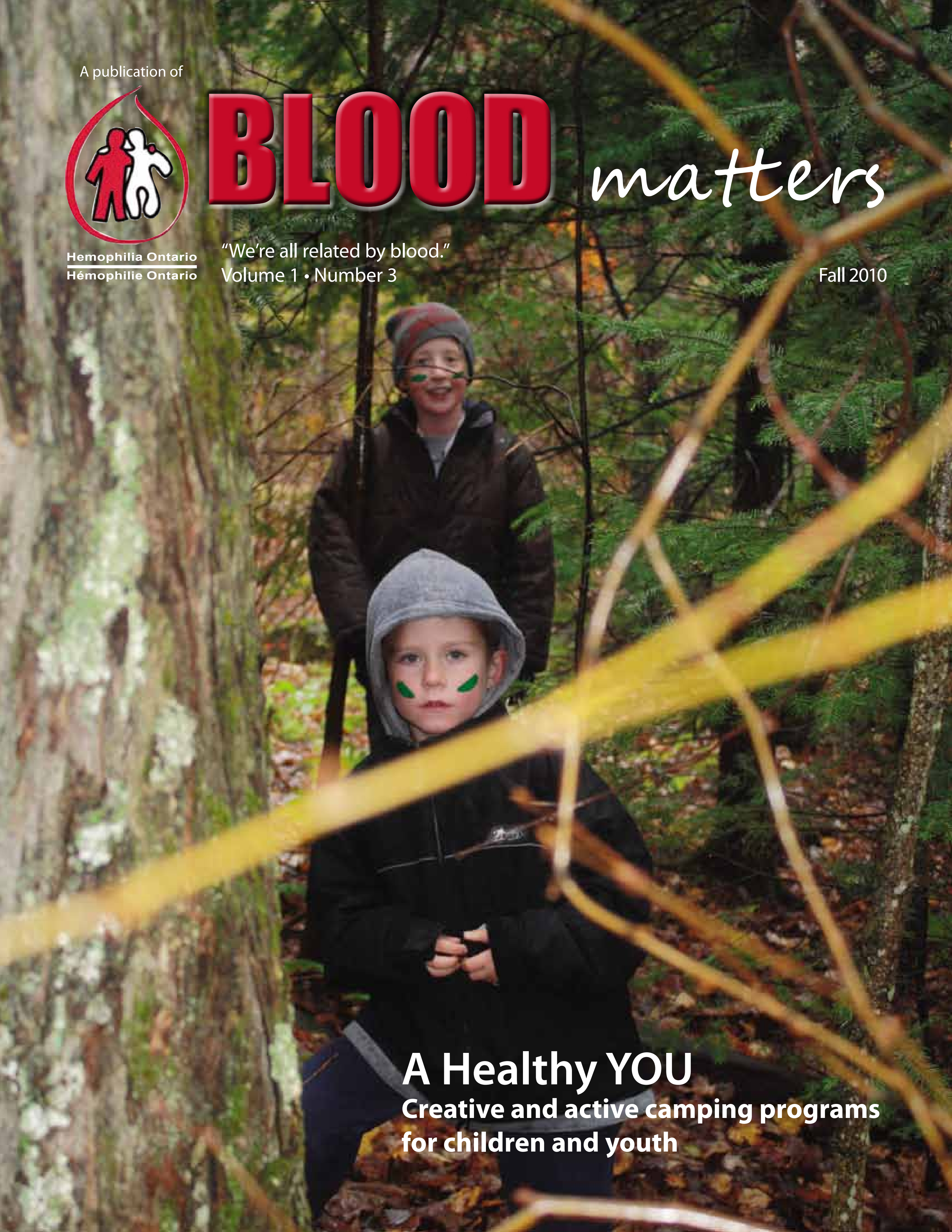
A publication of

Hemophilia Ontario
Hémophilie Ontario

BLOOD matters

"We're all related by blood."
Volume 1 • Number 3

Fall 2010



A Healthy YOU

Creative and active camping programs for children and youth

Hemophilia Ontario

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What's in this issue?

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Information from Hemophilia Ontario and its Regions.

For easy reference, the pages of *Blood Matters* are colour-coded.

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Hemophilia Ontario provides opportunities for educational and fun activities, such as this SWOR Just the Guys weekend.

Message from the President

OVER THE PAST FEW MONTHS, I have felt a consistent theme of nostalgia at Hemophilia events. At a most recent Family Weekend at Camp Wanakita it struck me so vibrantly that I actually made note of it before the families in attendance. I think that what struck me was that feeling of community and safety that comes when people share something that crosses the borders between families. Everyone was there because they had a child with a bleeding disorder and they wanted to know more, and know that they were not alone.

I brought these reflections to some of my own family gatherings to see how my impressions compared to my parents'. I was curious to find out what brought them to an event and got them involved. The themes were very similar. They wanted to know more and have perspective on what their children were going to face. My parents' reflections did reveal something that nostalgia did not pick up. All the networking and information gathering was something they definitely valued, but what they truly sought was the ability to protect their children. By ensuring that my brother and I got proper, efficient and safe health care they could aim to give us a relatively normal life by challenging and advocating not only the hospital, but the companies that provided our blood products. This goal, as they saw it, was something that had to be broader and that would benefit other families. This feeling was equally present and shared with their peers. Many, including my parents, became involved in Hemophilia Ontario to affect this aim directly. As I see the families continuing to benefit from the events that Hemophilia Ontario sponsors, I wonder whether we still have that common objective.

It goes without question that parents of people with bleeding disorders are passionate advocates for their kids. I have had the privilege of volunteering alongside many parents and people with bleeding disorders and have seen this in action. The best were those that were able to use their personal connection but also think about the bigger picture. That legacy is the comfort that we have today. So when nostalgia peeks out at me at different events I hope that is not all that happens. My hope is that there is still that drive to protect—to protect what we have gained as a community and to protect those special events that allow it all to happen. ♦

Dane Pedersen, President
Hemophilia Ontario

Message from the Executive Director

Dear Members,

I WANTED TO LET YOU ALL KNOW how wonderful you have been to me, whether it was during a special event or a weekend conference. Your willingness to give of your time and expertise to build better programs or services has been outstanding. Due to the leadership of Dane Pedersen, Julia Sek, Jeff Beck, Maury Drutz and Mike Beck, many positive changes have been made, including the consolidating of the magazine, *Blood Matters*. At this time I would also like to recognize the HIV/HCV Program Manager and the Hemophilia Ontario Regional Service Coordinators, who are to be commended for their work and enthusiastic support.

As you read through the 2010 Fall issue of *Blood Matters*, you will see the enormous amount of creating and planning that has taken place between volunteers and staff across the province.

It is on this high note and with a sense of great accomplishment, that I felt very comfortable in deciding to leave the organization as of November 1. I have made many true friends and will take with me a lot of fond memories. I want to wish you all every success for the future.

Thank you again for giving me the opportunity to serve you.

Heather Heagle

Impetus for Bott-Harrington Fellowship

by Andrew Cumming

MY ADVENTURES AS A HEMOPHILIAC started when I tried to walk at nine months of age in early 1960 and my ankle blew up like a balloon. I was living in Gravenhurst at the time with my parents. Dr. Bill Cumming, my father, was a young general practitioner. He drove me to Sick Kids Hospital in Toronto to see if the problem could be diagnosed, but he had a pretty good idea what it was. Turned out I was a severe Factor XIII hemophiliac. And so it started.

He brought me back to Gravenhurst where I waited another nine months before trying to walk again. I guess that bleeding ankle must have hurt quite a bit. Once or twice a week my Mom or Dad would take me up to the nearest hospital, in Bracebridge, where I would get a unit or two of fresh frozen plasma in an attempt to treat my bleeds. Cryoprecipitate wouldn't come along for another five years and freeze-dried factor concentrates were still in the far distant future.

Mine has been a life of close calls and very fortunate timing. The fact that cryoprecipitate came out just as I started to become active and go to school, and the fact that my Dad was a doctor, meant that we kept supplies of the stuff on hand at home. Both Mom and Dad could infuse me at the first sign of trouble. This meant that I was on the vanguard of the first wave of hemophiliacs to lead relatively "normal" lives. By the time I was in Grade 1 our family had moved to Toronto. I was able to participate in most gym and schoolyard games, and when I did have a bleed I was infused and sent off to school on crutches for a few days. I started to self-infuse at the age of eight. The remainder of my school days were uneventful. I ran cross-country, joined the swim team, snow-skied, water-skied, played in the band, and in high school became a competitive sailor, winning a number of regional and national championships. Many of you will find all of this unremarkable. Most hemophiliacs today participate in a full complement of sports, recreational and social activities. Forty or 50 years ago this was not the case for most of us. No sports, poor academics due to lengthy absences from school and crippled bodies led many hemophiliacs raised in the '60s and before to lead unproductive lives professionally and socially. It is in this sense that I was so very lucky to benefit, at an early age, from the miracle of cryoprecipitate.

In 1978, after a year of university, I decided that I wanted to take a run at the 1980 Olympics in sailing. My Dad helped me buy a Flying Dutchman class sailboat and I started dragging it around the continent going to regattas to train for the Olympic Trials to be run in the spring of 1980 to determine who would be on the Canadian Olympic Sailing Team. Half way through those trials, the Americans and most of their allies announced that they would be boycotting the Moscow games because of Soviet military involvement in Afghanistan, and so ended my Olympic dreams. Ironically, we and the Americans are there now doing pretty much the same thing the Soviets were trying to do 30 years ago.

As I was preparing to go back to university in the fall of 1980, I noticed an enlarged and hypersensitive testicle. Thinking this must be somehow related to my hemophilia, I treated it with the then novel product known as freeze-dried Factor VIII concentrate. After a few weeks I was cajoled by my girlfriend to go see a urologist. I never made it back from the hospital. They whisked me into surgery to excise the offending organ and biopsy it. I was diagnosed with Embryonal Cell Carcinoma, an incredibly aggressive cancer that kills 95 percent of patients within a month. Cancer was on everybody's minds and tongues at that time. Terry Fox was half-way through his historic run across the country and had visited Toronto a scant few weeks before. My Dad told me that I probably had a couple of weeks to live. Luckily, my oncologist knew better. There was a new drug, cis-platinum, which was barely a few months old and indications were that it was effective in a chemotherapeutic cocktail on this type of tumour. This is the second instance of extraordinarily fortunate timing in my life. Needless to say, the new therapy saved me, as it now does some 70 percent of patients with the kind of tumour I had.

The next few years went by without incident. Surviving cancer gave me an entirely new outlook on life. Whereas, up to that point, I had more or less cruised through school and most of my activities, after the close call with death (and constantly living with the spectre of relapse hanging over me), I attacked life and all of its aspects with increased determination and verve. I went back to university determined to be the best student in the class (which didn't happen, but I tried). I became intent on going to a top-flight school to do a Ph.D. and worked single-mindedly to that end. I spent my summers working in professors' labs, and nights studying harder and harder to bring my marks to the highest level of which I was capable. I was rewarded for this effort with a spot in the physics Ph.D. program at Massachusetts Institute of Technology (MIT). During my undergraduate studies I met Ann Harrington, the nurse coordinator of the new comprehensive care clinic for hemophilia at St. Michael's Hospital in Toronto. I also met Drs. Jerry Teitel and Bernadette Garvey, and very gladly handed my care into their capable hands.

Now we get to the part of the story that is common ground for all severe hemophiliacs in Ontario and indeed most of North America and Europe. In my case, D-Day was December 20, 1985. I was in Toronto for Christmas break at the end of the first term of the second year of my Ph.D. studies. I had just had a tumour marker assay and a final visit with my oncologist, and was declared cured of the terrible cancer I had contracted five years earlier. On that basis, and with that great news in hand, I proposed that morning to my girlfriend. We had both been a little trepid about proceeding with marriage if the cancer issue was unresolved. Now that was behind us. She accepted my ring! Later that same day, I had what I thought was going to be a routine checkup at St. Mike's with the hemophilia team there. Then the bomb dropped. I (and indeed virtually all of the patients of the clinic) had been infected with HIV. As many of you will recall, at that time HIV was probably the most feared and loathed illness on earth. People routinely killed themselves when they found out they had it. It was universally assumed to be highly contagious and lethal in all cases. The people who had it became social pariahs, often ostracized by their communities. Young hemophiliacs all over the world were asked not to come to school. In extreme cases violence was perpetrated on HIV-positive people, including children. People's houses were burned down (I happened to be friends with Ricky, Robert and Randy Ray, who were all campers at a hemophilia camp I volunteered at in central Florida during the '80s, and whose house was burned in an attempt to drive them out of town). People lost their jobs. People lost their lovers and spouses, and couldn't find new ones. It was a truly horrible time, as those of us who lived through it remember so well.

My fiancée decided to stay with me, which was a great relief, and we were married in June, 1987. As the '80s wore on and many hemophiliacs around the country started to show signs of full blown AIDS, I carried on with my studies, a post doctorate and finally landed a professor position at a major university, all while waiting for what seemed to be the inevitable. Probably the most challenging aspect of this illness, at least for me as a seemingly healthy victim, was the necessity to keep confidential the information that I was HIV-positive. The prejudice and hysteria surrounding this disease was intense, took literally decades to subside, even with the massive educational efforts by both governments and NGOs, followed by legislation concerning the human rights of HIV sufferers. With all the work I had put into my education and career since surviving cancer, there was no way I was willing to have my dreams and aspirations sidelined by a bigoted and ignorant public.

More and more was being learned about the virus by researchers, and we patients, who were still not sick, carried on with life, monitoring CD4 levels and viral loads, and watching the newspaper obituary page for death notices of our friends. And there were many. I was lucky in that despite astronomical viral counts, my CD4s stayed in the 300s up until the presentation to the HIV population, generally the therapeutic alternative of AZT. I stayed away from AZT for a year or so because I was still feeling very healthy and the side effects of this potent and toxic medicine were far from being well understood. I eventually started taking it when I realized that the key to survival was getting the viral loads down, reducing the rate of mutation, which would eventually yield up a strain that was able to overcome what was left of my immune system, and maybe even drug therapy in the future.

By the early 1990s, with virtually all of the severe hemophiliacs infected with HIV, and more than 75 percent of them dead, dying or showing signs of AIDS-related illnesses, many professionals in the field started looking to new areas in which to practice. It truly seemed that within a few more years there wouldn't be enough hemophiliacs left to support the clinics. Some giants in the field, like Dr. Peter Levine, who was a pioneer in the creation of comprehensive care clinics for the treatment of hemophilia, abruptly abandoned their posts when their clinical patient cohort, their own lives' work, were eviscerated by this horrible "hemophilia holocaust," as I call it. At St. Michael's Hospital clinic where I was a patient, we were luckier. Drs. Teitel and Garvey and, most importantly for me personally, Ann Harrington, stayed on station, treating, consoling, commiserating with and supporting their flocks as they shepherded them through the fires.

This is how we come to the Bott-Harrington Fellowship in Nursing. I feel that there is a need to recharge the ranks of the nurses specifically trained in dealing with hemophiliacs. There is a whole new batch of hemophiliacs born in the past quarter century who were spared exposure to the HIV virus. Hemophilia—this special disease whose treatment is so effective if it is carried out expeditiously—has so much better clinical outcomes if the education and support of capable and dedicated nurses such as Ann Harrington is brought to bear. A bleeding disorder like hemophilia complicates almost any other illness a patient might fall prey to. Ann is the kind of nurse whom we could call at work or at home at all hours of the day or night for advice, or to ask to phone ahead to the ER if we had to go make a visit there for a hemophilia-related issue or something completely different. She was not only competent in the comportment of her duties, but utterly dedicated to her boys, always there like a saint or a mother. I am hopeful that with this fellowship, we can instil this same set of values in a new generation of nurses to take care of a new generation of hemophiliacs.

> *Hemophilia—this special disease whose treatment is so effective if it is carried out expeditiously—has so much better clinical outcomes if the education and support of capable and dedicated nurses …is brought to bear.*

But there are two names in the dedication of this fellowship. There are hundreds of stories of tragedy, heartache and loss in the hemophilia community in Canada because of this holocaust that has played itself out over precisely the past 25 years. Frank Bott and Denise Orieux represent just one of those stories, but to me their story is especially poignant. They lost both of their hemophiliac sons—Greg and Martin—to this damnable scourge. I have known the Bott family for some 40 years, and knew Greg and Martin as bright and likable boys a bit younger than I. The name Bott is known to most readers of this magazine. Frank Bott its editor, and both he and Denise have been tireless advocates for hemophiliacs since his two boys were born with the disease, over four decades ago. Frank has been the President of the Canadian Hemophilia Society, Denise the President of the Ontario Chapter, and both of them have worked as hard as anybody to lobby government on policy and research funding issues. They have directly raised hundreds of thousands of dollars for hemophilia research, and they continue their dedicated work to this day, a decade after their beloved boys have passed away. In my mind they are emblematic of not only the depth of the tragedy this community has endured, but its capacity for forgiveness, determined strength, and hope for the future, for a future of good health and fine living for hemophiliacs who are growing up now and into the years to come.

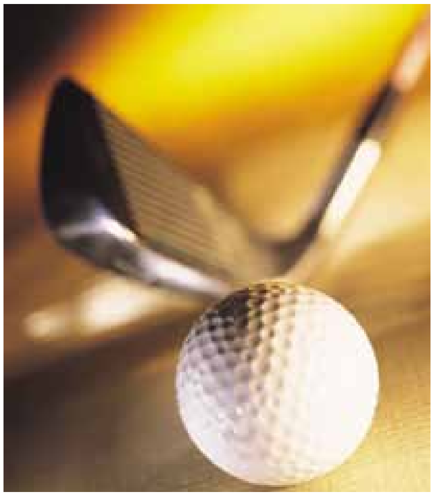
As for me, my life of close calls and fortunate timing continues. It is an unhappy fact that the woman I married in 1987 left me in 1994. I didn't really know why at the time, but in retrospect I think it is because she didn't want to have children with somebody who was sure to die before they grew up. Ironically, by the time this happened I was responding very well to the cocktails of drugs they were serving up and my viral load had become undetectable. I had never had an HIV-related opportunistic infection. I was maintaining my CD4 levels. But I admit that there was a huge element of uncertainty as to what the future would hold for me. I was devastated, of course. I knew that it would be impossible to marry anyone else. Who in her right mind, would even go on a date with a crippled HIV-positive divorced man? But I was wrong. I am always amazed at the capacity for courage and compassion that some human beings possess. I was able to start dating again, and met my soul mate, Hillary, in 1996. By this time I had abandoned my career as a physics professor, and had become a financial derivatives trader (that's another whole story) at a major bank. Hillary worked there. We were married in 1998 and were blessed with children in 2000 and 2001. I continued my work on Bay Street for another few years before the "other virus" (Hepatitis C) started to work its spell on my liver. By 2003 I had had several hospitalizations for bleeding from esophageal varices, which for hemophiliacs are extremely dangerous. I knew it was only a matter of time before one of these bleeding episodes killed me. By late 2004 I had a fully decompensated cirrhotic liver and was in danger of dying from the complications of advanced liver disease directly, even if I managed to continue to dodge the internal bleeding for a while longer. I was lucky enough (and wealthy enough—a direct outcome of moving from academia to finance, although that was not why I made the move originally) to get onto the liver transplant list at the University of Miami in Florida, and in May of 2005 managed to get a transplant. Curing my HepC infection turned out to be a struggle. I was on a double dose of interferon for 18 months because the standard interferon/ribavirin therapy had failed to clear the virus in an earlier attempt in 1999. Those who have endured that particularly sinister form of chemotherapy know the hell that it was to live through. The only good thing I can say about it was that it worked.

I am now clear of HepC, my HIV is totally under control (still undetectable viral loads and CD4s in the 400s), and wonder of wonders, my hemophilia is cured. The liver is where Factor VIII is manufactured, so when you get a new liver, you get a clotting factor factory at the same time. Too bad my poor old knee, ankle and elbow are so messed up from a lifetime of hemarthroses, or I would be perfect.

As a footnote to this story, Hillary and I have celebrated my re-emergence into the land of the living and our all-around good fortune by having another baby this summer. Now we are five, plus two dogs, a gecko and some goldfish. We also hatched the idea for the Bott-Harrington Fellowship to honour and give something back to a community that I have been a part of for a half-century, a community that has suffered beyond words for half that time, but will persevere as it always has in supporting its constituents with courage and conviction—your community, the hemophilia community.

Please help make this a reality by giving generously and also by helping to raise funds for the Bott-Harrington Fellowship in Nursing at St. Michael's Hospital. These fellowships will ultimately benefit every hemophiliac in Canada, now and into the future. It is a matching campaign. Anything you donate, or anything you raise with your fundraising activities will be matched dollar-for-dollar by Hillary and me.

Please make a donation to this cause by sending a cheque made out to The St. Michael's Hospital Foundation, 30 Bond St., Toronto, Ontario, M5B 1W8. Put "Doubling Up Campaign for Hemophilia Nursing" in the memo field. Alternatively, check out the website at www.stmichaelsfoundation.com/andy.



The Liam Barbour Charity Golf Classic

by Heather Heagle

ON BEHALF OF HEMOPHILIA ONTARIO and all of the regions across Ontario, I would like to take this opportunity to thank Jennifer and Brad Barbour for the tremendous support that they have shown to our organization over the years. This year's financial support in the amount of $15,000, designated for Camp Wanakita, is most appreciated by the 45 families whose children had the opportunity to attend camp this year.

Jennifer, I understand that you went above and beyond your responsibilities in producing a fabulous event, which included a very touching video. You and Brad are to be commended for the work you do to support the bleeding disorders community. You both have touched many people's lives in the community, giving campers opportunities and experiences to grow and gain independence. In addition, you both have given families respite from the ongoing care that, as you know, can be overwhelming to parents and siblings.

As noted by Leo Rosten, "The purpose of life is to matter, to be productive, to be useful, to have it make some difference that you have lived at all."

Thank you, Brad and Jennifer for making a difference. ♦

Toronto Marathon … a big success

by Robin Nobleman

ON SUNDAY, OCTOBER 17, over 15,000 runners participated in the Toronto Marathon. Among them were 20 participants from TCOR and SWOR who came out to do the 5K run/walk to support Hemophilia Ontario. A huge thank you goes out to Victoria Kinniburgh, Suzanne Beavan, the Reids, the Travaglinis, and last but certainly not least, the Sapage/Linhares clan who made up half the Hemophilia Ontario team with ten families members running. Our friends and sponsors at Pfizer ran the full marathon in a relay team on behalf of Hemophilia Ontario as well. All runners worked hard collecting pledges which quadrupled last year's total to reach $8,800, an increase of 71%.

Andre Linhares was the youngest participant at age nine. Andre was proud to have run 4k more than he'd ever run before. When he started to get tired, he asked his mom how far they had left, "I couldn't believe we were only at 3km!" he commented after the race.

A committed team of Hemophilia Ontario volunteers made sure the event ran smoothly. Derrick Reid and his family arrived bright and early to help out at the information booth at Queen's Park, welcoming runners and giving away goodies. Meanwhile, 20 energetic volunteers ran the "rehydration station" where they were kept on their toes handing out water and Gatorade to passing runners.

It was a great way to spend a beautiful fall day and the funds raised will go towards Hemophilia Ontario's valuable programs. Thank you to all the dedicated volunteers and runners who made it possible. Until next year, keep training! ♦

▲ *The Linhares and Sapage families*

▶ *Trevor and Jenna Reid*

▲ *Members of the Frank family (front of canoe) and the Dakran family (in back) with Robin Nobleman, TCOR RSC.*

Healthy YOU Camp, Camp Wanakita

October 22 to 24, 2010

by Jeenetha Kulasingam

CAMP IS ONE OF THE GREATEST experiences of life, and the participants of Healthy YOU Camp concur that they had a wonderful time. Over 100 members plus staff from the bleeding disorders community across the province attended the camp. Families began arriving at 3:30 pm, with the last family joining us at 8:00 am on the Saturday morning.

YMCA Camp Wanakita staff was well prepared with creative and active programs for children and youth. From high ropes, to survival games, from camp fires to the talent show, to crafts—great fun, new experiences and new friends were part and parcel for each day. The older youth 17-25 were treated to workshops with Joe Rich, MSW and Larry Borins, MSW, two terrific experienced professionals who talked about relationships, what parents should know and stress management. Parents who attended also had the pleasure of listening, learning and participating in Joe Rich's three workshops.

Larry Borins was kind enough to send in some of the responses from his session with young people between the ages of 11-14. The question that was asked of the group was, "What should parents know about growing up with hemophilia?"

Youth Responses

- "Parents are over-protective."
- "We can think for ourselves and are independent!"
- "Not to worry so much about us."
- "When kids hit a certain age they start to realize that they can take care of themselves and a parent being overprotective is not necessary."

Don’ts for Parents:

- “They shouldn’t follow us around.”
- “Don’t think we can take care of ourselves.”
- “Worry that if we make one wrong move we are going to wind up in the emergency room.”
- “Don’t isolate us from activities that we would normally do if we have a small injury.”
- “Stop saying “don’t do that” and “don’t do this.”

Do’s for Parents:

- “Should let us play more variety of sports; more hands-on sports.”
- “Parents should try to see things from our perspective.”
- “Compromise”—e.g., enjoy horseback riding
- “If they let us do a contact sport we should be taking extra precautions.”
- “Give us more freedom to choose what we want to do.”
- “Parents should get hobbies instead of stalking us, following us around.”

Comments from Parents from the weekend:

- “Everything was good—not sure what or if anything could be better.”
- “It was an action-packed weekend and we enjoyed it all.”
- “It was a great weekend, the kids certainly loved it all and in the end it is all about them.”
- “Have the camp in warmer weather.”
- “This has been an amazing experience. YMCA staff are enthusiastic and fresh, not “oh yeah, we have to do this again…” The hemophilia folks are kind, caring and really down to earth. I get weepy thinking about the support I alone have received here. Thank you Heather, Steph, Colin, Eli and everyone!”
- “Everything was fabulous. Wanakita is a great place to come to. The speakers were fantasitic.”
- “All was so wonderful.”
- “Thank you for the opportunity to connect with other families.”

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▼ *L to R: Sarah Dakran, Megan Dakran, Sarah Thomas, Angela Dakran and Micaela Bauman.*

Hemophilia Ontario would like to thank Bayer, Baxter, Pfizer, Novo Nordisk and CSL Behring for their financial support. Their partnership is essential to continuing this quality educational event.

Healthy YOU will take place every two years. Mark it on your calendars for 2012.

Healthy YOU Experience

– The Children's Perspective

THIS YEAR we handed out evaluations to the youngsters (5–16 years) as well as to the adults. We knew the kids would have a lot to say about their experience at the camp and wanted to give them a chance to express it through writing or pictures.

Below are the questions incorporated in the survey and the common answers from the 23 evaluations received back.

1. What did you enjoy most about the camp?
   The general consensus among the children about this question was hands down "playing survival" (similar to predator and prey, but each team is designated as either an herbivore, omnivore or carnivore and based on their nutritional needs must obtain as much food as possible). This interactive and challenging game definitely was a hit for the kids and they would like to see such games at future events.

2. What was your favourite talent?
   The talent show starred comedians, interpretive dancers, hip-hop dancers and more. There is a great deal of talent within our community.
   Most of the children enjoyed all the talent, but most emphasized their enjoyment of one particular YMCA staffer and his unique ability to whistle and act out the famous children's story, "Goldilocks and the Three Bears."

3. What activity did you and your family enjoy the most?
   Some children enjoyed spending their family time at the teeter totter, others enjoyed the campfire, some enjoyed archery while others enjoyed the climbing wall. Most had a hard time choosing a favourite as they enjoyed all the activities with their families.

4. What would you like to see new at the camp next year?
   A lot of children expressed interest in an indoor pool. Some mentioned marshmallows for the campfire as well as a longer campfire.
   Other children listed the following:
   - TV. (Mom says No Way!)
   - A Beaver
   - More free time with families
   - Us here!

5. Rate your camp experience out of 5 (1 = not so fun; 5 = will definitely come again next year!).
   After averaging the ratings from all the children's evaluations, it's safe to say that the outcome of the weekend from a child's perspective was beyond satisfactory! ♦

Evaluations reviewed by TCOR Regional Service Coordinator: Jeenetha Kulasingam.

World Congress in Buenos Aires

by Cameron Peters

I ATTENDED the 2010 Hemophilia World Congress in Buenos Aires in July, 2010 as a youth recipient of the Karttik Shah fellowship. Through my experiences at Congress, I learned a number of things that I will be able to use in my work with Hemophilia Ontario. First, I engaged with the broader hemophilia community in Canada. Having not attended a national or international event before, the congress allowed me to meet with leaders in our community from across the country and to share experiences and ideas on how to meet the needs of our membership. This, in turn, has led me to new ways of viewing issues in my work in Ontario. I understand better how research is done in Canada and how the Canadian Hemophilia Society and its provincial chapters interact with health professionals across the country. These important aspects of our organization could only have been learned through attending the Congress.

Second, the Congress was an excellent opportunity to learn about the latest advancements in areas that relate to my particular health challenges. Experts on Hepatitis C provided an update on the future of treatments. In particular, protease inhibitors, projected to be available in the next few years, are expected to significantly improve treatment outcomes, especially for those affected by Genotype I Hepatitis C. Physiotherapists presented studies on total joint replacement of ankles, which is still considered to be a rather novel therapy as ankle fusion remains the preference for many treatment centres in the developed world.

Third, I was able to meet other youth delegates and share experiences with them about our health difficulties. There were dozens of youth delegates from all over the world at the conference, and meeting them provided a different perspective on how their NMOs work to help individuals affected by bleeding disorders. For example, I spoke with a youth delegate from Latvia, who is currently involved with her NMO in helping hemophiliacs with court cases where they are taking the government to court over its decision to restrict funding for treatment. Also, I spoke with many youth from Tunisia,


Photo credit: Mike Beck

Cameron Peters, Candy Terpstra and Mike Beck at the World Congress in Buenos Aires, Argentina where they battle chronic shortfalls in factor products and are involved in rationing factor among themselves to ensure that only those who are in a crisis situation receive factor.

Finally, being exposed to people and medical professionals from around the world presented me with a new understanding of the issues that individuals with bleeding disorders experience. The level of care that we have attained in Canada—that most of us take for granted—is clearly not the standard that the majority of those with bleeding disorders receive. Learning about different experiences, particular from developing countries, has enriched my life as a person living with a bleeding disorder. These different perspectives show us that we are fortunate, but they also show us that there is much work to be done at the national and international level to support improved treatment and care for individuals with bleeding disorders, particularly in developing countries. In summary, by being able to attend this Congress, I have learned to bridge the gaps by raising awareness and developing links between people, programs and resources around the world. ♦

Photo credit: Mike Beck

Editor's Message

TCOR Community news

TCOR Golf

BLOOD matters

Fall 2010

A Healthy YOU

Creative and active camping programs for children and youth

I WAS LOOKING AT A COPY of the old *TCOR Community News*, which consisted of 12 pages, with almost half the articles written by me. We've evolved to a province-wide publication of over 40 pages, with me as Editor doing mainly editing. Credit for this development goes to Heather Heagle. It has been a pleasure collaborating with her in the production of a much-enlarged magazine both in content and scope. I wish Heather all the very best in her future endeavours. ♦

Frank Bott

Central Western Ontario Region

Regional Spotlight

Message from the Chair

IN THE CENTRAL WEST REGION of Hemophilia Ontario we are wrapping up a very successful year of programming and are currently in the process of finalizing our roster of programs for 2011.

In the spring of 2010, we hosted men's and women's events led by our own members that were well attended, with participants taking home some very valuable shared experiences and education. Our summer event was held at Marineland in June, attended by 170 people. We took that opportunity to reconnect with our members and to find out what kind of programs they want to see in the future. Our region was also a participant in the Just the Guys event, which drew record numbers and brought together the traditional Hemophilia community for a fun and educational weekend. We closed out the season with our first event aimed solely at parents, focusing on parenting experiences and helping to build support networks for our members outside the clinic setting. Our winter event will be held on November 14 from 2:00 pm-4:30 pm at Mountsberg Conservation Area. This event is always well attended and provides another chance for families to get out, have fun and rekindle relationships. This year Kay Decker, Nurse Coordinator will conduct an interactive presentation on traveling with a bleeding disorder. In all of our programming, we strive to provide education, the opportunity to share experiences and ideas and to have a little fun at the same time.

Our program roster for 2011 will continue the very successful programs mentioned above. In addition, we are very excited to announce two new events for our region. The first will be an Open House education seminar to be held in conjunction with our AGM in February. We will invite doctors, nurses and other members of the comprehensive care team to educate our members about improvements in treatments and therapies for all kinds of bleeding disorders—a first for our region. We are also proud to announce that we will kick off our Youth Adventure Program at the Open House in February. In conjunction with McMaster University, we will offer a range of adventure style sports opportunities for youth over the age of 16 throughout 2011. We hope to provide a safe, fun and comfortable environment for youth with bleeding disorders to come together and learn new skills and build new friendships.

Providing education, programming and support for our membership has always been a crucial aspect of the work that Hemophilia Ontario does for our community and I am proud to say that 2011 is going to be even better than 2010 in that regard. If you live in the Central West Region and would like to contribute ideas for future programs, or have any questions about what we do, please contact our Regional Service Coordinator, Alex McGillivray. We would be happy to hear from you. ♦

Cameron Peters
Chair, Central West Region

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

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
Igor Ristevski, Director

Alexsandra McGillivray –
Regional Service Coordinator
10 George Street 4th
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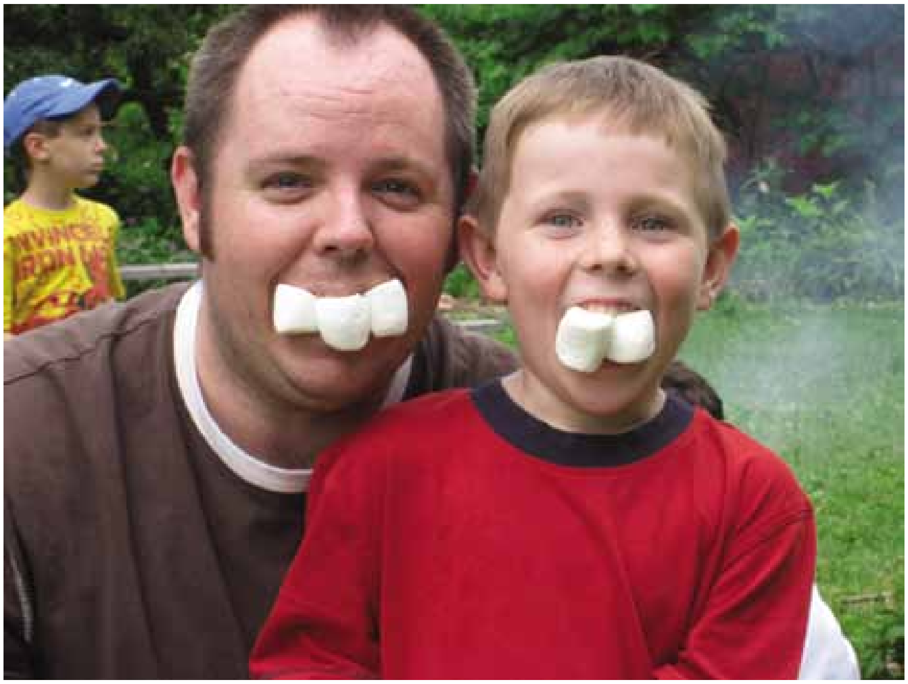
CWOR's First Father's Day Event

Left: Three generations of José Morenos!
Above: The group learns to use their GPS before going on their Treasure Hunt.
Below: Justin and Hunter Terpstra enjoy their marshmallows.

A NEW PROGRAM in CWOR's 2010 line-up, the Father's Day event was held on Sunday June 6, 2010 at the Royal Botanical Gardens in Burlington. Fathers, sons, brothers and grandfathers alike came out to enjoy a fun-filled day that included an education session on Geocaching with a GPS unit, and then a GPS treasure hunt on the beautiful Royal Botanical Gardens grounds.

The kids also got a chance to roast marshmallows and make s'mores around a campfire after all of the treasure-hunting was complete. Many thanks to everyone who came out and made this event a great one. ♦



Annual Summer BBQ

NEARLY 170 PEOPLE turned out on Saturday, June 12 for Central West Region's second Annual Summer BBQ at Marineland. Children enjoyed a craft activity centre as well as cooperative games that included scoop ball and parachute fun. The adults got a chance to mingle while playing an interactive ice breaker game that had everyone talking.

The event proved to be a great day for all families. Special thanks to CWOR volunteers Dane Pedersen and Igor Ristevski for their help in delivering the event. Many thanks are also extended to Leslie Bauman and Lisa Shewchuk for their enthusiasm and work with the children's activities. Our youth representatives Shaun Bernstein and Lex Cloete-Zito were also a tremendous help on the day of the event by capturing the day through photos as well as engaging the participants. Thank you all.

If anyone has any suggestions, comments or feedback to provide for future Summer BBQ events, please contact Alex McGillivray, Regional Service Coordinator.

Above L to R: Brad Barbour, Jillian Frank, Jana Campbell and Sasha Zito get acquainted during the ice breaker game. Left: Kids enjoyed the parachute activity with Leslie Bauman.

Just the Guys Weekend 2010: Wacky World of Sports

JUST THE GUYS weekend is a program designed for boys ages 5-15 years and their fathers or an accompanying male role model age 19 and above to participate in learning more about the child's condition.

This year the event's theme was the Wacky World of Sports. Teams participated in challenges such as the Olympic torch building competition, beverage pong and a stinky foot oatmeal.

This year saw CWOR's largest enrolment in the program. We thank all the families that participated in the event. In addition, we thank Karen Strike, Physiotherapist, Hamilton-Niagara Regional Hemophilia Clinic for conducting two interactive presentations with the group.

We look forward to seeing everyone again in 2011. ♦

Top: Karen Strike, Physiotherapist, Hamilton-Niagara Regional Hemophilia Clinic does her presentation.
Right: L to R: Justin and Hunter Terpstra, and Eli and Marvin Bauman do their morning infusion.
Below: Eli and Marvin Bauman

L to R: Filomena Calabrese, Alfonso Calabrese, Sherry Meszaros, Rachel MacPherson-Meszaros, Marvin Bauman, Leslie Bauman, Lesia Finstad, Caroline-Mulder Sutton, Nicole Finstad, Alan Sutton, Alex McGillivray (seated)

Parents' Education Day

ANOTHER NEW PROGRAM for CWOR in 2010—the Parents' Education Day—was created to meet the needs of parents who expressed an interest in learning about what it's like for a child growing up with an inherited bleeding disorder.

The parents met at Pillitteri Winery located in the heart of Niagara on the Lake's beautiful wine country. The program consisted of a facilitated discussion with questions designed by Linda Waterhouse, Social Worker, Hamilton-Niagara Regional Hemophilia Clinic, and Alex McGillivray, Regional Service Coordinator, followed by a tour of the winery. Parents had the opportunity to share stories about their children and also ask one of our youth representatives, Nicole Finstad, about her experiences growing up with von Willebrand. A heartfelt thanks is extended to all the parents who openly shared their stories and to Nicole for her willingness to share her experiences. It is collaboration like this that families find the most useful. 🩸

Get Involved!

CWOR IS ALWAYS LOOKING for new volunteers and fresh ideas. We encourage you to share your ideas on speaker topics and programs. For more information on our current list of programs, please contact Alex McGillivray, Regional Service Coordinator at 905-522-2545 or amcgillivray@hemophilia.on.ca. 🩸

Start of Phase I/II Gene Therapy Clinical Trial for Hemophilia B

AMSTERDAM, MARCH 10, 2010

AMSTERDAM MOLECULAR THERAPEUTICS (Euronext: AMT), a leader in the field of human gene therapy, announced today that the first patient has been dosed in the Phase I/II exploratory clinical trial with a gene therapy product for hemophilia B, a seriously debilitating and potentially lethal disease.

The trial is an open label dose-escalation study using a vector-gene combination developed at the renowned St. Jude Children's Research Hospital. Dr. Arthur W. Nienhuis of St. Jude is the principal investigator of the ongoing trial. The work was initiated at St. Jude more than a decade ago by Drs. Andrew Davidoff and Amit Nathwani and the collaboration has continued following Dr. Nathwani's return to London. The collaboration involves St. Jude and University College London and other institutions in the US and Britain. The objective of the trial is to assess the safety and efficacy of different doses of hemophilia B gene therapy. Hemophilia B is an inherited condition in which patients may have repeated and sometimes life-threatening bleeds after accidental trauma or medical interventions, because they do not have sufficient functioning of an essential blood clotting factor, called Factor IX.

AMT will build on the outcome of this exploratory trial and is preparing for additional clinical development to establish safety, tolerability and proof-of-concept with Factor IX gene therapy produced using AMT's proprietary, clinically validated production system. AMT has the exclusive commercialization rights to the Factor IX gene used in the St. Jude trial and has the ability to produce gene therapy product for hemophilia B at high quality on a commercial scale. Additional developmental work using AMT's production system is ongoing at St. Jude with AMT support.

Jorn Aldag, CEO of AMT, said: "Dr. Andrew Davidoff and his group at St. Jude, together with Professor Nathwani in London, have done very important scientific work on hemophilia B. We are really looking forward to the results of the trial for continuing our collaboration, aiming for a real cure for patients with this bleeding disorder. Use of the Factor IX gene fits perfectly with AMT's proprietary gene therapy platform and our business strategy of developing cures for seriously debilitating orphan diseases."

This hemophilia B gene therapy, administered once, will introduce the functional gene for the Factor IX protein into the patient's liver cells with the goal to restore blood clotting functionality long-term. In pre-clinical studies, Factor IX gene therapy resulted in long-term production of Factor IX protein at a therapeutically significant level after a single administration. If this approach is successful, the long-term efficacy of one-time administered hemophilia B gene therapy is expected to be perceived as a significant advance over the current regular dosing of recombinant Factor IX. In addition, the efficacy profile of this gene therapy is anticipated to exceed that of current therapy, as the gene therapy should lead to stable Factor IX levels, whereas current recombinant protein treatment causes peaks and troughs. It is hoped that hemophilia B gene therapy, therefore, can potentially replace all recombinant Factor IX products.

The UK Medicines and Healthcare products Regulatory Agency, as well as the US Food and Drug Administration, have approved the current trial.

About the Disease

Hemophilia B is characterized by severe episodes of external and internal bleeding, resulting in significant morbidity. The episodes cause long-term damage, for instance to the joints, and may be fatal if they occur in the brain. The defect in blood clotting in hemophilia B is caused by the absence of functional clotting Factor IX as a result of mutations in the gene encoding this protein. The factor IX gene is located on the X chromosome. It is an X-linked recessive trait, which explains why only males are usually affected.

Hemophilia B is a rare disease, occurring in 1 in 30,000 people, almost always in males. The total number of patients in Europe and the USA together is estimated to be between 35,000 and 40,000.

Currently, frequent intravenous administrations of recombinant Factor IX are required to stop or prevent bleeding. Protein replacement therapy is costly, cumbersome and does not completely prevent bleeding.

Amsterdam Molecular Therapeutics

AMT, founded in 1998 and based in Amsterdam, is a leader in the development of human gene based therapies. Using AAV as the delivery vehicle of choice for therapeutic genes, the company has been able to design and validate what is probably the first stable and scalable AAV production platform. This safe and efficacious proprietary platform offers a unique manufacturing capability which can be applied to a large number of rare (orphan) diseases that are caused by one faulty gene. Currently, AMT has a product pipeline with several AAV-based gene therapy products in LPLD, Hemophilia B, DMD, Acute Intermittent Porphyria and Parkinson's Disease at different stages of research or development.

HCV News

Hepatitis C damages brain cells

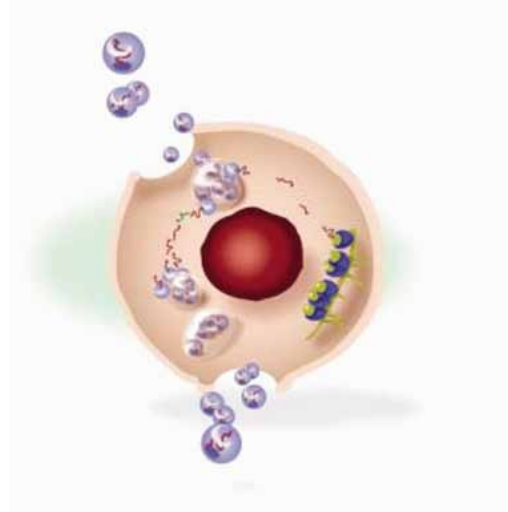
by Catherine Scott

October 20, 2010

UNIVERSITY OF ALBERTA VIROLOGISTS have recently confirmed that the hepatitis C virus (HCV), commonly known as a disease that affects the liver, also adversely affects certain cells in the brain.

Working with a team of virologists, Dr. Christopher Power and Dr. Pornpun Vivithanaporn exposed a hepatitis C protein to glial cells—the structural cells of the brain—and discovered that it is possible to infect them. The infected cells also release toxic factors that can potentially damage neurons.

The findings are important because of the number of HIV patients that contract hepatitis C as well. Because HIV is known to cause neurological damage, the U of A study considered both of the infections in order to determine that hepatitis C can cause neurological complications on its own.



Once a glial cell is infected with a hepatitis C protein, it becomes inflamed and releases viral proteins, which interrupts autophagy—or the "self-eating" mechanism—which is the process in healthy neurons that devours unwanted proteins. From this, neurons accumulate undesirable proteins, stop working properly, and could die. Power noted that the results of this study could educate people on an infection whose effects they do not fully grasp.

"This raises awareness of the adverse impact of hepatitis C on the brain because people really don't have an appreciation of that," he said.

Power added that, as a neurologist, many of his hepatitis C patients complain of memory and concentration impairment. However, until now, the virus' presence in the brains of infected patients had not been confirmed.

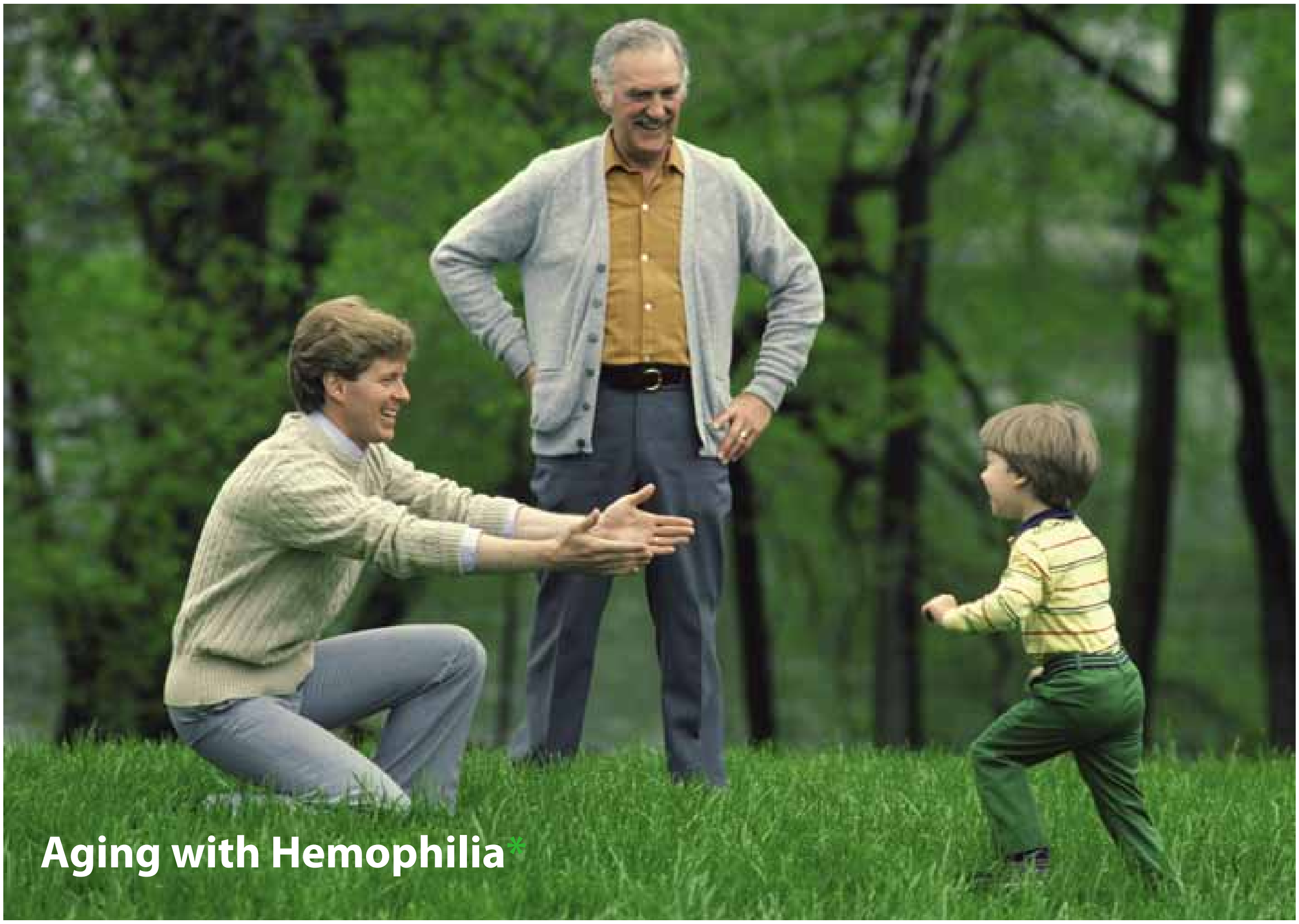
"We were the first people to show that, in fact, you can infect brain cells. That in itself, is a technical advance," he said.

Power explained that these findings may provide greater insight in developing and improving adequate treatment options for hepatitis C.

"Treatment is limited to a combination of a drug called interferon-alpha and another drug called ribavirin. Interferon has really nasty side effects. It makes people confused and depressed, and it only works in a subset of patients, depending on the type of virus you have. So any new treatments would be beneficial to hepatitis C," Power said.

Vivithanaporn echoed this statement, noting that the strain of hepatitis C found in North America is a particularly stubborn one. He also stressed the importance of this technical advance, which is but one step toward further discoveries about hepatitis C's impact on the brain.

"It's kind of exciting to us because most people perceive this virus as the one that injures the liver, but this is the first time we've shown that it actually can infect glial cells [in the brain] too. We found that maybe it is part of the link to the neurological complications. That's what is exciting about that."



Aging with Hemophilia*

by Robert Dinsdale, Oakville ON

I HAVE BEEN ASKED to write an article about aging with hemophilia, so I thought the best way to do this is to start with my history and how the actions of my youth impact me today.

I am a clinically severe Factor IX hemophiliac. I was born in Toronto in 1954 and grew up in a very different time from now in terms of the understanding and treatment of hemophilia. The first indication of my bleeding disorder was when I was two and had a bleed that led to my diagnosis. The first major impact of my being a hemophiliac was when I was eight years old; I was hit in the left eye by a badminton racquet while playing doubles at a family gathering. I began bleeding into the back of my eye—I believe it is called hyphema. It continued to bleed internally with no indication of stopping, and I went to The Hospital for Sick Children in Toronto where they gave me unit after unit of plasma to try and get some clotting started. As a result, I pretty much spent my summer in the hospital that year and lost the sight in my left eye. The day I came home from the hospital is really my first clear childhood memory, and then of course going to school that September and having people look at me with what I now called my bad eye—the bleeding and damage had left me with one pretty colourful eye. It wasn't until I was 19 that technology and the development of clotting factor allowed me to have my bad eye removed and an artificial one made.

When I was young there wasn't a specific treatment for hemophilia as we know it today. In fact, the only treatment was ice and rest, and if you were hospitalized you would be given fresh frozen plasma in the hope that the clotting factor in it would help stop the bleeding. So when you had a bleed you ended

**Please note that the opinions, beliefs and stories shared in this section belong to the author, and not to Hemophilia Ontario – Central West Ontario Region.*

up in bed, on the couch, or with more severe bleeds in the hospital where you would be treated with plasma. (Specific clotting products were not available until the late 1960s and self home care was non-existent.)

Over my early years and my teen years there were numerous bruises, swollen joints, etc., most of which meant that I was confined to the couch or bed anywhere from a week to two or three months. I missed a great deal of school, as was common for most of the guys in the hemophilia community during that era.

A number of my bleeds were the result of my determination to be a normal kid. I love sports, and I love playing sports. I played ice hockey, and of course ball hockey with my friends on the street. I should point out that I played ice hockey at the local park and back yard rinks, non-contact shinny—not at an organized full contact level. I played touch football, did a lot of running, cross-country skiing, and golf. I have paid a price. Both hips became very arthritic due to my activities and I have had them both replaced. In fact I had one done twice. I have an arthritic right elbow, and a few other areas that are pretty stiff and sore at times.

The early clotting factors did carry the risk of being contaminated with blood-borne virus or disease. Unfortunately, I was exposed to hepatitis Cin the early 1980s—the result of having a tooth removed and needing subsequent treatment with clotting factor. I had hepatitis C for 20 years. My family and I lived with the knowledge and fear that at anytime it could flare up and put me in serious peril. Nine years ago I underwent a year of treatment for hepatitis, which some of you may be familiar with. The treatment is a year of injections and pills of antiviral medicines that are used to kill the virus. I was fortunate that it worked for me.

During the past couple of years hemophilia has had a major impact on my life, as well as my family's life. I had problems with one of my artificial hips—major infection, surgery and a prolonged recovery. I have not been able to work or really do too much other than focus on getting healthy again. This, of course, impacts my family in many ways. I am very fortunate to have a supportive family. I am on the road to wellness, but I find that I am not bouncing back as I would have when I was younger. I may have to reassess my career as I am used to being very active and being able to travel, visit clients etc., I will have to assess if that is still realistic.

As I get older I take nothing for granted; for example, the gift of movement, and general good health—people really need to take care of themselves. I believe we should all try to exercise and stretch every day. The staff at your Regional Centre can help you with this to insure that you are doing exercises that will not damage your joints. I use exercise tubing for strength training as I feel it is easier on my joints than free weights, and I find Pilates and walking very beneficial. Recently I have discovered that massage therapy is helpful in dealing with stiffness and muscle soreness. Before undertaking any exercise program or therapy, be sure to talk to the staff at your local clinic to insure you are doing things that are appropriate for you.

My major health concern for the future is maintaining my mobility. I do everything I can to maintain the hips that have been replaced, exercise, keep my weight down, and try not to do anything foolish. I have resolved that at the first indication of a bleed that I will treat with Factor IX, If I can maintain my current level of activity, all things considered, I would be happy. Something that makes growing older with hemophilia less stressful for me is my association with the Hemophilia Clinic at McMaster University Hospital. I would like to thank the staff at the McMaster 3F Clinic for all they do for me and the other members of our community. The peace of mind in knowing that the clinic is there is priceless to me. I am sure that all members of the hemophilia community feel the same way about their regional clinic.

Having hemophilia and having to deal with some health issues has given me a healthy perspective on life. I have learned that no matter how dire your situation may seem, there are always people in far worse situations. I know you have all heard that before, but it is true. It is important to remember that what you do today will impact you as you get older. I am paying the price today for my activities, (although I probably wouldn't change much). For young people reading this, please know that with proper use of today's clotting products you can live a relatively active life and have healthy joints when you get older. Listen to the doctors and nurses at your clinic and do what they say. Getting older seems a long way off, but believe me it happens quickly (ask your parents and grandparents). To be in the best shape possible in the future means doing the right things today.

Liam Barbour Scholarship Award

THE CENTRAL WEST REGION of Hemophilia Ontario is proud to present the Liam Barbour Scholarship Award, made possible through the generosity of the Barbour Family and the proceeds from the Annual Liam Barbour Charity Golf Classic.

The Liam Barbour Scholarship will offer a $500 award to any affected member for their first year of post secondary education. This amount is to be evaluated annually, 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 reside 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 of their enrolment at a post secondary institution to the Central West Region.
- CWOR and its Board of Directors have been empowered with the disbursement of funds on an annual basis. The award will be paid in/around the first week of October of the first year the student is enrolled in post secondary education.

Deadline for receipt of scholarship applications is August 1, 2011. Faxed or late applications will not be accepted. For more information, to obtain a Liam Barbour Scholarship Award application, or to mail your completed application, contact Alex McGillivray, Regional Service Coordinator, Office 19, 4th Floor, 10 George St., Hamilton, ON L8P 1C8; 905-522-2545; amcgillivray@hemophilia.on.ca. ♦

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.

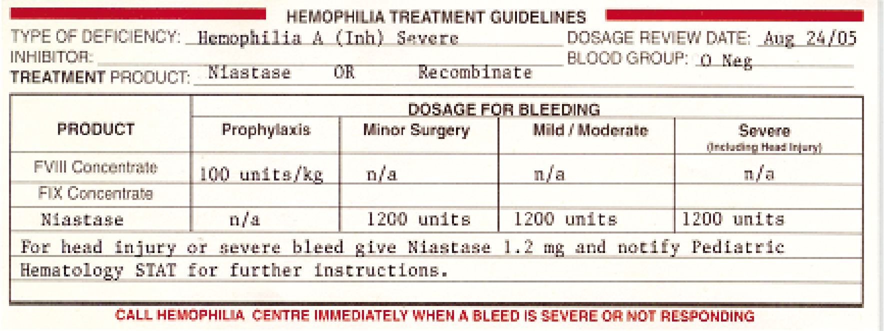
If you are going to be flying and are carrying factor concentrate, be sure to contact the clinic well in advance for your travel letter. The clinic has followed the advice of Transport Canada in composing the travel letter and it is designed to expedite your airport screening process. However, it is 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: Niastase 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				
Niastase	n/a	1200 units	1200 units	1200 units

For head injury or severe bleed give Niastase 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

North Eastern Ontario Region

Regional Spotlight

AS WE ENTER the fall and winter season, I must say, "Where did the summer go?" I hope everyone enjoyed their summer vacations boating, golfing or just relaxing before the hustle and bustle of school shopping, early mornings, running the children out the door to catch the bus. By now hopefully everyone has their routines in order. The NEOR spent the summer planning for the fall events and looking for new volunteers. I have also been looking at the possibility of new fundraising ideas and bringing new events to our region in the upcoming year.

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

NEOR Staff

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Clinic Day

THIS FALL, our clinic was held October 16, 2010 at the Laurentian Hospital in Sudbury. This year we held our first Halloween Party for the children and families. We all dressed up, including some adults, and pharmaceutical reps brought costumes but did not wear them. We had the pleasure of our Program Manger, Eli Bennett joining us at our clinic, dressed as a security guard. Eli was nice enough to judge the costumes for us and pass out prizes. I hope he had a great time as well. We played games such as decorating our own little pumpkins and colouring Halloween pictures. Goody bags were handed out to the children. The new Passport to Wellbeing on Travel was introduced to our clients on a one-to-one basis. We had fun eating homemade cookies, muffins for breakfast and pizza for lunch. Thanks to all.

It is very important for all of our clients to show up at the appointed times that the nursing staff have set up for your families. This ensures the staff and the blood lab can work efficiently together and also provides us with a correct count if we are going to serve lunch. We look forward to seeing you all in the spring.

▲ Clinic day at NEOR, L to R: Scott Moore of Bayer; Eli Bennett; Deren Svendsen of CSL Behring; Teresa Genereux, RSC; Sophy Oommen of Baxter and Chris Frietag of Pfizer.

▶ Eli Bennett addresses the costumed participants at Clinic day.

Celebrating 40 Years of Service

BETTY ANN PARADIS has been the Hemophilia nurse for Northeastern Ontario since its inception 30 years ago. In fact she is the longest standing nurse in hemophilia care in Canada. In her 30 years Betty Ann has been extensively involved in the hemophilia care in the region, province, nationally and internationally—both as an employee and a volunteer. Recently she chaired the Canadian Association of Nurses in Hemophilia Care, and is currently the chair of the World Federation of Hemophilia Nursing Committee. In these roles she has traveled throughout the world (Delhi, China, Syria, Tunisia and Brazil) where her expertise and knowledge was shared with other health care providers. On her own time Betty Ann continues to volunteer at Camp Wanakita—a summer camp for children with bleeding disorders. She recently became a recipient of the Canadian Nurses' Association Centennial Award, honoured as one of 100 registered nurses whose personal contributions have made an outstanding and significant impact on the nursing profession. We are very fortunate that Betty Ann has chosen not to retire, and continues with her efforts with significant impact on hemophilia care as well as HIV care. All of her peers have tremendous respect for Betty Ann; not only for her knowledge but in the way she interacts with others, always showing respect and integrity.

An Employee Service Recognition was held May 27, 2010 at the Caruso Club, where they also celebrated 25, 30, 35 and 40 years of service and retirement of the HRSRH employees. Congratulations to all!!!

Thank you, Betty Ann, for all your hard work in the past 40 years. I have known Betty Ann now for seven years and she is truly someone who is a role model to me and my family. Her patience in teaching me and my two children how to live with bleeding disorders, and the knowledge and support she gives us all is a true blessing. Betty Ann is known as our guardian angel. I also want to thank her for all her support and volunteering with me in my role as the RSC for the last two years with Hemophilia Ontario in the NEOR. All the best to you, Betty Ann. ♦

◀ *Betty Ann Paradis with hospital CEO, Mr. Roy.*

Opening Doors Conference

I HAD THE HONOUR of attending my second Opening Doors Conference for HIV, October 18-20, 2010, held at the Howard Johnson Hotel in Sudbury. This was a very exciting time providing me with much information. It was great to see familiar faces and make new partnerships with the introduction of Aboriginal people to the conference. The speakers were amazing and loaded with information on so many levels; the presentations were fabulous. I would also like to thank the Access Centre Staff for promoting this excellently prepared conference. ♦

▲ *Vicki Kett*

▲ *Christine Coutu*

◀ *Richard Rainville*

CHS Youth Workshop

ON OCTOBER 15-17, two of our volunteers, Kaitlynn McDonald and Kristopher Onucky, had the opportunity to attend a Youth Workshop in Mississauga, held by the Canadian Hemophilia Society. Although we missed having them at clinic, they had a great time and brought back much knowledge to help us grow in our region.

First of all, both Kaitlynn and I would like to thank Helene Bourgaize and CHS for inviting us to the Youth Leadership Workshop in Mississauga, held at the Delta hotel. We were able to broaden our knowledge of bleeding disorders and how to cope with this disease. A number of guest speakers presented useful information which included Non-Profit Sectors (Owen Charter), Career Searching (Allison Jones), Healthy Eating (Stephanie De Maio), and Physical Fitness (Nichan Zoukirian). Other information we learned included travelling with a bleeding disorder and the obstacles you face, being a part of the CHS whether its planning a summer camp, fundraising, being a committee member, being a board member, or even just being a youth member.

Besides all of the information that we learned, the experience itself was incredible. People from across the country and even some from outside the country came together to participate in this workshop. We were able to share our personal experiences.

Our goal after this workshop is to plan a youth camp for Northern Ontario. It will take time, but with what we learned from everyone at the workshop, and the support we will get, this will be possible.

We look forward to using the new skills we have learned in the near future. Thank you to all.

Kristopher Onucky

Fundraising Ideas

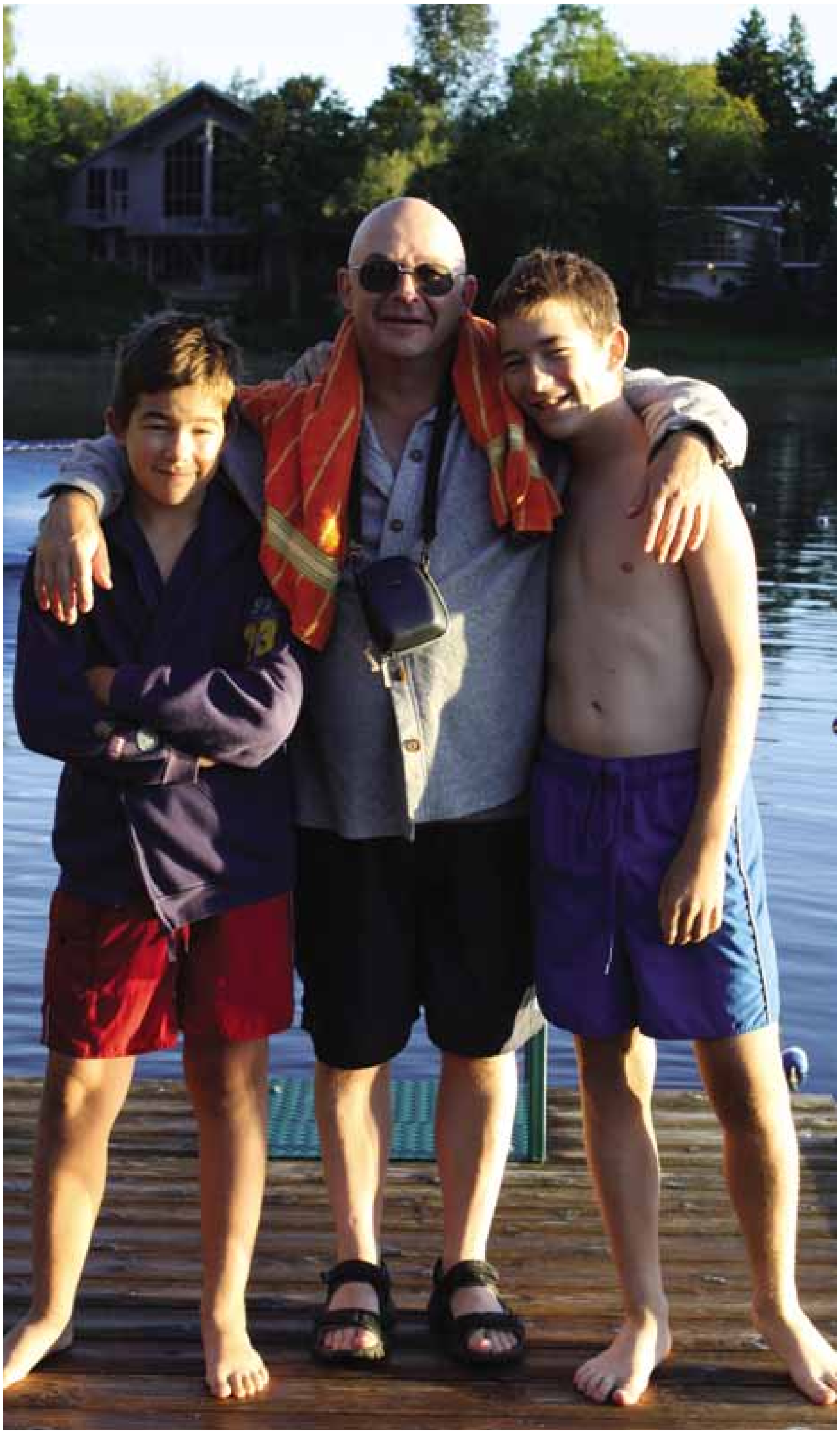
I WOULD LIKE to prepare a calendar for our region to sell to raise funds for future programming in our region. I would like to ask you to send me your family picture of your child/children with birthday dates to add to the calendar. In addition, I would like to ask you send in your favourite family recipe(s) to make our first cookbook.

I look forward to your responses with these new initiatives to raise funds within our region.

Please send your calendar and cookbook contributions to me at the address at the beginning of the NEOR section.

Just the Guys 2010

by Daniel and Evan Bouffard



THE BOUFFARD FAMILY trip from Sudbury started with an extended truck ride to Just the Guys campsite. When we arrived, we were happy to get out of the truck and onto the camp grounds. We were ready for the many activities awaiting us that weekend. As soon as we arrived, we felt the warm atmosphere surrounding us, as we met Terri Lee, A.K.A. the motherly father figure.

Our first activity was a snack, followed by the selection of our team which was represented by bandanas. We had a team challenge which involved making a tower out of spaghetti with a marshmallow at the top held together with a ribbon of tape. We enjoyed more stuff, then we had a little campfire.

Day two was even more amazing. Things started off on a funny note with a polar bear dip. It was fun to watch people jump in, only to find the water too cold, and then watch them swim as fast as they could to get out—except Kelsey who stayed in for about five minutes. When everyone was out and dry, we had a great breakfast. Then you either had free time or you took your treatment of prophylaxis. We played tether ball and it was fun. After that, we, the children, had an education session about prophylaxis and another about joint bleeds. It was already time for lunch. In the afternoon, the camp had a team challenge, followed by a snack. Then, we liked the hour of activities—low ropes, climbing wall and waterfront activities. Dinner soon followed, and then the third team challenge was afoot. Our own Dad made the campfire that night and it was big and almost too hot. As proof, the marshmallows almost cooked instantaneously. The last day started off with the polar bear dip, when my Dad did a front-flip into the water (he has an amazingly hydrodynamic head). The arts and craft activity, where we made a portrait of our cousin, Dylan, was another great family activity. This was followed by the fourth and final multi-challenge. Then lunch came and went.

After that, we got our awards, did our evaluations and said our good-byes. Then we packed, said our final good-byes and set out for home.

Our Dad is David, the master campfire builder and he even received an award for that. Please find on this page some Bouffard family recipes to enjoy. ♦

> *"May all be fed, may all be healed, and may all be loved." ~ John Robbins*

SALMON & TROUT

Ingredients for preparation. Mix the following for the marinade—soya sauce, brown sugar, sea salt (to taste), 150ml (½ cup) water. Insure that the fillets are covered with the marinade. Let marinate overnight.

Baste with the following marinade just before and after cooking: 1 orange (equivalent amount of orange juice will work), ½ cup honey, 4-6 tbsp. soya sauce.

Bake in oven at 350º C. for 20 minutes. Don't forget to baste again immediately after removing from oven.

BASS & PIKE

Marinate in milk for 1 hour, then choose your preference:

Coating Mix: 1 cup flour, ½ cup bread crumbs, ½ tsp. lemon pepper

Dip in a mixture of beaten egg and water, then into the coating mixture. Cook on stove top in olive oil until crispy. Salt to taste

Batter Mix: 2 cups flour, ½ tsp. baking powder (Magic), 1 cup water or 1 bottle of beer.

Cook fillets the same as for the coating mixture, that is, on stove top in olive oil until crispy and salt to taste.

FISH CANDY

This recipe is for smoked fish.

Marinate (rainbow) trout in brown sugar and soya sauce overnight. Leave skin on for smoking process. Note: the fish will need to be 'smoked' for 8 hours. This is to be done outdoors.

Ingredients: 1 bottle of pancake syrup (you will not use it all, it is to be used for basting throughout the smoking process). If available, use genuine maple syrup.

1 bag of brown sugar (you will not use it all, it is also to be used for basting throughout the smoking process).

Place fillets flat on grill, spread marinade over fillets, cover in the smoker, and baste with syrup and a sprinkle of brown sugar every 1½ - 2 hours for the entire 8 hours.

Remove from grill, and enjoy! Bet you can't control yourself once you taste this!

Fish recipes provided by Robert Madahbee

Commemorative Tree

THIS YEAR the NEOR is very pleased to have held its first Tainted Blood Commemoration Ceremony on October 27 at the Tom Davis Commemoration Forest along the Nature Chalet on South Bay Road in Sudbury. An Urban Maple (the leaves turn a deep red) was planted along the lake shore. I look forward to visiting this tree and watching it grow over the years to come.

The tree is an important symbol in nearly every culture. With its branches reaching into the sky, and its roots deep into the earth, a tree symbolizes life. For families who have lost a loved one, it can be a daily reminder that the person is not forgotten, that his or her memory lives on.

It has often been said that the lessons learned in the Tainted Blood Tragedy must not be forgotten and that the pain and suffering experienced by so many must not be in vain. The Canadian Hemophilia Society (CHS) intends to ensure that this does not happen by holding an annual National Commemoration of the Tainted Blood Tragedy that will acknowledge those now silent victims.

October 27, 2010 was a cold and blustery day in Sudbury, Ontario with 90km winds off the lake and tree branches breaking off of surrounding trees. We held our service with our heels dug into the dirt. I would like to extend my thanks to all who dared to venture out on this day. Thank you to Michelle for doing a reading and to John from 99.9 FM radio, and CBC for attending.

Thank you Carol Legault from BRAN-KOR Trophies and Engraving for the beautiful plaque that was placed by the tree at the ceremony. Many thanks to John and his staff at the Home Hardware in Levack for their help with picking the right tree.

Winter Safety

WITH WINTER COMING upon us soon, it is important to remind ourselves and our children of the importance of staying off of creeks, swamps and lakes before the ice is fully frozen. Please ensure the ice is safe (normally in cold weather ice should be 10-12 inches thick) before going on it for walking, skating or with snowmobiles. Dress properly for the weather, and when ice fishing or snowmobiling, always let someone know where you are going and your expected time of arrival back home. This is also a reminder to have safety gear in your backpacks or the trunk or back seat of your vehicles in case you get stranded or stuck. These should include a blanket, extra mittens, sweater, flashlight, waterproof matches, candles, water bottles, granola bars and flares. In case of emergency, remember not to panic and to stay calm.

Websites of Interest

http://www.kelleycom.com/books.html
http://www.factorsupport.com

Events Calendar

PROGRAM/EVENT	EVENT DATE
The HAVEN Committee will hold their meeting at the Withdrawal Management Services on Pine St., Sudbury	November 18
Access to AIDS annual Breakfast for World AIDS Day	December 1
Annual Old Timers Winter Carnival (details to be announced)	February, 2011

North Western Ontario Region

Regional Spotlight

NEED SUPPORT or information? Would you like to volunteer? Please contact Sylvia Storozuk, Regional Service Coordinator, at 1-807-662-9012 or sstorozuk@hemophilia.on.ca.

All articles in this section, unless otherwise indicated, are by Sylvia Storozuk.

NWOR Staff

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

Rained out!

HEMOPHILIA ONTARIO was scheduled to have a booth at the Victoria Avenue Fall Festival on September 11. Unfortunately, due to the storm, we were rained out. However, we were there the following morning and it was nice to see people taking an interest in what is happening with the blood disorders community. We handed out a lot of information that morning, creating more awareness in Thunder Bay.

It doesn't hurt

AT THE OCTOBER 5 Clinic at the Thunder Bay Regional Health Sciences Centre, I was pleased to meet several new and very young clients. Dr. LaFerrier gave a wonderful presentation that was very helpful to some new clients and a great refresher for our more seasoned group. Hemophilia Ontario is currently looking at ways to make the Clinic a more satisfying experience for clients. We appreciate any input you may want to offer.

Sylvia—aka Sam

MOST OF THE MEMBERS and staff at Hemophilia Ontario know me as Sylvia Storozuk. However, there is a name change in the works and I will be reverting to my name prior to marriage, which was Sam Helfrich. Some of you are already calling me Sam and that's good. It may be a little confusing at first, but yes, I am the same person you met at Clinic, Here's my picture! This name change will be complete by the end of the year, so I wanted to give people time to get used to it.

Commemorative Tree Planting

DURING THE FIRST week of October, Hemophilia Ontario arranged to have a beautiful Red Oak planted in Vickers Bay, one of the oldest and most beautiful parks in Thunder Bay. This tree was planted to commemorate the loss of our loved ones in the Tainted Blood Tragedy. On Saturday morning, October 23, we had our commemoration service to honour those lost. It was a beautiful morning for it, too! The Tree Commemoration is an annual event held in October. Next year, we plan to have the plaque with our name, erected beside the tree during the commemoration service.

Commemorative planting: Pictured are (Left) Dan and Vicky Anniuk and (Right) Sylvia Storozuk

Changing with the Times

AS NEEDS CHANGE, so do directions. Our intended focus for both 2010 and 2011 has been community awareness and that has not changed. Having said that, what will change is that a little more time will be focused on building, training and maintaining a solid volunteer pool. Hemophilia Ontario has the potential to be a loud voice and advocate in the north, for people with bleeding disorders. I know that with our membership, we can realize that potential.

I have been very fortunate to have had a wonderful volunteer—Amanda Green—with me for the past year. Unfortunately, due to time constraints, Amanda is no longer able to assist me. We have events that we would like to facilitate for the members and for fundraising purposes, but cannot do any of these without the volunteers to help. I have communicated this need to our membership in Thunder Bay, and knowing the hearts of people in the city, I expect a positive response at our November 3 Volunteer Meeting. Notices have been sent out. I know that we will pull together as a community, yet again, and am very much looking forward to working with you.

Meet & Greet Potluck

YUP! JUST WHAT IT SAYS. A Meet & Greet. You. Me. We're not going to talk about blood disorders or volunteering or anything else like that. We're gonna talk about you… and me … and what we like to do. I want to know who YOU are. Hopefully, you like making new friends, too. This is a pot luck and you know what that means—bring a dish of something. If you can't cook, call me. I'll assign you to bread and pickles. This will be a fun, relaxed, late afternoon thing, so wear whatever makes you comfortable. For us to be effective as a support for each other, as well as garnering support in the community, we need to bond as a group. This is a step in that direction.

This is one of the first events that new volunteers will be arranging and notices will go out at the end of November. Watch your e-mails and mail boxes.

Ottawa and Eastern Ontario Region

Regional Spotlight

16th Annual Shawn Duford Golf Tournament for Hemophilia

▶ *Diane Stanton and Denis Duford*

by Steve Van Dusen

THANK YOU for joining us for our 16th Annual Shawn Duford Golf Tournament for Hemophilia, on August 14, 2010 at the Meadows Golf and Country Club in Ottawa. It was another successful year.

Our golf tournament fosters friendships between our members, friends and our business partners, and is our major fundraising event. The day includes 18 holes of golf, the golf cart, lunch prior to tee-off, and a succulent banquet dinner. In addition to the golf, we have a lot of great gifts, contests, draws and a silent auction. Those unable to play golf can join us for the banquet. Each year, there is an opportunity to win extraordinary prizes while helping to support the Ottawa and Eastern Ontario Region of Hemophilia Ontario.

This is a fun tournament for all to enjoy. Although the number of golfers decreased from last year, we did extremely well. It is an educational day as well with questions on bleeding disorders at each of the 18 holes for participants to answer and qualify for a prize.

We look forward to seeing you next year on August 13. Let's make the 17th year the luckiest and the best ever for the Shawn Duford Annual Golf Tournament for Hemophilia. ♦

Your 2010 Golf Tournament Committee
Hemophilia Ontario, OEOR

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Jennifer Lelièvre, Past Chair
Jennifer Van Noort, Vice Chair
Ashwani Kurichh, Secretary
Brian Van Dusen, Treasurer
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Darlene Villeneuve, Fundraising Chair
Jaime Villeneuve, Director
Raja Ammoury-Alami, Director
Lori Kavanagh, Director
Bruce Myers, Director
Trevor Sauvé, Director

Colin Patterson
Regional Service Coordinator
613-739-3845
cpatterson@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 Colin Patterson, Regional Service Coordinator, 613-739-3845 or cpatterson@hemophilia.on.ca.

PROGRAM/EVENT	EVENT DATE
Holiday Party	December 5, 2010
Sleigh Ride/Education Event	January, 2011
Membership Meeting/Education Event	February, 2011
Bowl-a-thon	March/April 2011
Regional Annual Meeting	March, 2011
Hemophilia Ontario AGM	April, 2011

Your child is born,
The tests are done.
Your hemophilia journey
Has just begun.

At first it's confusing.
So much to learn.
With all this info,
And nowhere to turn.

But as time goes on
You will surely find
That all us bleeders
Are one of a kind.

Supporting each other
In any way we can,
Opening doors
And lending a hand.

Fighting for rights,
Supporting our cause,
Talking to governments
To change the laws.

We've had many successes,
And still more to come.
Thanks to the volunteers
And all that they've done.

The nurses and docs
Are the best in town,
Picking us up
When we get knocked down.

So come out and join us.
There is so much to learn.
When you think you're done,
The road starts to turn.

We need your support
In all that we do.
The journey of Hemophilia
Depends on you.

by Nancy Sauvé,
Darlene Villeneuve

Hemophilia Ontario's Healthy YOU Camp

WE JUST ENJOYED a wonderful weekend at Camp Wanakita, Healthy You Family weekend and meeting people from as far away as Thunder Bay.

Thanks so much to the great speakers Joe Rich and Larry Borins, for their insight and the tips and tools they gave us. On November 27 at the Children's Hospital (CHEO), families interested in sending their children for a great camp experience at Camp Wanakita will meet for a pizza lunch between 10:00 am and 12:00 noon to complete their registration forms. As a parent who sent my child to Wanakita camp for nine years, I can honestly say that this is the best gift Hemophilia Ontario could give my son. He developed leadership skills and confidence from both the camp and self infusion programs.

We will hold a Holiday Party on December 5. There will be many great activities and lots of fun. Watch for invitations that will be mailed out soon. Get your family ready for the upcoming Bowl-a-thon in April, 2011. Details to follow.

Donations and sponsors are still needed.

Calling all youth ideas

What would you like to see us put together that would interest youth to come together with other youth. E-mail Nancy at mik6903@hotmail.com.

Make sure Colin Patterson at OEOR has your e-mail address so you don't miss any of our exciting events this year. Colin can be reached at 613-739-3845 or drop him a message at cpatterson@hemophilia.on.ca.

Nancy Sauvé, Programs Chair
Darlene Villeneuve, Fundraising Chair

Wanted!
Youth 12 - 21

to participate in a Web Cast Pilot Project.
It is the intent to assemble a group of interested youth to network/communicate through Skype to plan, organize and implement activities for youth, by youth. For more information on this exciting project, E-mail Colin Patterson at cpatterson@hemophilia.on.ca.

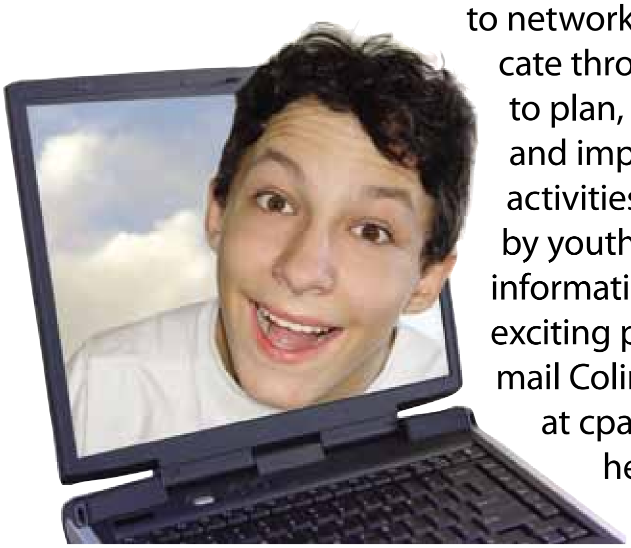

Photo credit: iStock.com

Tainted Blood Commemorative Ceremony

CAMPERS, STAFF, FAMILIES AND COMMUNITY came together on August 29 at Camp Menesetung in Goderich to honour and remember those from SWOR and across Canada affected by the Tainted Blood Tragedy in the planting of our Commemorative Tree. We chose to remember and honour those individuals and families in our region as part of the closing ceremonies of Pinecrest Adventures Camp. Eric Stolte addressed those present and reminded us all that it is okay to be sad and angry but that we need to use these emotions to work toward positive change. He shared the following thoughts:

"The tree that has just been planted is a special tree. In the program it's called a Tree of Life. But today, I'd like to call it a "Remembering Tree." After today, we can come back here to this spot and remember something special. Some things are easy to remember, other things are hard. Some memories we like to think about. Other memories we like to forget, because they are about something sad. But sometimes, these sad memories can be the most important!

"This Remembering Tree is meant to help us remember a very sad time in our hemophilia community. We had trusted certain people to keep our factor product which we use to stop bleeds safe. But, these people let us down. So, some people who we loved very much died. This made us very sad and also angry. So we used our sadness and anger to make things better—to make our factor products safe, so no one would have to worry anymore about using their factor product. And we did! Now, our products are safe.

"This Remembering Tree will help us keep remembering this sad time to help us make sure that we continue to work hard so that no one else will ever be hurt in the same way.

"But also, this Remembering Tree will grow strong and tall. It will have many more branches and leaves. Strong branches and many leaves. This will remind us that we who have hemophilia or other bleeding disorders need to continue to grow strong together so that we can help others. Just like a tall, strong tree, a tree with strong branches and many leaves provides shelter for birds and shade for people, we need to grow strong together so that we can help others too. This is because there are many people with hemophilia around the world that don't yet have the kind of care that we do. Many of them have lots of pain in their elbows and knees and have to use crutches to get around.

"So, this tree reminds us that together we can be strong to help get care and treatment for those who don't yet have it like we do.

"So, this Remembering Tree will help us remember two things. It will help us remember a very sad time so that we'll continue to work hard so no one gets hurts ever again. It will also help us remember that in growing strong, we can use our strength to help others who don't have what we have.

"Make sure you come here often enough so that this Remembering Tree can do its job of helping us remember these two very important things." 🩸

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

Regional Board and Staff

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Pinecrest Adventures Camp

▶ *Top: Jumping in the pool, L to R: Christine, Ashley, Holly, Sarah, Adryanna, Frances, Julia and Juliana*

Bottom: Leonidus (Alex Mikler) represented Sparta and Hercules (Charlie Pangborn) represented Athens in the no-hands pie eating contest.

IT WAS SPARTA VS ATHENS relived as Pinecrest Adventures Camp went back in time to the ancient Greek Olympics. Visited by Zeus at our first campfire, campers were introduced to the warriors, gods and goddesses who would lead them in the tasks set for the days to come. The next day, Zeus created the teams and the games began. Together they met the challenge of playing "Things in a Box – Pinecrest Edition," participated in Pinecrest Idol, yelled their loudest for the glory of winning Run and Scream and went face first into chili bread bowls for a no hands dinner. Whether staff, leader-in-training or camper, everyone contributed to make this week an incredible success.

Sincere thanks to:

- the amazing staff who volunteered their time to make camp a reality—Paul, Charlie, Nick, Brittany, Holly, Jake, AJ, Bret, Ashley, Denise, Shane, Alex, Rob and Tyse
- Paul, Charlie and Nick for their countless planning hours
- The 2010 Camp Committee (Kevin, Lori, Keira, Mary Jane, Eric, Paul, Nick, Charlie and Terri-Lee) who began planning in October for 2011
- Baxter, Bayer, NovoNordisk and Pfizer whose continued support of Pinecrest helps to ensure camp is a reality each summer. ♦

"I like this camp very much. I really liked the talent show and all of the silly camp songs we learned. I was very excited to see all my friends again. We had to wear our clothes backwards one night. It was really fun. I liked when the Spartans and Athens teams had to eat pie with no hands and had to use their mouths. We built sandcastles and it was lots of fun. It was neat being interviewed for a commercial and at the end of camp I got the "Movie Star" award. I am really excited to go back next year again." ~ Adryanna, age 9

▲ *Above: Paul Travaglini is presented the John Meyers Award by Director Paul Wilton.*

◀ *Left: Julia and Johnny Lepera in costume.*

Check out the photos online: http://www.lhsc.on.ca/Patients_Families_Visitors/Bleeding_Disorders/SWOR/Pinecrest/index.htm

Just the Guys Weekend

> "It was the best weekend! I really liked the rock climbing wall. One morning before our Polar Dip, we had to wait because there was a very big turtle in the water. Dad and I jumped in together and I was on the dock before Dad even got up out of the water. I really liked spending time with my Dad and making lots of friends. We had to walk a very long walk to get to our cabin, but once we were there it was very cool. We were the green team and we did some really fun challenges but we lost, so I am looking forward to going back next year and winning."
> Nathaniel, age 8

▶ Nathaniel Cruse and his dad, Kevin.

▼ Matthew on tires – part of low ropes activity.

CAMP KI-WA-Y hosted our Wacky World of Sports Just the Guys Weekend September 17-19 for boys age 5-15 affected by an inherited bleeding disorder and their accompanying male role models. The weekend provides the opportunity for male youth and their father or male role model to gain a better understanding of their diagnosis and to connect with other families.

The Wacky World of Sports twisted traditional sports activities resulting in lots of fun for the four teams competing for the glory of the win. Friday evening saw them building team torches out of spaghetti and two marshmallows. Saturday's first challenge—Sports Shootout—incorporated three sports basketball, soccer and hockey. The fourth station challenged their knowledge of their bleeding disorder with a trivia quiz. In the evening a raucous game of Beverage Pong ran for over an hour until one team was declared the winner. Sunday morning Fishing 1-oh-1 saw each father/son team fishing in porridge with one foot to find the candy spiders while trying to avoid the candy leaches (mini tootsie rolls).

Other favourite activities this year were low ropes, the climbing wall and the ever popular waterfront (new and returning participants love to take out the canoes and kayaks or jump on the water trampoline for hours).

Julia Sek, Clinical Consultant, used red construction paper and goldfish crackers to help younger participants understand a little more about what happens during a bleed. Karen Strike, the physiotherapist from Hamilton's Bleeding Disorders Program, used cooked chicken wing bones to help the boys understand their joints and the importance of taking care of them. Thank you ladies for your innovation.

Again this year, Ryan K participated as our region's Youth Leader Volunteer and did an outstanding job. Thank you for sharing your leadership and mentoring our leaders of tomorrow.

All in all it was a great weekend. Many new connections were made and old friendships revisited. A special thank you to event sponsors, Pfizer, Baxter and Bayer Burford International—without your support this event would not be possible. 💧

BleedHERS – Just for Ladies

WOMEN CAN HAVE bleeding disorders too. A bleeding disorder results from a flaw in the body's clotting system. Specialized proteins in the blood are called clotting factors. If they are missing or do not work properly, a bleeding disorder can result. Most bleeding disorders are inherited, caused by a genetic mutation, but some can occur spontaneously. People with bleeding disorders bleed longer, not faster, than those who do not.

You may have a bleeding disorder if you have one or more of the following symptoms:

- Heavy menstrual periods (bleeding for more than seven days, from the time it began until it stopped; Flooding or gushing of blood, limiting daily activities such as housework, exercise or social activities; Passing clots that are bigger than a quarter; Changing tampon and/or pad every two hours or less on heaviest day
- Low in iron or have been treated for anemia
- Your family history includes bleeding symptoms and/or a bleeding disorder, such as von Willebrand disease, or a clotting factor deficiency, such as hemophilia
- Heavy bleeding from dental surgery, other surgery, or childbirth and/or have other additional bleeding symptoms such as: frequent prolonged nose bleeds (longer than 10 minutes) or prolonged bleeding from cuts (longer than five minutes) or easy bruising (weekly, raised and larger than a quarter)

If you have one or more of these symptoms, please speak with your doctor or other healthcare professional.

The most common bleeding disorder in women and girls is von Willebrand Disease (VWD). It affects 1 in 100 Canadian women (approximately 150,000 women). VWD is an inherited bleeding disorder. It is caused by a defect in or deficiency of von Willebrand factor, a protein the blood needs for clotting. Women and girls can also have the most common types of hemophilia which is hereditary. Some are symptomatic carriers of hemophilia, meaning that they not only carry the gene, they also display symptoms.

Although men and women with bleeding disorders have similar symptoms, such as bleeds into joints and tissues, women can experience added complications during menstruation, pregnancy, labour and delivery. Some doctors are not familiar with bleeding disorders in women, many of whom are undiagnosed or misdiagnosed. Women with undiagnosed and untreated bleeding disorders risk serious complications. If you have symptoms of a bleeding disorder, it is important to get a proper diagnosis and treatment from a specialist, called a hematologist. Have your doctor refer you to the Bleeding Disorders Program for testing. Should you be diagnosed, you could begin to receive comprehensive care specific to your needs. ♦

Other Resources

http://www.hemophilia.ca/en/bleeding-disorders/women-with-inherited-bleeding-disorders The Canadian Hemophilia Society (CHS) dedicates a section of their website to providing information to women and girls with bleeding disorders.

www.hemophilia.ca/genes CHS also has a new interactive animated video Me and My Genes that provides pre-teen and teenage carriers with relevant and age appropriate information about what it means to be a carrier.

www.mygirlsblood.org is one of several online international social networks dedicated to sharing the lives of girls and women with bleeding disorders.

Dare to Dream

▶ *Fred in his F1 car*

SWOR SOLD BOTH winning tickets for the CHS Dare to Dream Raffle drawn on August 6 at the Hemophilia Ontario offices. Fred S and Jeff R each won Thrill of a Lifetime Packages that included travel from their location to Bridgestone Racing Academy in Mosport, one night hotel accommodations, in-class instructions, track and car orientation, one-on-one driving instructions, a 15-minute warm-up lap and two 20-minute lapping sessions. Tickets, sold through the local office, were only $20 each or six for $100. The value of the prize—$1,500. Being a winner—priceless! Read Fred's story:

Exhilaration

by Fred Schumann

It was a typical day at the office as I took the next phone call and was taken aback for a moment. I had forgotten about purchasing a ticket for the Dare to Dream contest when I was informed of my luck. My response was, "Did I win a hat or a T-shirt?" as I thought to myself, "Why would I win anything other than that?" I am always pleased to win anything at a golf tournament, my grandchildren's school raffle and even a free ticket on a lottery ticket, just as anyone else would be. Well I was wrong as to my luck. I was informed that

presented by Pfizer

Dare to Dream for a Cure
for inherited bleeding disorders

Suited up for the ride

I and 12 other lucky individuals from across our great country had won the opportunity of a lifetime—to actually be driving an F-1 race car at the Bridgestone Driving Academy at Mosport Raceway! At that precise moment my heart rate shot up, adrenaline pounded through my body and I was jumping up and down in my office in sheer excitement. Fellow colleagues were just as excited for me (as well as wishing that they had won).

I arrived at the Marriott for the beginning of this fantastic adventure and found myself in a suite for the evening. Each moment just kept getting better. At the hotel I met the other participants from the different provinces and we were all feeling different levels of excitement—fear of the race track and apprehension at being taken out of our comfort zone. You could see the excitement in each of our faces as we arrived at the Bridgestone Driving Academy as we looked down at the race track.

We were put at ease from the start. Not only have they never had an accident since opening 25 years ago; when driving, it was all about our comfort level and skill as individuals, not a competition between drivers. After completing a training session we were geared up—race jump suit, gloves, shoes, head and foot protective stockings and a helmet. Fully suited, we headed to Pit Row for our vehicle indoctrination and safety features review. You look at the cockpit and think, am I going to fit into that little space? Absolutely!

Sitting in the car as it warms up, you have to keep the rpms at 2,000. (This information is on the removable digital steering wheel along with the oil and engine temperatures. There is no speedometer!) This vehicle's torque, power and agility propels you from 0-100 km in just five seconds, followed by you catching your breath and having your eyes return to your eye sockets. Warm-up laps last 10 minutes. You follow each other at a six-car-length distance, and get the feeling of your own car. Return to Pit Row for a driver and vehicle check and then back in the cars for a 20-minute G-force thrusting adventure! Your eyes focus on the car and track ahead of you and you are already anticipating your next sequence of movements. Turning—challenging. For a left turn you aim for the apex (centre of corner) downshift and brake quickly, entering the corner as fast as possible, turning the wheel simultaneously as you aim for the next right-hand corner 50 feet away and do it all again. At the same time, you keep checking your side mirrors to see who is behind you or coming up on you and try to maintain your position ahead of them—testosterone overload level like a tyrannosaurus rex chasing his lunch. This session ends too quickly and we return to the pit. Bright-eyed with excitement, we share our experience and seek advice from the crew to enhance our next 20-minute ride. We wait with anticipation to get back into that car as fast as humanly possible. The experience of the rush you feel driving, of pushing the envelope which you can never do anywhere else—legally that is—explains extreme sport junkies. Our second driving session was a fantastic game and when our 20 minutes came to an end we couldn't believe it. "Time flies when you're having fun" aren't just words when driving these cars! The best track record is one minute and five seconds for over a mile course. The pit crew estimated we were finishing the day at about one minute and ten seconds. Racing is won in thousands of a second. During the course of the day a photographer was there capturing our experiences. A great gift on top of the entire event was to receive a DVD with 536 photos on it for the day. I wish to convey a special thank you to my fellow comrades at the wheel sharing in the experience, the support staff at the track and especially the Canadian Hemophilia Society for the experience of a lifetime.

Events Calendar

EVENT DATE	PROGRAM/EVENT
November 1-29	**Wreaths, Pots and Swags Fundraiser** – Wreaths and Swags sell for $16 each and Patio Pots for $35. To place your order, contact thiggins@hemophilia.on.ca or call 519-432-2365.
December 1	**World AIDS Day Vigil** – SWOR joins several partner agencies in hosting a service dedicated to remembering, honouring and celebrating those individuals who lost their lives to HIV/AIDS. The Aeolian Hall, 795 Dundas St. E., London. Attendance is free.
March 3-4, 2011	Opening Doors HIV Conference – For the past three years, SWOR has participated as a planning member for this educational conference, funded by the AIDS Bureau and the Ministry of Health and Long Term Care, to discuss issues of treatment, support, depression, stigma, access to services, cultural diversity training, disclosure, safe space training, nutrition and alternative therapies. The event is open to those living with HIV/AIDS and their family and friends, professionals, students and anyone interested in learning more. Contact Terri-Lee for information at thiggins@hemophilia.on.ca or 519-432-2365.

Websites and Resources

Below are links to various sponsored websites and resources that may be of interest:

Bayer

www.frankly.net (click on Speaking Frankly). Bayer pharmaceuticals hosts this website for youth 17 and up living with hemophilia and takes on some of the questions that youth may not be comfortable discussing with their family, friends and healthcare providers.

K Comic – the newest edition is fresh off the press. Contact your RSC for registration forms if you don't already receive it.

Kojo for older youth (under 12) / Kogee for younger youth (under seven) Register to receive these activity sheets. Send a request to Kojo OR Kogee Club, 67 Mowat Ave, Suite 433 Toronto, ON M6K 3E3.

Pfizer

www.embracelife.ca Pfizer (formerly Wyeth) hosts this website as an online resource for individuals living with hemophilia and their caregivers. It provides information on active living, resources and hemophilia management guides, feature stories and general information on hemophilia. Additionally, they have produced a booklet, *Living with Hemophilia* that is available by contacting your RSC

Baxter

Baxter has recently donated "Green Bags" to the Bleeding Disorders Program. Making it more convenient for you to pick up your product, these reuseable bags 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. Ask about these bags when you place your next Factor order.

A Bright Future – DVD Series *Hope, Information and Inspiration for Families and Educators.* This three-set DVD Series is designed to assist families, the extended family and educators about living with hemophilia. The Hemophilia Diagnosis (The Parents), The Hemophilia Diagnosis (The Extended Family), explores the process families navigate from diagnosis and how family relationships can be affected. Hemophilia – Teaching the Educators benefits the busy educator who has a child with hemophilia in their school. www.baxter.ca

Novo Nordisk

www.novonordisk.ca – Novo Nordisk provides details about inhibitors on their Canadian weblink or on the American website on the National Hemophilia Foundation website http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=227&contentid=424&rptname=inhibitors (click on Changing Possibilities) includes case studies and a facebook link.

CSL Behring

www.cslbehring.ca – CSL Behring hosts this website noting their passion is to help improve the quality of life for people with rare diseases, hemophilia and von Willebrand Disease. Recently they announced that their vWD product is the only product produced from Canadian plasma collected by Canadian Blood Services.

Toronto and Central Ontario Region

Regional Spotlight

President's Message

ONCE AGAIN I have been afforded the opportunity to write a brief summary of TCOR's recent summer successes and upcoming events. In June we held TCOR's 11th Annual Golf Tournament at Station Creek Golf Club at which we netted close to $15,000. This could not have been achieved without the support of our generous pharmaceutical partners, our valuable volunteers and of course the many golfers that continue to lend their support year after year.

At the beginning of September, we were lucky to add two new RSCs to the TCOR team. Robin Nobleman and Jeenetha Kulasingam have already been a positive influence on TCOR with their bright innovative ideas and enthusiasm. Keep an eye open for new programming in the coming months.

The weekend of September 18-20 was dedicated to Just the Guys. At this event 75 boys accompanied by their fathers or other positive male role models attended the "Wacky World of Sports." This program was designed to include many educational workshops for both the younger and older participants. Other friendly sports competitions were included to create a fun and friendly atmosphere. This was a huge hit for all of our participants. Great thanks to everyone who came out.

Our new RSCs have been avidly attending St. Mike's every Tuesday to provide continuous support for patients undergoing various treatments. Other volunteers from the Speakers' Bureau have attended various federal government speaking events as part of the HealthPartners fundraising campaign. Their time and generosity is immensely appreciated and acknowledged.

On October 17, runners and volunteers from TCOR and Hemophilia Ontario participated in the Toronto Marathon. Sixteen of our TCOR members took the initiative of collecting pledges and also participating in the 5K run in support of Hemophilia Ontario. This was great fundraising resourcefulness on their behalf.

On November 13, the Families in Touch picnic and a puppet show took place. This was an awesome way to involve people of all ages and raise awareness of bleeding disorders creatively.

November 20 was a day dedicated to the workshop run by Inalex Communications. The main objective of this workshop was to help build stronger relationships between parents of children with various bleeding disorders.

Without the help of our volunteers these wonderful events would cease to exist. They are owed an immense amount of respect and gratitude for their hard work and taking time out of their busy schedules to make a positive difference in the lives of people with bleeding disorders.

I wish you good health and happiness. ♦

Maury Drutz,
President, TCOR

TCOR Board

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

Staff

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

Volunteer Experiences with TCOR

by David Neal

WHILE ENROLLED as an undergrad at York University, I was approached by Karttik Shah and asked if I was interested in participating in the Youth Committee with Hemophilia Ontario. Unfortunately, I had to decline at the time because I was focused on my studies. I did advise Karttik that I would consider volunteering once my studies were completed. So, upon graduation in the spring of 2003, I approached the Society to see what opportunities existed. At the time there was the opportunity to volunteer on a couple of committees and with Bingo. After a couple of years in these roles, I was approached in spring 2005 to join the TCOR Board of Directors. I felt that this would be a great way to gain exposure within the Society. Once elected, I was introduced to some members who had dedicated many hours (and years) of their spare time to ensure that TCOR (and the Canadian Hemophilia Society) continued to reach out and help members of the bleeding disorders community. I was able to learn from these members, and as a result, I have forged strong friendships that will last well into the future.

There are many opportunities to volunteer with TCOR, regardless of whether you are a board member or not.

This past fall I was asked for a second time to speak publicly on behalf of the Canadian Hemophilia Society (CHS) through HealthPartners—an organization that consists of several charities in Canada and works in partnership with the federal government ministries. After the great experience last year, I wanted to speak again on behalf of the CHS, and continue to practice my public speaking skills. It can be nerve-wracking to stand up in front of a group of strangers to talk about anything, but this is one way for the Society to gain exposure. I am a firm believer that knowledge is power, and by speaking on behalf of the CHS, more people will become aware of hemophilia and the bleeding disorders community. After one speech this year, one of the employees approached me and asked me more about hemophilia.

Remember to send us your change of address so you won't miss a single issue of this 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 ____________________

We sat and chatted over a coffee, and he was inspired by the information I provided. I would highly recommend that other members of the TCOR community volunteer with HealthPartners, as it is a great way to overcome any fears one may have about public speaking!

As a board member, I was pushed out of my comfort zone, and learned new skills that I would not otherwise have learned. I was introduced to the process of passing resolutions as well as the budgetary process. The people I volunteer with at Bingo are very caring and dedicated individuals, and over time we have become a tight-knit group that enjoy each other's company. Our Saturday morning sessions are ideal for anyone interested in volunteering, as it is not that busy.

There are many opportunities to volunteer with TCOR, regardless of whether you are a board member or not.

Besides, once the session is over, you still have the rest of your weekend to spend time with family and friends. The money earned from Bingo is one of TCOR's highest revenue generators, and volunteers are necessary to ensure that TCOR will receive this vital revenue in the future.

I find volunteering with TCOR to be a truly rewarding experience. Volunteers are able to expand their skill set and forge great friendships. The future of the TCOR organization will continue to hinge on the strength of its volunteers, and I highly recommend and challenge you to look into volunteering in the future and push yourself out of your comfort zone. Who knows...you may discover a hidden talent, and make a difference to the future of TCOR and the CHS. I hope to see you at a Bingo session or on the board in the near future. ♦

"Never doubt that a small group of committed people can change the world. Indeed, it is the only thing that ever has." ~ **Margaret Mead**

Join our volunteer team!

For more information about volunteering, contact Robin Nobleman, Regional Service Coordinator at 416-972-0641, Ext. 12 or rnobleman@hemophilia.on.ca.

Toronto & Central Ontario
Regional Hemophilia Society

Holiday Party

Join us to celebrate the year's end at TCOR's holiday potluck.

December 9, 2010
6:00 – 9:00 pm
45 Charles St. E.,
Suite 802
Toronto, ON M4Y 1S2

Dress code: Come as your favourite—or least favourite—entity of Winter. The most original costume will be rewarded.

RSVP
Robin – 416-972-0641 Ext 12
rnobleman@hemophilia.on.ca
or
Jeenetha – 416-972-0641, Ext. 14
jkulasingam@hemophilia.on.ca

Film Screening Commemorates the Tainted Blood Tragedy

IN COMMEMORATION of the Tainted Blood Tragedy, TCOR held a screening of a new documentary film, *Bad Blood: A Cautionary Tale*. This feature-length movie was released in July, 2010 in the United States but had never been shown within Ontario.

In the United States, 10,000 people were infected with HIV and 15,000 were infected with Hepatitis C through tainted blood products. The film explores the tragedy though the heart-wrenching stories of six affected families and the doctors and nurses who cared for them. Emmy award-winning producer Marilyn Ness takes a critical look at what governments and pharmaceutical companies knew and what patients weren't told. *Bad Blood* highlights the key role of the bleeding disorders community in fighting for justice and a safer blood supply.

Twelve members, family and friends attended the screening and found the movie hard-hitting and well done. The movie was followed by a discussion on personal experiences of the Tainted Blood Tragedy and the future of blood safety in Canada. The screening coincided with a conference put on by Canadian Blood Services and Hema-Quebec in Toronto on risk-management in the blood supply. Several attendees of the screening had also participated in the conference and enriched the discussion with insights from it.

For those who missed it, the film is set to come out on home video DVD on December 1 and may be shown on PBS early next year. TCOR will make a copy available for borrowing in December.

Robin Nobleman

Book Review

"Lesson from God"

by Jennifer Rhea Cross
Published in *Chicken Soup for the Kid's Soul: 101 Stories of Courage, Hope and Laughter*

Reviewed by Jeenetha Kulasingam

THIS IS A TRUE STORY written by Jennifer Cross about her brother Brad Cross who had hemophilia and was infected with the AIDS virus.

The story is written from Jennifer's perspective. She walks readers through a challenging journey of someone having hemophilia to someone then acquiring the AIDS virus. It was very touching as she speaks about her relationship with Brad and how he starts off as her protector before acquiring the virus and how he slowly weakens after. As his symptoms became obvious, Jennifer felt uncomfortable bringing her friends over to the house; she spent time feeding him through tubes and changing his diapers; she resented God, needing someone to blame. After Brad's passing, she struggled with the idea of life and death. Her family and she have made an effort to make a difference in the way people with hemophilia and AIDS are regarded. They appeared on the *60 Minutes* show and went to Washington D.C to support the "Ricky Ray Bill" as it was passed by congress. The Bill was named after Ricky Ray, a 14-year-old with hemophilia who died from acquiring the AIDS virus. His home was also burned down by individuals who lacked the knowledge of the transmission of AIDS.

Near the end of the short story, Jennifer mentions that her understanding of God changed as she realizes that Brad was a gift who opened her eyes about life and how truly valuable it is.

It's important to have stories like this to read to children. It not only raises awareness about genetic disorders, but stirs up emotions within the reader about the struggles that families face as a result, allowing children to develop empathy and understanding.

I give this story a rating of 4/5. It is well written and easy to understand from a child's perspective and there is an underlying message about lessons learned from struggles.

Book Review

Birth Marked

by Caragh M. O'Brien
reviewed by Paula Sapage

Intended audience: Teenage girls ages 13-17 years

THE NOVEL FOCUSES on a midwife living in poverty and working for an enclave where the births of the first three children born are to be brought to the enclave without consent from the birth parent. A young female named Gaia (about 16 years of age), follows her mom's footsteps and becomes a midwife at a very young age. She gives birth to her first baby and brings the baby to the enclave. Midwives such as Gaia follow strict orders commanded by the enclave. They are to deliver healthy and perfect babies within half an hour after delivery. They are to obey these orders without question and hesitation. All babies brought to the enclave are dropped off at the gates to a midwife living within the walls where there is no explanation or traces of the future of each baby within the walls. The midwives are paid and given water or food by the enclave for their loyalty. The community within the walls is made up of educated and wealthy families living in a dream world filled with abundance. The families living outside the walls live on a day-to-day basis with very little means.

Everyone within the enclave is genetically selected, leading to the development of analogous genes. The individuals outside the society are tainted with physical or genetic conditions that are not favourable.

No one living outside the enclave's walls is allowed in or has any contact with the enclave's community.

The story goes on about Gaia losing her parents to the enclave, where they are kept prisoners for reasons unknown to her. A guard named Leon from the enclave questions Gaia, but she is clueless as to why the enclave would arrest her parents, since her mother was the best and most faithful midwife. She herself had lost two brothers to the enclave, whom she had never met nor known anything of them. She knew she wasn't exceptional because of facial scars from a burn as a little girl. The enclave did not accept any abnormalities. Gaia grew suspicious of her parents' arrest and acted on it.

Young and determined, Gaia made her way into the enclave. Once inside, Gaia was arrested by the guards by exposing herself when trying to save a pregnant woman ready to be hanged. Gaia's image about the enclave was obscured after witnessing such horror. She was arrested for trespassing and used as a midwife due to her exceptional expertise in delivering babies, and so she could decipher her mother's encrypted diary. While in prison Gaia discovered her mother had kept a diary in which she noted all her deliveries. She spent her days in prison thinking of ways to get out, rescue her parents and run as far away as possible. With determination and bravery, Gaia studied all possibilities for escape. She discovered that Leon is the protectorate son, who served the enclave as a faithful soldier. He later became a fugitive himself upon discovering he was adopted from outside the walls and was eager to find his birth parents. Gaia is then questioned about her mother's diaries, which are all encrypted in ways Gaia can't comprehend. Later she learns all of the hidden messages written and reveals all the encrypted codes. She realizes that the birthmarks on the baby's feet—the birth dates followed by a list of names of birth parents—are connected, and trace each baby back to its parents.

Meanwhile, an outburst of hemophilia has affected a lot of babies within the enclave. The underlying cause of the outbreak is the lack of genetic diversity and it is at this point that the enclave comes to the realization that they need more babies advanced from the outside to increase genetic variation and minimize the development of genetic disorders such as hemophilia.

Gaia escaped with the help of her new-found brother who served the enclave as a fine soldier. She then was helped by a baker who lived in the enclave and lost respect for the enclave after the loss of his daughter to hemophilia. She discovers that her father was killed when he tried to rescue his mother and escape from the enclave. Gaia, with the help of Leon (the protectorate's adopted son) whom she had once distrusted, now worked with her and they helped each other as they were both fugitives of the enclave. Gaia sets off to rescue her mother, which she accomplishes, but unfortunately loses her again after the birth of her daughter, Maya, which Gaia delivered in the midst of their escape. Gaia is left to raise her newborn sister by herself. In the end Leon's sacrifice helps Gaia and Maya escape and run to the wasteland far away in the deep forest.

The book brings you power, determination, bravery, family values, and love. The story is well written and the reading level is understandable but difficult to comprehend the era in which it takes place and its relation to bleeding disorders.

The story does take place in the future but it seems that society has not evolved. In my opinion, this story has nothing to do with hemophilia or any bleeding disorder.

I would recommend it to females above the age of 16 specifically because the main character is a young teenager herself.

I would not recommend this book to anyone who is looking for a story line based on bleeding disorders such as hemophilia. As for ratings, I would give it a four out of five for a well written story, and one out of five for bleeding disorders and hemophilia content. ♦

World AIDS Day Events Near You

by Robin Nobleman

DECEMBER 1 is World AIDS Day – a day to commemorate those who have passed away and promote awareness and prevention of HIV. This year's global theme is Universal Access to Treatment and Human Rights. You can read more about World AIDS Day at www.worldaidsday.org and keep an eye on planned events on the CATIE website, www.catie.ca.

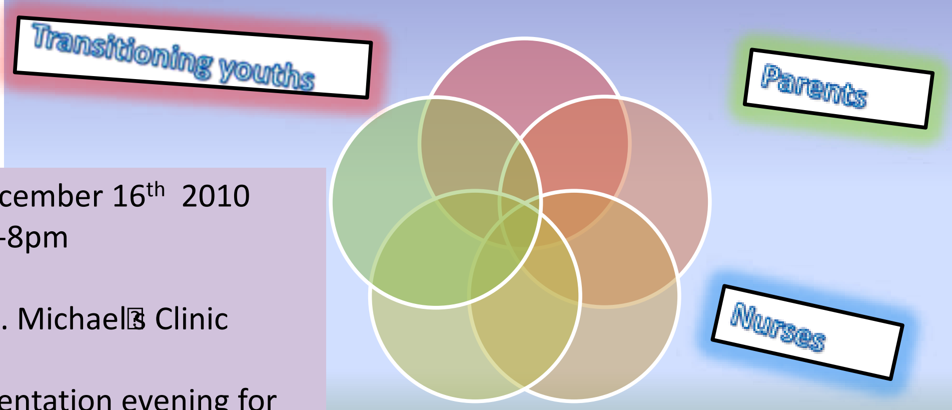
What: **Community Carnation Memorial**
A vigil featuring diverse speakers affected by HIV/AIDS, including one from the bleeding disorders community. This year's theme is Family.
Where: 519 Church Street Community Centre
Details: 5:45 pm
Contact: Robin Nobleman, 416-972-0641, Ext 12

What: **World AIDS Day Breakfast**
Proceeds support organizations that support women living with HIV and that fight to stem the tide of HIV among women, young women and girls.
Where: Café Bon Appétit, 401 Bay Street (at Queen St. W.), 8th Floor
Details: Registration 7:00–8:00 am, Program 8:00–9:00 am
$45 per ticket (Advance ticket sales only)
Contact: Leah Stephenson (Telephone/Fax: 416-422-0114; E-mail: WADBreakfast10@gmail.com)

What: **Condom Stuffing Party – AIDS Committee of Toronto**
Nimble fingered individuals needed to make condom and lube packs for HIV prevention.
Where: 399 Church Street, Room 220
Details: 5:30-8:00pm. No need to register. Pizza and snacks will be provided.
Contact: 416-340-8484. ♦

Clinic Corner

TRANSITION PROGRAM



WHEN: December 16th 2010 from 6pm -8pm

WHERE: St. Michael's Clinic

WHAT: Orientation evening for all patients transferring to St. Michael's Clinic

For ALL TRANSITIONING PATIENTS and families, come out to an informative orientation evening and become familiar with your NEW clinic, your NEW nurses and your NEW doctor!

Contact RSC: Jeenetha Kulasingam if interested • Tel: 416-972-0641 ex 14 • email:jkulasingam@hemophilia.on.ca

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 Stain, 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:

St. Michael's Hospital
Tuesdays 1:00pm to 3:00pm
Your RSCs are Robin Nobleman
E-mail: rnobleman@hemophilia.on.ca
Phone: 416-972-0641, Ext. 12
and Jeenetha Kulasingam
jkulasingam@hemophilia.on.ca
Phone: 416-972-0641, Ext. 14
802-45 Charles St. E., Toronto, ON M4Y 1S2
1-888-838-8846, Fax: 416-972-0307
http://www.hemophilia.ca

Families in Touch Picnic with Puppets

LOCKE LIBRARY in downtown Toronto was the scene of the TCOR Families in Touch event On November 13. We held an indoor picnic with a puppet show by the very talented and always entertaining, "Teaching Awareness Through Puppetry" Troupe with puppeteers Judi, Kirsten and Sylvia. This troupe performs puppet shows in elementary schools around Toronto to teach awareness, sensitivity and understanding about severe hemophilia, using a puppet that represents the late James Kreppner as a child.

Judging by the laughter of the children, it was very enjoyable and also allowed some children to express their difficulties in explaining hemophilia to their friends.

The children also showed their creativity by making their own puppets and spent the rest of the afternoon playing games that were coordinated by our very talented RSC Robin Nobleman and her equally talented brother, Josh Nobleman.

We will hold another Families in Touch event next August and anticipate that it will be as successful as this one.

Jeenetha Kulasingam

▶ *James Kreppner puppet*

Events Calendar

EVENT DATE	PROGRAM	DESCRIPTION	WHO SHOULD ATTEND
November 15 - February 1	Camp Wanakita Registration	Registration is now open for Camp Wanakita. To register, contact Stephanie Darroch at 416-972-0641 or 1-888-838-8846.	Any family with a child that wants to attend camp.
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.	Anyone wanting to honour a loved one or raise awareness about HIV/AIDS.
December 9	Holiday Party	Celebrate the holiday season at TCOR's potluck dinner. Prizes for the best winter-themed costume.	All are welcome. This is a great place to meet people and catch up with old friends.
December 16	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.

Toronto Marathon

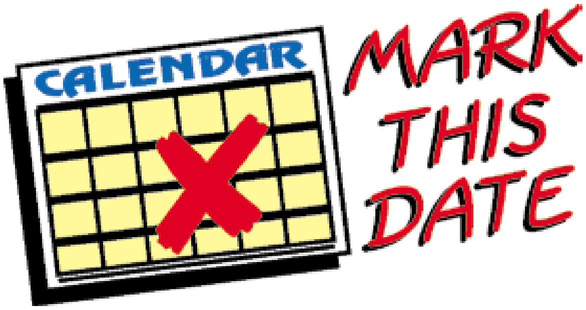
The 2011 Toronto Marathon has been moved to **May 15**

Plan now to get involved.

Register for the:
- Full marathon (40K)
- Half marathon (20K)
- Relay race (8 people/team)
- 5K run/walk

Volunteer for Hemophilia Ontario's
- Water station
- Information booth

Contact Stephanie Darroch at
416-972-0641, 1-888-838-8846
or sdarroch@hemophilia.on.ca.



Hemophilia Ontario Calendar 2011

EVENT DATE	PROGRAM/EVENT
April 17	World Hemophilia Day
May 15	Toronto Marathon

Hemophilia Ontario
Hémophilie Ontario

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