A publication of
Hemophilia Ontario
Hémophilie Ontario

BLOOD matters

"We're all related by blood."

Volume 2 • Number 3
Fall 2011

Youth Engagement

Training Leaders for the Future

Hemophilia Ontario

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What's in this issue?

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Cover photo: Youth volunteers at this year's Just the Guys weekend (L to R) Zachary Adams, Ryan Kleefman, Josh McCormack and Jordan Cabral. Photo credit: Terri-Lee Higgins

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PROVINCIAL PROGRAM MANAGER'S Report

by Terri-Lee Higgins

IN HER BLOG, Hildy Gottlieb shares ideas to help communities and nonprofits work more effectively. She writes, "We are people… we are all interconnected and interdependent, whether or not we wish to acknowledge that. None of us is independent of the rest of us. As individuals we bring our talents and skills, dreams and desires to the group or community we are involved in. We are not simply threads of a fabric, we are brilliant strands in an interwoven fabric of community. And like cells in a body, we are powerful only when acting in concert toward what's in *all* of our best interests – making sure the collective whole is healthy, resilient, at peace."

Collaboration requires effective teamwork. Team members must trust and respect each other. There must be open communication and willingness to accept input from others. Technology today enables us to share ideas, strategies and tools in ways that dramatically increase collaborative links. We also want a high degree of cooperation for a win-win environment where we can creatively search for solutions that mutually satisfy the needs of the team. This is not without its unique challenges. One of the most difficult tasks is constructively managing conflict that inevitably arises. Ignoring conflict is a barrier that inhibits open and honest communication on important issues which is a critical first step in conflict resolution.

Collaboration occurs when two or more people work together and realize shared goals. They can obtain greater resources, recognition and reward. Hemophilia Ontario continues to focus on becoming a stronger chapter through the efforts of many individuals including the provincial and regional boards, various committees, our HTC teams and our staff. We are a collective unit, and strive to function as one. It's not about what's good for each one of us as individuals; it's about finding ways to make what we do have a positive, and perhaps greater, impact. 💧

PRESIDENT'S Message

by Paul Wilton

AS A YOUNG ADULT, I realize that the advances in care that we have had over the past decade may cause us to become complacent. Many young people with bleeding disorders who were born after me have never even had a bleed. Therefore; the natural inclination is to say, "This disease barely affects me, what difference can I possibly make by becoming involved with Hemophilia Ontario as a volunteer?" The answer is: "You can make a huge difference."

Our community has achieved much over the years, but to sustain and to continue to improve care we must remain vigilant and involved. We currently have a safer blood supply. We have access to treatment and a high standard of care. This was not a natural evolution. These successes happened because of the efforts of informed and engaged volunteers. Furthermore, these accomplishments are not permanent. If our generation plans on keeping our current standard of care, we too need to be informed and engaged.

Here's a test for you:

- How are blood products screened for potential viruses?
- When will the current contracts for factor replacement products expire?

- In what ways does our community support research toward a cure for bleeding disorders?
- Do resources (human and financial) allow your hemophilia treatment centre/bleeding disorder clinic to provide care that meets best practice guidelines?

These are important questions. The answers have a significant impact on your care and your quality of life. If you do not know the answers, start asking questions. Do not take your care and treatment for granted. Crises are often what prompt individuals to get involved with a cause, but sometimes that is too late.

Advocating for our own care is vital, but what about our moral obligation to other people with bleeding disorders around the world? Imagine having a bleeding disorder where you didn't have treatment at all. Remember the pain you had when you ran out of your factor replacement on a weekend. We can use our experience and knowledge to help others around the world. We can make a difference.

Those volunteers who became leaders in advocacy for Hemophilia Ontario and the Canadian Hemophilia Society have fought for a safe and secure blood supply, along with a high standard of care and treatment for many, many years. They have earned the right to ease back and allow a new generation to take over. This transition must happen if we are to sustain care and treatment. Those leaders are willing to mentor and support our generation to take over this vital role. We cannot let this opportunity pass us by.

Parents, if you are reading this issue, please make sure youth in your family read it too. Youth, in addition to becoming a great advocate for yourselves and others, you can benefit by developing your leadership and communication skills, and enjoying the camaraderie and shared experience with other individuals with bleeding disorders.

You can make a difference. *We* can make a difference. 🩸

Message from the **EDITOR**

by Shaun Bernstein

FORGIVE ME A MOMENT for being forthright. I'm ashamed to admit how long it's taken me to sit down and craft this article. In my defence, I recently started a new full-time job, and have also been focused on my grad school applications. But that's no excuse for Hemophilia Ontario to fall by the proverbial wayside.

If anything, I think this illustrates the exact point of the issue, the importance of youth involvement and the challenges that surround it. As you'll see in the feature, Hemophilia Ontario has thrived on strong youth involvement for decades. Where would we be without the dedication of John Plater, the gentleness of Karttik Shah, or the energy of Marc LaPrise, just to name a few? That's not a Hemophilia Ontario I'd ever want to envision.

That's also not to downplay the leadership we've had from all ages and all walks of life, each of whom has brought us to where we are today and continue to bring us further ahead. But even the most mature of our leaders say the youth bring something special to the table. It's an uncommon drive and commitment, likely coupled with a naiveté that lends itself to achieving the impossible.

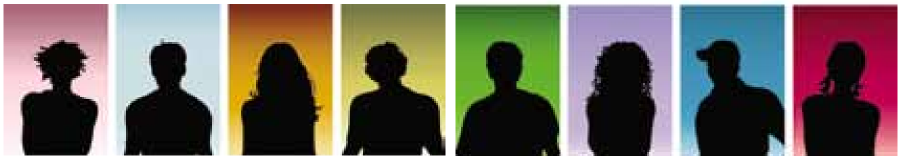
So if this youth leadership is so crucial, why is it so rare? We're certainly blessed to have it in key pieces of our organization. Without giving away numbers, it's plain to see that Dane, Paul, and even I belong to a certain generation, along with some of our key staff members. But even for all our efforts, it's still an achievement to find someone determined enough to give themselves unconditionally to the organization.

I'd like to see this issue of *Blood Matters* open a dialogue. The challenge of engaging youth is not a new one, nor is it likely to end anytime soon. The reality is simply that youth are busy building their own lives, and often don't have the time to take on extra tasks. The other, harsher reality though is that youth are fickle. I can hear a chorus of parental laughter (even from my own) as I write about the difficulties of getting youth to commit to and follow through on a task.

I'm grateful to the leadership we have of all ages. Without them, there wouldn't be a Hemophilia Ontario, and there certainly wouldn't be a *Blood Matters*. But the need to promote and foster young leaders will never cease. We need to continue to strategize ways both to make this organization attractive to young leaders, and to maintain a culture that promotes leadership development among young people, that clearly shows not just our gratitude for their work, but how important they are to the organization.

That's a culture I'd like to be a part of.

Have a pint on me. 🩸



YOUTH LEADERS
Past, Present and Future

by Shaun Bernstein

VOLUNTEERING IS A CRUCIAL SOCIAL RESPONSIBILITY for any age group. Volunteers can often be seniors, who spend their new-found leisure time generously giving back to a community in need. They can be persons with busy careers who contribute what little free time they may have to a cause they feel is worthy. But in Hemophilia Ontario, some of our most important volunteers are also some of our youngest.

Through our decades of rich history, young people have left some of the greatest impact on this organization, and hopefully will continue to do so through decades to come. Yet the challenge inherent in young people volunteering is also one of time. In some cases it's lack of availability; between busy school and work schedules, there can be too few hours in the day available for an organization. But for most young people, it's a question of consistency. Volunteering for an organization such as Hemophilia Ontario requires a long-term dedication from a young person who is willing to continually give of themselves to the cause, and encourage their peers to do the same. We wanted to take some time to highlight some special youth volunteers who have impacted our organization, as well as look at ways for young people to get more involved.

> *"Without youth involvement, the organization doesn't grow, it withers."*

Marc LaPrise has been involved with Hemophilia Ontario his entire life. As a child, Marc's parents were active with the Toronto Auxiliary, as it was then called, and LaPrise has fond memories of Christmas parties in church basements. "I was only aware that most of the boys at these get-togethers were also living with hemophilia," says LaPrise.

LaPrise says it was his involvement as a young adult that motivated him to take a leadership role in the organization. Exposure to older hemophiliacs he could emulate, and the new-found sense of community, helped him become the leader he is today. "I think the main thing I took away from being part of the society was the enthusiasm, fortitude and charisma," says LaPrise, who was a Regional Service Coordinator for TCOR from 1999 to 2004 and a board

Shaun Bernstein

Marc LaPrise and his children

Karttik Shah

member from 2004 to 2006.

LaPrise attributes his involvement to a combination of selfishness and selflessness. Selfishness because the society has done so much for him and his loved ones, and now he is able to selflessly give back. He says he's immensely proud of programs such as the HIV/HCV compensation, Just the Guys, the Now Experience Wellness program, and the Families in Touch program, and suggests the best way to learn more about any activities in the society is to get involved.

Unfortunately, some youth leaders in the organization passed away before they could see their hard work come to fruition. Karttik Shah's name is recalled with a fond smile by anyone who knew him, and especially those who knew him through various levels of the Hemophilia Society. Shah began attending Camp Wanakita at age 10, and was active as a young leader by age 16 when he became Chair of the Hemophilia Ontario Youth Committee, according to his parents, Fulchand and Amritben Shah. They say Shah believed in the power of generosity at any age; "everyone must be a giver, even the little ones." Shah was motivated by the efforts of other young leaders such as John Plater, who helped foster him into taking on more responsibility in his roles.

Shah's parents say that being involved in hemophilia advocacy work brought him a sense of acceptance and community, in spite of his various health challenges. They add that he was surrounded by a group of fellow young leaders who all faced similar challenges and were equally motivated to achieve their goals. In this supportive environment, Shah was elected to the TCOR and Hemophilia Ontario boards and held the position of TCOR President from 2001 until his death in 2004. Most importantly, Shah's leadership during his time with the organization is best remembered for his sense of compassion. This was especially demonstrated during his work on the twinning program, and the way he motivated other young leaders such as this author. Shah's parents say there are lessons to be learned from their son's compassion, determination, and forward thinking. They add that involvement is a responsibility of young people, and should be instilled by parents. While his years were too few, it was that determination that led him to make such a powerful difference in such a short time.

Ryanne Radford

Personally, I doubt that I would be as involved as I am today if it were not for some of the aforementioned youth leaders. As the child of an involved parent, I was surrounded by other children my age whom I knew faced similar circumstances, but I was unready to interact with the Society any further. It was not until I reached adulthood that I realized I needed some peer support in dealing with my bleeding disorder, and it was time to revisit Hemophilia Ontario and the CHS. I'm grateful for what I found.

All young people make choices with regard to their bleeding disorder, and my choice was *not* to attend Camp Wanakita. But as I gradually rejoined the Society, I discovered a rich network of people my own age formed by Wanakita, and then grew to discover others like myself who had been out of the fold almost entirely. Thus my goal as Youth Chair for Hemophilia Ontario has been to represent those quieter populations, the ones who may want to take a role in the Society but have never been involved before. It's crucial that we foster their leadership by presenting involvement opportunities that are tailored to their schedules and interests.

There are strong examples of youth leadership in hemophilia happening outside of Ontario as well, and they're not all from young males. Ryanne Radford is a young woman in Calgary with Factor V hemophilia who is making a difference. Her blog, Hemophilia is for Girls, has almost 100 regular followers, and has been mentioned in several American publications. Currently, Radford is serving as the vice-chair of the CHS National Youth Committee.

While Radford only became involved in the Society after moving to Calgary five years ago, she's made her activism an important part of her daily life. Radford says that while she admits to spending a large amount of time with her hemophilia involvement, she's proud of the work she's accomplished, such as a recent event in Calgary for young girls ages 10 to 16 who are affected by bleeding disorders. She says her primary motivators are to help others affected by hemophilia, and build awareness. She has been able to accomplish that with her international online following.

Ryanne Radford, Marc LaPrise and the family of Karttik Shah all agree that young people are the future of hemophilia societies on every level. Shah's parents said it best, "Without youth involvement, the organization doesn't grow, it withers." In this society, our elder spokespeople are tragically limited, and so it is up to the younger generation to see that this Society continues to thrive.

But this is a tall order. Current youth leaders must continue the cycle and reach into the next generation, offering wisdom and guidance that will prompt those even younger to take an active role. The newest generation of children with bleeding disorders is growing up with health profiles previously unthinkable, and the risk is that they'll be even less likely to see a need for being involved in the Society. Yet there are still battles to be waged, issues to be dealt with, fun to be had, and ways to make a difference. It's up to every generation to continue to foster and promote effective youth leadership that will make Hemophilia Ontario a powerful force for years to come. 🩸

YOUTH ENGAGEMENT Strategy

by Paul Wilton

THE HEMOPHILIA ONTARIO board and the Canadian Hemophilia Society have identified youth development and succession planning as key priorities through their Strategic Plans. Considering this, Interim Executive Director David Page and Paul Wilton have asked leaders of our organization to take the following steps:

- Regional boards to recruit two youth members (18-25)
- Hemophilia Ontario board to recruit one youth member (18-25)
- Position for youth member in Terms of Reference of any existing committees
- Interim Provincial Program Manager to prepare report on potential mentoring opportunities for youth, and how youth can become more involved in the work and decision-making of our organization.

In addition to the listed opportunities, there are many more ways to get involved in existing programs or to initiate your own. Please contact your Regional Service Coordinator to find out how you can become involved in your community. ♢

MAKING CONNECTIONS at the Wellness for Women Conference

by Teresa Genereux

"WELL WORTHWHILE, positive and inspiring," was how one participant described Hemophilia Ontario's Wellness for Women (W2) conference at the Delta Meadowvale Hotel in Mississauga, Ontario. On October 22–23, 67 women from around the province gathered to network and learn more about the bleeding disorders affecting them and their families.

Participants enjoyed a wide range of speakers' topics, including Dr. Diane Francoeur's talk on gynaecological management of bleeding disorders, a panel discussion on raising a child with a bleeding disorder, and hemophilia nurse Sherry Purcell's session on navigating the emergency room. Bleeding disorder-focused educational sessions were balanced by workshops offering strategies for stress relief and resiliency.

Throughout the conference, participants were able to meet others who faced similar situations and exchange experiences and advice. As one woman put it, "It made me more aware of my problems and that I'm not alone. There are others out there with VWD."

There was time for fun as well at W2. After a lovely dinner Saturday evening everyone teamed up to play trivia. A great time was had by all as ladies got to know each other through some friendly competition. The winning team was Blood Buddies, followed closely by Moms on the Loose.

Thank you to all the participants and to the fantastic speakers who enabled everyone to go home with new knowledge and skills in dealing with inherited bleeding disorders. See you in 2013. ♢

Camp Wanakita Bleeding Disorders Program – 2011

This year, Camp Wanakita offered 53 participants an opportunity to:

- Learn to infuse for the first time
- Build leadership skills
- Enjoy peer-to-peer support
- Build rapport between campers and nurses
- Experience camp activities with other children with and without a bleeding disorder.

Next summer marks the 20th anniversary of the Bleeding Disorders Program. The dates for 2012 are July 29 - August 11. Registration opens in December.

Jeenetha Kulasingam

Camp Wanakita

First Time WANAKITA CAMPER

by Jeenetha Kulasingam

▶ **ROBBIE CHARBONNEAU-SAUVÉ**, a 7-year-old from OEOR, was a first-time camper at Wanakita and enjoyed every moment of it. According to his dad, Mike Charbonneau, when he and his wife initially presented the idea of sending Robbie to camp, he didn't seem too interested. However, the family attended Healthy You and Robbie had a wonderful time and reconsidered going to the residential program. He, like most first time campers, was a little scared at the beginning. However, when his week ended, he came back home with new experiences, new friends that he will miss dearly, and he successfully did his first infusion with confidence. Next year, Robbie is ready for two weeks of camp and is looking forward to making new friends and memories.

From Mike's point of view, camp increased Robbie's self-confidence and will help make his journey growing up easier. He is grateful for Hemophilia Ontario and Camp Wanakita for providing the best experience for Robbie.

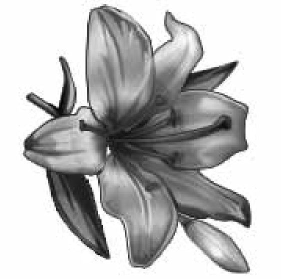
My Wanakita EXPERIENCE

by Jordan Cabral

I'VE BEEN GOING to Camp Wanakita for 10 years now. Through those 10 years I have learned so much. I have learned about becoming a leader, people skills and most importantly how to infuse by myself. These past two summers, I learned how to be a counsellor by participating in the Student Counsellor Program. This program is divided into two years. The first year student counsellors do more of the physical work. We achieve levels in all of the activities such as swimming and canoeing. The second year student counsellors focus on leadership and problem solving.

At camp they teach through experience. We hear from people who have had lots of experience being a counsellor. They share their stories of different problems they went through and proper ways to deal with them. For example, if a child gets hurt we apply first aid and bring them to the nurses' station. This program has been the best experience of my life. It has shaped me into a better person. It showed me the joys of life. What happened at camp doesn't just stay at camp. We bring those skills back home with us and teach them to our family and friends. Camp Wanakita has inspired me to become a great counsellor and I got to act on this as a youth leader at Just the Guys.

The people I have come to love and the knowledge I have gained live with me every day. The memories that I've gained over the 10 years at Camp Wanakita are truly unforgettable.



changing
possibilities in
hemophilia

HEMEROCALLIS
for hemophilia

by Jeenetha Kulasingam and Matthew Maynard

SWOR, CWOR AND TCOR had the opportunity to do a new fundraiser for their regions during the first week of September.

Dave Mussar from Novo Nordisk has a unique hobby of hybridizing daylilies and he generously offered to have us come and dig out plants from his garden and sell them as a fundraiser. We eagerly took him up on the offer and spent a Thursday digging daylilies from his beautiful estate. Plants were sold in all three regions at varying locations. TCOR sold these plants at the SickKids Farmers' Market and Mainstreet Markham's Farmers' Market. TCOR made $410 dollars that will be put towards programs.

SWOR presold many plants and raised a total of $600 for regional programs. There are a few left which can still be planted next spring ($10 per plant, five for $25 or 12 for $50). Contact Matthew or Terri-Lee at 519-432-2365 to get your plants next spring.

JUST THE GUYS A "Super" Duper Weekend

by Murray and Matthew Waboose, Thunder Bay

FOILING THE BEARDED BANDIT'S quest to sabotage our weekend was both fun and adventurous. On the first night we were split into teams with coloured bandanas. Our first task was to come up with a super hero team name, to stop the evil villain from ruining our weekend. We named ourselves the "Mean, Green, Coagulating Machines." Throughout the weekend, all of the teams participated in challenges to win clues. Each clue provided a brief hint of where the Bearded Bandit was hiding to elude capture. On Sunday afternoon, the Bearded Bandit was captured and finally got what he deserved. The kids enjoyed taking turns shaving his beard off and stripping him of his evil powers.

Murray and Matthew Waboose

The weekend was well planned and organized with numerous opportunities to share, talk, laugh and play together. Mealtime, cabin time and the group challenges gave us a chance to get to know one another and share personal experiences. The educational workshops gave fathers and sons valuable information on dealing effectively with bleeding disorders. It was a great opportunity for fathers and sons to build a special moment that could last a lifetime. The schedule gave Matthew and me an opportunity to spend some quality one-on-one time. A Saturday morning hike in the woods gave us a chance to talk and laugh together. I was also able to see how Matthew really enjoyed being in the woods. There was an uprooted tree, just off the trail. He told me, "This is where bears sleep." He also said that he wanted to go hunting sometime. I told him, "Perhaps, when you get older we might." Watching him play with sticks and jump over fallen trees and stumps was my highlight of the weekend. We hope other fathers and sons had special one-on-one experiences together as well.

Matthew and I would like to sincerely thank the planning committee, staff members of Hemophilia Ontario, workshop facilitators and the nurses on site. And finally, we would like to thank the other fathers and sons for sharing their time and experiences with Matthew and me. It is nice to know that we are not alone.

Jesse and Wesley Frank enjoy some waterfront time.

Just the Guys

by Alex McGillivray

IT'S A BIRD! It's a plane! No wait… it's Just the Guys Superheroes! From September 16-18, participants from all over the province came to enjoy a fun-filled educational weekend at Camp Ki-Wa-Y in St. Clements. Just the Guys is a program for boys ages 4-17 and an accompanying male role model who wants to take an active role in the boy's care.

Mark September 21-23, 2012 in your calendars.
It's the date of next year's Just the Guys weekend.
See you there.

Bleeding Disorders News

THE ONTARIO FACTOR CONCENTRATES
Redistribution Program

by Sarah Crymble, Hemophilia Provincial Coordinator

CLOTTING FACTOR concentrates are expensive fractionated blood products used primarily for prevention or treatment of bleeding episodes in patients with hemophilia and other congenital or acquired bleeding disorders. These products are distributed to patients through the hemophilia home care programs (self-infusion program) and are also kept as stock in a number of hospitals across Ontario. Hospitals will keep stock particularly when patients with factor deficiencies are known to be in the catchment area. When a hospital needs to administer a factor concentrate, it is often in an emergency situation in which there is no time to order the product from Canadian Blood Services (CBS) and wait for delivery.

The shelf life of factor concentrates is two to three years. However, since demand is difficult to predict, products may not be requested for use before their expiry date, resulting in product waste.

To ensure little to no wasting of expensive resources, the Factor Concentrate Redistribution Program (FCRP) was created in 2007. The Blood Programs Coordinating Office, a division of the Canadian Blood Services (CBS), is funding a program to eliminate waste due to outdating in the hospital transfusion services. The FCRP has implemented quality assurance procedures to ensure product safety during transportation. All products are transferred according to CBS standards and therefore will be safe for use when received for redistribution. This program was on a trial basis for six months starting May 1, 2007, but has been extended to the 2011/2012 year.

The FCRP's main goal is to eliminate the expiry of factor concentrates in Ontario. Through communication to all 156 hospitals in Ontario, the FCRP asks that all hospitals check their inventory on a monthly basis, to see if they have any product expiring within the next six months. If they do, they contact the FCRP program coordinator, Antonette Travas, to have the product shipped for use before expiring. St. Michael's Hospital, the largest Hemophilia Treatment Centre in Ontario, takes the lion's share of the product as they can use it quickly within their patient population.

To date, the FCRP has saved a total of 1,986,626 IU, resulting in over $2 million of savings.

For more information please contact Sarah Crymble at crymbles@smh.ca.

GENE THERAPY SHOWS PROMISE as hemophilia A treatment in animal studies

by Robin Nobleman

FOR THE FIRST TIME, researchers have combined gene therapy and stem cell transplantation to successfully increase factor VIII levels in sheep with severe hemophilia A, opening the door to the development of new therapies for human patients.

Researchers at Wake Forest Baptist Medical Center's Institute for Regenerative Medicine in North Carolina found that a single injection of genetically-modified adult stem cells in two sheep converted the severe disorder to a milder form.

For the study, the scientists first inserted a gene for factor VIII into engineered mesenchymal stem cells, a type of adult stem cell that has the potential to turn into bone, muscle or other cell types. The cells—acting as a carrier for the gene—were then injected into the abdominal cavity of the sheep. In the treated animals, the cells migrated to the joints and stopped ongoing bleeding. In addition, all spontaneous bleeding events ceased, enabling them to resume a normal activity level.

Lead author Christopher D. Porada, PhD, cautioned that challenges will need to be overcome before the treatment can be applied to humans. The sheep developed an immune response to the therapy because the genetically modified mesenchymal cells are foreign to the body; that could decrease its effectiveness and duration.

The importance of SCIENTIFIC RESEARCH

by Mojtaba Khezry

THE PROCESS OF scientific research may be simplified into a few steps but truly each step along the line requires blood, sweat and tears. Before a question is asked about how to improve technology or medication in the field, a researcher must go digging into published journal articles to see what has already been established. The researcher applies for a grant, which may come from taxpayer's money (i.e. a government fund), industry contributions, marketing firms or charitable organizations such as the Canadian Hemophilia Society.

The second step along the line is finding research provisions, which include laboratory equipment, dedicated research personnel and finally research subjects, which could be model organisms such as hemophiliac dogs or a select group of patients who would volunteer and participate in a study. In the most common type of study, called a randomised controlled trial, research subjects are randomly assigned to receive either the new treatment or a placebo which has no effect. Subjects and their doctors usually don't know which group they are in.

When you participate in a research study, many steps are taken to maintain your confidentiality. You are identified only by a number and your results are combined with those of other participants.

Finally, the research outcome has to be statistically validated. This involves comparing people who received the new drug to a control group who received a placebo. It's sometimes difficult to find a statistically significant difference between these groups in studies that involve human patients due to a low number of participants.

If the desired outcomes are achieved, the study may expand to question various other aspects of the new drug, such as safety and efficacy as compared to traditionally available treatments. If all goes well, it may take up to 10-15 years for a new treatment or product to reach the market.

This is the beginning of a *Blood Matters* series on participation in scientific research. Future articles will focus on each of the steps involved in scientific research.

Advocacy News

Canadian Blood Services **TO REVIEW BLOOD BAN**

by Robin Nobleman

CURRENTLY, men who have had sex with a man even once since 1977 are permanently excluded from donating blood in Canada based on their higher prevalence of HIV infection. On October 19, the Canadian Blood Services board of directors approved a motion to re-examine this policy to reduce the ban to between five and 10 years.

In the United Kingdom, a recent change to the policy makes it possible for men who have sex with men (MSM) to donate if they have not had sex with a man in the last 12 months. CBS is not considering this shorter deferral period as a risk analysis conducted by the McLaughlin Centre for Population Health Risk Assessment suggested a one-year deferral could introduce additional risk to the blood system. According to Ron Vezina, Director of Communications for CBS, there is no international scientific consensus on a favourable deferral period for MSM.

Given Canada's history of tainted blood, trust in the blood system is an important concern. The Canadian Hemophilia Society is not opposed to an eventual change in the deferral period but believes that any modifications must be made based on scientific evidence and good public health policy and result in a blood supply system that is as safe or safer than what currently exists.

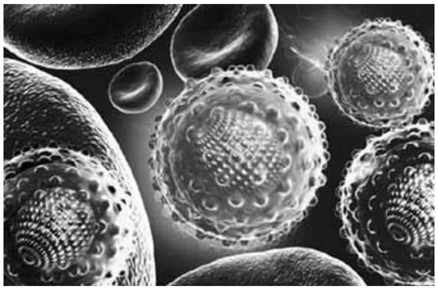
CBS will conduct research over the next few months with input from several groups including donors, patient groups, including the Canadian Hemophilia Society, the heads of various lesbian, gay, bisexual and transgender advocacy groups, as well as community members. CBS will ask Health Canada to have the MSM deferral changed by March, 2012 after it has collected data and received input from various stakeholders.

With information from Xtra Magazine *Ottawa (Noreen Fagan, November 2, 2011) and the Canadian Hemophilia Society.*

HIV AND HCV News

HIGH SUCCESS RATES for new HCV drugs

by Robin Nobleman



Hep C virus

TWO NEW oral hepatitis C-protease inhibitors, Vertex's telaprevir (Incivek) and Merck's boceprevir (Victrelis) were recently licensed for the treatment of chronic HCV in Canada. They both work by inhibiting HCV replication in the body. The new drugs are more effective at clearing the virus from the body than the standard peginterferon-ribavirin treatment alone, especially when treating genotype 1. In one study, treatment success rates for patients treated with Incivek and the standard treatment were 66 percent for treatment-naïve and experienced patients combined. Treatment-naïve patients had even higher success rates. Victrelis has been shown to triple the response rate in previous non-responders, and double response rates in treatment-naïve patients, and may allow patients to finish treatment sooner with response-guided therapy.

This is very promising news for the many people who have deferred treatment in anticipation of more effective drugs and the 50 percent of patients who do not respond to the standard treatment.

The possible benefits of these treatments must be weighed with their disadvantages. They are associated with side-effects and a complicated treatment regimen. Studies are ongoing about the effectiveness of the drugs for co-infected people, but early results are promising. Ask your specialist (hepatologist or gastroenterologist) about whether these treatments are appropriate for you.

Boceprevir and telaprevir are not yet covered by the Ontario provincial drug formulary. While the province makes a decision, other coverage is available for some people. If you have private insurance, it may cover these drugs. Also, under the 1986-1990 HCV Class Actions Settlement, the new drugs are covered when prescribed by a specialist. Prescriptions should be submitted to the plan administrator who can be contacted through www.hepc8690.com or at 1-877-434-0944. Those admitted under the Pre-1986/Post-1990 Hepatitis C Settlement Agreement are not covered by a treatment reimbursement mechanism, the lump sum compensation payment they received was meant to cover their present and future needs.

Clinic Corner

St. Michael's
Inspired Care.
Inspiring Science.

St. Michael's **HEMOPHILIA CLINIC STAFFING UPDATE**

by Georgina Floros, Nurse Coordinator

THE BLEEDING DISORDERS CLINIC at St. Michael's Hospital has undergone some changes in staff and we wanted to let you know about the people currently involved in your care.

Dr. Jerry Teitel remains the clinic's medical director, and he is now joined by Dr. Michelle Sholzberg to provide the physician care.

The nursing team is led by Georgina Floros who works full time in the clinic and is supported by two part time nurses—Joanne Solarski and Rachel He. Joanne has a long history with the clinic as she worked alongside Ann and Paul in the past. Rachel is newer to hemophilia but brings a wealth of general nursing experience to the program.

Antonette Travas has returned from her maternity leave after the birth of her son and continues to provide administrative and data managerial support to the program. Antonette is the person from whom you order your factor and who works to ensure a smooth process for those on the home infusion program.

Dr. Rachel Shupak, rheumatologist, has a regular monthly clinic that focuses on the musculoskeletal system. She is joined at that clinic by Caroline Jones, physiotherapist. The team has also gained a new member in Dave Hadley, physiotherapist, who works on the inpatient unit primarily, but is now available to offer some outpatient support to the program. Vashti Campbell is our social worker.

The first people you will see when you come to clinic are the receptionists for the 4CC North clinic area—Aziz Jiwajee and Janice Hayes.

The St. Michael's Hospital Hemophilia Staff are your partners in care. We strive to provide a supportive environment for health and wellness.

Canadian Hemophilia Society News

CHS Launches **WOMEN'S PROGRAM**

by Chantal Raymond

CODErouge
WHEN WOMEN BLEED TOO MUCH | POUR TOUTES CELLES QUI SAIGNENT TROP

CODErouge is the name of the new CHS women's program spearheaded by Dr. Rochelle Winikoff, director of the Women's Hemostasis Program at CHU Sainte-Justine in Montreal, with the financial support of CSL Behring. The CODErouge program aims to increase diagnosis and access to care for women and girls with inherited bleeding disorders. To promote this new program, a web landing page has been developed—www.coderouge-women.ca—which takes visitors to the newly revamped section of the CHS website called WOMEN.

The official launch of the program will take place at the first Canadian Conference on Bleeding Disorders in Women on May 25, 2012 in Toronto. This conference, hosted by the CHS, will be held in conjunction with the annual meetings of AHCDC, CANHC, CPHC and CSWHC.

CODErouge ambassadors will be identified in each province and sponsored to attend the conference and participate in a training workshop to enable them to help with the implementation at the chapter level.

Further details regarding CODErouge and the first Canadian Conference on Bleeding Disorders in Women will be posted on the CHS website. In the meantime, those interested in attending the conference are encouraged to reserve the May 25, 2012 date in their agendas.

World Federation of Hemophilia News

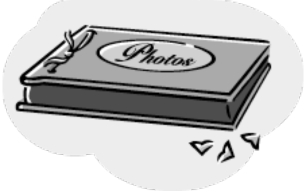
CITY OF LIGHTS to brighten 50th anniversary celebrations

by Craig T. McEwen, WFH Congress and Meetings Director

THE WORLD FEDERATION OF HEMOPHILIA (WFH) will celebrate in a big way in Paris, France, next year. The 2012 World Congress will mark the 30th anniversary of WFH Congresses and will also launch the WFH's 50th anniversary celebrations. Play a role in WFH history from Sunday, July 8 through Thursday, July 12, 2012!

Congress Program

The plenary lectures will focus on the international history of hemophilia and inherited bleeding disorders development, providing tribute to the many people in our community, both past and present, who strive to improve treatment and care throughout the world. The medical program will include new scientific research and clinical trials profiling future advances in treatment products and clinical care. The multidisciplinary track will deliver and discuss holistic patient healthcare issues, lifestyle opportunities, and provide approaches, if not solutions, for the challenges ahead. Women's and youth issues are highlighted throughout and there will be professional development workshops in publishing and clinical research to support the WFH's research program.



Be part of the WFH's 50th

The WFH will celebrate its 50th anniversary in 2013, but anniversary celebrations will be launched at the WFH 2012 World Congress in Paris. In preparation, we are gathering stories, photographs and memorabilia for a historical display and publication. If you have memories or memorabilia that you would like to share, please contact Elizabeth Myles at emyles@wfh.org.

Register Early

Some discounts are available for WFH members. Register online at www.wfhcongress2012.org.

Pharmaceutical News

Novo Nordisk AWARDS CUBAN PROGRAM

Based on "Cuban Program to Treat Hemophiliac Patients Wins Award," Cuban News Agency

THE NOVO NORDISK Foundation for Hemophilia, which supports hemophilia care in developing countries, awarded the Institute of Hematology and Immunology (IHI) in Cuba the Prize for the Project of 2010.

The award was presented to the Cuban group during the 22nd International Congress of the Latin American Group of Haemostasis and Thrombosis in Uruguay. Cuba was selected on the basis of optimizing care initiatives for patients that included both medical and awareness components.

During the congress, the IHI presented its achievements in the field and Dr. Jose Manuel Ballester, the president of the Cuban Society of Hematology and the director of the IHI, reported on the measures that Cuba has been taking to guarantee comprehensive medical care to the over 400 hemophilia patients who reside on the island.

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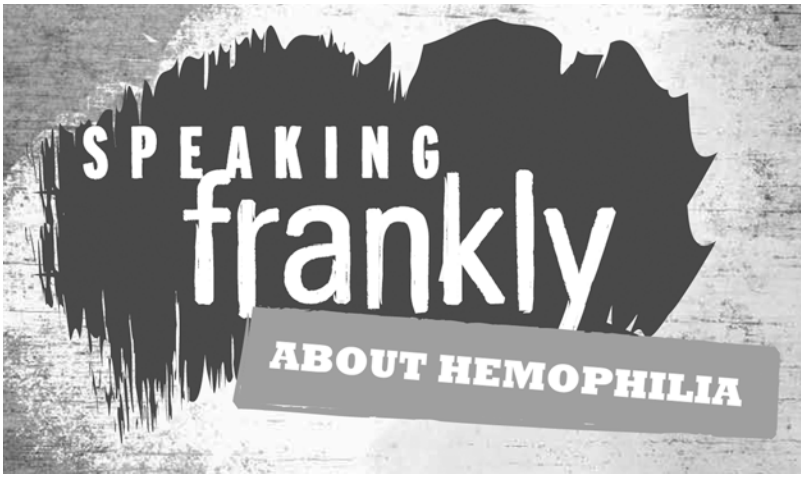
SPEAKING Frankly

TOOL FOR YOUNG ADULTS WITH HEMOPHILIA COVERS TABOO TOPICS SUCH AS SEX, DRUGS AND DEPRESSION



THE TRANSITION FROM adolescence to adulthood can be a difficult time filled with worries, questions and concerns that are especially difficult or embarrassing to talk about with family, friends or healthcare providers. For young men with hemophilia, this time can be even more challenging. To empower these young men as they become independent adults, Bayer initiated the Speaking Frankly about Hemophilia series of magazines to provide answers to some of early adulthood's most difficult questions.

Written by young men for their peers, the *Speaking Frankly about Hemophilia* series provides support and solutions that are credible, honest and relevant for the reader. Focusing on intimate, personal issues such as depression, anger, pain and rebellion, the series gives readers information that can enable them to better understand challenges they're facing. It also covers lighter topics such as travel, entertainment and lifestyle.

Speaking Frankly delves into sex and relationships, including information on how to talk about the disorder with sexual partners as well as key information such as safe sex practices. It also provides much-needed answers to questions like the safety of tattoos or piercings, the effects of smoking marijuana, and the potential health hazards of herbal supplements and over-the-counter medications.

Available through local chapters of Hemophilia Ontario and at hemophilia clinics, *Speaking Frankly* is a reliable source for answers to tough questions. There is also an online companion site, www.frankly.net that contains additional information, articles and resources. ♢

The sound , vibration, and excitment to see nothing but bikes as far as the eye can see !
Well that is happening with 18, 000 or 32 kms of nothing but bikes.
Come out and help Hemophila Ontario break the world record of the

LARGEST PARADE OF BIKES !

Saturday, July 21, 2012
Western Fair District, London, Ontario

REGISTRATION FEES: $30.00 for bike and $40.00 for bike with a passenger.
Fees include an official Guinness Ride T-shirt, secure motorcycle parking while you enjoy live entertainment (bands/comedians) contests and food. (Secure parking extends until 3 pm the following day.)
Early Bird Draw: July 1st 2012 (then the prices rise by $10.00 per person)

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

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

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

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

A great day of contests & prizes !

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

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

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

Ottawa and Eastern Ontario Region

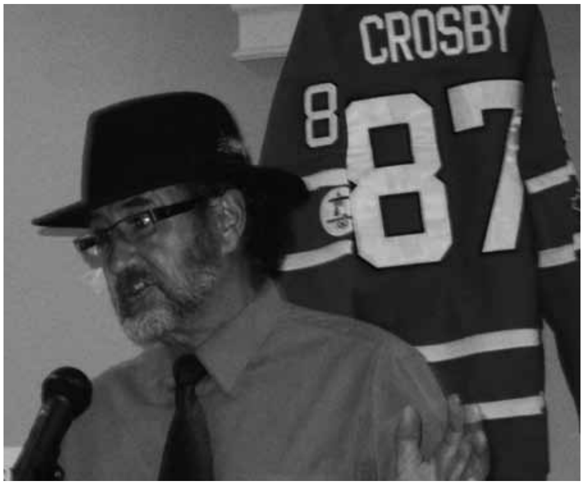
SHAWN DUFORD GOLF TOURNAMENT raises funds and awareness

by Steve Van Dusen, Chair of OEOR

OEOR HAD ANOTHER successful golf tournament in honour of Shawn Duford. It was a beautiful day and we were able to raise funds for our region towards financial assistance and support for our community.

Everyone had fun and it was educational as well, as we had questions on hemophilia at each of the 18 holes for participants to answer to win a prize. We passed out pamphlets on hemophilia to all the golfers to assist them in answering the questions. This activity is beneficial to all to understand the importance of bleeding disorders.

With activities during the day and donations from various companies, we were able to raise over $8,000 this year. As usual, silent and open auctions contributed to our success, emceed by our own Colin Patterson. Our police patrol was another success with volunteer time provided by our local heroes. Looking forward to one more year in 2012.



Colin Patterson

Nurse Sherry Purcell helps Santino do an infusion.

NEW AND OLD CAMPERS MIX at Camp Wanakita

IN 2011, OEOR saw encouraging and varied participation at Camp Wanakita. We had three new one-week campers in Yousef, Giovanni and Robbie. The following brave campers attended for two weeks: Omar, Kevin, Frederic, Mikaela, Sarah and Santino. Our three promising counsellors-in-training—Jordan, Cameron and Vincent—learned valuable leadership skills and perfected their swimming and canoeing techniques.

Now we have 13 campers at all three levels of involvement and experience. It is a very positive situation for the organization and for the future as these individuals will advocate, educate and promote the values and mandate of Hemophilia Ontario. Thanks to Lyanne and Jessica Cabral, Raja Ammoury/Alami and Bill Neill for volunteering and providing transportation supervision for our campers to and from Camp Wanakita.

Events Calendar

DATE	WHAT AND WHERE?
November 2011	Camp Wanakita registration pizza party
December 2011	OEOR Holiday Party
January 2012	Kingston education presentation

Regional Board and Staff

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

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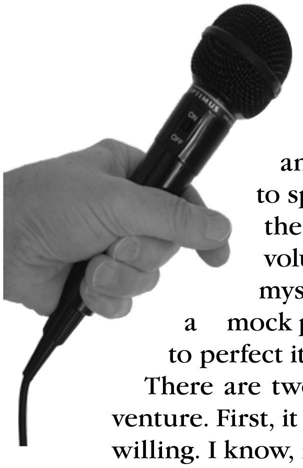
Toronto and Central Ontario Region

SPEAKING OUT for a good cause



by Samuel Leon

IT WAS ONE HECK OF AN EXPERIENCE for me to speak at Citizenship and Immigration Canada on October 5, 2011.

It all started when I received an e-mail from the Toronto and Central Ontario Region (TCOR) about the opportunity to speak at different Federal Government workplaces as part of the Healthpartners fundraising campaign. I replied to it and volunteered to be part of their Speakers' Bureau. I quickly put myself to work and wrote my speech. Of course, I went through a mock practice speech in front of the Regional Service Coordinator to perfect it.

There are two main reasons that pushed me to be part of this kind of venture. First, it was a desire to give back to the community that made me so willing. I know, it might sound like a cliché when I say this but I really mean it. Growing up in Haiti, there was no effective treatment available for my physical condition. It was really hard and precarious on a daily basis to deal with it. Since I came to Canada, not only did I find treatment (Factor VIII) but I also found TCOR. TCOR helped me in many areas for which I will be forever grateful. One example is the financial assistance they provided me for an orthopaedic shoes prescription, much needed to alleviate my joint pain. I couldn't think of a better way to express my gratitude than to volunteer at the Canadian Hemophilia Society. I have lived with hemophilia for over 25 years now and therefore feel it's important to encourage people to donate in order to help others with inherited bleeding disorders.

The second reason was actually that public speaking was a way to squash my timidity. That one may sound funny but that does not make it less true. Speaking in front of an audience of 50 people or more might look frightening. But I must say this: one way to solve a problem is to step up and confront that problem. My philosophy was that all the great speakers in the world went through this before owning the microphone. Although I panicked a little bit, that day I spoke louder than ever before because I knew what I was saying and was greatly convinced of the seriousness of this noble cause.

I look forward for the next opportunity.

To volunteer for next year's Speakers' Bureau, contact Robin Nobleman at rnobleman@hemophilia.on.ca. 💧

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

Contact Information

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Toll free: 1-888-838-8846

CAMP WANAKITA Registration and HOLIDAY PARTY

THE YMCA CAMP WANAKITA Bleeding Disorders Program coordinated by Hemophilia Ontario is an excellent opportunity for your child to gain increased autonomy through self-infusion while making friends and having fun in a fully integrated camp environment. With onsite hemophilia nursing staff, safety and education are at the forefront of the Camp Wanakita experience. Camp Wanakita is not just an opportunity to have fun; it's an opportunity for your child to expand his/her horizons, while also providing needed respite to caregivers. Although self-infusion teaching is a key component of the camp program, Camp Wanakita is open to all children between the ages of 7-16 living with a bleeding disorder in Ontario regardless of severity.

Like many parents and guardians, you may have many questions and concerns about the camp experience. TCOR would like to provide you with a chance to have your questions answered by inviting you to attend our Camp Wanakita Registration and Holiday Party on the afternoon of Saturday, December 3 at the 519 Community Centre in Toronto (519 Church Street at Wellesley Street). 💧

REMEMBERING the tainted blood tragedy

by Jeenetha Kulasingam

ON OCTOBER 15, 12 TCOR members volunteered to plant trees at a public planting in Heathercrest Park as a fitting way to commemorate the tainted blood tragedy. A private ceremony followed afterwards with a moving speech by Antonia "Smudge" Swann. The trees planted at the park were a symbol of the strength and resiliency in our community. The occasion allowed for reflection and a sense of inner peace while bringing together long-time members for a chance to reconnect.

Thank you to all that came out that day to remember the past while working towards building a stronger community.

BINGO!

by Susan Turner

TCOR IS FORTUNATE to be licensed to run Bingos at the Delta Bingo Hall in Toronto. Funds raised support different programs and permit TCOR to provide community members with financial assistance for many medical and treatment-related expenses that are not covered by OHIP or private medical insurance. In 2011 our Bingo funds covered:

- Camp Wanakita registration fees for 14 TCOR campers
- Orthotics
- Dental
- Travel to medical appointments at St Michael's and Sick Kids clinic
- Hospital parking
- Medication
- Medic Alert Bracelets

We are always looking for new volunteers. If you can spare 4½ hours on a Saturday morning once a month, you could help TCOR keep our Bingo running well and support the current volunteers who have been running the Bingo for many years.

Events Calendar

DATE	WHAT AND WHERE?
December 1	World AIDS Day Community Carnation Memorial
December 3	Wanakita Registration and Winter Party
March	Annual General Meeting

▲ *The prize for the lowest score was awarded to the foursome of (L to R) Bob Gibson, Randy Neal, Ivan Leong and Stephen May.*

Hemophilia **GOLF CLASSIC**

by Susan Turner

THE 12TH ANNUAL TCOR Hemophilia Golf Classic took place on June 27, 2011 at DiamondBack Golf Club and it was a beautiful day for a round of golf. An enthusiastic group of 44 golfers came out to support the programs and services of TCOR.

After a great day on the course the group gathered for a dinner, auction and presentation of golfing awards. Bradley Golding, a youth from the TCOR community, spoke eloquently about how TCOR provided him with the opportunity to attend Camp Wanakita and the positive impact this had on his life.

The prize for the lowest score of the day was awarded to the foursome pictured above. A special prize was awarded to our most honest foursome of the day: Dave Mussar, Veronica Carson, Bob Forsyth and Liz Sugerman.

TCOR staff, board and golf committee would like to thank all those that came out and helped to make the day a true success. The 2011 Hemophilia Golf Classic raised more than $8,000 to support programs and services for the TCOR community.

VOLUNTEER Spotlight

ROB DINSDALE JOINED US as a volunteer in 2011 after attending CWOR's Regional General Meeting in March. While Rob is not a board member, he has enthusiastically volunteered his time, efforts and expertise at each of our meetings since.

Rob was selected as a candidate to attend the CHS Rendezvous Conference in Calgary, AB this past May. I had the pleasure of sitting with him during many of the conference's wonderful education sessions. I could see the gears of his mind turning and I knew he was going to take the information he was learning and put it to good use. After he attended a focus group on aging with a bleeding disorder during the conference, he came to me and said that our region should have a program like this. Naturally, I couldn't resist, and Rob has been a guiding force in the creation of CWOR's upcoming Aging with a Bleeding Disorder program for 2012.

Rob is always willing to lend a helping hand. He has written numerous articles for *Blood Matters* as well as *Hemophilia Today* on the topics of aging and careers. Rob also dedicates his time to local events. He and his wife Jane recently gathered a plethora of donated items for the Big Sale on the Little Street fundraiser, and they even volunteered their time to help run the event. They've already volunteered to help out for our annual holiday event.

The Region and I would sincerely like to thank Rob for all of his hard work and dedication. Without volunteers like him we would not be able to provide the growth and services that we do. Please join us in celebrating Rob and all of his volunteer efforts. ◊

THE BIG SALE
on the Little Street

by Mary Pedersen

THIS WAS MY FIRST FUNDRAISER for the Central Western Region of Hemophilia Ontario. The event owed some of its success to the extra activity of the Locke Street Festival, but the yard sale could not have happened without the generous donations of goods from Julia Sek, Jane and Rob Dinsdale and their friends. I would like to thank my volunteers, Jane, Rob, Igor, Alex and Nola, for making it a fantastic day. Thanks to my very young volunteers Robin and her brothers William and Oliver for all their effort. This event raised $500 towards our regional programs. ◊

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

Regional Board and Staff

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Igor Ristevski
Dane Pedersen
Jace Pedersen

Alexsandra McGillivray –
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GET INVOLVED: Join us at our Community Meetings

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

Events Calendar

DATE	WHAT AND WHERE?
December 10	Holiday and Wanakita Registration Party
February/March	Regional General Meeting

NORTHERN ONTARIO Presentations

WITH NORTHERN ONTARIO being such a large area and the two Hemophilia Treatment Centres located so far apart, it became apparent that smaller hospitals needed some input on how to treat our clients with bleeding disorders. When these patients came into the emergency department or for surgery, many had difficulty getting the treatment that they needed. We decided to present the basics of hemophilia and VWD, and the importance of the Factor First card with a question-and-answer period for both clinicians and families.

In Thunder Bay, hemophilia nurse Karen Roberts has done several presentations in the emergency department and the pediatric and surgical departments within the hospital to raise awareness of the importance of care and treatment when patients present to hospital.

Betty Ann Paradis and Teresa Genereux of Sudbury presented at Timmins Hospital in August where the emergency and blood bank staff attended along with parents. In the first week of October, Betty Ann and Teresa ventured to Sault Ste. Marie to do two Northern Presentations with the emergency department and blood bank staff. The second year nursing students also attended.

Bobbi Rushon, a mother from the area, stated, “The presentation at Sault Area Hospital was informative and inspiring. It has been some time since SAH has been privy to an in-service on the subject of bleeding disorders. It was a diverse crowd, and the information was presented in a way that everyone understood and came away with new information. Even me!”

Overall, the presentations were a success. What came across most is that all clinicians need to be aware of the symptoms, available testing, the Sudbury and Thunder Bay Hemophilia Treatment Centres, and that affected individuals need understanding and extra care at critical times. 💧

BLEEDING DISORDERS AWARENESS Month in the North

NOVEMBER IS Bleeding Disorders Awareness month. The NOR has blood drop pins made by Cynthia Pulsifer. We are asking for a minimum $5 donation for each pin to raise funds for our region. Alana Brassard from Sault Ste. Marie will be hosting a third party fundraiser to raise awareness in November. 💧

Fun at FALL CLINIC DAYS

SUDBURY HOSPITAL held its fall clinic on October 15. It was a fun-filled day, with our volunteer, Danika, making paper puppets with the children while they waited to see the doctor and get blood work. This gave parents the opportunity to visit with the pharmaceutical representatives. After a long day at clinic, Hemophilia Ontario held a buffet dinner at Perkins for our clients. Betty Ann Paradis did a presentation on navigating the emergency department.

On October 31 and November 1, Thunder Bay Hospital held its fall clinic with a Halloween costume theme. Hemophilia Ontario passed out goody bags to the children and hemophilia nurse Karen Roberts did a Lunch and Learn on emergency department strategies. 💧

Events Calendar

DATE	WHAT AND WHERE?
November	Bleeding Awareness Month
December 1	World AIDS Day
February	Winter Carnival

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

Regional Board and Staff

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Betty Ann Paradis
Kristopher Onucky
Kaitlynn McDonald
Cassie Green
Brad Pearson
Alana Brassard
Chad Bizier
Tammi Deveau
Stephanie Gray

Teresa Genereux, Regional
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Levack, ON P0M 2C0

South Western Ontario Region

Winners of the 333

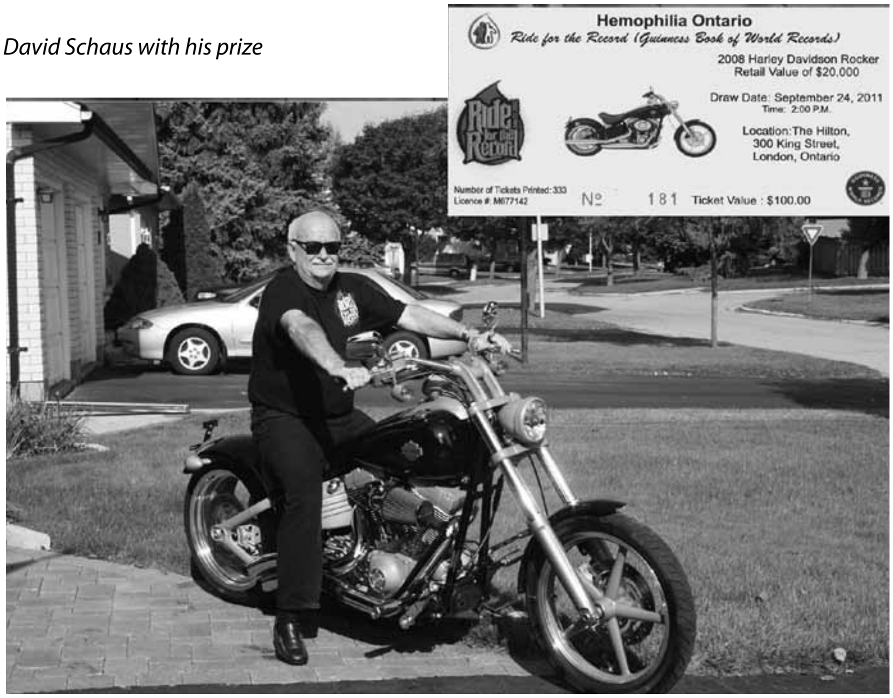
DRAW FOR THE ROCKER

THE SOUTH WESTERN Ontario Region of Hemophilia Ontario is pleased to announce the winners of the 333 Draw for the Rocker:

- First Prize Event – 2008 Harley Davidson Rocker: David Schaus, London, ON
- Second Prize – $100: Wayne Cocker, London, ON
- Third Prize – $100: Kevin Williams, New Hamburg., ON

The draw was hosted by The Hilton, London, ON and conducted by Bill Paul, better known as the Town Crier for London. We would especially like to thank all the volunteers and members who helped with this raffle. We also thank Evans Service Centre of Hanover, Ontario. ◊

David Schaus with his prize



Hemophilia Ontario

Ride for the Record (Guinness Book of World Records)

2008 Harley Davidson Rocker
Retail Value of $20,000

Draw Date: September 24, 2011
Time: 2:00 P.M.

Location: The Hilton,
300 King Street,
London, Ontario

Number of Tickets Printed: 333
Licence # M677142

№ 181 Ticket Value : $100.00

RIDE FOR THE RECORD July 21, 2012

IF YOU KNOW of a motorcycle show, belong to a club, or go to a swap meet in your area, we would like to hear from you. We hope to have 18,000 motorcycles in the Ride for the Record to set a new world record for the number of motorcycles in a parade.

Please send along the show or club information to Brendon Beer, 519-630-7223, beerzieuswa@yahoo.ca or contact Matthew Maynard at 519-432-2365, mmaynard@hemophilia.on.ca. ◊

All articles in this section, unless otherwise indicated, are by Matthew Maynard.

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

Matthew Maynard, Regional Service Coordinator
Terri-Lee Higgins, Acting Program Manager
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519-432-2365
thiggins@hemophilia.on.ca

Events Calendar

DATE	WHAT AND WHERE?
December 5	SWOR Winter Celebration – Windsor
January 25, 2012	London Knights Hockey Game 50/50 Draw
July 21, 2012	Ride for the Record, London

PINECREST Adventures Camp

by Terri-Lee Higgins

SEE A LION ROAR and a giraffe sing. Watch King Kong battle an airplane for the girl. Beware the wicked witch... Hooray for Hollywood was the perfect chance to see and share these silver screen moments this summer at Pinecrest Adventures Camp. Sixteen first-time campers discovered what the 26 returning campers already knew—the five days at camp are the best of the summer. The fabulous volunteer staff stepped up to ensure this year exceeded expectations. Whether leading the way into the pool for the polar bear dip, diving face first into a plate of mac and cheese, getting loud and crazy at campfire or holding a hand when needed, they made camp seem effortless. Friday night was our first ever Drive-In campfire run by the LITs. Buzz Lightyear and Woody tested our *Toy Story* trivia; *Jersey Shore* showed us what it takes to be ready for a night out. We learned about the songs that didn't make the hit list (*Who Let the Cats Out?*) but inspired megahits; saw the *Ghostbusters* trap a ghost, and yes Frances, Nick shaved off his moustache during the moustache song. ♢

Sarah and Adryanna during Twin lunch.

GOLF TOURNAMENT
version 4.5

by Terri-Lee Higgins

BEAUTIFUL, WARM SUNSHINE was the order of the day as we finally began the postponed Golf Tournament for hemophilia and other inherited bleeding disorders at the Highland Golf and Country Club in London.

Forty-eight golfers took to the links in support of SWOR, participating in various contests throughout their golf game. Following our roast beef and Yorkshire pudding buffet dinner golfers watched the Pinecrest video and campers Nicholas and Courtney shared why Pinecrest Camp is such an important part of their summer.

Thanks to our amazing volunteers, the tournament committee, the staff at Highland, and last but not least our numerous sponsors. We couldn't have done it without you. ♢

VOLUNTEERS not 'voluntold' in SWOR

by Terri-Lee Higgins

INDIVIDUALS OF ALL AGES share the gift of their time, skills and expertise to keep SWOR a strong, viable region. From participating on the board of directors and the various committees, volunteering at events, or helping with office administration, volunteers make a difference every day. Our boards and committees guide our region. Camp and event volunteers plan and implement a variety of activities and games, while admin makes sure mailings are completed and out on time.

When asked how much time SWOR expects their volunteers to share, I always answer with, "How much time do you think you can share?" A few hours a year gets a mailing ready or runs an event. A few hours every month builds a fundraiser, plans camp, or guides the region. It's really a matter of whatever time you're willing and able to donate.

One year is winding down, another is on the horizon. Before the end of the year, everyone will receive a schedule of planned events for 2012. Check your calendars to see what suits your schedule and step up and volunteer. Will 2012 be your year? ♢

Youth Adventures **MAKES THE MOST OF SUMMER**

by Robin Nobleman

HEMOPHILIA ONTARIO'S new and innovative youth program brings together young people with bleeding disorders from TCOR and CWOR to try out new outdoor recreation activities. In collaboration with McMaster University's Altitude program, the Youth Adventures group challenged themselves on a 50-foot swing in July and went canoeing in September. For the last event of the year, the group met in Toronto for a Personality Dimensions training by Terri-Lee Higgins where they learned more about their "colour type" and how best to work with others of different types. Later, the group of 12 youth planned next year's Hemophilia Ontario Youth trips and then let loose with bowling and billiards.

Several members of the Youth Adventures group are now involved as volunteers with Hemophilia Ontario or their region. We look forward to getting young people from around the province involved through next year's youth program. ♦

L to R: Kaylin, Robin, Tiffany, Alex, Josh, D'Marc and Allan

Youth Perspectives

Jordan and Ryan lead an activity at Just the Guys

Here's what our **YOUTH LEADERS HAVE TO SAY**

"JUST THE GUYS was an amazing weekend. It was a privilege to be able to volunteer there. By taking part as a youth volunteer, I was able to help boys who have hemophilia just have fun and be kids, as well as help male caregivers learn to take care of their boys with hemophilia. The event had a variety of activities – from archery, to swimming, to educational sessions, to the well loved hockey games during every spare minute of free time. The weekend was a huge success, with a large attendance of both old and new families. It was great to see connections being made between families from around the province as well as between fathers and sons."

Ryan Kleefman, SWOR

"THIS YEAR I attended Just the Guys as a youth volunteer and had an amazing time. Just the Guys is a wonderful event, filled with extremely important information. I learned lots of stuff that could have helped me and my family when I was growing up. I believe every hemophiliac child should go to this event. It is a great opportunity to meet new friends, have the time of your life and learn to live and deal with hemophilia. I am really grateful to have been a part of this experience. Being a leader at the event was extremely rewarding. I learned how to problem solve and to become a better leader. I was surrounded by amazing staff and volunteers who were all willing to teach and learn. It was a once-in-a-lifetime experience and I'm looking forward to doing it again."

Jordan Cabral, OEOR

"BEFORE BEGINNING as a Youth Volunteer at the 2011 Just the Guys weekend, I had many feelings of uncertainty and anxiety due to my unfortunate lack of previous participation in any Hemophilia Ontario events. Since being diagnosed with hemophilia at the age of seven, I felt that as long as I did not participate in any hemophilia-related events I might have been able to try and forget that I had hemophilia. Attending this weekend has opened my eyes to the fact that I am not alone in feeling this way. Sitting here now, after experiencing an amazing weekend with the hemophilia community and meeting incredible people, I feel a deep sense of regret that I had neglected something so important to my development as a hemophiliac and as a person.

> *I feel a deep sense of regret that I had neglected something so important to my development as a hemophiliac and as a person.*

The Just the Guys weekend showed me something I had never seen before: the deep friendships and sense of community that lie within the hemophilia community. From the moment I arrived I was welcomed with open arms and was able to quickly feel at home meeting all of the new faces, from the wonderful fathers and sons to the Hemophilia Ontario staff and the other youth volunteers. The best memory of the weekend was definitely the Fashion Show challenge, where everyone let loose to have a great time; being a judge made me surprisingly more attractive! The Just the Guys weekend was definitely a life-changing event for me and showed me that no one should ever hesitate to get involved. So get involved! Thank you to everyone who made this weekend a success. I'm looking forward to September 2012!"

Zach Adams, TCOR 💧

Why am I INVOLVED?

by D'Marc Lewis

I FOUND THAT getting involved has never been the result of a pressure tactic, or something obligatory. Funny enough, I started (even with all the calls the societies do for help) when a retired nurse actually suggested I volunteer with TCOR's Bingo. I figured I had nothing to lose. And all the volunteering that followed suit helped land me my first job, got me my volunteer hours for high school, and helped me realize the essentials of community, hospitality and customer service. Contributing to this magazine, Photovoice, and annual retreats all have their benefits. Now, if only it could have me driving off in a Hyundai at the Superbowl... Really, it's all about giving back to the community, *n'est-ce pas*?

I plan for the near future to continue my tenure here. My next objective is to change this bloody picture I had them put up. I look like a ruffian about to get deported. Maybe I should wear a tie. Hmm, the clot thickens. All I can say at this point is that there are benefits and challenges. So I ask you now, will you step forward and get involved?

Keep the peace. 💧

D'Marc Lewis

Amy Griffith

An opportunity to GIVE BACK

by Amy Griffith (VWD type IIA)

I REMEMBER WHEN I FOUND OUT I was diagnosed with VWD. Granted, I did not know a whole lot about what was going on – foreign medical terms, lots of needle pokes, long hours at the hospital with my parents, and lots of different people telling me what seemed to be the same thing over and over again. I remember what it felt like to be told I was "different," or as Sick Kids put it, "special." I was not happy about it. I didn't want to wear a bracelet that gave everyone permission to treat me as if I was breakable.

> *The number one support system for us was TCOR and Hemophilia Ontario.*

Now that I'm older, I have a greater understanding not only of my own disease, but I'm also well aware of all the support my family received during those first few years when we hadn't the faintest idea what the next day would bring. The number one support system for us was TCOR and Hemophilia Ontario. We began by attending Families in Touch picnics, information sessions at the Ontario Science Centre, and I started my first of 10 years at YMCA Camp Wanakita. My mother and I fundraised and competed in the Toronto Marathon as team members on the Hemophilia Ontario relay team, and I started volunteering with the kids that I used to play with at the family picnics. Today, I find myself speaking at the Wellness for Women conferences and writing for *Blood Matters*, while my mother plants trees for the victims of the tainted blood tragedy.

For my family, Hemophilia Ontario was reassurance from so many different people that our family was going to be okay. The main reason I choose to stay as involved as I am is because I feel that it is the least I can do. That diagnosis is a scary thing for everyone involved. Your whole life is about to change, and Hemophilia Ontario members and coordinators have the resources, stories and outlets that you need to start to believe it will all work out in the end. When *Blood Matters* was created, I saw my opportunity to truly give back. As an individual affected by VWD, I had a lot of questions that no one could answer for me. Now today looking back, I've "been there and done that," and *Blood Matters* is a chance for me to share those experiences with other affected youth out there with those same pressing questions and concerns. For me, that is the best resource that anyone who is affected, or knows someone affected, can have.

Why **NOT?**

by Holly Valenta

WHY VOLUNTEER? Why take time out of your day to do something small and impactful for someone else? Why take time out of your summer and time off from your job to spend a week chasing kids around? Why give up a weekend to fly to a conference? Why not?

I've been volunteering for SWOR for about three years. I started off as a Leader In Training at Camp Pinecrest and worked my way up to camp counsellor and then to Spirit leader for the past two years, as well as recently becoming a member of the National Youth Committee and a member of our Regional board. When I started as a camper at Camp Pinecrest in 2001 I noticed right away that the counsellors seemed to really love what they do and the nurses and staff not only had a drive for their work, but a passion for what they did. As the years went on, like any kid, I decided I wanted to grow up and become my childhood superhero. I knew I would become a nurse.

So naturally I wanted to become as involved as I could in the Hemophilia Society. It's hard for me to relay in text how passionate I actually am about the volunteer positions that I hold. It's hard for me to try and tell you how every single staff, doctor, nurse and camp counsellor is so amazing, unless you've already met them yourself. It's hard for me to make you understand how much of an amazing and deserving cause this is, unless you already know. I have learned so much about myself from the people involved in SWOR and they all have impacted my life in such significant ways that I can honestly say I wouldn't be the person I am today without their influence.

Holly Valenta

Volunteering does a lot for one's self. It allows you a way to focus your time and energy on something other than yourself. The experience teaches you that the world doesn't revolve around you, but that even someone like you has the ability to make a difference in the world.

"Unless someone like you cares a whole awful lot, nothing is going to get better. It's not." ~Dr. Seuss

Thank You to...

Wellness for Women

- W2 Committee and the volunteers for all their hard work in helping with the success of W2
- Pharmaceutical partners Baxter, Bayer, CSL Behring, Pfizer, and Octapharma for their generous support
- Purdy's Chocolates and The Keg Steakhouse for prize donations

Camp Wanakita Bleeding Disorders Program

- Our supporters, Bayer, Baxter, Novo Nordisk and Pfizer, who make it possible for children in our community to attend camp
- Pfizer who financially supports four leadership roles at camp

Just the Guys

- Karen Strike, Linda Waterhouse, Georgina Floros and Lisa Thibeault who provided excellent educational sessions and nursing care over the weekend
- Our major sponsor Bayer Pharmaceuticals for making this event possible
- Home Depot Ancaster for donating supplies to build model arms

TCOR's Golf Tournament

- Golf Committee: Maury Drutz (Chair), Mike Beck, Gerry Mudge, Don Tucker and David Neal
- The dedicated team of tournament volunteers who ensured that the day ran smoothly: Marc LaPrise, James Beckwith, Claire Cronier, Samuel Leon and Mojtaba Khezry
- David Goodman who donated his time and effort to run the "Beat the Pro" contest
- Shaun Bernstein who did a fantastic job as our MC at dinner
- Our sponsors: Bayer, Pfizer, Novo Nordisk and CSL Behring
- Hole Sponsors: Perry Bitterman, Martine Celej, Captain Printworks, Dr. Julian Geller, Strype Barristers, Neal and Smith, Barristers and Solicitors, Av Reps, Marinucci & Company, SCS Consulting

TCOR Bingo

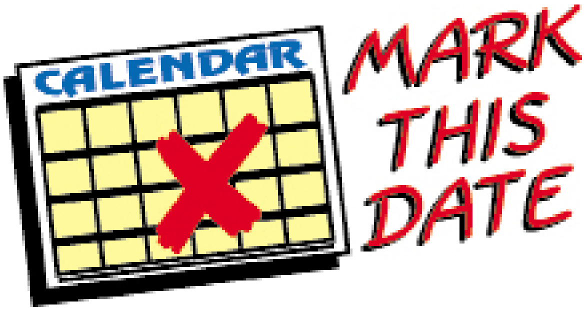
- Our current Bingo volunteers Gloria Allain, David Neal, Randy Neal, Joan and Murray Kinniburgh, Phyllis Gray, D'Marc Lewis, James Beckwith and Maury Drutz

Pinecrest Adventures Camp

- Our sponsors Baxter, Bayer, Novo Nordisk and Pfizer
- Beta Sigma Phi Sorority for purchasing the Oscar figurines and saving the tuna cans, paper rolls and cardboard for crafts, and World Class Carpets in London for donating carpet rolls that became palm trees and spotlights

SWOR Golf Tournament

- The Tournament Committee: Travis, Lynda, Fred, Maureen, Charlie and Matthew for your countless hours
- Event Sponsors: Pfizer, Source for Sports, Bayer, Baxter, Novo Nordisk, London Police Association, Rocky's Harley Davidson, May-McConville Insurance
- Hole Sponsors: Acorn Landscape, Walmsley Brothers, Jake L's Grammie and Gramps, The Maynard Family, Creston House, Cando Contracting, London Professional Firefighters Association, Western Fair District, the Navigators, Ozen
- Prize Donors: Aquascape, Cando Contracting, Dr. Brad Carson (Sunningdale Dental), Catton family, C&M Liquidators, Christine Ross, CIM, Country Paws, Curry's, Gift Fairy, Goodlife Fitness, Susan Gray, Hartz Canada, Kathleen Hazelwood, Travis Hazelwood, Hannah Higgins, Jim Higgins, Hilton London, Jam Sessions, Knowledgeshare, Magna, Toyota, Pioneer Hybrid, Proable Hardware Specialties, Silver Spoon, Smoke N Bones, Spectrum Photography, Stover Chiropractic, Mike St. Peter, the Stoltes, Waseikai, Walmsley Brothers Ltd.



Hemophilia Ontario Calendar 2012

DATE	WHAT AND WHERE?
April	Hemophilia Ontario Annual General Meetings
July 21	SWOR Ride for the Record
July 29 - August 4 ~ Section C1 August 5 – 11 ~ Section C2	Camp Wanakita
September 21 – 23	Just the Guys Weekend
October 19 – 21	Family Camp

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