

A publication of



Hemophilia Ontario
Hémophilie Ontario

BLOOD

matters

"We're all related by blood."

Volume 3 • Number 2

Summer 2012



Staying Fit and Healthy:
Safe sports and exercise

Hemophilia Ontario

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Hémophilie Ontario

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*Cover photo: Boys staying active at Just the Guys camp by
playing a game of Run and Scream.*

Photo credit: Terri-Lee Higgins

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Leadership Messages



Paul Wilton

PRESIDENT'S Message

by Paul Wilton

HEMOPHILIA ONTARIO is very pleased to announce that Terri-Lee Higgins has accepted the position of Executive Director of Hemophilia Ontario, effective April 30, 2012. Terri-Lee, very well known to the bleeding disorder community, has been with the organization for five years, including the last 15 months as Provincial Program Manager. She has proven her ability to work effectively and collaboratively with volunteers and staff, corporate partners and health care provider teams in Ontario's nine bleeding disorder clinics.

Terri-Lee has over 20 years experience in the not-for-profit sector, including work with the London Association for Adults with Disabilities and Community Living London.

The new position of Executive Director combines the roles of Provincial Program Manager and Executive Director.

Thank you to David Page, Interim Executive Director, CHS President Craig Upshaw and all the CHS staff for their support during this time of transition. The close links developed between the national office and Hemophilia Ontario will endure.

On behalf of Hemophilia Ontario and its members, I wish Terri-Lee a long and productive term as Executive Director. ♦



Terri-Lee Higgins

EXECUTIVE DIRECTOR'S Message

by Terri-Lee Higgins

IT IS WITH GREAT HONOUR AND EXCITEMENT that I write my first report to you as Executive Director of Hemophilia Ontario.

Our organization weathered many changes in 2011, and 2012 is shaping up much the same.

- The Ontario Board welcomed new members at the AGM; together we will continue to build a stronger and more cohesive organization
- Staff continue to offer regional and provincial programs despite declining program sponsorship
- Staff will change in September as Robin Nobleman goes on to law school
- TCOR will officially amalgamate with Hemophilia Ontario by December 31, 2012, becoming a region of the provincial chapter

The Ontario Board of Directors and staff show care, concern and dedication to serving our members and this drives our communication, behaviour and actions. By meeting member needs, we achieve our purpose, resulting in more personal fulfilment and appreciation for our contributions.

It takes courage to be accountable, to not cover up, escape or pretend, to admit what doesn't work and trust that as an organization we have the strength and resources to eventually find solutions. What I have appreciated about working with the Ontario Board over the past year is their willingness to consider new possibilities, embrace creativity and see things from a new perspective, and it is my personal opinion that we are stronger as a result. I look forward to the upcoming year and the challenges it will bring. ♦



Shaun Bernstein

Message from the EDITOR – Time to Get a MOVE ON!

by Shaun Bernstein

A **BLEEDING DISORDER** can be a strange beast. You'd be hard-pressed to find a patient who hasn't, at one point or another, felt older than their years, especially during a bleed. I've been blessed with wonderful health, and yet even on my best of days still endure the sore ankles, stiff knees and tender elbows not uncommon in my peers. Again, I would not begin to complain for a second—it's simply a fact of our lives.

This is precisely why healthy living is so important. People with bleeding disorders are living longer today than ever before, and in many cases well into old age. We've reached an unprecedented point in this community where our lifestyle choices are more and more our own, and not simply a matter of circumstance. Due to these changing demographics, we're living long enough to see the impact of the lifestyle choices we make, starting in our youth and carrying well through adulthood.

In many cases, these can be negative choices that affect us. Personally, I speak with shame and regret about the toll the excess weight I gained as a child has taken on my joints now, and the challenges I've had recovering both my health and my mobility. For others, injuries obtained from taking unnecessary risks have resulted in a lifetime of bleeding-related consequences that could have been easily avoided.

Healthy living, however, is one of the smartest moves we can make in the bleeding disorder community. Proper nutrition and moderate, safe exercise can do wonders, not only for maintaining one's overall health, but especially the health of one's muscles and joints. While physicians can sound repetitive stressing this, the proof is in those individuals who have made smart choices, and have the mobility to show for it.

As patients, we already have enough restrictive challenges in the way of healthy living. Take control wherever possible, and get outside and play this summer.

On a more personal note, this will be my last issue at the helm of *Blood Matters* as I brace myself to begin law school this fall. I want to offer my sincere gratitude to all of our authors and volunteers, and especially our top-notch editorial team. I couldn't have done it without you.

Have a pint on me. ♦

Hemophilia Ontario News



CHEO Nurse Diane Bissonnette and Jordan Cabral, recipient of the Leader of Tomorrow Certificate

Hemophilia Ontario ANNUAL GENERAL MEETING – April 21, 2012

by Terri-Lee Higgins

OTTAWA hosted our 56th Annual General Meeting on Saturday, April 21, 2012 with more than 50 people attending. The morning education sessions provided the opportunity for valuable insight on advances in treatment and care, and suggestions on improving our self-advocacy. Dr. Robert Klaassen, Hematology Director of the Children's Hospital of Eastern Ontario (CHEO) and an extensively published author on the quality of life for children with bleeding disorders and cancer, presented exciting advances in care and new studies. Dennis Garvin, Specialist in Patient Advocacy, reinforced that you are the only person who can raise concerns about your care. Participating on a Patient Experience Committee provides the opportunity to have your voice heard. Thank you to Dr. Klaassen and Dennis for your engaging presentations and for your time.

The Annual General Meeting led by President Paul Wilton, provided highlights of the year including rebuilt partnerships with CHS, the regions, funders, volunteers and the membership, as well as the updated governance and operational policies. Paul recognized the Policy Committee for their time and commitment to this project. David Page, completing his contract as Interim Executive Director, thanked the outgoing Board of Directors and Provincial Staff for working diligently through the past year's challenges. He stated that the efforts of all have resulted in a stronger, more streamlined chapter as supported by the presented audited financial statement. The Toronto and Central Ontario Region's (TCOR) Motion of Amalgamation was accepted by the membership and TCOR will become a region of the provincial organization by December 31, 2012. Terri-Lee Higgins was introduced as the new Executive Director for Hemophilia Ontario.

Coinciding with National Volunteer Week, we presented the outstanding volunteers with recognition for their time and dedication to the Society. ♦

2011 AWARD RECIPIENTS

Leader of Tomorrow Award – Jordan Cabral

Ann Harrington Award – Sherry Purcell, RN

Shawn Duford Award – Lynne Cabral

Staff Leadership Award – All 2011 Hemophilia Ontario Staff: Alexandra McGillivray, Colin Patterson, Jeenetha Kulasingam, Teresa Genereux, Matthew Maynard, Robin Nobleman, Susan Turner and Marina Seliverstova

Please visit our website for a copy of Hemophilia Ontario's 2011 Annual Community Report.

Our sincere thanks to Octapharma and Baxter for providing sponsorship for this important meeting. ♦



The 2012-2013 Ontario Board of Directors

Hemophilia Ontario BOARD OF DIRECTORS 2012-2013

by Terri-Lee Higgins

THE FOLLOWING INDIVIDUALS were elected to the Hemophilia Ontario Board of Directors at the AGM:

- President – Paul Wilton
- Vice-Presidents – David Neal, Mike Beck
- Secretary – Jace Pedersen
- Past President – Jeff Beck
- Directors - Venanzio D'Addario, Igor Ristevski, Paul McNeil, Raja Ammouy, Ash Kurichh, Steve Van Dusen, Travis Hazelwood, Victoria Kinniburgh, Maury Drutz, Samuel Leon, Kiran Gopie, Kristen Luszka, Phyllis Gray, Mojtaba Khezry

The CHS Delegates for this year are Paul Wilton, Mojtaba Khezry, Ash Kurichh, Raja Ammouy and Mike Beck. ♦



Hemophilia Ontario Staff from left to right, Marina Seliverstova, Robin Nobleman, Alex McGillivray, Susan Turner, Teresa Genereux, and Matthew Maynard

Changing of the Guard in TCOR

by Terri-Lee Higgins

IT IS WITH mixed emotions that we wish Robin Nobleman, TCOR Regional Service Coordinator for nearly the last two years, a fond farewell as she begins law school in September. This is an amazing opportunity for Robin and we are very excited for her and her future. Her professionalism and “go-get-em” attitude will be greatly missed by staff, members, and the TCOR Board. Robin, thank you, and best of luck in your future endeavours. You will be greatly missed. Sarah Wood will be taking Robin's place as of July 19. Sarah comes to us from the Regional HIV/AIDS Connection in London, ON and we are confident that she will do an excellent job. ♦



Robin with TCOR kids Justin El-Rassi and Trevor Reid

IT'S ALMOST TIME for Summer Camp

by Jeenetha Kulasingam

THE BLEEDING DISORDERS Program (BDP) at Camp Wanakita is drawing near and we're anticipating another great year. This year, registration filled up rather quickly with a total of 48 participants, a few of which are new faces.

For the last 20 years, this program has allowed many of our children and youth living with bleeding disorders to participate in a residential summer camp program. We have children attending a week, two weeks, and some long-timers enrolled in the Counsellor-in-Training program for a month.

A unique feature of the BDP at Camp Wanakita is that children living with bleeding disorders are fully integrated into the regular camp program. At camp, children with bleeding disorders participate in activities that they may have otherwise not had an opportunity to engage in—activities such as a high ropes course, canoeing, kayaking and hiking.

In addition, during the BDP, six nurses from hemophilia clinics across the province are on hand to supervise and teach self-infusion, treat injuries and to ensure the health and well-being of our campers. ♦



The Bayer Den where hemophilia nurses supervise and teach self-infusion

NEW FAX LINE for All Offices

OUR FAX SYSTEM has changed and we have a new number that can be used across the province. Please send faxes to 1-888-958-0307. ♦

The Ontario ACCORD

by Terri-Lee Higgins

THE ONTARIO AIDS NETWORK has proclaimed 2012 as the year of the Ontario Accord on the Greater Involvement and Meaningful Engagement of People with HIV/AIDS in Ontario (GIPA/MIPA). GIPA/MIPA is about human rights, inclusion, self determination and dignity of the full human being and has been a guiding principle of the HIV/AIDS movement for almost three decades. Hemophilia Ontario actively strives to fulfill GIPA/MIPA principles by engaging our members living with and affected by HIV/AIDS. The staff, Board and members restated our commitment to the philosophy of GIPA/MIPA by signing the Ontario Accord. The Accord will be prominently displayed in the Toronto head office and in all regional offices. ♦

THANK YOU to the Pancorvo Family and GEPM GROUP INC.

AS YOU FLIP through the pages of *Blood Matters*, you may not realize the work that goes into designing each page and getting the magazine from a rough draft to the final printed form you hold in your hands. Hemophilia Ontario would like to give our heartfelt thanks to Gustavo, Donna Lee and Mark Pancorvo of GEPM Group for designing, editing, printing and mailing *Blood Matters* (and prior to that the TCOR Community News) at low cost for the last nine years. They are committed to supporting the bleeding disorders community through this publication and we sincerely appreciate their efforts. ♦



Celebrating Community CAMP – Community EDUCATION Weekend

by Terri-Lee Higgins

ON OCTOBER 19-21, 2012 **Celebrating Community Camp** will provide a fun and educational weekend for individuals with inherited bleeding disorders, their families and support persons. In 1992, YMCA Camp Wanakita opened their doors to children living with inherited bleeding disorders. To celebrate our 20-year partnership, Camp Wanakita was selected as the location for this educational weekend.

Throughout the weekend, attendees will be provided with educational sessions and recreational activities, the opportunity to participate in our commemoration of the Tainted Blood Tragedy with a tree planting, and a celebration of our 20 years of involvement with Camp Wanakita. All former campers and family members are welcome to attend. If you wish to attend only the commemorative tree planting, a detailed schedule will be provided soon to help you plan your visit.

Thanks to the planning committee—Leslie, Diane, Kay, Lori, Betty Ann, Mary Jane, Susan and Alex for their time and commitment to this provincial program. They are working to finalize speakers and the weekend schedule which will be mailed out in August. Watch your mail for registration details or contact Susan at info@hemophilia.on.ca and she will provide the materials once they are available. ♡

SUMMER Hours

ALL HEMOPHILIA Ontario offices will be operating on summer hours through July and August. Staff will work extra hours throughout the week and offices will close at 1pm on Fridays. ♡

Penny for Your Thoughts Fundraiser

by Teresa Genereux

WE ALL HAVE LOOSE CHANGE in our pockets and purses. Not sure what to do with all the pennies and coins in the jar at home? Donate them to our new provincial fundraiser, A Penny for Your Thoughts!

This is your chance to let your change make change in the lives of children, youth, and adults living with the pain of inherited bleeding disorders. Just drop your change off at one of the locations listed below and we'll do the rest. Tax receipts will be provided for donations greater than \$10.

Please consider supporting Hemophilia Ontario to help us make a “change” today. ♡



REGION	LOCATION	Drop off locations
CWOR	CWOR Office Aldershot Home Hardware 484 Plains Rd. E, Burlington, ON	
NOR	NOR Office Maslack Supply Ltd 3535 Highway 144, Chelmsford, ON	
SWOR	SWOR Office Woodstock and other regional locations Regional Events Contact Matthew for more details	
TCOR	Hemophilia Ontario Head Office Any TCOR Event	

HONORARY LIFE MEMBER Retrospective: Shawn Duford

by Susan Turner



Lyanne Cabral receives the Shawn Duford Grassroots Leadership Award from her parents and David Page, Executive Director of the CHS. The award was created to honour Shawn's legacy within the bleeding disorders community.

A **DISTINCT GROUP** of volunteers has been awarded an Honorary Life Membership for their efforts. In this *Blood Matters* series, we tell the stories of these individuals. Shawn Duford of OEOR was awarded an Honorary Life Membership in 2000 at the AGM. Shawn gave a wonderful acceptance speech which we thought we would share with the community as we honour him.

"This truly is an honour for me to receive the Honorary Life Member award. I came home late from work two weeks ago and noticed that I had received a courier package from Hemophilia Ontario. I was floored and stunned to learn that my efforts were being recognized in this manner. Karen, my wife, asked me what was wrong after she saw tears in my eyes. She quickly joined in my emotional state once I shared the news with her.

"I took over from my late Uncle Ray as chairman of OEOR some 10 years ago. Being the great man he was, I was determined to follow him and make him proud. I wanted to do things to improve the quality of life for the hemophiliac community for my nephew, uncles, cousins and the many friends I quickly came to know. All of the long hours and weekends were driven by this... knowing that I could make a difference for this community and the ones I love. I would like to think that I succeeded in many of the projects initiated, but it came with a few expenses as well.

"Often, Karen would come and get me from the computer to come to bed, or we would cancel social plans so that I could finish Hemophilia things that would otherwise impact OEOR. A lot of time was sacrificed that I could have spent with her. Then, one year, she joined me to attend one of the weekend-long Board meetings and retreats. It was then she realized all of the other great work and tremendous efforts put in by many other truly wonderful volunteers. From that point on, it was understood why I put in the time I did and where I got my drive from.

"Shortly after that, Karen joined the OEOR board so that we could spend some time together on something that I loved to do. Together, we created and established a successful annual golf tournament, started doing the Children's Christmas parties and bowling to name a few...

"I feel intimidated to accept the award when there are so many other volunteers who put in the hours they do to accomplish the critical tasks that benefit us all. Without them, we would not even be close to the positive position we are in and the benefits we all received from their heroic efforts. My name will be shared on the letterhead with some of the great leaders that I got to know, such as John Plater, James Kreppner, Frank Bott and Dave Mitchell, and that is an honour which I have yet to come to grips with.

"My acceptance of this award is dedicated to my beautiful wife, Karen, and my two children who will be joining us very soon. I'm ready for you.

Respectfully,
Shawn Duford ♡

LIVING WELL FEATURE ARTICLES

LET'S TALK About...

by Mary Jane Steele, Physiotherapist, Southwestern Ontario Bleeding Disorders Program, London Health Sciences Centre

RECENTLY, within our pediatric program in London, Ontario, team members have begun chatting informally with older adolescents about lifestyle choices, including alcohol and drug usage, tattooing, piercing, sexual relationships, and other issues which at times can be difficult or embarrassing to talk about with family, friends or healthcare providers. This is our attempt at assisting our younger patients at becoming empowered in asking for information or assistance at any time, without fear of being lectured at, talked down to, or moralized. These conversations are not always easy, as we have known most of these young men since infancy or toddlerhood—but we are trying to step out of traditional instructional roles and open up some dialogue. Intimate personal issues and choices can be difficult to navigate for any adolescent (or adult); they can be even more challenging to those with hemophilia. Our goal is to try to talk openly with our patients about the choices they may be thinking of making—and to help assess the risks and benefits which might be associated with any lifestyle choice. We are trying to shape our role as healthcare team members in our Bleeding Disorders Program in a non-judgmental manner, in order to encourage our patients to seek appropriate and timely health care.

It is our hope that by engaging in frank and open discussions with our younger patients, many of them will continue to return for ongoing assessment once they have graduated to the adult program without a fear of being lectured at. We are open to talking about any topic with adults as well and appreciate patient feedback if we are not totally successful in minimizing the moralizing.

For those looking for an online resource that may answer some questions around these topics, please check out Bayer's "Speaking Frankly About Hemophilia" website—www.frankly.net. This website offers reliable information written by young men for their peers.

As always, please feel free to discuss any issue of concern with the healthcare team members from your local Bleeding Disorders Program. This has been a collaborative effort in our program, and is a direct result of providing a highly integrated comprehensive care program in conjunction with our patients. ♡

STAYING FIT with a Bleeding Disorder

by Robin Nobleman

EVERYONE KNOWS that regular exercise is important for your health, but did you know that it has extra benefits for people with bleeding disorders? Despite these benefits, people with bleeding disorders may also face additional barriers to exercising and have to consider many factors when choosing an activity. Summer is a perfect time to get active, so this *Blood Matters* feature will give you and your family some tips on staying fit and safe with a bleeding disorder.

Benefits of physical activity

Although someone with a bleeding disorder might be concerned about joint bleeds from exercise, a healthy diet and exercise can actually help prevent joint bleeding by helping one to maintain a healthy body weight. Less weight means less stress on joints. In fact, one study on young men with hemophilia found that "dietary interventions designed to reduce weight among persons with bleeding disorders... may be the most effective prevention for range-of-motion loss besides avoidance of joint bleeds." Physical activity can also help prevent injury by strengthening muscles, improving your sense of where your body is in space, quickening your reflexes and improving coordination.

Not only can exercise reduce the chance of injury, it can also help reduce pain. Dr. Michael Jeavons of the Pain



Youth try out the alpine climbing tower at the Youth Adventures Program

Service at the Hospital for Sick Children in Toronto says, “We know that exercise makes the body release chemicals, called endorphins, that not only make us feel less pain but also make us feel good. It’s something you can control and do for yourself.” Additionally, increased blood flow to tissue from exercise can help heal injuries to tendons, muscles, cartilage and bone. Of course, restarting exercise after an injury should be done under the direction of a physiotherapist.

How to choose an activity

There are many factors to consider when you choose a physical activity when you have a bleeding disorder. The choice is different for everyone and depends on your interests, your current level of physical fitness, your mobility limitations and more. But some considerations are important across the board.

- **Contact**

Contact in hockey, for example—between players, with the puck, against the boards—is much greater than in soccer. The risk of injury, therefore, is higher.

- **Speed**

Motorized sports like snowmobiling and dirt biking carry a greater risk of injury than regular biking because of their speed.

- **Force of impact**

Football and boxing, for example, are extremely risky, even to people without a bleeding disorder, because of the high force of impact.

- **Height**

The more height involved, such as in downhill skiing, snowboarding and hang-gliding, the greater the risk of serious injury.

- **Unpredictable conditions**

Waves in water skiing, and icy surfaces when downhill skiing, are examples of how unpredictable conditions can affect the degree of risk.

Once you consider all of the factors above, there are things you can do to make an activity safer. Proper equipment, like shin pads in soccer, and supportive, well-fitting shoes can help prevent injuries. Adjusting your prophylaxis schedule so that you infuse before an intensive activity may also be helpful, if suggested by your clinic team.

Your region may offer financial assistance to help fund your child’s participation in physical activities. Ask your Regional Service Coordinator.

Of course, participating in sports is not the only way to stay fit. Even everyday activities like gardening, mowing the lawn, going for a walk and playing with the kids are all great ways to get active. Get out there and enjoy the summer!

With information from “Passport to Wellbeing: Destination Fitness,” published by the Canadian Hemophilia Society. For more resources on physical activity and bleeding disorders, visit www.hemophilia.ca, under Educational Material. ♡



A CYCLING ODYSSEY: Becel Ride for Heart 2012

by Dave Neal

WHEN I WAS THIRTEEN YEARS OLD, my grandfather died of a stroke, and I always wanted to honour his memory and do my part for heart and stroke research. So when I was approached by a co-worker a few years ago and asked if I was interested in participating in the Ride for Heart, I jumped at the chance, not only because it was a fundraiser, but it was also a way for me to increase my fitness levels (and the fact that I get to ride my bike on the highway was a great incentive too). As a severe hemophiliac, it is so important

for me to stay as active as possible and build up muscle strength, and cycling allows me to do that (and I *always* ride my bike with my helmet). I joined my co-worker on the 50km route that first year. It was the toughest bike ride I ever took, but I completed the Ride in two hours and 30 minutes.

This year I participated in the Ride for the seventh time. It was also special because it was the 25th anniversary of the Ride in Toronto. Over the years I have slowly reduced my time, and this year's goal was to complete the course in less than two hours.

As I began the ride at Exhibition Place, I kept this goal in my mind the entire way. The trek up the Gardiner and DVP wasn't too bad. There were some tough inclines, but none as tough as the incline from Lawrence Avenue up to York Mills Road. Despite this incline and the fact that I used all but two of my gears (I have a 21 speed mountain bike), I got to the halfway point in one hour. "This is great!" I thought. I was right on pace to meet my goal. As I headed south, closer to the Gardiner, I thought my goal was within reach. I reached the Gardiner with 15 minutes to spare. However, once I got to the top of the Gardiner on-ramp, there was a headwind in my face the rest of the way, which slowed me down. Although I did not meet my goal, I did set a new personal best of 2:10—quite an accomplishment for a 50km route and with that headwind! So next year the plan is to finish under two hours. With my dedication to keep as physically fit as possible, I know I can accomplish it. ♡



WHEELS for the World Fundraiser

by *Matthew Maynard*

STARTING ON JUNE 17, 2012 Barry Haarde is biking across America from Astoria, OR to Portsmouth, NH and will pass through Sarnia, London, Brantford and Niagara Falls, Ontario around July 26-29. Barry Haarde has severe hemophilia A and is a 30+ year survivor of HIV and hepatitis C, contracted through blood products used to treat hemophilia. He also suffers from peripheral neuropathy and has a total knee replacement. He lives and works in Houston, Texas and participates in many local cycling events. Come out to support him. Contact redsaleen97@yahoo.com for more information. ♡

◀ *Barry Haarde*

Canadian Hemophilia Society News

Parents **EMPOWERING PARENTS** Program

by *Mike Charbonneau and Nancy Charbonneau-Suave*

OUR FAMILY OF EIGHT has been in the hemophilia family for 20 years now. Two of our three boys have hemophilia, and two have ADHD—one being the bleeder. We were one of the families selected for the Parents Empowering Parents (PEP) program offered by the Canadian Hemophilia Society. We really learned a great deal and gained many useful tools. It is a privilege to be able to have this for any family – especially families that have special needs and higher stress conditions such as hemophilia or other bleeding disorders.

Parents are also affected along with the children. When parents are running day after day, either grieving, or confused, or mentally exhausted, this type of education really benefits the children in the end. It is also reassuring to get together with other parents to share stories and struggles and know you're not alone. We would really like to thank the facilitators and Hemophilia Ontario for this opportunity. Our family will benefit from this in a very positive way. ♡



The Charbonneau family

**CHS launches
CODerouge May 25,
2012**

by Teresa Genereux

CHS HELD THE FIRST CANADIAN Conference on Bleeding Disorders in Women on May 25, 2012 at the King Edward Hotel in Toronto, Ontario. This unique event was in fact the first conference in the world that brought together healthcare professionals such as hematologists, nurses, obstetricians, gynecologists, family physicians, physiotherapists and social workers to learn about women and bleeding disorders.

It was well received with over 260 participants. CODerouge featured many topics ranging from an overview of bleeding disorders in women with Dr. Rochelle Winikoff, a panel on quality of life where women shared their stories, information on the multidisciplinary management of bleeding disorders with Dr. Paula James and Dr. Diane Francoeur and much more.

This was also the launch of the Coderouge Ambassadors program. Following the conference, specially selected women affected by bleeding disorders from across Canada were trained as Ambassadors to raise awareness in their communities and reach out to undiagnosed women.

Once again, thank you to CSL Behring for all your support for CODerouge 2012. ♡



World Federation of Hemophilia News

**Hemophilia Ontario Announces WFH CONGRESS
Attendees: Paris, the “it” Place to Be!**

by Jeenetha Kulasingam

EVERY TWO YEARS healthcare professionals, people affected by inherited bleeding disorders and hemophilia organizations worldwide gather together in one setting to learn about the latest advances in bleeding disorders treatment, to discuss, debate and contribute to a strong global organization and community. This year, this will happen in beautiful Paris, France.

We are fortunate enough to send the following individuals to represent Ontario from the regional, provincial and national levels:

- 1) Paul Wilton, Hemophilia Ontario President
- 2) Terri Lee Higgins, Executive Director of Hemophilia Ontario
- 3) Raja Ammoury, Board Member of Hemophilia Ontario
- 4) Ryan Kleefman, Karttik Shah Award recipient at the national level
- 5) Michelle Lepera, Julia Lepera and Holly Valenta attending as SWOR regional representatives ♡



Clinic Corner

ANN MARIE STAIN Retires

by Robin Nobleman

AFTER OVER 20 YEARS of service, Ann Marie Stain is retiring as the Nurse Coordinator of the Comprehensive Care Hemophilia Program at the Hospital for Sick Children. We give our heartfelt thanks for the excellent care she has provided TCOR families over the years and wish her all the best in her retirement.

Ann Marie has touched the lives of countless patients and their families over the years and has watched many children grow up. She was a pioneer in teaching young children self-infusion at Camp Wanakita's residential summer program and her very presence at camp put parents' minds at ease. She has also advised on numerous resources for people with bleeding disorders and has been a fierce advocate for her patients.

From the staff and families of TCOR, and Hemophilia Ontario, we will miss you and wish you a wonderful retirement.

Sick Kids has hired Vanessa Bouskill, a Nurse Practitioner with experience in organ transplants and the Emergency Department at Sick-Kids. We look forward to working with Vanessa to provide the best care possible. ♡



Ann Marie Stain at Camp Wanakita

Bleeding Disorders News

IT KEEPS GOING AND GOING... Longer Lasting Factor Products

by Robin Nobleman

ONE OF THE CHALLENGING parts of living with hemophilia is the need for frequent prophylactic infusions. Frequent infusions are necessary because factor replacement products for hemophilia last for a set amount of time in the body and once that time runs out, your factor goes back to its natural (low) levels. Scientists are currently studying ways to make factor last longer in the body so you will not need to infuse as often.

Factor only lasts a certain amount of time because factor proteins have what's called a *half-life*. The half-life is the time it takes for the amount of a medication in your bloodstream to decrease by half. For factor VIII, that time is 8-12 hours and for factor IX it's 18-24 hours.

New longer-lasting factor products would lengthen that half-life so you would be able to go longer without an infusion. Several companies are developing longer-lasting factor products; they are all currently in various phases of clinical trials. A small study of 16 patients called *A-long* found that a new factor VIII product had a half-life 1.7 times longer than normal factor VIII. A similar study called *B-long* with factor IX found that the half-life of the new product was three times as long as usual. Some patients in this study only had to infuse every two weeks. Both of these products are now part of larger studies to prove their efficacy and many other studies on longer-lasting products are ongoing.

There are several methods being studied to increase the half-life of clotting factor products. One involves fusing the clotting proteins with antibodies that are difficult to break down. When they travel together in the bloodstream, the clotting factor benefits from the protection of the antibody. Another method is called PEGylation. It involves binding a chemical called PEG to the clotting factor to create a protective shield that temporarily keeps the factor from being broken down by enzymes. All of these studies are being done on recombinant factor products, meaning they do not use human plasma and do not carry a risk of blood-borne infections. Pharmaceutical companies must also ensure that longer lasting factor products work just as effectively as current products.

Thanks to Dr. Robert Klaassen and David Page for their input. ♡

Tracing the Origins of **HEMOPHILIA B** in one Ontario Family

by Dennis W. Galley

THROUGH GENEALOGICAL research, I have traced the origins of the hemophilia B that I inherited to my great-grandmother, Catherine Isabel CLINE. This has been proven through many of her descendants who either had, or carried this bleeding disorder.

Catherine CLINE was born in Dundas, Ontario on December 10, 1848 to William CLINE and Margaret NELSON. She may have inherited the hemophilia B gene from either her father or mother.



Big Stock Photo 12541415

On the CLINE side, William had three brothers and eight sisters. Descendants of William's sisters include the surnames: CODDINGTON, GARDNER, PEARSON, SMITH and WIMAN.

On the NELSON side, Margaret had one sister and one brother that I am aware of. The sister married a HAMILTON first, and then another NELSON (not related).

I am most interested in hearing

from any possible descendants of either side who have inherited the hemophilia B disorder. If you have any of the surnames mentioned above, please contact me via e-mail at: galleyd@bmts.com. ♡

HIV/HCV News

People with **BLEEDING DISORDERS** and **HCV** – Unique challenges

by Robin Nobleman

PEOPLE WITH bleeding disorders make up a disproportionate number of those with the hepatitis C virus due to infection through tainted blood products. This population has unique needs and the Hemophilia Federation of America (HFA) has identified some of them and begun to take action. The situation in the United States may foreshadow what's to come in Canada.

The results of studies on new HCV drugs may not be easy to interpret for people with bleeding disorders. This is because people with bleeding disorders are medically different from others with HCV. Most have had HCV for a long time as they may have been infected in early childhood. Additionally, side effects of HCV drugs that affect clotting ability would affect people with bleeding disorders more severely. To find out exactly how our community would react differently to new drugs, the HFA is advocating for people with bleeding disorders and HCV to be included in clinical trials. One pharmaceutical company in the US has already agreed to provide this population group with timely notice for their clinical trials of a new and promising drug.

Better notification of upcoming clinical trials will not be helpful to those with advanced disease who



may not meet the eligibility requirements of a drug trial. According to one recent paper, 25 percent of adult hemophiliacs with HCV have advanced liver disease. These people need the therapy most but are often ineligible for trials. To aid people in this difficult situation, the Food and Drug Administration (FDA) has said that they will encourage pharmaceutical companies to provide drugs outside of studies as a "curative protocol" for those with no other options. The HFA is working to create a self-selected list of people with advanced HCV who are poor candidates for existing therapies and will be at great health risk if they do not receive a curative protocol within the next few years. Taken together, these actions may enable access to new therapies for people with bleeding disorders and advanced liver disease.

Based on People with Bleeding Disorders and HCV by Mark Antell and Paul Brayshaw access.hcv.therapy@google.com. Hemophilia Federation of America website: www.hemophiliafed.org. ♡

World **HEPATITIS DAY**

AN ESTIMATED 250,000 people in Canada are living with hepatitis C and many don't know it. To raise awareness about hepatitis C and its effect on our community, Hemophilia Ontario – TCOR will participate in a community health fair on July 27 in honour of World Hepatitis Day. The fair will take place at Queen West Community Health Centre at 168 Bathurst Street from 10:00am to 4:00pm. If you would like to volunteer for any part of the day, please contact Susan Turner at 416-972-0641 ext 21. ♡

Pharmaceutical News

HEMOPHILIA and Your Joints – Baxter Launches New Website

WHETHER YOU'RE TAKING an afternoon stroll, breaking out your best dance moves at your cousin's wedding, or just vowing to start taking the stairs, your joints play an important role in keeping you moving. But if you have a bleeding disorder, you know—more than anyone – just how challenging the world can be when your joints hurt. Even worse, joint bleeds can become a chronic problem when a target joint develops.

Baxter is therefore pleased to announce Joint Health, an interactive website which offers great information and videos demonstrating how joint bleeds occur and how they can lead to further damage. It also provides interesting tips and advice on ways to manage and prevent joint bleeds, in order to help you maintain joint mobility.


To better understand joint damage, visit "Make at Move" at www.baxterjointhealth.com. ♡

Think **OUTSIDE THE** hemophilia **BOX**

LIVING WELL means more than taking your medication and avoiding bleeds. Pfizer Canada's healthy living website, www.morethanmedication.ca is a well-rounded resource for health and wellness. It includes tips on reducing stress, how to speak to your healthcare provider more productively, eating well and much more. It even has interactive games and apps to stay healthy while you're on the go. ♡

Speak your mind

At www.relatedbyblood.org




Relatedbyblood.org is Hemophilia Ontario's new online support forum. It's a private and confidential online network where you can exchange advice and support with the bleeding disorders community.

Whether you're newly diagnosed and looking for support, need some advice on raising a child with a bleeding disorder, or want to chat with others living with HIV or hepatitis C, this is the space for you.

www.relatedbyblood.org

Sign up today!

For more information please contact Teresa Genereux at tgenereux@hemophilia.on.ca or Matthew Maynard at mmaynard@hemophilia.on.ca



Other **HEALTHY RESOURCES**

Pfizer — embracelife.ca
Bayer — livingwithhemophilia.com
CSL — allaboutbleeding.com
Novo Nordisk — changingpossibilities-us.com (US site) ♡

JUST THE GUYS 2012

Online Registration Now Available!

CWOR, SWOR & TCOR—September 21-23, 2012 @ YMCA Camp Ki-Wa-Y

NOR—September 21-23, 2012 @ YMCA Camp Falcona

OEOR—September 7-9, 2012 @ YMCA Camp RKY

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

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

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

www.hemophilia.on.ca



Central Western Ontario Region



Meagan Bordi

Congratulations MEAGAN BORDI!

CWOR WOULD LIKE to officially congratulate youth volunteer Meagan Bordi on winning one of the CHS' \$5,000 James Kreppner Memorial Scholarships.

Meagan is currently one of CWOR's regional council members, and is actively involved with the planning and implementation of many of the region's programs and services. She is also an active student at her high school where she has spearheaded many of the school's fundraising activities, including a bottle drive and a cancer awareness campaign.

Meagan plans to attend McMaster University in the fall to pursue a Natural Sciences degree. We wish Meagan all the very best, and know that she has a bright future awaiting her. Congratulations Meagan! ♡

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

The Big Sale on the LITTLE STREET

JOIN US this year on Saturday, September 8 for our second edition of the Big Sale on the Little Street third-party community fundraiser. The sale takes place during Hamilton's Locke Street Festival (www.lockestreetfestival.com).

You can find us just off of Locke Street at 4 Fanning Street. If you would like to donate any items, please contact Alex McGillivray, Regional Service Coordinator. Please make sure items are in good condition, and we ask that you do not donate any large electrical items. All monies raised from this event will be donated towards CWOR programs and services. ♡

Hamilton SUPERCRAWL BOOTH

SUPERCRAWL is a yearly free cultural festival within the Hamilton downtown core that draws over 50,000 people from across Southern Ontario (www.supercrawl.ca). This year CWOR will set up an information booth during the event on Saturday, September 15, to raise funds and awareness about inherited bleeding disorders within the community. We'll be promoting the provincial "Penny for Your Thoughts" fundraiser, so come visit us and help us make change for those living with inherited bleeding disorders. ♡



Volunteers Rob Dinsdale and Mary Pedersen

World Hemophilia Day BAKE SALE

THIS YEAR on World Hemophilia Day, CWOR held their fifth Annual Bake Sale at 150 James Street North in Hamilton. It was a beautiful day and the event raised funds and awareness for the inherited bleeding disorders community. Many thanks to our volunteers for the day—Rob Dinsdale and Mary Pedersen. Special thanks to Jane Dinsdale, Mary Pedersen, and the entire hemophilia clinic team at McMaster for donating their baked goods to this great cause. We'd also like to thank our honorary volunteer, Molly the dog, for supporting the cause. ♡



Honorary volunteer, Molly the dog, enjoys the bake sale

Regional Board/Council and Staff

Rob Dinsdale, Mary Pedersen
Jace Pedersen, Igor Risteovski
Kay Decker, Debbie Bordi
and Meagan Bordi
Alexandra McGillivray –
Regional Service Coordinator
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4th Floor – Office #19
Hamilton, ON, L8P 1C8
905-522-2545
amcgillivray@hemophilia.on.ca

DATE	WHAT AND WHERE?	Events Calendar
Sept 8	The Big Sale on the Little Street 4 Fanning Street, Hamilton, ON	
Sept 15	Supercrawl Booth James Street North, Hamilton, ON	
Oct 13	Parents Education Day Location TBD	
Nov 3	Agging with a Bleeding Disorder Program Dundurn Castle, Hamilton, ON	

Northern Ontario Region

CLINIC DAYS IN NORTHERN ONTARIO

OUR SPRING CLINIC in Thunder Bay was held April 23-24. Lucie Lacasse, Hemophilia Nurse Coordinator from the Ottawa General Hospital held a lunch and learn webinar on Hemophilia and Aging, which was very well received by clients and staff. It was great to see new faces and connect with everyone again.

In Sudbury, our clinic was on May 12. It was a great day as the children decorated flower pots as Mother's Day gifts for their moms and many participated in our fifth Annual Walk-a-thon. ♡



SUPPORT NOR AND ENJOY GREAT THEATRE
THE NORTHERN ONTARIO Region and Theatre Cambrian have partnered up with NOR to offer our members a special rate on theatre tickets. The more exciting part is that a third of the profits generated from the sale of these tickets will be donated to fund local programs and services in our region.

The cost of the tickets are to attend three shows, and the rates are as follows:

- Adult Tickets:** \$60
- Seniors and Students:** \$52.50
- Children:** \$44

For more information, please contact Teresa Généreux, Regional Service Coordinator. ♡



Baby Landon with his Grandma and Mom

Fifth Annual WALK-A-THON

WE HAD GREAT SUCCESS in raising funds and awareness in many of our smaller communities in the north. We held our fifth Annual Walk-a-thon this year on Saturday, May 12, our spring clinic day at Health Sciences North Hospital—and what better than to have our clients from out of town with us!

To start off our walk, Stephanie Morrison read a proclamation from the Mayor of Sudbury that proclaimed April 17 as World Hemophilia Day. Baby Landon started off our walk holding his mother and grandmothers' hands, and even took a few steps on his own. It was a busy day with clinic and the walk, but a lot of fun was had by all. Our top prize winner was Baby Landon raising \$820! The total amount raised was just over \$2,100 with donations still coming in. ♡



Participants getting ready to take on the 5th Annual NOR Walk-a-thon

NOR

Regional Board/Council and Staff

- Paul McNeil
- Kaitlynn McDonald
- Betty Ann Paradis
- Cynthia Pulsifer
- Kris Onucky

- Fundraising Committee:
- Tammi Deveau
 - Lorissa McDonald
 - Allan Ferdette

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

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

DATE	WHAT AND WHERE?	Events Calendar
July 28	World Hepatitis Day	
Aug	Office moving to Red Lake	
Sept 16	1st Annual Golf Tournament	
Sept 21-23	Just the Guys NOR	
Oct TBA	Thunder Bay and Sudbury Bleeding Disorder Clinics	

Ottawa and Eastern Ontario Region

18TH ANNUAL Shawn Duford GOLF TOURNAMENT for Hemophilia

by Alex McGillivray

JOIN US ON SATURDAY, August 11 at the Meadows Golf & Country Club for our 18th Annual Shawn Duford Golf Tournament for Hemophilia. This is an exciting event that provides you the unique opportunity to network with our members, friends, family, and the corporate community.

This best-ball tournament is full of fun activities, draws and sponsored holes. It includes a box lunch, 18-hole golf game, a power cart, a succulent banquet dinner, and an awards presentation. A live and silent auction will be held during the day and evening.

For more information, to sponsor or to register for the tournament, please contact Alex McGillivray, Acting Regional Service Coordinator for OEOR, at 905-522-2545 or amcgillivray@hemophilia.on.ca. ♡

Regional Board/Council and Staff

Raja Ammoury-Alami
Jordan Cabral
Lyanne Cabral
Ashwani Kurrichh
Nancy Sauvé
Brian Van Dusen
Steve Van Dusen
Darlene Villeneuve

Alex McGillivray,
Acting Regional Service Coordinator
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amcgillivray@hemophilia.on.ca

OEOR 2012 Regional GENERAL MEETING

by Steve Van Dusen

ON MARCH 18, 2012 we held our Regional General Meeting in Ottawa. We had an excellent presentation provided by Hany Elgendy on hemophilia which was very informative and well received by the audience. A presentation for the children was done by Sylvie Renaud from the Kids on the Block organization.

We elected our OEOR Regional Council (see sidebar) and delegates to the Hemophilia Ontario Board of Directors: Raja Ammoury, Ash Kurrich and Steve Van Dusen. Through fundraising, we will arrange and pay for escorted return transportation for seven campers to attend Camp Wanakita and hold our annual Shawn Duford Golf Tournament for Hemophilia.

In addition to these activities, our board has kept abreast of the community's activities and concerns through the participation of our RSC at regular meetings with Ottawa Carleton Council on AIDS, HIV Primary Care Group, Hep-C task force, Healthpartners, Blood Services liaison committee, Canadian Liver Foundation, World AIDS Day, as well as attending bleeding disorders clinics at the region's hospitals.

We look forward to a productive 2012/2013 with the continuation of tried and true programs, and the implementation of some promising new ones. ♡

DATE	WHAT AND WHERE?	Events Calendar
Aug 11	18th Annual Shawn Duford Golf Tournament The Meadows Golf & Country Club, Ottawa, ON	
Sept 7-9	Just the Guys OEOR, YMCA Camp RKY in Parham, ON	
Oct TBA	Bowl-a-thon	

South Western Ontario Region

SWOR TOOK THE PLUNGE

MEMBERS FROM LaSalle to Woodstock gathered on an April afternoon at Little Beach in Port Stanley for our third Annual Polar Bear Dip to celebrate World Hemophilia Day and be part of a global effort to raise awareness of inherited bleeding disorders.

Dippers not only raised awareness (and a few eyebrows), but also raised over \$2,200 for programs in the region. Thanks to Mike and Amy, our sponsorship leaders. A special thanks to all of our dippers, sponsors, volunteers, and Mother Nature for just a little light rain and no snow or ice on Lake Erie. ♡



SWOR dippers getting ready to take the plunge



Paul Wilton presents the Volunteer of the Year Award to John Lepera (right)

WE ACCOMPLISH Together Thanks to VOLUNTEERS

DURING OUR REGIONAL General Meeting, South Western Ontario Region had an opportunity to recognize and honour many of our active volunteers.

Our volunteer of the year, John Lepera of Windsor, has been an active volunteer with the Just the Guys program for 10 years as well as supporting the programs and events in the region in a variety of ways. SWOR also has four retiring council members who have provided great leadership and involvement on the council and in supporting SWOR's programs both individually and together. Thank you to Adriana Balderas-Lopez, Brendon Beer, Sam Davis and Joyce Jeffreys.

Another part of Hemophilia Ontario's volunteer recognition involved honouring volunteers who actively volunteer for the region. It is amazing that we had over 15 new volunteers this past year as well as some volunteers who have been active for over 12 years in a row.

The contributions of energy, enthusiasm, and ideas from volunteers throughout the region and through the year make the difference in what we accomplish together. ♂

ALL IN AT THE PINECREST staff training weekend

by Nick Higgins, Director – Pinecrest 2012

ON THE WEEKEND of June 8-10 the Pinecrest camp staff was engaged in a pre-camp training weekend. The idea of this weekend was to train and build a team atmosphere in anticipation of camp. Many of the counsellors attended the North American Camping Conference of Hemophilia Organizations (NACCHO) this year, or in the past, and it showed. A lot of what happened at the training weekend were ideas and information that was derived from experiences at NACCHO.

These ideas ranged from new songs to new games, and even new procedures that we could implement. Fresh ideas on staff training were also put to use where staff had to care for eggs as though they were campers. We also brought back the idea of inviting guests to help train our staff. We had presentations on our own and other peoples' personalities, leadership, customer service, and on bleeding disorders. These sparked many discussions about how to apply what we learned at camp.

Through our discussions we also came up with a goal that we as a staff will strive for this year at camp. From the presentations, we decided that the phrase "All in" fit what we were going for best as it is a quick little

saying that can be applied to many different scenarios. Most importantly, "All in" means we are going to give every last ounce of energy at camp because we know that the campers, parents, and our fellow counsellors deserve our best performance.

With the ideas brought back from NACCHO, and with the help of our guest speakers, the weekend was a big success. I want to extend a big thank you to Kevin Cruse, Jaclyn McKenna, our nurses Lori and Keira, and Terri-Lee for helping make this weekend of learning a possibility. ♂

Regional Board/Council and Staff

Dawn Harman
Kathleen Hazelwood
Travis Hazelwood
Ryan Kleefman
Michelle Lepera
Maureen Schaus
Marion Stolte
Holly Valenta
Paul Wilton

Matthew Maynard, Regional Service Coordinator
Terri-Lee Higgins, Executive Director
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All articles in this section, unless otherwise indicated, are by Matthew Maynard.

DATE	WHAT AND WHERE?	Events Calendar
July 26-29	Barry Haarde's Wheels for the World Fundraiser Sarnia, London, Brantford and Niagara Falls	
Aug 22-26	Pinecrest Adventures Camp Goderich, ON	
TBA	The 5 th Annual SWOR Golf Tournament for Hemophilia and Inherited Bleeding Disorders is being rescheduled. Check back at www.sworgolftournament.com for details	

Please note that the Ride for the Record has been cancelled

Toronto and Central Ontario Region



Samuel Leon

SAMUEL LEON wins CHS JAMES KREPPNER Memorial Scholarship

by Robin Nobleman

TCOR IS PROUD to announce that Samuel Leon, one of our committed volunteers, is one of the recipients of this year's CHS James Kreppner Memorial Scholarship. Samuel will receive \$5,000 towards his post-secondary tuition.

Samuel has volunteered at various TCOR events, is a member of our Speakers Bureau and an active member of the TCOR and Hemophilia Ontario Boards. He is also keen to get involved in international partnerships with hemophilia societies in developing countries as a result of his early experience growing up in Haiti without access to treatment.

Samuel is entering the second year of his accounting degree at George Brown College in Toronto. We wish him every success and congratulate him on this well-deserved award. ♡

THANK YOU to WORLD HEMOPHILIA DAY speakers

by Robin Nobleman

ON WORLD HEMOPHILIA DAY, TCOR held a panel discussion for medical students at the University of Toronto where TCOR volunteers shared their experiences. The students learned from four fantastic speakers about how to improve bleeding disorders diagnosis, care and treatment. Thank you so much to our speakers for giving their time and energy to this event. The students were very curious and hopefully walked away with more knowledge about bleeding disorders and perhaps an interest in further pursuing this field of study.

Thank you to Bayer for providing educational materials and sponsoring this program. ♡

HEALTHPARTNERS Speakers Bureau VOLUNTEERS needed

by Robin Nobleman

ARE YOU LOOKING for a way to get involved and give back to the Hemophilia Society? TCOR is looking for volunteers for the Healthpartners Speakers Bureau to tell their story and help raise money to support the Canadian Hemophilia Society (CHS).

Healthpartners is a partnership of national health charities raising funds exclusively through workplace charitable giving programs. Healthpartners provides Canadians with the choice to direct their gifts towards improving the health of Canadians, through payroll deduction or cash donations. Donors can choose to direct their money to the health organizations of their choice, including the CHS.

Throughout September and October, Healthpartners will organize speaker sessions at locations in the GTA. Volunteers can attend speaking events that fit their schedule. All training will occur in August.

If you are interested in joining the Speakers Bureau, please contact Sarah Wood by August 1 at 416-972-0641 ext 12. ♡



Lara and Mark Oulahen (aka Wonder Woman and Buzz Lightyear) and other dippers brave the cold

TCOR TAKES THE PLUNGE for WORLD HEMOPHILIA DAY

by Robin Nobleman

TCOR'S FIRST ANNUAL Polar Bear Dip in honour of World Hemophilia Day was a huge success. The dippers collected more than \$10,000 in pledges and bravely plunged into Lake Ontario on April 14, 2012. Some even came in costume.

Congratulations to our top fundraisers—Team Crazy Polar Bears and Lara and Mark Oulahen. The funds raised will support programs and services for people affected by bleeding disorders in Toronto and Central Ontario.

Thank you to all our dippers, their cheering squads and all of the generous donors. ♡



FAMILIES in Touch heads TO THE ZOO!

by Jeenetha Kulasingam

We can't be sure if it's the dancing penguins, the funny looking hippos, the rare white tigers, or the lovely Pam Hilliard herself, but something drew 84 members to our summer Families in Touch event. This was the largest FIT event since Robin and I started at TCOR.

While the kids were chasing peacocks, playing games with our enthusiastic volunteer, Tashika Griffiths, and munching away at the potluck, the parents listened attentively to physiotherapist Pam Hilliard's presentation on one of the Passport to Wellbeing sessions, "Destination Fitness".

Pam provided valuable information about why fitness is necessary for your joints, blood flow and mental health. She also explained which activities were safe and not so safe for someone with an inherited bleeding disorder. Lastly, she went over the variables to consider when signing up a child for a particular sport.

In addition to the great session by Pam, Trevor Reid, one of TCOR's older kids, provided a positive perspective on a sport that most people would think twice about. His passion and experience in fencing was great to hear and has opened the eyes of other parents to the activity.

After satisfying everyone's stomachs with great food and fulfilling their neurons with great knowledge – TCOR staff went home with a smile.

Thanks to Pam, Trevor and Tashika for making this the best FIT event ever. ♡

First ever TCOR VWD WEBINAR

by Jeenetha Kulasingam

TCOR HAD ITS SUCCESSFUL first VWD webinar given by Dr. Paula James, renowned researcher on von Willebrand disease, and run by Deren Svendsen, our CSL representative who operated "behind the scenes" to ensure the webinar ran smoothly. The webinar was open all across the province and resulted in a turnout of roughly 20 members.

Dr. Paula James covered all aspects of von Willebrand disease, from the history, to the genetics behind the disease, to treatment options and more. She also spent an extra half-hour answering the many questions asked by our inquisitive members.

This was definitely a great session and well overdue. We will definitely have another for next year.

Thanks to Dr. James and CSL Behring for making it happen. ♡

GO-KARTING for Guys

by Robin Nobleman

AFTER SEVERAL YEARS' hiatus, TCOR's men's program is back. On Saturday, May 12 a group of men with bleeding disorders met up at Grand Prix Kartways for some friendly competition and discussion. After a tight race, the group settled down for a conversation led by Jordan Lewis, the hemophilia clinic social worker at St. Michael's Hospital, and Marc LaPrise, a member with lived experience. The conversation was wide-ranging, covering a variety of topics related to life with a bleeding disorder. We hope to see more of you join us next year and welcome your suggestions on activities for the next men's program.

A special thank you to Marc for helping to plan this program from start to finish. ♡

Regional Board/Council and Staff

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

Staff

Susan Turner, Executive Assistant/Bookkeeper
Robin Nobleman, Regional Service Coordinator
Jeenetha Kulasingam, Regional Service Coordinator
Sarah Wood, Regional Service Coordinator

Contact Information

Hemophilia Ontario - TCOR
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416-972-0641
Toll free: 1-888-838-8846

DATE	WHAT AND WHERE?	Events Calendar
July 27	World Hepatitis Day community health fair Queen West Health Centre	
Sept 14	Annual Hemophilia Classic Golf Tournament Nobleton Lakes Golf Club	
Sept - Oct	Healthpartners Campaign	
Oct TBA	Commemorative Tree Planting	
Oct TBA	Women in Touch support group	

Youth Section



Michael Kwadwo Bosompra

The long ROAD TO EXERCISE

by Michael Kwadwo Bosompra

M_Bosompra@botmail.com

IT TOOK MANY years of prophylaxis, a whole lot of tinkering, and my fair share of swollen joints, but I finally found an exercise regimen that works for me. I played basketball for several years and my ankles definitely felt all of those years. I got inspired by world class boxing but quickly realized that my knees couldn't handle jogging and jumping rope on a daily basis. I tried treadmills and stationary bikes but quickly got bored of the monotonous scenery. But after a decade of experimenting I found a combination that works for me and now I'm in the best shape of my life, feeling better than ever, and taking factor less frequently than I can ever remember.

I swim four mornings per week, an exercise that I find engages my entire body and leaves my joints feeling great. Additionally, I've joined a dragon boat team that practices once per week, and lastly I try to get to the weight rooms once per week. All in all I think I lead a pretty healthy lifestyle and I don't think my hemophilia holds me back in any way.

My journey was a long one, and like I mentioned, was filled with bumps, bruises and everything in between but it was fun every step of the way. As I reflect on it I think the key to healthy living is enjoyment, consistency and finding activities that aren't terribly intensive on the joints. It took me a while to find my winning combination. Hopefully you find yours faster!

Cheers. 💧

Trial, error AND RUNNING

by Lorissa McDonald

lorriemcdonald@botmail.com

STAYING FIT is important for everyone. There are so many sports to choose from, but most people with a bleeding disorder have to limit their choices to a range of safer sports, swimming or biking being just a few of the many examples.

I personally used to love football, and before I was diagnosed I used to play every day at school. As you know, football is pretty rough, and when you're playing with the senior boys' team it gets a little more challenging. So I had to quit playing football, which was a huge disappointment and I struggled to find a new sport I enjoyed. I tried soccer for a bit but I was scared of the ball, and I was too short for the basketball team. Volleyball looked alright, but I never could hit the ball properly and I ended up with purple spotted fingers. Then I finally stumbled upon it—something that didn't require much skill and could be done at any point in the day. I started to run track.

If you have a hard day you can run. If you're bored and don't have much to do you can run. There is no place you can't decide to just go for a jog and it doesn't require any previous experience. It goes faster if you bring a friend; I bring my dog Foreman with me and it's the best time of day for the both of us and we get to see some really beautiful scenes.

It is still a challenge to do my exercises daily, but now that I've found a sport that works for me, it's not a chore anymore. It's something I love to do. 💧



Lorissa McDonald

Making THE RIGHT CHOICES

by Zach Adams

zach_adams100@hotmail.com

HAVING JUST COMPLETED my second year in Honours Kinesiology at McMaster University, I have been made all too aware of the vast array of problems which are associated with an unhealthy lifestyle. I chose Kinesiology because of my interest in the human body as well as having a passion for sports and active living. Being diagnosed with hemophilia somewhat late, at the age of seven, I was forced to stop playing hockey and soccer which I had grown to love and which also allowed me to remain active. I am sure many others with hemophilia have had the same struggles in finding a way to keep physically active while also trying to protect against bleeds.

After a few years I began to explore other activities which led me to take up golfing, swimming, biking and running as non-contact sports which would keep me active and help improve my joint strength. Taking part in physical activity helps you to develop greater muscle strength, balance and coordination which all help not only to prevent bleeds but will improve your quality of life.

Active living with hemophilia does not only involve exercise; a healthy diet is another vital aspect which I have learned to incorporate into my life. Personally, as well as in speaking to others, I have found that motivation to begin exercising is a barrier that many people must overcome, but once they begin exercising, it is something that will remain incorporated into their daily life. So what are you waiting for? Start moving! ♦



Zach Adams



D'Marc Lewis

Making EVERY STEP COUNT

by D'Marc Lewis

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AS SOME OF YOU have known me through the years, you know I'm a larger than life sort of fellow. It's no secret, really. And I've heard it all before—"Eat fruits and vegetables... You're on a road to a heart attack... Just take a walk and it'll do wonders." To those who say simplistic things like this: "You're just not cut out to be a motivational speaker or a toast master. Keep your day job."

Although I have never had a surgery in my life, my weight does pose a risk for forming target joints. I would have to thank my moderate-busy lifestyle that typically incorporates me being on my feet or always moving that keep the muscles around my joints as pumped up as possible.

I take public transit, and push myself to walk a little longer than I did yesterday, and I cycle. In an effort to get my bloodstream pumping, I now bus and bike to work, but I don't mean riding my bike to the bus stop two minutes down. I mean cycling a 30-minute stretch to/from Toronto's extremes. And if

no bus shows once I'm within Toronto limits, I head home on my bike. I'll continue until I see a bus nearby. Taking transit is an obvious health benefit, provided you're not just sitting on your backside for an hour. Just think for a second: the walk to the bus stop, the dash down and up the stairs to the train, or choosing to stand. Simple things, no?

For me with the bike and bus, the benefit I get out of it is that I get my morning exercise, I'm less tired, I struggle less to fall asleep when I can or must, and the ladies start to notice. Oh joy! The bigger benefit is I keep my joints in check, God willing. "What motivates me to do this?" you may ask. I save money this way and in some cases, I reach work and home sooner than I thought. That's my fitness piece for now.

As for nutrition...ahh well look at the time! I've got to cut it short. See you in the next edition. ♦



Ryan Kleefman

Montreal – JE T'AIME!

by Ryan Kleefman

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ON MARCH 30, 13 individuals made their way to Montreal for the Hemophilia Ontario Youth trip. Arriving in mid-afternoon, the rest of the day was spent exploring the surrounding area and playing games.

On Saturday morning, the group traveled by bus and subway (a first time experience for some) to McGill University. Here, the group learned about and discussed HIV/AIDS, issues surrounding disclosure of a bleeding disorder, and the Tainted Blood Tragedy. Saturday afternoon was spent exploring the city, visiting Mount Royal, and having a scavenger hunt in the Old Port region.

On Sunday morning, the group did more sightseeing. Throughout the weekend, the group enjoyed some delicious foods, everything from Mexican, to Korean BBQ, to traditional Quebecois fare such as poutine and croissants. On Sunday afternoon, all the participants parted ways to make the long journey home, having quite enjoyed the weekend trip. Many thanks go out to the chaperones, planners and sponsors who made this exciting (and educational) getaway possible. ♦

IN THE LAND OF POUTINE – A DREAM COME TRUE

by Jordan Cabral

jordancabral94@hotmail.com

THE YOUTH TRIP to Montreal was an amazing and awesome experience. On the first night we had a blast playing games and getting to know each other better. My favourite part of the weekend was all of the amazing food we ate—from the smoked meat at Schwartz's to the Korean BBQ, but my ultimate favourite was of course the poutine. I actually led the group to the restaurant we ate poutine at by following my nose on Sunday.

The education sessions planned by the staff were also very good. We learned about the Tainted Blood Tragedy, and also about disclosure by having a discussion as well as playing an interactive game. I walked away knowing I had learned something new.

During the weekend I met up with people I already knew, and I even made some new friends. Thank you to everyone who made this great trip a possibility and also an experience of a lifetime. ♦



The Hemophilia Ontario Youth group at the top of Mount Royal

HOW YOU CAN GET INVOLVED

IF YOU ARE A YOUTH between the ages of 16-26 and are interested in participating in our Hemophilia Ontario Youth activities, or would like to get involved with writing for *Blood Matters*, please get in touch with Alex McGillivray, Regional Service Coordinator at 905-522-2545 or amcgillivray@hemophilia.on.ca. You can also find us on Facebook at our Hemophilia Ontario page. Our next HOY program will be taking place during the Celebrating Community Camp Weekend at Wanakita on October 19-21. ♦

SAVE THE DATE



Aging with a Bleeding Disorder

Hemophilia Ontario—Central Western Ontario Region

CWOR's goal in providing this program is to equip the aging population and their caregivers with the proper knowledge and tools for the care of older people with inherited bleeding disorders.

For more information, please contact:

Alex McGillivray—Regional
Service Coordinator

(905) 522-2545
or

amcgillivray@hemophilia.on.ca

Please save the date of:

Saturday November 3, 2012

9:30am—3:30pm

Dundurn Castle

Save the Date!

Hemophilia Ontario
Hémophilie Ontario



Community Camp

WEEKEND

OCTOBER 19-21, 2012

CAMP WANAKITA

1833 Koshlong Lake Rd., RR#2

Haliburton, ON K0M 1S0

This two night, two day residential camping experience is for individuals, adults, or children living with a bleeding disorder and their support persons. The weekend provides participants the opportunity to experience camp and participate in educational sessions.

Friday Arrival: 7pm Sunday Departure: 1pm

For more information, please contact:

Susan Turner
1-888-838-8846 ext. 21
sturner@hemophilia.on.ca

501-65 Wellesley St. E
Toronto, ON
M4Y 1G7



**MARK
THIS
DATE**

Hemophilia Ontario Calendar 2012

DATE	WHAT AND WHERE?
July 29-Aug 11	Camp Wanakita
Sept 21-23	Just the Guys (TCOR, SWOR, CWOR)
Oct 19-21	Celebrating Community Camp



Find Hemophilia Ontario on Facebook



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

Hemophilia Ontario
Hémophilie Ontario

