, when it came to moderate bleeds and milder, it was like I was living a pseudo-moderate hemophiliac lifestyle, complete situations that are a “Hit and miss.”

You would come to expect a high standard from the very people you rely on, especially when your wellbeing depends on their expertise. So for someone to negotiate your standard of care would just be detrimental. But of course *this can also be a bad thing*, because you get too comfortable, you don’t pay attention to the more minute but important details that still hold much merit. You end up showing up for a doctor’s appointments or to adult care, not knowing everything you should know or have documented. You are literally left on a big reconstructive learning curve. Eventually, you are signing away for others to speak on your behalf and maybe just getting a nod out of you. But it’s not to say they are doing so to do ill unto you. You just might agree to it for whatever reason and it may not be for you.

I started going to the hospital alone at age 16. That was great. I didn’t have to wait on my mother to get ready and look good any more. I didn’t end up coming mad late. “Yeah, Mum. Show up whenever you feel, I’ll be back home by the time you’re ready to leave...” I can take the bus instead of a cab. Needless to say, it was much cheaper. I started to learn what was expected of me, and was more able to answer for myself by the time I was

18. But a recurring bleed coupled with other issues signed off on that would be the end of on-demand treatment. I couldn’t keep it up and was suggested to go on prophylaxis. That meant a visit every so often to St. Mike’s. It varied—every other day, three days a week, two days a week, three one week, two the other, treatment on an off day—you name it. But I stayed at the clinic instead of home care; it was supposed to be easier. But it wasn’t easy.

To my surprise, Emerg at St. Mike’s didn’t know how to care for bleeding disorder patients. Butterflies, treatment—nothing. I was better off sitting around, not clotting from glass shards brought on from a bar fight in comparison. There were many disagreements and resistance. That itself was a learning curve; learning to deal with a totally new round of Emerg

Whoever thought of this transition program is a genius.

visits. It was terrible. I said “Never again.” But then Ann Harrington was told of my first-time experience, and before I knew it people came upstairs to the clinic and decided to learn there would be more people like me—to put it nicely—showing up. Future unintended visits were easier from there on in.

Nurses have come and gone since Ann. Running a Hemophilia Treatment Centre isn’t easy. Some resigned, moved on elsewhere near and far. Some didn’t see eye-to-eye with me. Most of the middle of the seven years meant running a search for the Next Top Nurse.

We scored big time when we got Georgina. So, ha!

Whenever I am at these Adult Transition programs speaking to the youths, I usually try to stress one thing. Parents: Once he or she’s at St. Mike’s, you’re allowed a few visits at

most. After that, stay out of the way. I highly suggest to both the kids and parents that if you haven’t started by now, that you start getting yourself and/or your youth educated and start learning everything you need to know. Everything you *think* you need to know—or what’s worth knowing anyway.

Little Hemos and von Willies: Start learning “how to” on your own and know how to talk to the “Hemo Fellow” dude (whatever they call him now...), your nurses, doctors and so on once you pass 16. Your parents (or guardians) should only be attending to you for so long or else you’ll begin to regret it.

You must be able to stand up for yourself; you have the right. Speak for yourself, especially when you end up in Emerg. Otherwise, you end up in a total reconstructive learning curve, starting from scratch, messed up, and it may end up taking you what... three, four, five years to bring yourself up to code? Start early.

Whoever thought of this transition program is a genius. If you are yet to come out to one—and I strongly suggest you do, you can feel free to ask any one of the older out-patients anything, gain some insight, some perspective—something! All of the doctors will be there (I hope) to tell you what’s good. You can still ask them questions with no sweat. There’s no such thing as a stupid question—just the ones that aren’t asked. And you never know, it could cost you if you don’t. Never hurts to ask. Did I mention complimentary sandwiches at this event?

I still look forward to meeting this “Fellow.” If you are that person, find me. You are indeed a person of mystery.

Anyway, live life excitingly like you’re chasing the last bus for the week and I’ll see you again in the fall.

Keep the peace. ♦

Shaun Bernstein



ONE OF THE MOST IMPORTANT series of choices that denotes my day-to-day life as a hemophiliac isn't work, or relationships, or even school.

It's travel.

I've been fortunate enough in my life to have the means to do a fair bit of travel. But it's always come down to a series of well thought out decisions, first by my parents, and then by me.

One of my earliest memories is actually having to cancel a last-minute trip to Buffalo, NY because my mother was having trouble with venous access. I was probably 3 or 4 years old, which means I was already on prophylaxis, but my pediatrician was still the skilled set of hands leading the charge. I remember the Saturday morning trip to his house so he could help with the infusion (there were a lot of those in the early days) and I remember how sad I was that I wouldn't get to cross the border for the first time.

Throughout my childhood, and even as a teenager, I was able to travel a great deal, but always with Mom in tow. I can honestly admit that, having never gone to camp, I didn't start self infusing until about age 15. So I was able to take the family vacations like

any other kid, but Mom was always there. I went on the Grade 8 grad trip to Quebec City, but Mom came with. The school was able to use her as a parent chaperone, and she stayed in a separate hotel, but we did meet up one evening so she could pump me full of factor.

In high school, things started to change. I joined a youth group that had me going on weekend trips with hundreds of friends throughout Ontario, New York, Pennsylvania and Ohio. The trips were heavily staffed, and a number of the group leaders became second, third, and fourth Moms. I may have been the one infusing, but I had a few dozen eyes watching out for me, making sure I could be a fun teenager without being a foolish one.

It meant learning those limits, and even though I pushed them on a few occasions, I still knew I was doing it in a safe environment, with easily accessible care.

These trips really meant making my own decisions. Growing up with hemophilia is an exercise in learning your limits, while at the same time testing them, and realizing how amazingly few there are. The last thing I wanted to do was sit out for an activity that all my friends were doing, and I rarely did. Sometimes it meant tiring myself out, or doing things a bit beyond what I felt I was capable of. It meant learning those limits, and even though I pushed them on a few occasions, I still knew I was doing it in a safe environment, with easily accessible care.

The greatest test of these judgment calls was also the greatest travel experience I've ever had; a trip to Israel three years ago on a program called Birthright. The program grants Jews

18-26 a free 10-day trip to Israel, where you get to see the country at a rapid pace with 40 other people on a coach bus. It is, for most participants, the opportunity of a lifetime.

Israel has one of the greatest health care systems in the world, and each trip includes a full time medic from the Israeli Army who can attend to small traumas. Of course, this didn't stop the trip organizers from planning ahead. Before leaving, I had consultation with my trip staff, the organizers in Israel, as well as the nearest hemophilia society to where I'd be staying. Barely after I'd first touched the ground, the trip organizer in Israel greeted me warmly as if I was already a familiar face, and then explained that there were a few more strenuous events, such as hiking and military exercises, that I wouldn't be participating in.

The trip was an exercise not just in making friends and discovering my roots, but in advocating for my own health care, like so many of my travel experiences have been. I was okay with not doing the hikes I was advised not to do, because I knew a bleed would ruin my entire trip. I knew that even though I spent New Year's Eve sleeping in a Bedouin tent in the middle of a foreign desert, I still had to start the next morning with an infusion before I went off to ride a camel and climb a mountain (in that order).

Now that I'm doing it more and more on my own, travel has been an amazing exercise in learning how to advocate for myself. When you're on your own as a hemophiliac, especially as you get older, you know the benefits of making smarter choices and the consequences if you don't. I've come to learn over the years that by being responsible and making smart choices, I can have the amazing quality of life that smart prophylaxis is designed to afford me. ♦

Mojtaba Khezry



AS THE OLD SAYING GOES, “Yesterday is history, tomorrow is a mystery, and today is a gift.” We have been blessed with compassionate parents, professional medical teams, and a state-of-the-art medical facility to normalize our lifestyle. This is true about yesterday and today, but how much of that remains? That’s up to choices we make today.

One major milestone to hit as hemophiliac youth today is probably the career choice. We finished high school, now what?! What shall I do? How can I positively contribute to my own society today, provide for my family tomorrow, and at same time maintain a healthy lifestyle? These are questions I wrestled with as I was finishing high school. Though hemophilia is no longer a limiting condition with availability of prophylaxis treatment; we still need to take into consideration some important questions when deciding for the mysterious future. How passionate are you about your choice? How will you serve your society and yourself? How willing are you to persist through the hardships associated with your career choice? Is there a minor chance that you will need to change your career path half-way through?

To better explain the last question, I offer you my personal experience. Please note that this is a personal experience, and it may not apply to everyone. I have always had keen interest in healthcare; therefore I did an undergraduate in biological science to keep my options open further. Then I decided to do the MRI (magnetic resonance imaging) program at “The Michener Institute.” However, I was soon faced with the reality that to be an MRI technician, you can’t have any medical prosthetic devices. Looking at my current status, it is likely that I will need a knee replacement, in which case I will have to change my career again in the near future. Instead, I decided to do my masters in biophysics and serve the scientific community.

I would like to conclude with another famous quote, “Prepare for worst, hope for best.” Today we need to take a proactive role in researching our options—both the positive and negative aspects of them. My advice is to keep your choices healthy, and above all, keep it real. ♦

Central Western Ontario Region

Regional Spotlight

Message from the Chair

Dear Friends and Members:

I am writing to you as the new Chairperson of the Central West Ontario Regional Chapter of Hemophilia Ontario, having taken over the position in the spring of 2010.

The region is busy with a full range of programs and activities in the spring and summer. Our programs include Mother's and Father's Day's events, and our very popular family event at Marineland. Our programs continue to be well attended and offer an excellent opportunity for our members to network with others in a safe and fun environment.

We have had several successful fundraising events this year, including a comedy night and Biking to Stop the Bleeding. The fundraisers that are held in the region are always well attended and they offer an exciting opportunity for our staff and members to raise awareness about bleeding disorders while raising much-needed funds that help to run our programs and improve the lives of individuals affected by bleeding disorders.

The region was proud to host Hemophilia Ontario's Annual General Meeting on April 24, 2010. At the meeting, Hemophilia Ontario approved a new Strategic Plan, which the region is excited to be a part of. As a result of the changes brought about by the Strategic Plan, we will be able to reach out to recent immigrants and others that have barriers to accessing our health care system. We will also seek to expand our membership into all inherited bleeding disorders. There are exciting changes afoot, stay tuned!

*Best wishes,
Cameron Peters*

Regional Board and Staff

Cameron Peters, Chair
 Dane Pedersen, Treasurer
 Jace Pedersen, Secretary
 Justin Terpstra, Program Chair
 Donna Montminy,
 Fundraising Co-Chair
 Gail Cameron, Fundraising Co-Chair
 Trish Nelson
 Igor Ristevski, Director

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

Should you have any questions regarding the Board of Directors, meeting dates, or any of the 2010 programs, please do not hesitate to contact Regional Service Coordinator – Alex McGillivray at 905-522-2545, or e-mail amcgillivray@hemophilia.on.ca. ♦

World Hemophilia Day Celebrations



by Alex McGillivray

WORLD HEMOPHILIA DAY is celebrated around the world on April 17 to increase awareness about Hemophilia and other inherited bleeding disorders. The first World Hemophilia Day celebration was held on April 17, 1989 in honour of the World Federation of Hemophilia founder Frank Schnabel, who was born on this day.

World Hemophilia Day Bake Sale!

ON WEDNESDAY, April 14, 2010 the Central West Ontario Region in conjunction with the Hamilton-Niagara Regional Hemophilia Clinic held a bake sale which not only raised awareness about inherited bleeding disorders, but also saw \$375 raised for the region. Many thanks are extended to the Hamilton-Niagara Regional Hemophilia and 3F Clinic teams for providing their baked goods, as well as getting us permission to use the hospital space. Thanks are also extended to the following CWOR Board Members: Kay Murphy for her beautiful blood drop necklaces; Gail Cameron for the donation of Budding Gardener kits; and Trish Nelson and Donna Montminy for their delicious baked goods. CWOR also sends their appreciation to our Nursing Student Volunteer Ayeza Co-barde for spending the day to help us with the running of this event.



▲ Bake sale goodies on display outside the 3F Clinic at McMaster Hospital

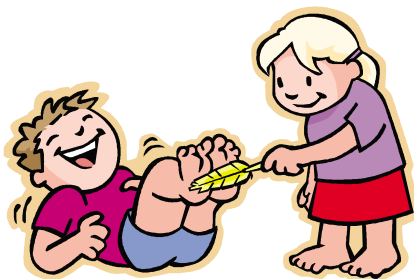
Severely Awesome Puppet Show

THE KIDS ON THE BLOCK Puppet Troupe visited Cardinal Newman Catholic Elementary School in Niagara Falls on Friday April 16 and performed their John Plater Hemophilia Skit for the children in Grades 1 through 4. Children had a chance to learn about hemophilia first hand from this interactive puppet show that included positive messages such as “I have Hemophilia and I’m severely awesome!” The presentation also saw the students asking multiple questions about John and his everyday life with an inherited bleeding disorder. We would like to thank the Calabrese Family for coming out to support the event with their two sons Luciano and Michael. Our thanks are also extended to CWOR Board member Trish Nelson for her attendance.

Cardinal Newman also held a Red White & You event all week which saw students collecting money for the Central West Ontario Region. The students raised \$130! CWOR would like to thank Cardinal Newman for supporting the Kids on the Block Puppet Show, and also for their support of the Red White & You event.

► *Top: On the right is the famous John Plater puppet with his Kids on the Block friends.*

Below: The kids of Cardinal Newman School raise their hands with enthusiasm to find out more about John Plater and Hemophilia.



Laughing Away for World Hemophilia Day!

Justin Terpstra, CWOR Program Chair arranged a third-party fundraiser in conjunction with Comedy Club 54 in Burlington. The evening was hosted by Ben Guyatt and guests had the opportunity to watch three comedians do their acts. A total of \$528 was raised for CWOR at this event. Many thanks to Justin for his efforts in arranging this event, and also to the Board members who attended.

CWOR's First Mother's Day Event



Chloe and Mom Jennifer Trotter watch RGB instructor Stacey teach everyone how to make a decorative card.



Emma Yanyk puts her Mom Mary-Rose Steed's decorative card through the cuttlebug machine.

ON SATURDAY, May 1, CWOR held their first ever Mother's Day event at the Royal Botanical Gardens in Burlington, Ontario. Participants had the opportunity to work together on various crafts with the guidance of a Royal Botanical Gardens instructor. Some of the crafts the women and girls got to make were decorative cards, as well as garden stone decorations.

One of the most touching moments of the day was when three of the mothers began talking to each other about their children's different bleeding disorders. It was so interesting to hear the similar stories that these mothers shared despite having children with different bleeding disorders.

One of the event's participants, Kristy Andersen said:

"I have to admit that I am not an artistic person, but the day that Alex arranged for the Mother's Day event was fun. I was able to let my crafty side loose and came home with some really beautiful stuff. It is also always nice to make some connections with other families that live with bleeding disorders. Thanks Alex." ♦



Travel Tips

BE SURE TO HAVE safe travel plans in place such as the Bleeding Disorder Clinic location for the place(s) you are traveling to. These can be found at www.wfh.org/2/8/8_1_Passport_Directory.htm.

Remember to carry your current wallet card. It is important to attend your annual review appointment with the clinic to ensure that your wallet card is kept up to date.

If you are going to be flying and are carrying factor concentrate, be sure to contact the clinic well in advance for your travel letter. The clinic has followed the advice of Transport Canada in composing the travel letter and it is designed to expedite your airport screening process. However, it is advantageous to always check prior to your flight for any changes in regulations.

The following websites can be helpful:

- Transport Canada: <http://www.tc.gc.ca/en/menu.htm>
- Canadian Air Transport Security Authority (CATSA): <http://www.catsa-acsta.gc.ca>

Please Note: Factor concentrate must be carried on Board in proper cooler containers and never packed with your luggage so as to avoid any loss and also to maintain proper temperature control.

Should you require any more information or assistance, the CWOR office now has a *Travelguide for People Living with a Bleeding Disorder*. ♦

HEMOPHILIA TREATMENT GUIDELINES				
TYPE OF DEFICIENCY: Hemophilia A (Inh) Severe		DOSAGE REVIEW DATE: Aug 24/05		
INHIBITOR:		BLOOD GROUP: O Neg		
TREATMENT PRODUCT: Niasstase OR Recombinate				
PRODUCT	DOSAGE FOR BLEEDING			
	Prophylaxis	Minor Surgery	Mild / Moderate	Severe (Including Head Injury)
FVIII Concentrate	100 units/kg	n/a	n/a	n/a
FIX Concentrate				
Niasstase	n/a	1200 units	1200 units	1200 units
For head injury or severe bleed give Niasstase 1.2 mg and notify Pediatric Hematology STAT for further instructions.				
CALL HEMOPHILIA CENTRE IMMEDIATELY WHEN A BLEED IS SEVERE OR NOT RESPONDING				

Wallet card

Liam Barbour Scholarship Award

THE CENTRAL WESTERN REGION of Hemophilia Ontario is proud to present the Liam Barbour Scholarship Award. This scholarship is 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 for as long as it exists.

Scholarship Requirements

- To qualify for this award, the applicant must be residing in the Central West Region, be an active member of the Central West Region, and be recognized by their individual disorder.
- The applicant must provide proof to the Central West Region of their enrollment at a post secondary institution.
- 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 Sunday, August 1, 2010. 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 – Regional Service Coordinator, 10 George St., Office 19, 4th Floor, Hamilton, ON L8P 1C8; 905-522-2545; E-mail: amcgillivray@hemophilia.on.ca. ♦

Events Calendar

Please note that dates listed are tentative. Information will be forwarded to your attention as soon as dates are confirmed. We encourage you to share any ideas you may have on speaker topics and programs. Contact Alex McGillivray, Regional Service Coordinator, 905-522-2545 or amcgillivray@hemophilia.on.ca.

PROGRAM/EVENT	EVENT DATE	DESCRIPTION	GOALS AND OBJECTIVES
Couples' Program	October 16	An event for couples to learn about how to deal/cope with the stresses that may affect their lives.	To provide an opportunity for couples to bond, and to learn about stress relief.
Holiday Party 2010	Nov/Dec	Education and Networking.	To provide membership an opportunity to meet other individuals and families with similar conditions. Encourage networking.
Wanakita Registration Program	December	An information event to provide parents and potential camp participants with support.	To leave parents with a sense of ease in sending their kids to camp. To encourage youth to attend camp in the future.

North Eastern Ontario Region

Regional Spotlight

by Teresa Genereux

AS WE LEAP into spring and summer from a cold, but mild winter, the NEOR has been very busy promoting the importance of bleeding disorders, HIV as well as Hep C awareness. I hope everyone is enjoying the nice change in the weather.

Onaping Winter Carnival

It was a cold yet sunny morning as the community of Levack and Onaping gathered for the yearly winter carnival. If it were not for the men's old timers hockey league, this fun event would not happen. There were many events which included men's and ladies' hockey, two-by-four races, snowmobile ride, curling, water boiling competition, and log cutting competition.

This is the second year that the NOER Hemophilia Society attended this event raising awareness of bleeding disorders and hemophilia. We have gained two new volunteers this year—Brad Pearson and Cassandra Green. Their help was and still is greatly appreciated. At our display table we sold charms, key chains and necklaces and for the kids we made a spin-n-wheel having them answer questions about bleeding disorders. With the help of our volunteers we have raised over \$200.

During the log cutting competition Kaitlynn McDonald and Cassandra Green won first place for the fastest time to cut the log. All in all the carnival was a great success and we look forward to it again next winter.

I am very proud of all the volunteers for helping me continue our partnership with the old-timers hockey team and a special thank you goes out to all for your hard work and efforts while I was away in Phoenix, Arizona on a work conference. I would also like to thank Ellard Durling once again for letting Hemophilia Ontario be a part of their special event each year. ♦

HIV/AIDS Opening Doors Conference

NEOR Staff

Teresa Genereux, Regional
Service Coordinator
705-966-3957
tgenereux@hemophilia.on.ca

I had the extreme pleasure to be a part of this conference with our partnered ACCESS AIDS Network in Sudbury, Ontario at the Howard Johnston Hotel on March 22-24. This was a fact-filled week with many outstanding speakers, ranging from HIV medical updates, prevention, keeping up the energy, and much more. It was a great pleasure to see many people I knew but also meeting new faces. I have learned so much from this experience as well as becoming a member of the HIV committee. I attended my first meeting May 7 at the Vale Inco Hospice. I look forward to working with the ACCESS AIDS and HEPC Network and gaining the knowledge to move forward with Hemophilia Ontario. ♦

World Hemophilia Day

IN SUDBURY ON APRIL 17 along the boardwalk on Ramsey Lake Road at the Science North to Bell Park, Hemophilia Ontario did their Second Annual walk. This year we had 35 people attend. Even though it had snowed that morning, everyone had fun. We all enjoyed coffee and hot chocolate, played games, and sold tulips and key chains. We raised over \$2,000 this year. I had many volunteers to help me with the sale of tulips. Tammi Deveau went door to door weeks prior to our walk, as well as selling tulips on the day of the walk. Kaitlynn McDonald and Cassie Green sold tulips at **Vrab's Independent** in Sudbury. A special thank you goes out to all the staff and owner of the Independent. I would like to thank Mary Martel of **Levack Mini Mart** for selling tulips as well.

I have many people and companies to thank for all of their support in donating prizes and refreshments:

- Kim Sherman at **Curves** in Chelmsford for supplying a two month membership. Kim also worked with me doing a presentation at our Hospital Clinic. This prize was given to Tammi Deveau for highest tulip sales as well as key chains.
- Dolly Andrews at **Splendid Beauty Lounge** in Chelmsford for supplying a beauty gift bag and a \$25 gift certificate to the Splendid Beauty Lounge. Dolly is also a huge part of the HIV ACCESS Centre in Sudbury area and spends time attending the Taste for Life events that the ACCESS Centre holds. This prize was given to Cassie Green for the most volunteer hours and dedication to Hemophilia.
- Thank you **Michel Paradis** for supplying the Sun Chips to our participants. This is Michel's second time supplying our participants with a treat.
- We are very appreciative of **Chris's Value Mart** of Dowling for supplying the bottled water for our participants. Chris has just recently bought the Value Mart in Dowling and is doing a super job.



- Thank you **Good Life Fitness** in Sudbury for sharing 30 two-day passes for give aways.

We appreciate **Science North's** generosity for allowing us the use of their grounds once again this year, as well as providing passes as a prize. This prize was given to Stephanie Morrison and her two sons for largest amount of donations.

I applaud all who donated as well as those who attended the walk to make it the success that it was. Without everyone's help we could not be making the progress we are.

In addition, I would like to make a special mention of a little girl who worked very hard at promoting World Hemophilia Day. **Katiya Gareau-Jones** held a lemonade stand and raised her funds. Katiya was presented with a certificate of appreciation as well as a little present from Teresa Genereux. Katiya wrote her own story for us in French and English. ♦

Katiya's Juice Story

ON A BEAUTIFUL DAY in April, I asked my mom if I could do a lemonade stand to raise money for Hemophilia. I got my little ABC table, lots of glasses and a container for the money. We made lemonade and fruit juice. I worked for three hours. Lots of people came to drink a glass of juice. I had a great day! ♦





**OFFICE OF THE MAYOR
CITY OF NORTH BAY, ONTARIO**

PROCLAMATION

**HEMOPHILIA AWARENESS DAY
~ April 17, 2010 ~**

WHEREAS hemophilia is a bleeding condition, which can lead to severe mobility impairment, crippling arthritis, uncontrolled bleeding episodes and shortened life span; and

WHEREAS although treatment products have helped to lessen the impact of Hemophilia, many people who have used these blood derived products have been exposed to HIV and Hepatitis C and now face the debilitating effects of these diseases; and

WHEREAS there is an urgent need to raise awareness about Hemophilia and the services of the Northeastern Ontario Chapter of Hemophilia Ontario for the sake of bettering the lives of those it touches;

NOW, THEREFORE, I, Victor Fedeli, Mayor of the City of North Bay, do hereby proclaim April 17, 2010 as

HEMOPHILIA AWARENESS DAY



In witness whereof I have hereunto set my hand and caused the seal of this city to be affixed

**Mayor Victor Fedeli
Dated this 17th day of April, 2010**

Comprehensive Care Clinic Corner

Clinic Day

ON MAY 15, we held our clinic at our new location in our New Laurentian Hospital on the second floor. We had the pleasure of having Sylvia Storozuk, the Regional Service Coordinator from Thunder Bay, and Heather Heagle, Executive Director for Hemophilia Ontario attending our clinic.

I would like to acknowledge the financial support and participation of representatives from the following pharmaceutical companies, Sophy Oommen, Baxter; Scott Moore, Bayer HealthCare; and Chris Freitag, Pfizer.

It was a busy day for all the staff and clients. We saw and welcomed many new faces to the clinic. The children made stained glass tissue paper from which Teresa Genereux cut pieces and placed into frames for the children to remember their day at clinic.

We had a discussion on Pain Management and Kim Sherman from Curves did a presentation regarding safe exercises with pain.

We all went to Perkins at the Travel Lodge for a wonderful dinner and it was a chance for the clients to relax and get to know each other. ♦



On a personal note

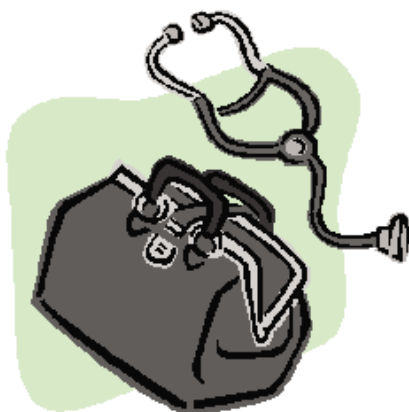
I (Teresa Genereux) became a grandmother on May 7, 2010 at 4:00am. I am very proud to announce to the world Emily-Mae Marie who weighed 6 lbs. 13 oz. She was 19.5 inches long with blondish hair. Beside my own children she is the light in my eyes. I am very proud of my daughter and son-in-law (Jessie and Michael). I am so proud of Michael for being there throughout the delivery and being sleep-deprived for days to come. On May 15, Michael was deployed to Afghanistan for seven months. He is doing well and my thoughts and prayers are with him and our families every day. ♦

North Western Ontario Region

Regional Spotlight



Amanda and Sylvia



I WENT TO SUDBURY in May and met with the rest of the Hemophilia Ontario staff, who always have great ideas and are very supportive of the north. Hopefully we will be able to implement some of these ideas in our area soon.

A presentation is being planned currently for Fort Frances. I will be there for one day (date, time and location to be announced). If anyone would like to speak with me while I'm there, please contact me by e-mail or phone first, and I will be sure to arrange for enough time.

We will also have a booth at the Westfort Fall Fair where we will hand out information and sell our logo keychains. Make sure you get one while they're still available.

On April 17 we were in Intercity Mall in Thunder Bay, selling tulips and Hemophilia Ontario keychains for World Hemophilia Day. Thanks to our volunteer, Amanda Green, we were able provide quite a bit of information that was requested at the table *and* sell some tulips. The funds raised from these tulip sales will go towards our Community Awareness Campaign.

April 19–20 were Clinic Days at the Thunder Bay Regional Hospital. Teresa Genereux, our Sudbury Regional Coordinator, was in Thunder Bay to meet our nurse, Karen Roberts and some of the other hospital staff. We spent April 19 observing and speaking with the clients and parents of clients that came in. April 20 was spent planning with the clients for our upcoming fall clinic. To that end, NWOR clients will receive a questionnaire in the mail. Responses to that questionnaire will have an impact on our plans for future activities at clinics.

A special thank you to Teresa for all her help. ♦

Sylvia Storozuk

NWOR Staff

Sylvia Storozuk, Regional
Service Coordinator
1-807-622-9012
sstorozuk@hemophilia.on.ca

OUR VOLUNTEER, Amanda Green, will be working with me to develop and expand our volunteer pool. We provide training and are very flexible regarding the available time people have. So if you have just a few hours a month, we can work with that. Some of you may have noticed difficulty in reaching me in the past few months. I now have a new phone system and number, which is listed below. Hopefully, communications will be smoother now.

You'll notice in this edition of *Blood Matters* that we're having a contest and asking members to submit pictures of their best friend—their dog. I encourage members from North Western Ontario to submit your photos before the end of September and see if your pooch will win a prize from Purina.

If you would like more information on blood disorders, upcoming events or volunteering, please contact Sylvia Storozuk, Regional Service Coordinator – NWOR at 807-622-9012 or sstorozuk@hemophilia.on.ca. ♦



Last year we held a Candlelight Vigil in Patterson Park to commemorate our lost loved ones. This year, we will hold a Tree Planting Ceremony in October. Date, time and location will be advertised. Watch for it.

Anemia –The Invisible Blood Disorder

ANEMIA COMES FROM the Greek word meaning, “loss of blood.” It is defined as “The condition of having less than the normal number of red blood cells or less than the normal quantity of haemoglobin in the blood.” The oxygen-carrying capacity of the blood is, therefore, decreased.

There are more than 10 different forms of anemia. More than three million people in the United States have anemia and it occurs in all age, racial and ethnic groups. Thirty percent of people with HIV have anemia.

People with anemia may feel tired and fatigue easily, appear pale, develop palpitations and become unusually short of breath. Children with chronic anemia are prone to infections and learning problems.

Anemia is also a common and early complication of chronic kidney disease and worsens as the disease progresses. In some cases of anemia, a rapid or irregular heartbeat can develop, causing damage to the heart over time and possibly resulting in heart failure. (They may say she had a heart attack, but where did it really start?)

It does not seem that anemia is a condition that is taken very seriously by any particular medical group, despite the growing number of anemia-related deaths and hospitalizations, and despite the fact that it's directly related to the blood. Many of these deaths and hospitalizations could be prevented with some public awareness. ♦

Sources:
Wikipedia Online Encyclopedia.
The Internet Encyclopedia of Science – Health and Disease.

Ottawa and Eastern Ontario Region

Regional Spotlight



OEOR

Message from the Chair

THE OEOR REGIONAL ANNUAL MEETING was held on March 28 this year and was very successful. We have 10 members for this year's Board of Directors, and our Past-Chair, Jennifer Lelièvre is going to continue to provide support for our fundraising and Board activities.

Jennifer Lelièvre has been our Chair for the last four years and did an excellent job. Her knowledge of medical conditions as a pharmacist was invaluable. She was instrumental in our Shawn Duford Golf tournaments and will continue to participate in this major fundraising event. We are all involved in the planning for the 16th Annual Shawn Duford Golf Tournament which will be held on August 14, 2010 in Ottawa.

As well, we are reviewing our programs for 2011-2012 and hope to have more activities for our consumers. We like to focus on our children and provide educational and fun events that will get our members out to more of our activities. We will send children to Camp Wanakita again this year and will continue to support our members with financial assistance as much as we can.

Our Resource Development team within OEOR is working on new fundraising initiatives which will contribute to our ability to assist more members in their financial requests.

Colin Patterson, our RSC (Regional Service Coordinator) will continue to work with the new Board to implement our major goals and objectives, which includes the Outreach Program to local hospitals. We need to educate more communities outside of Ottawa on our worthwhile cause and our charity on blood related diseases.

Our ultimate goal is to find a cure with medical research and we will continue to support the CHS Million Dollar Club in this important venture.

In addition to these activities, our Board is kept abreast of the community's activities and concerns through the participation of our RSC networking at regular meetings with Ottawa Carleton Council on AIDS, HIV Primary Care Group, Hep-C Task Force, HealthPartners, Blood Services Liaison Committee, Canadian Liver Foundation, World AIDS Day, and CHS Hep-C Advisory Committee as well as attending bleeding disorders clinics at the region's hospitals.

This should be an exciting year for OEOR within Hemophilia Ontario and we all look forward to providing support to this worthwhile cause.

*Steve Van Dusen
Chair, OEOR* ♦

Regional Board and Staff

Steve Van Dusen, Chair
Jennifer Lelièvre, Past Chair
Jennifer Van Noort, Vice Chair
Ashwani Kurichh, Secretary
Brian Van Dusen, Treasurer
Nancy Sauve, Program Chair
Darlene Villeneuve, Fundraising Chair
Jaime Villeneuve, Director
Raja Ammourey-Alami, Director
Lori Kavanagh, Director
Bruce Myers, Director
Trevor Sauve, Director

Colin Patterson
Regional Service Coordinator
613-79-3845
cpatterson@hemophilia.on.ca

Program and Fundraising Chairs' Message

I WOULD LIKE to introduce myself. I am Nancy Sauvé, the new Chair of Programs, and my sister Darlene Villeneuve who is the new Chair of Fundraising. We are excited and looking forward to this year's planned activities. As well as planning new and exciting programs for the next year, we are looking for any ideas and new volunteers for the upcoming programs. Students, this is a great opportunity to earn volunteer hours for your high school diploma. Contact Colin Patterson or e-mail darville-neuve@yahoo.com. We would like to thank Heather Heagle (Executive Director) for her ongoing support and excellent words of wisdom.

Let's have a good year!

Nancy Sauvé, Programs Chair ♦

Regional Annual Meeting

THIS YEAR the Regional Annual Meeting (RAM) was held once again at the RA Centre on March 28, and there was an excellent turnout of new members and guests.

Dane Pedersen, President of Hemophilia Ontario, and Heather Heagle, Executive Director for Hemophilia Ontario, were present. Dane provided an overview of the Hemophilia Ontario's strategic plan.

Children that were at the meeting were entertained (see pictures) and a good time was had with bowling provided afterwards at the same facility.

We had an excellent turnout for the elections and there are now 10 members for 2010-2011 OEOR board of directors. They are listed at the beginning of this OEOR section. ♦



Events Calendar

Please note that dates listed are tentative. Information will be forwarded to your attention as soon as dates are confirmed. We encourage you to share any ideas you may have on speaker topics and programs. Contact Alex McGillivray, Regional Service Coordinator, 905-522-2545 or amcgillivray@hemophilia.on.ca.

PROGRAM/EVENT	EVENT DATE
16 th Annual Shawn Duford Golf Tournament	August 14
Rural Outreach Renfrew Telehealth	September
Commemoration Day of Blood Tragedy	October 27
Semi-Annual Program/Planning Meeting	October-November
Transition Program	November
World AIDS Day	December 1

16th Annual Shawn Duford Golf Tournament for Hemophilia



OUR 16TH SHAWN DUFORD Annual Golf Tournament for Hemophilia will be held on Saturday, August 14, 2010, with a shotgun start at 1:00pm at the Meadows Golf and Country Club, 4335 Hawthorne Rd., Ottawa. Registration will be on a first registered basis, so don't delay.

Our golf tournament fosters friendships between our members, friends, and our business partners, and is our major fundraising event. The cost of \$100 per person includes 18 holes of golf, golf cart, lunch prior to tee-off, and a succulent banquet dinner. In addition to the golf, we'll also have a lot of great gifts, contests, draws and a silent auction. Those unable to play golf may join us for the banquet for \$30. You will have opportunities to win extraordinary prizes, while helping support the Ottawa and Eastern Ontario Region of Hemophilia Ontario.

We are accepting donations of \$100 to sponsor a hole in your family or company name, as well as donations for door prizes and the silent auction. Income tax receipts will be issued for the value of the donation.

This is a fun tournament for all to enjoy. Don't forget to bring your hat and sunscreen. Please complete the Registration Form below and send it to us with your payment by mail or by fax (613-739-3820). We accept cheques, MasterCard, Visa and cash. (Please note on the Registration Form: you can pay by credit card online yourself or if you prefer, Colin Patterson will process the online payment for you.) If you have any questions, please do not hesitate to call the office at 613-739-3845; if Colin is out when you call, leave your name and a detailed message and he will return your call promptly

We look forward to seeing you on August 14. Let's make the 16th year the luckiest and the best ever Shawn Duford Annual Golf Tournament for Hemophilia

2010 Golf Tournament Committee ♦

✂

Registration Form 16th Annual Shawn Duford Golf Tournament for Hemophilia

**August 14, 2010
1:00pm
Meadows Golf and
Country Club**

Players				
	Name	Address	Telephone	E-Mail
1				
2				
3				
4				

Register and pay in full, 2010 Fee \$100/player.

Number of players _____ x \$100 = \$ _____.

Just for dinner _____ x \$30 = \$ _____. Total \$ _____

If paying by cheque or money order, amount enclosed \$ _____.
Please make cheques payable to "Hemophilia Ontario - OEOR" (no post-dated cheques). If paying by credit card: <http://www.events.hemophilia.on.ca/php>.

All credit card information will be treated as protected information. A charge will be placed on your card equivalent to the amount indicated above.

Fax this form to 613-739-3820 or send the information by e-mail to Hemophilia Ontario - OEOR, c/o Golf Tournament, Room B151D, 2445 St. Laurent Blvd., Ottawa, ON K1G 6C3.

E-mail to cpatterson@hemophilia.on.ca. Check our website <http://www.hemophilia.on.ca/>.

South Western Ontario Region

Programs



Polar Bear Dip

Regional Board and Staff

Paul Wilton, Chair
 Brendon Beer, Vice Chair
 Joyce Jeffreys, Treasurer
 Charlie (Bailey) Pangborn, Secretary
 Adriana Balderas Lopez, Director
 Travis Hazelwood, Director
 Genna Kusch, Director
 Marion Stolte, Director
 Frank Trovato, Director

Terri-Lee Higgins
 Regional Service Coordinator
 866-545-1647
 thiggins@hemophilia.on.ca

SWOR RECOGNIZED World Hemophilia Day on April 17, 2010 with their first-ever Polar Bear Dip. A total of 24 individuals between the ages of 6 – 60 braved the cold lake waters and falling snow to help raise awareness of living with an inherited bleeding disorder. The amazing part of this event is that two-thirds of those who went into the water were there to support an affected friend or family member. When we asked people why they jumped in, responses varied. Travis did it to support his two young sons both living with severe hemophilia, Elsie realized that she could make a difference in the lives of people living with severe hemophilia, including her grandson Aidan. Hannah brought her friends out to help ensure that our regional youth continue to have the opportunity to participate in camp and other educational programs. The “dippers” were well supported from the shoreline by over 30 friends and family who cheered them on and wrapped them in big fuzzy blankets when they emerged. At the end of the day not only were we featured on a local news channel, we raised over \$5,000.

Chair Paul Wilton said, “The polar bear dip was inspired by many of our campers’ favourite event at Pinecrest Adventures. It was a great opportunity to raise funds and awareness about bleeding disorders. It was inspiring to see people

varying in age from 5 to 70 bracing the elements and showing their support for people with bleeding disorders. We look forward to making this an annual event.”

Want to watch the fun? Check out our YouTube channel HEM-AblogTV where you can also find the thoughts of two regional youth on how living with hemophilia has affected their lives. Visit http://www.youtube.com/results?search_query=HEMablogTV&aq=f). ♦



Golf Tournament

THE WEATHER GODS were smiling on May 20 for the SWOR 3rd Annual Golf Tournament for Hemophilia and Inherited Bleeding Disorders at the Highland Golf and Country Club in London. As one of only six tournaments hosted by one of London’s oldest private courses, we appreciate all the efforts of General Manager Leo, Pro Mike, Assistant Pro Tyler and Food Manager Karen and the members who all helped make our day perfect.

Congratulations to tournament winners Jim Higgins, Brandon Prust, Mike McNeil and Mike Uytterlinde, who finished with a 58.

We would like to thank the golfers for their participation. Without you this day would mean nothing. To our amazing volunteers, the four constables who made the police patrol a great success, and photographer Eddie Manuel (eddiemanuel.com), our sincere thanks for the gift of your time. Additionally we would like to thank Youth Speakers Bureau graduate Paul Travaglini for sharing his perspective on living with an inherited bleeding disorder. While final



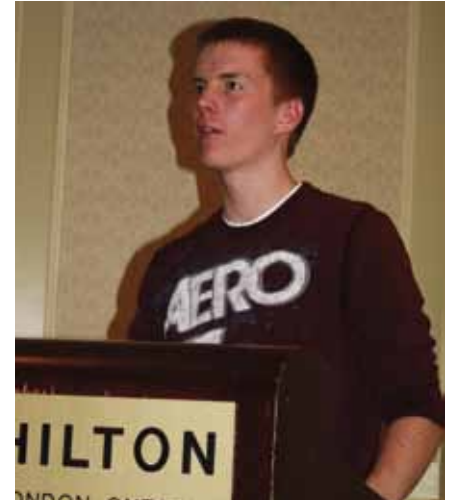
numbers are not yet in, it is estimated we netted \$8,000 - \$10,000 (Watch the SWOR newsletter for further details). Thank you to our major sponsors, Source for Sports Teamworks, Pfizer, The London Police Association, Bayer, Baxter, NovoNordisk and WestJet for helping make this event a great success. We couldn’t do it without you. ♦

Regional Annual Meeting and Education Day - March 27, 2010

Telling our Stories, Sharing our Lives

by Jennifer Crump

IT'S MY TITLE, but one which reflects the experience of all participants who were privileged to enjoy the facilities of the London Hilton Hotel for our regional annual meeting. The day began with some well-planned workshops featuring Lori Laudenbach, Advanced Practice Nurse, who discussed Prophylactic treatment for bleeding disorders, incorporating the recently released video *Hemophilia Heroes: Active Today and Active Tomorrow* illustrating patient experiences and featuring two families from our region. Julia Sek of Baxter Pharmaceuticals discussed Pain Management and ideas from the Passport to Wellbeing Roadmap to Managing Pain. The telling of personal stories followed, generously shared by Brad Baillie and Tammy Ouellette. It was particularly encouraging to see the number of youth participants attending, many of whom participated in leadership training in preparation for camp, provided by Mike Pearse. Paul Wilton has been training youth speakers and two of our young men gave talks about how bleeding disorders impact their lives. Clearly our future is secure with such knowledgeable and positive young people. ♦



Youth speaker Ryan Kleefman

Adventures in Leadership

ADVENTURES IN LEADERSHIP was provided by Eric Sloat, a professional trainer in leadership and management, who spoke about leadership styles and characteristics of successful leaders. All of the participants were asked to consider desirable traits for leaders and managers. Mr. Sloat's presentation emphasized that we all have something to contribute, whether ideas or a specific set of skills we can offer.

Thank you to all who planned and organized the day—it was more than I expected and a day which was thoroughly enjoyed by all. ♦



Paul Wilton Named SWOR Volunteer of the Year

PAUL WILTON, pictured with Past Chair Emil Wijnker, received SWOR's Volunteer of the Year recognition for 2010. Paul is involved at all levels of the Hemophilia Society. Locally, he is the Chair of the SWOR Board of Directors, Director for Pinecrest Adventures Camp and Chair of the Fundraising Committee. Please join us in thanking Paul for his continued commitment and enduring passion that is helping to shape the future of SWOR. ♦

Pinecrest Camp Training

by Genna Kusch

THIS YEAR at the Regional Annual Meeting, we were pleased to have Mike Pearse lead two workshops with some of our returning staff, new staff and LITs. Mike is currently the co-owner and Director of Camp Tawingo in Huntsville and has been a Motivational Speaker and Workshop Leader for over 20 years. He used his time with us to focus on how our positive actions as counsellors—no matter how small—can make a difference to someone else. Rather than telling us what to do, he showed us in his tone and actions effective ways of leading a group. His sincerity was appreciated and we are now motivated to incorporate what he provided into Pinecrest as well as our daily lives. ♦



Mike Pearse and the Pinecrest LITs.



Polar Bear Dip volunteers Sam and Marion at the registration table

Thank you SWOR Volunteers

Thank you to each volunteer in SWOR! Whatever contribution you have been able to make, it has made our region stronger. Some of you have volunteered by speaking at various events—thank you. Some of you have coordinated the logistics of events—thank you. Some of you have run in marathons, or been willing to be interviewed on TV to talk about hemophilia and bleeding disorders—thank you. Others of you worked diligently to secure prizes and golfers for our Golf Tournament in May—thank you. And still others of you braved the cold (brrrrrr!) and “dipped” in the water at Port Stanley for our World

Hemophilia Day Polar Bear Dip. Thank you very much. Each contribution and volunteer effort helps bring us all together in our endeavours to “improve the quality of life for all people living with inherited bleeding disorders and to find a cure.” On behalf of the South Western Region of Hemophilia Ontario and Volunteer Recognition Week, we celebrate YOU – OUR VOLUNTEERS! Thank you for all you do! ♦

Marion Stolte, Chair Volunteer Committee

Events Calendar

EVENT DATE	PROGRAM/EVENT
August 25-29	Pinecrest Adventures Camp - Open to youth ages 5-16 living with an inherited bleeding disorder and their siblings). No cost to participate. Youth age 15-16 may participate in the two-year Leader in Training program, designed to teach skills that will allow them to take increased leadership roles at camp, in the bleeding disorders community, and in their own lives. Youth over 17 may be able to participate as staff. Contact Terri-Lee at 519-432-2365 or thiggins@hemophilia.on.ca. All forms available online at http://www.lhsc.on.ca/patients_families_visitors/bleeding_disorders/SWOR/index.htm .

Toronto and Central Ontario Region

Regional Spotlight

President's Message



HELLO, MY NAME IS MAURY DRUTZ. I have a Factor XI deficiency, and have personal experience dealing with the hardships of living with an inherited bleeding disorder. It is my priority, as the newly appointed president, to improve the health and quality of life for our community.

In my six years' journey of volunteering with TCOR I have worked on various committees, chaired TCOR's Annual Golf Tournament for past four years and have been Vice President and President Elect for the past two years. In taking over from Mike Beck I realized that I have big shoes to fill. I am dedicated to doing my very best to continue the same leadership and passion that Mike has demonstrated during his past six years as president. A most fitting end to Mike's tenure as president was his achievement in receiving the James Kreppner Distinguish Volunteer Award. Mike will continue on the Board as Past President.

This year's Annual General Meeting was held in March at Dave and Buster's in Woodbridge, Ontario and we owe thanks to our staff for making this event a great success. The highlight of the AGM was the presentation of the new Hemophilia Ontario Strategic Plan. Ahmed Hassan, Cameron Peters and the Strategic Planning Committee worked for countless hours creating this remarkable document. The plan was presented to all the Hemophilia Ontario regions for their input to create a final draft. The draft was then presented at the Hemophilia Ontario Annual General Meeting and the Hemophilia Ontario Board voted to accept the five-year strategic plan.

The Joint Clinic Meeting was held in April at the Hospital for Sick Kids. This annual meeting brings together clinic staff and physicians from St. Michael's Hospital and the Hospital for Sick Kids. This meeting proved to be an excellent opportunity for both sides to exchange ideas to improve practices and to work together as a team to provide better services to patients, members and clients. Dr. Marshall Freilich, an oral surgeon on staff at Sick Kids was present to discuss his current treatment protocol for patients requiring dental care.

The World Hemophilia Day was celebrated on April 17. The main objective of this event was fundraising and awareness within the general population. Manisha Ramrakhiani organized TCOR's Second Annual Tulip Sale event in coordination with the YMCA and membership volunteers. Huge thanks to everyone who participated!

Bingo continues to be our top fundraising program. We are always looking for new volunteers to join our Bingo team. There are some Bingo days when we struggle to have enough people to cover the workload. This would only require giving up an occasional Saturday morning. It is a fun morning and the four hours go by very quickly.

On June 28, 2010 we will hold our 11th Annual TCOR Golf Tournament. It's a great day of fun and education. We need more good and bad golfers to

TCOR Board

Maury Drutz, President
 Mike Beck, Past President,
 Signing Officer
 Kevin Ball, Treasurer, Signing Officer
 David Neal, Vice President
 Lyf Stolte, Vice President
 Ahmed Hassan, Co-Chair,
 Program Committee
 Mark Lubinski, Co-Chair,
 Program Committee
 Sheldon Rose, Chair
 Communications Committee
 Marc LaPrise, Director
 Chris Rotolo, Director
 Mojtaba Kherzy, Director
 Tim Jessop, Director

Staff

Susan Turner, Administration
 and Finance Assistant
 Eli Bennett, Regional
 Service Coordinator

Contact Information

Hemophilia Ontario - TCOR
 802 - 45 Charles St. E.
 Toronto, ON M4Y 1S2
 416-972-0641
 Toll Free 1-888-838-8846

come out to help us generate the much needed dollars to fund our many programs. Let make this year's tournament the best ever!

On behalf of my fellow TCOR board members, and our staff, I wish you a very healthy, safe and fun summer. ♦

Maury Drutz



"What we are doing is just a drop in the ocean. But the ocean would be less because of that missing drop." - Mother Teresa

Together we can build a strong and healthy community. Join our Volunteer team today!

**For more information about volunteer opportunities at TCOR, contact:
Eli Bennett
Regional Service Coordinator**

Looking for information on how to become a **member** of Toronto and Central Ontario Regional (TCOR) Hemophilia Society?



Contact Susan Turner

Toronto and Central Ontario Regional Hemophilia Society
802 - 45 Charles St. E.
Toronto, ON M4Y 1S2
E-mail: sturner@hemophilia.on.ca
Toll free: 1-888-838-8846
416-972-0641 Ext. 21
Fax: 416-972-0307

There are **no membership fees!**



**Got ideas to share?
Programming
Experience and
Tips?**

Get your paper and pen and start writing! Mail, e-mail or fax your ideas to
Eli Bennett
802 - 45 Charles St. E.
Toronto, ON M4Y 1S2
E-mail: ebennett@hemophilia.on.ca
Fax 416-972-0307

Membership/Volunteer Information

The Beck Brothers' Volunteer Journey

by Manisba Ramrakbiani

How many years you have been volunteering with the organization?

(With deep breaths and smiles on their faces, Mike and Jeff respond.)

Mike: My first volunteering project with TCOR was in 2000, so about 10 years ago.

Jeff: I am not sure when I started, but it has to be about 10 years ago.

When and how did you join the organization?

Jeff: My wife actually got me started. She was sitting on the Admin & Finance Committee and I started going to other meetings with her. I believe my start on the Hemophilia Ontario scene was through the Hep C taskforce. That's where I discovered the wealth of talent in the organization and the passion and commitment that makes the organization so successful. That drive and energy is also the reason that makes the organization so respected by other organizations and government bodies.

Mike: Ann Harrington recruited me to sit on panel with nurses as a consumer in the fall of 2000 and that's when I started my volunteering journey with the organization.

Do you recall any major or tough challenge you have faced while volunteering with the organization? How did you handle it? What was the outcome and how do you feel about it?

Mike: When I first became President, TCOR was facing a financial crunch and a severe personnel shortage. Between James Beckwith and me we ended up doing things like the T3010A and Visa entries for the golf tournament. We got a new Board to-

gether and figured out our priorities. I worked with our single RSC to ensure that she was not overwhelmed. In the end we made it through, our finances mended themselves and we got the much-needed staff in place. I felt pretty good about it. There were other crises to deal with but we were able to start looking at programs and who we were serving instead of struggling for survival.

Jeff: My effort has always been directed toward taking the passion and commitment that the organization thrives on and using that to improve



our governance and management regimes, so that we can respond quickly and more effectively to whatever issue or difficulty presents itself. It is important so that we can maintain our solid reputation and rapport with



Remember to send us your change of address so you won't miss a single issue of our new magazine and other information.

Please fill in the information below and mail, e-mail or fax it to:
 TCOR Hemophilia Society
 802 - 45 Charles St. E.
 Toronto, ON M4Y 1S2
 E-mail: sturner@hemophilia.on.ca
 Fax: 416-972-0307

Name _____
 Old Address _____
 City/Prov/PC _____
 Telephone _____ Cell _____
 E-mail _____
 New Address _____
 City/Prov/PC _____
 Telephone _____ Cell _____
 E-mail _____
 Moving date _____

other organizations and governments to be able to continue to provide necessary support and services to our community. I think this was a challenge because the Society was built on hard work done around kitchen tables by people with high stakes goals and considerable personal and emotional investment—all of which earned them a certain ownership. My challenge, as I see it, was to convince people that the reforms I saw as crucial were not a threat. Kind of like an owner's manual recommending an important tune-up. I know that some people struggled (and some maybe still do) with the changes that came about and are still evolving, but I like to think that by involving everyone and asking them to discuss the issues and learn why the reforms are necessary, we have been able to move forward. I believe the strategic review and resulting Strategic Plan are clear indicators of how successful Hemophilia Ontario and all of its Regions have been at embracing necessary change. As always, I am very proud to be associated with this organization and with this community.

Which experience still brings a laugh or smile to your face?

Jeff: There are so many of them! While my foggy memory does not

bring a particular example to mind, let me just say that most of the best moments usually involve some sort of social gathering. I really enjoyed those times when we made the effort to get together or socialize. What inspired me and made me feel that all the hard work was worth it was when I got a chance to meet people in the community and see the direct effect the Society had on people living with a bleeding disorder.

Mike: There have been many social occasions that felt really good. Being the MC for the Ann Harrington appreciation night was great, and the same goes for the dinner for Dr. Garvey, but the most gratifying was watching the people in Jordan and the genuine appreciation they had for what we were trying to do.

What, according to you, was your biggest volunteering achievement?

(Laughs: Mike and Jeff)

Mike: Going to Jordan was the biggest by far with surviving as President in TCOR for five years

Jeff: I think I went on about that for too long in question 3.

What are your future plans and hopes for the organization?

Jeff: I don't really have any plans. I think I need a chance to breathe for a while. The last five years have been very busy. I hope the organization can stay engaged in its mission, continue to build a strong administrative and governance base and stay focused on its mission. Many of the distractions that arise will pale when compared to the work accomplished in achieving the mission. Seeing the effect of that in the community will be inspiring and tremendously rewarding.

Mike: I hope that we can stay on mission and that TCOR and Hemophilia Ontario can work with CHS for the strategic reviews and make a cohesive plan that works for all, since we are all one organization. I think my brother is much more eloquent in his remarks than I ever will be so let me second his response to this question. Personally I need to sit back a bit and consider what I'm doing, but that said I'm still interested in Twinning and I won't leave TCOR high and dry.

Jeff and Mike: Thanks for the opportunity to talk about ourselves. Working with everyone at all three levels of the organization over the years has really been a tremendous honour. We are much richer for the experience. ♦

HealthPartners Speaker's Bureau Volunteer Call

by Manisba Ramrakhiani



EACH YEAR HealthPartners raises millions of dollars which is distributed to its member organizations. As one of the HealthPartners charities, the Canadian Hemophilia Society receives a portion of that money. In turn, the CHS distributes this money to the provincial chapters to fund local activities. Hemophilia Ontario receives funds each year from the HealthPartners campaign. How much money is received is determined by how many people name the Canadian Hemophilia Society as their HealthPartners charity of choice. The more people name us, the more funds we get in Ontario to fund our local services and programs.

In 2009 TCOR formed a Speaker's Bureau to help us with HealthPartners speaking engagements.

Once again the TCOR Speaker's Bureau invites you to be a part of the great cause. As a member

of the bleeding disorders community, you will share your stories of how your life has been impacted by a bleeding disorder and the work of Hemophilia Ontario and the Canadian Hemophilia Society. You can help people see the difference their money can make.

About Speaker Sessions

In the month of September HealthPartners will be organizing 40 to 70 speaker sessions. All member charities will be given an opportunity to send their volunteers to speaking engagements.

A speaker's sole requirement is to share their experiences/stories and how their connection with the member organization has made a positive difference in their life, or the life of a loved one. Notice of speaking engagements will be provided one or two weeks in advance.

TCOR will need a group of six to eight volunteers to act as spokespersons. These speakers will be provided with training materials and a comprehensive orientation prior to the campaign kickoff.

For more information and to be a part of the HealthPartners Speaker's Bureau contact Eli Bennett, Regional Service Coordinator (TCOR), ebennett@hemophilia.on.ca, 416-972-0641, Ext 12. ♡

Comprehensive Care

Hemophilia Treatment Centres in Toronto

The Hospital for Sick Children

Haematology/Oncology Clinic Ward 8D
555 University Avenue
Toronto Ontario M5G 1X8

Dr. Victor Blanchette, Director
Dr. Manual Carcao
Anne Marie Satin, Nurse
Diana Cottingham, Social Worker
Pam Hilliard, Physiotherapist

St. Michael's Hospital

Haematology/Oncology Clinic
30 Bond Street
Toronto, Ontario M5B 1W8

Dr. Jerome Teitel, Director
Georgina Floros, Nurse Coordinator
Paula Havill, Nurse Coordinator
Caroline Jones, Physiotherapist

Tuesday Clinics

Every Tuesday a Regional Service Coordinator (RSC) from the Toronto and Central Ontario Hemophilia Society (TCOR) visits the Hemophilia Treatment Center (HTC) at:

The Hospital for Sick Children

Tuesdays 9:30am to 12:00pm

St. Michael's Hospital

Tuesdays 1:00pm to 3:00pm

Your RSC is Eli Bennett

802-45 Charles St. E., Toronto, ON M4Y 1S2

Phone: 416-972-0641, Ext. 12, 1-888-838-8846, Fax: 416-972-0307

E-mail: ebennett@hemophilia.on.ca

<http://www.hemophilia.ca>

Clinic Corner

Secondary Prevention in Hemophilia and Other Bleeding Disorders

by Kaz Jonusonis, Hemophilia Provincial Coordinator

IN A PREVIOUS ARTICLE, I focused on primary prevention related to inherited hemophilia. This article analyzes secondary prevention initiatives.

Secondary prevention involves early screening and detection of a disease, acute treatment of a disease—short-term management of acute cases and factor infusion prophylaxis at HTC and self-infusions at home. Secondary prevention in the treatment of Hemophilia and other bleeding disorders involves so-called Primary and Secondary Prophylaxis. These are regularly scheduled infusions to prevent bleeding episodes and to maintain level of factor above 1 percent.

Primary prophylaxis is provided prior to the development of joint damage.

Secondary prophylaxis is started after joint damage occurs or following any other bleeding (intracranial bleeding).

Different modalities of treatment

Home infusions gradually become the mainstay of Hemophilia prophylaxis management.

On-demand therapy is provided only when acute bleeding or bleeding risk is suspected.

Prophylaxis therapy involves infusions one to three times/week.

Long term prophylaxis is a lifelong

commitment.

Short term—episodic, from time to time—prophylaxis treatment lasts three to six months.

Occasional prophylaxis or on-demand prophylaxis takes place before surgeries, dental procedures, and other upcoming events involving risk factors for bleeding to occur. Home infusions are especially liked and utilized by young patients, who have learned how to infuse factor concentrate at home.

These are the numbers accounting for patients on home care/total number of patients registered at HTC (2009):
 Toronto SMH 150/526
 Hamilton 92/489
 Toronto HSC 86/478
 London 39/327
 Ottawa GH 38/381

Advantages of home infusion program

- The patient can get quicker treatment when bleeding happens. Early treatment means that fewer complications are likely to occur.
- Fewer visits to the doctor or emergency room are needed.
- Home treatment costs less than treatment in a medical care setting.
- Home treatment increases quality of life

Applied at home, prophylaxis can be



avoiding strenuous physical activity, and active bleeding can be managed non-pharmacologically by RICE (i.e., rest, ice, compression and elevation of the affected part). When to start prophylaxis is a very important issue. Swedish studies have shown that early prophylaxis can prevent joint damage. The age of first joint bleed ranges from 0.2 to 5.8 years. The arthropathy is best prevented if prophylaxis is started before the second or third joint bleed. Generally, children who started prophylaxis at 1-2 years (mean age of 3 years) had a better clinical outcome than those who started at a mean age of 5 years (Teitel et al., 2004). Recently it is thought that prophylactic treatment should be individualized according to patient characteristic (Lee, Berntorp, Hoots, 2005).

The pharmacologic treatment is the most effective treatment for prophylactic reasons as well as for the treatment of acute bleeding. Recombinant factor concentrates supplied by CBS are the most reliable remedies. Factor VIII, IX, rVIIa and APCC (activated prothrombin complex concentrate) are main factor substitutes for the treatment of hemophilia A and B and inhibitor related complications.

There are some controversies surrounding early prophylaxis treatment. The risk of inhibitor development, difficulty with venous access

and side effects of using central venous catheters are the main concerns. With the use of IVADs it is now possible to administer factor concentrate at home. These implantable devices are safer and more compatible with ADL of young patients than external central venous catheters (Teitel et al, 2004).

Optimized prophylaxis currently became a hot topic in the treatment of all bleeding disorder patients. Doctors are looking for the development of optimal treatment dosing regimens. The goal is to find the most useful and effective factor concentrate dose to provide prophylaxis and treat acute incidents of bleeding, taking into account also the cost effectiveness of the treatment. 📌

References:

- Barr, R. S., Furlong, W., Horsman, J., Sek, J., Pai, M., and Walker, I. (2002). Health Status and Health-Related Quality of Life Associated with Hemophilia. *American Journal of Hematology*, 151-160.
- Biss TT, Chan AK, Blanchette VS, Iwenofu LN, McLimont M, Carcao MD (2008) *Current practice in haemophilia prophylaxis: results of a Canadian survey*. *Haemophilia. the Association of Hemophilia Clinic Directors of Canada (AHCDC) and the Canadian Association of Nurses in Hemophilia Care (CANHC):*
- CBS Reports 2009; CHARMS data Base 2007-2009
- Hoots, W. (2003). *Comprehensive care for hemophilia and related inherited bleeding disorders: Why it matters. Current*
- Ministry of Health and Long-Term Care. (2007). *LHIN Bulletin No. 26 - February 16. Toronto: Government of Ontario.*
- *Mosby's Medical Dictionary, 8th edition. © 2009, Elsevier*
- Ontario Hemophilia Steering Committee. (2005). *Ontario Hemophilia Comprehensive Care Standards.*
- Ontario Hemophilia Treatment Centres. (2009). *Clinic Data.*
- Revel-Vilk S, Blanchette VS, Sparling C, Stain A.M., Carcao MD (2001). *DDAVP challenge tests in boys with mild/moderate haemophilia A. British Journal of Haematology.*
- Teitel, J.M., et al. (2004) *Home management of hemophilia. Hemophilia* 10, 118-133.
- Teitel, J.M., (2007) *History of the development of bleeding disorder standards in Canada.* <http://www.multiwebcast.com/chs/2007/rendezvous/speakers/29581/doctor.jerry.teitel.biography.html>
- Teitel, J. (2005). *Hemophilia Comprehensive Care in Canada. Canadian Hemophilia Society Newsletter*
- *Sick Kids Programming at clinic Information*

Helpful Links

- The York Region Hepatitis C Education Group (Group that meets once a month to discuss and share their personal experience)
<http://www.hepcyorkregion.org/>
- Overlooked contaminant found in blood donations
http://www.foodconsumer.org/newsite/Nonfood/Healthcare/overlooked_contaminant_found_in_donated_blood_2002100421.html
- Genetic Cause Discovered for Rare Bleeding Disorder
<http://www.sciencedaily.com/releases/2010/03/100304093635.htm>
- Start of Phase I/II Gene Therapy Clinical Trial for Hemophilia B
 - i) <http://bleedingdisorder.wordpress.com/2010/03/10/start-of-phase-iii-gene-therapy-clinical-trial-for-hemophilia-b/>
 - ii) <http://blog.taragana.com/pr/start-of-phase-iii-gene-therapy-clinical-trial-for-hemophilia-b-14361/>
- Cancope is a free online health and wellness social network community. Cancope members can share their experiences and seek advice from others coping with similar health issues
www.cancode.ca
- Media Statement - World Hepatitis Alliance Applauds - World Health Assembly Decision on Viral Hepatitis – For more information read...
<http://www.worldhepatitisalliance.org/en/MediaCentre.aspx>
- GENEVA, May 21 (KUNA) – The World Health Organisation (WHO) Member States accepted the report to the World Health Assembly entitled “Viral hepatitis” and adopted a Resolution including a World Hepatitis Day on 28 July.
<http://www.kuna.net.kw/NewsAgenciesPublicSite/>

Women in Touch November 2010



For more information or to join the Women in Touch Planning
Committee

contact

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Events Report

TCOR's 40th Annual General Meeting

by Susan Turner

THE 40TH TCOR AGM took place on March 7, 2010 at Dave & Buster's in Concord. The children were entertained with a Birds of Prey show while the adults attended the AGM. The TCOR Board President, Mike Beck, thanked the staff, volunteers and Board members for their hard work in 2009. Mike was pleased to report that TCOR had a consistent staffing for the first time in several years. Mike thanked Heather Heagle for her expert guidance of the staff in 2009.

Volunteer Awards

Volunteer awards were presented to the following members for their hard work in 2009. Jamie Hill was awarded the Community Volunteer Award for volunteering to speak at four HealthPartners events in 2009 and for his time and effort as the Hemophilia Ontario delegate to the Ontario AIDS Network. Murray and Joan Kinniburgh were awarded the Community Volunteer Award for their volunteer time dedicated to the TCOR Bingo over the last year. Eddie Crosbie-Hirlehey was awarded the Community Volunteer Award for his hard work over the past year as the Toronto representative on the National Youth Board, speaking as a community member at both the TCOR Golf Tournament and the Transition Event and as a member of the Hemophilia Ontario Youth Committee. Shaun Bernstein was awarded the Community Volunteer Award for his hard work as the youth editor for the new *Blood Matters* community magazine and for being a member of the Hemophilia Ontario youth committee. Mike Beck received the James Kreppner Distinguished Volunteer

Award for his long term dedication as a TCOR Board member since 2001, his dedication to the success of the World Federation of Hemophilia Twinning of TCOR with the Jordanian Hemophilia Society and his countless hours on numerous committees and boards at all three levels of the organization. Julia Sek received the James Kreppner Distinguished Volunteer Award for her long term commitment

to the organization. Julia has served as camp nurse at Wanakita for many years and led the Hemophilia Ontario Youth on numerous treks and canoe trips through Ontario parks. Gerry Mudge was awarded the President's Award for his hard work as a member of the TCOR Golf Committee since the tournament's inception back in 2000. Gerry has worked hard at getting players out to the tournament and in acquiring many prizes for the tournament. Gerry was also instrumental in guiding TCOR as they first applied for and received an annual grant from the Dewdney Family Foundation back in 2005 to help send TCOR children and youth to Camp



Wanakita. TCOR received \$15,000 in 2009 and 2010 to help cover the cost of sending campers to Wanakita.

Treasurer's Report

Kevin Ball presented the 2009 Audited Financial Statements.

Financial position at December 21, 2009:

- A decrease in the cash of approximately \$10,000 from 2008 is due to the organization's expenditures exceeding its revenues in 2009.
- Unrestricted net assets decreased approximately \$20,000 due to excess of expenditures over revenues in 2009.

- Total revenues were up 22 percent in 2009, an excellent result due to the challenging economic times in 2009.
- TCOR ended 2009 with a deficit of \$20,535.
- The Treasurer reported that the organization is in a good position with cash reserves to ensure that all programs will run in 2010 without additional funding, but the organization is aware that we need to work harder at increasing our revenue and need to stop incurring deficits.

2010 – 2011 Board Elections

The following members were elected to the 2010 – 2011 TCOR Board of Directors: Michael Beck, Maury Drutz, Mark Lubinski, Marc LaPrise, Kevin Ball, Ahmed Hassan, Cameron Peters, Teresa Lubinski, David Neal, Chris Rotolo, Sheldon Rose, Bishu Girma, Mojtaba Kherzry, Vincent Lo and Tim Jessop. The TCOR delegates to the Hemophilia Ontario Board are Maury Drutz, Mike Beck, Kevin Ball, Ahmed Hassan, Cameron Peters, Mark Lubinski, Sheldon Rose, David Neal and Barb Peters. ♦

World Hemophilia Day Tulip Sale

by *Manisha Ramrakhiani*



ON WORLD HEMOPHILIA DAY, the Toronto and Central Ontario Regional Hemophilia Society held its 2nd annual Tulip Sale event from April 15-17, 2010. Red tulips were sold at various downtown locations including the TTC (Yonge and Bloor Station), GO Transit (Union Station) and St. Michael's Hospital. TCOR members got involved with the Tulip Sale and raised money by selling tulips at their workplaces and neighbourhoods. Bayer representative Nicole Serena and Business Communications Partner, Tiana DiMichele also got involved by selling tulips at the Bayer office.

The money raised from this event will be used to support the bleeding disorders community in TCOR including children's camps, support groups, financial assistance and other educational initiatives.

The Tulip Sale event was a huge success! None of this would have been possible without the generous contribution of time and energy by our 15 dedicated volunteers from the YMCA and within the TCOR membership.

TCOR would like to say a special thanks to:

- the TCOR Membership
- Natalia Koroleva, Volunteer Coordinator at Toronto YMCA Newcomer Center, who helped build an amazing team of seven volunteers from YMCA
- Phil Cragg, VP Business Development, Sales Manager at Bloomex Canada who provided beautiful tulips and excellent customer service
- Victoria Kinniburgh, Sylvie Devereaux and Adam Seanor for selling tulips at their workplace
- Our event sponsors, Baxter and Bayer HealthCare

Each year TCOR welcomes spring with new hopes and ideas. None of this can be possible without your generous help and support. Plan now and let us know what you would like to add or see happen for the next World Hemophilia Day event. ♦

The Life of a Hemophilia Hero



MY NAME IS Michael Justin (MJ) O'Grady and this year I was honoured as a Hemophilia Hero for World Hemophilia Day. I was diagnosed with severe Hemophilia A when I was just a few days old, but I have always believed in living big and not letting my condition get in my way.

As a Hemophilia Hero, I took part in a public awareness campaign supported by Baxter Canada to educate others about the condition. Often when people hear of hemophilia they think you can't do anything because the risk is too great, but I participate in sports such as Ultimate Frisbee, cross country, badminton, canoeing and kayaking – just like any other teenager – because I learned early on to make safe decisions and prevent bleeds with regular treatment. It was really exciting to be interviewed by and share my story with news outlets such as CTV, *The Toronto Sun*, 680 News and *The Haliburton Echo*. When I was seven, I first went to Camp Wanakita in Haliburton because they have a program for kids with hemophilia. I've gone back every year and now I spend the whole summer there as a counsellor.



If I had been born even 10 or 20 years earlier, I wouldn't have the opportunities I have today. Doctors and researchers know much more about hemophilia now than they did then. Better treatment options and comprehensive care make being a Hemophilia Hero possible.

The campaign helped bring attention to the World Federation of Hemophilia's podcast called the "Many Faces of Bleeding Disorders," which is available at www.wfh.org. I also took part in a Hemophilia H.E.R.O. video that's on YouTube: <http://www.youtube.com/watch?v=IC0FSQFaba0>



I graduated from high school this spring and heading to university this fall, where I plan to continue my outdoor adventures and live life to the fullest!

Baxter

Events Calendar

EVENT DATE	PROGRAM	DESCRIPTION	WHO SHOULD ATTEND
August 1–28	Camp Wanakita	For years, Camp Wanakita has been the place where kids learn independence through self-infusion. Under the instruction of caring nurses from clinics across Ontario, children aged 7 – 14 practice treating themselves, while experiencing the great outdoors. Nurses are on hand 24/7 to handle any emergency. A family camp is being launched in 2010. Space is limited; sign up early.	Children between the ages of 7-14 who are affected by a bleeding disorder. Families are welcome for family camp.
August	HOY Summer	A youth-planned outing to develop independence and leadership. A valuable experience for affected youth as they help create the curriculum.	Youth aged 12 – 16 and 17 – 26 who live with a bleeding disorder, and are interested in gaining experience in event planning.
October	Women in Touch	Following the success of W2 2009 last October, TCOR will hold its own women's program to learn more about themselves and each other.	Affected women, carriers and female caregivers.
November	Transitions	Youth transitioning from Sick Kids to the adult clinic at St. Mike's in 2011 are invited to attend. Held at St. Mike's and attended by staff from both clinics, Transitions provides an introduction to the clinic and introduces adult-centered care. Parents and youth who attend feel more comfortable making their first visit to St. Mike's.	Youth who will be transitioning to the clinic at St. Mike's during 2011, and their parents.
December 1	World AIDS Day	Recognizing the many families who have coped with infection from tainted blood products, TCOR partners with other HIV service organizations to promote World AIDS Day. Join us to honour those who have been infected, and build awareness for the importance of a safe blood supply.	Energetic, outgoing individuals who are passionate about informing people about the importance of a safe blood supply.
December	Camp Wanakita Registration	Not sure if Camp Wanakita is for you or your family? Do you have reservations about making your reservations? Come out to the Camp Wanakita Registration event, to learn more about the camp experience, ask questions and hear first-hand accounts from those who have attended before.	Any family interested in learning more about the camp experience. Those nervous about sending their child to camp are especially welcome.



**MARK
THIS
DATE**

Hemophilia Ontario Calendar 2010

EVENT DATE	PROGRAM/EVENT
August	HOY Summer Camp
August 1-14	Wanakita Camp
September 17-19	Just the Guys, Camp Ki-Wa-Y, St. Clements, ON. This three-region event held at Camp Ki-Wa-Y in Kitchener/Waterloo provides fathers (or male role models) and their sons opportunities to enjoy recreational activities, learn about their bleeding disorders and management, and meet new friends. Registration information will be sent to your attention in August.
October 17	Toronto International Marathon
October 22-24	Family Camp, Camp Wanakita
October 27	Tainted Blood Tragedy - Commemoration Day
November	Bleeding Disorders Awareness Month
November	<i>Blood Matters</i> magazine



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Hemophilia Ontario

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