

A publication of



Hemophilia Ontario
Hémophilie Ontario

BLOOD

matters

"We're all related by blood."

Volume 4 • Number 2

Summer 2013



Volunteers

Hemophilia Ontario

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What's in this issue?

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Information from Hemophilia Ontario and its Regions

	Page
Leadership Messages	3-4
Hemophilia Ontario News	5-9
Bleeding Disorders News	9-10
Healthy Living	11-12
HIV/HCV News	12-13
Pharmaceutical News	13-14
Central Western Ontario Region	15-18
Northern Ontario Region	18-19
Ottawa and Eastern Ontario Region	19-20
South Western Ontario Region	20-21
Toronto and Central Ontario Region	22
Celebrating our Volunteers	23-25
World Hemophilia	25
Hemophilia Ontario Youth Section	26

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Cover photo: Some of Hemophilia Ontario's volunteers from all across the province.

Leadership Messages



Paul Wilton

PRESIDENT'S Message

by Paul Wilton

VOLUNTEERS are the lifeblood of our organization. Our community is small so often our volunteers take on a large workload. Our volunteers include affected members, their families, members of hemophilia treatment teams, and others whose lives have somehow intersected with our community. Hemophilia Ontario realizes the vital role volunteers have already played in advancing our cause, and is preparing to ensure that we have the volunteer resources necessary to accomplish our goals in the future. The progress we have made and progress we will make in the future would not be possible without our volunteers.

Hemophilia Ontario and its regions started out as Kitchen Table organizations, small groups of parents and affected members got together to support each other and figure out how to advance the quality of life for people with inherited bleeding disorders. They wanted to ensure that their children were taken care of and that life would be better for those affected in the future. Throughout much of our history we did not have staff; we relied entirely on volun-

teers. Once we were lucky enough to be able to have staff to support our work, volunteers still drove the agenda of the organization and have been our most effective advocates. A desired outcome of our organization is to ensure that we have sufficient volunteer resources to function optimally. Our Executive Director's performance will be measured in part based on the ability of our organization to recruit new volunteers. In an era of limited resources we realize the important role volunteers will play in our future. We have begun to ensure that all of our programs have critical timelines that ensure that if volunteers were to take on a task from a staff member or from a retiring volunteer they would have clear documentation of the steps needed to prepare the activity.

Investing in young leaders is a good way to ensure a strong organization in the future. Hemophilia Ontario has set a goal that young people be involved at the provincial level and in each of the five regions. We require that each Regional Council have two youth members and each operational committee has at least one youth member. Our Board of Directors has at least five members under the age of 30.

We invest in our volunteers by providing funding opportunities to help volunteers develop their knowledge of inherited bleeding disorders and develop their leadership skills. We have offered funding opportunities for volunteers to attend the World Federation of Hemophilia's World Congress and the Canadian Hemophilia Societies' medical symposium. It is not enough to recruit volunteers, we need to make sure that our volunteers are well informed and have the skills they need to be effective advocates and ensure that our community's needs are being met.

To help our volunteers feel valued, we have recently revamped our volunteer recognition program. We want our volunteers and community partners to be recognized for their service to our organization, and that

our appreciation is being expressed for their work.

On behalf of Hemophilia Ontario I want to thank our volunteers for the work they do to make our community a better place. We will continue to strive to ensure that our volunteers feel appreciated. If a volunteer has made a difference in your life, please make a point of thanking them for their work the next time you see them. Our volunteers don't do their work to receive recognition, but a thank you can go a long way to ensuring that they know their work is valued. ♦



Terri-Lee Higgins

The Value of VOLUNTEERS

by Terri-Lee Higgins, Executive Director

WHAT IS A VOLUNTEER? What is the value of volunteering? Should there be a monetary value? The people that I spoke with say that it's not about applying a dollar value because volunteering is not about

money. It's about finding a way to contribute, give to or help a group or society as a whole. Volunteering is diverse. People volunteer for an endless number of reasons including developing new skills, meeting new people, trying something new or even gaining experience that may help with a new career path. The benefits to our bleeding disorders community, members and their families and friends, staff and those who volunteer are simultaneously direct and far reaching. Whatever the reason for becoming involved with us, a grass-roots organization, volunteers are an integral and indispensable part of the Hemophilia Ontario community.

There is a formula that determines the dollar amount that could be associated with volunteer involvement. Looked at in reverse it shows how much we *have not paid* to have our volunteers involved. We have no way of actually measuring the value and magic of the gift of the heart and sweat of the volunteers. What we do know is that volunteers add significant value to the work of paid staff, although it is not fully understood nor perhaps appreciated. In her paper *Reconceptualizing the value of volunteer work*, Canadian Linda Graff suggests that if the work done by volunteers does not serve the mission in a cost-effective manner, what justifies squandering resources in precious short supply on involvement that does not produce value?

We believe that our volunteers, like our staff, should be engaged in Hemophilia Ontario's mission "to improve the health and quality of life for all people with inherited bleeding disorders and to find a cure." Over the past two years, we have developed job descriptions, revamped old and continued to develop new volunteer opportunities. Hemophilia Ontario continues to ensure that we provide our volunteers with real value for their investment in us by maximizing volunteer engagement, thus paying our respects to the value of volunteers.

Please join me in recognizing and thanking the individuals who volunteer to help Hemophilia Ontario continue to meet its mission to improve the health and quality of life for all people living with inherited bleeding disorders and to find a cure. ♦



Tom Beer

ASK a Busy Person

by Tom Beer

WE'VE ALL HEARD that phrase. As a matter of fact many of us *are* the busy party, so, we get asked "to help."

Volunteering comes with parenting, comes with clubs, comes with jobs. It's not new. What is new is that more and more, in today's economy, we see situations where something needs to get done, there's no budget, so to get it done, someone volunteers.

Hands up if someone in your family is a coach or leader in some activ-

ity? Do you have an activity calendar? Different colours for each person? Staggered meals? And regular stuff to do when you come home? The modern norm! Why do we do that?

Hands up if you come home from that volunteer activity, tired, but with a smile on your face? There's your answer. We begin because we see a need and feel we should help. We keep doing it because we feel good about what we do. The rewards are hard to articulate, but...

"Did you see the look in that kid's eyes when she did that flip?"

"Did you hear the compliments when he served his cupcakes?"

Did you see the coach's smile?

Did you see the icing on his Dad's hands?

That's what volunteering is about.

Bailey, our 14½ year old golden retriever, is a "laid back" personality. He is also an equal opportunity dog, i.e., he believes that everyone should get a chance to pet him. So, we took him to St. John's training and he became a registered therapy dog. When we got out his "therapy dog scarf," his tail would begin to wag. He would jump into the car, walk into the centre, tail wagging, head up, with a big smile on his face. We went to a brain injury, Alzheimer's, stroke treatment centre. The smiles, comments and pats he received, (along with the treats) told us how valuable his visits became. And he learned as much as we did. Imagine our pleasure when we realized that he "knew" that John, a stroke victim, couldn't see from his left eye or use his left arm, so Bailey would approach him from the right side.

When we can, we expand our volunteer activities. Why?

We are rewarded by the results, by the smiles, by seeing progress, by helping those who can't help themselves, by fundraising, by being where we're needed, by giving of our time and talents to benefit others.

Busy? Sure. Too busy? Ask.

Hey! Volunteer! You know who you are.

Thank you. ♦

Hemophilia Ontario News



Amy Griffith & Michelle Lepera, both CodeROUGE ambassadors speak about women and inherited bleeding disorders

HEMOPHILIA ONTARIO'S 57th Annual General Meeting

by Terri-Lee Higgins

70 PEOPLE WERE PRESENT for Dr. David Lillicrap's keynote presentation on *Advances in Care* at the Annual General Meeting on Saturday, April 27 in Toronto. This presentation, available on our Facebook page (www.facebook.com/pages/Hemophilia-Ontario/192391854132304?ref=hl) had everyone engaged from start to finish. A world-renowned speaker, Dr. Lillicrap has the ability to present even the most complex information in a way that causes you to walk away saying, "I get it." The explanation of how stomach acids would negatively impact the option of ingesting factor in a pill form totally made sense. It was exciting to learn about the advances being made in gene therapy and to realize how far they have come with longer-acting half-life for Factor IX—research is yielding results! Thank you Dr. Lillicrap for sharing your insights.

CODErouge Ambassadors Amy Griffith and Michelle Lepera introduced the program which aims to increase diagnosis and access to care for women and girls with inherited bleeding disorders. The majority of women affected by a bleeding disorder are not yet diagnosed, and yet with treatment, women with bleeding disorders can lead full and active lives. Michelle and Amy are available for community presentations. Please speak with your Regional Service Coordinator for further details.

Social Workers Cindy Milne-Wren and Connie Shrubsole provided an overview of the HERO Study—a multi-national comprehensive analysis of the experience of living with hemophilia. HERO examined the disorder's effect on interpersonal relationships, careers, access to care and quality of life. It aims to improve outcomes in hemophilia by calling for enabling enhanced psychosocial support based on increased understanding and awareness of the issues.

On behalf of those present, thank you for making time to speak at our Annual General Meeting education session.

In Appreciation

It is with sincere appreciation that Hemophilia Ontario thanks the following for their support of Hemophilia Ontario's Annual General Meeting and everything it entails:

Baxter, Bayer, Octapharma – Sponsors

Tyler McGillivray – event photographer

Susan Turner – For ensuring that everything that was needed was done and there.

Marina Silverstova – For the "cram notes" helping me to present the financial reports.

Regional Service Coordinators – Thank you for your time and assistance on and off the job.



Mary Jane Steele receiving her award from Matthew Maynard

Volunteer Awards and Recognition

Recognizing and honouring volunteers sets a standard for service, encourages a sustained commitment to civic participation, and inspires others to make service a central part of their lives. Hemophilia Ontario Awards recognize individuals who have made a significant contribution to the inherited bleeding disorders community. Our Volunteer Award Program is a way to thank and honour those who, by their commitment



2013-2014 Hemophilia Ontario Board of Directors

and example, inspire others to engage in volunteer service. The recipients of this year's awards continue this tradition:

- Georgina Floros** – Ann Harrington Award
- Tom Alloway** – Honorary Lifetime Member Award
- Steve VanDusen** – Shawn Duford Grassroots Leadership Award
- Alexsandra McGillivray** – Staff Leadership Award

On behalf of Hemophilia Ontario, please accept our congratulations and sincere thanks for your dedication and involvement.

HTC Recognition

Hemophilia Ontario is proud to launch our new Hemophilia Treatment Centre Staff Program which recognizes the commitment of individuals associated with Hemophilia Treatment Centres—including doctors, nurses, physiotherapists, social workers and administrative assistants—providing service to persons in Ontario.



Steve Van Dusen receiving the Shawn Duford Grassroots Leadership award from Mike Beck

This year's recipients were:
Rebecca Goldsmith (Hamilton),
Linda Mansfeld-Smith (Sudbury),
Dr. Ian Chin-Yee (London), **Mad-
 eleine Borden** (Kingston), **Pat Rivet**
 (Sudbury) – *Five years*

Nicole Graham (Sudbury), **Cathy
 Walker** (Kingston), **Dr. Alan Tin-
 mouth** (Ottawa), **Joanne Solarski**
 (Toronto), **Georgina Floros** (To-
 ronto) – *10 years*

Dr. Kulwant Gill (Sudbury)
 – *15 years*

Dianne Bissonnette (Ottawa),
Sherry Purcell (Kingston), **Lucie
 Lacasse** (Ottawa), **Sheila Schembri**
 (London) – *25 years*

Pamela Hillard (Toronto),
Dr. Victor Blanchette (Toronto)
 – *30 years*



Tom Alloway receiving his Honorary Lifetime Member award from Jeff Beck

In compiling the details for these awards, we were not surprised to learn that patients of the Ontario clinics benefit from a combined 591 years of service! We also wanted to recognize the many more clinic team members that are not listed above for their years of service as well. Thank you to all HTC staff for your continued efforts and contributions – Hemophilia Ontario and the members of the bleeding disorders community. ♦



Teresa Genereux



Jeenetha Kulasingam



Laura Tomkins

STAFFING UPDATE:

CHANGE IS IN THE AIR at Hemophilia Ontario. Teresa Genereux, who has been on leave since November 2012, and who was the NOR Regional Service Coordinator for five years, has resigned. Teresa was instrumental in developing new programs and, along with her volunteers, implemented new fundraising initiatives such as the Walk-a-Thon. Words are inadequate to express our gratitude and appreciation of the work performance and attitude displayed during her employment. We wish her all the best.

TCOR RSC Jeenetha Kulasingam is also moving on. Jeenetha has been a dedicated and highly efficient member of the Toronto office for the past three years. The scope of programs has grown and she even jumped in the lake with other polar bear dippers! We know she will tackle her new ventures with the same passion and dedication displayed as part of our team. Working alongside her has been a privilege, and we know she will continue to succeed in this new phase of her professional career.

Saying goodbye is never easy, and it's even more difficult with employees like Teresa and Jeenetha who have been such a vital part of our team and corporate community. We wish you the best, both profession-

ally and personally, as you move on to new ventures. While we will miss the day-to-day interaction with you—you've been an invaluable part of our team—we know you will continue to do well and achieve major milestones. ♡

NORTH EAST ONTARIO REGION (NEOR) RSC

WE ARE PLEASED to introduce Stephanie Morrison as the NEOR RSC. Stephanie was involved as a regional volunteer and is a parent of an affected child. Her passion for growing the region and dedication to building strong educational opportunities will be key to her success in this new role. Welcome Stephanie. You can reach Stephanie at smorrison@hemophilia.on.ca.

NORTH WEST ONTARIO REGION (NWOR) RSC

WE ARE PLEASED to introduce Shelly Whitney as the NWOR RSC. Shelly has a background in client care and advocacy and has existing partnerships with many area agencies. She is excited to enhance Hemophilia Ontario's regional pres-

ence and utilise her ability to develop and implement new programs and events for members. Welcome Shelly. You can reach Shelly at swhitney@hemophilia.on.ca.

Sincere thanks to Diana, Vanessa, BettyAnn and Sandra for participating in the interview processes and providing your thoughts and input. Your time and commitment to helping us ensure we hire strong candidates is greatly appreciated. ♡

WELCOME

WE WOULD LIKE TO INTRODUCE and welcome Laura Tomkins as the new TCOR RSC. Laura, a graduate of McMaster University in Hamilton, has experience working with women's programming and with youth as a care provider, program supervisor and tutor. Laura's high level of enthusiasm and desire to get involved and become more familiar with inherited bleeding disorders is a good sign of things to come. Welcome, Laura. You can reach Laura at ltomkins@hemophilia.on.ca or 416-972-0641 Ext. 14. ♡

MANY THANKS to the BARBOUR FAMILY

by Terri-Lee Higgins

THE LIAM BARBOUR GOLF TOURNAMENT was initiated by Brad and Jenn Barbour in August, 2006. They started the tournament as a way to provide better support and services to those in similar circumstances, and to raise awareness and to honour their son, Liam, who has an inherited bleeding disorder. It is their way of making a difference.

The proceeds from this tournament have supported regional and provincial programs, supported members in need, provided post-secondary scholarships, and ensured the participation of youth with inherited bleeding disorders at YMCA Camp Wanakita. It also provided funds to the Hamilton-Niagara Regional Hemophilia Centre to purchase educational materials and tools for use in the clinic.

Their energy and enthusiasm to help others extends to many areas. Recently Brad and Jenn met an affected family at a child's car seat clinic and offered their personal assistance and contact information. Their genuine desire to help others has allowed us to make a difference in many ways.

Hemophilia Ontario is proud to be the primary recipient of the proceeds of the Liam Barbour Charity Golf Classic, which to date totals \$83,000. Thank you to the Barbour family and the tournament participants for your ongoing support of Hemophilia Ontario. We are truly grateful. ♡



The Barbour Family

Canadian Hemophilia Society News

HOLD THE DATE!



THE CANADIAN HEMOPHILIA SOCIETY IS HOSTING A WEEKEND WORKSHOP FOR YOUNG PEOPLE (AGES 18-30) AFFECTED BY A BLEEDING DISORDER

Interested in learning:

- 1) How to take ownership of your bleeding disorder?
- 2) How to become a good leader?
- 3) How to maintain and strengthen your mental & emotional health?



MARK your calendar for



September 13-15, 2013



The 2013 CHS Youth Workshop will provide you with the tips you need to increase your leadership skills. You will learn how to step outside of your comfort zone when dealing with mental health issues, the importance of taking ownership of your bleeding disorder and much more...

The workshop will take place at the Me to We Leadership Centre in Bethany, Ontario. Spaces are limited. Only 25 candidates will be able to take advantage of this opportunity. Make sure to be one of them! For more information or to request a registration form, please contact H el ene Bourgaize at 1-800-668-2686 or by e-mail at hbougaize@hemophilia.ca

Sponsored by:



JUST THE GUYS 2013

by Sarah Wood

ONLINE registration now open at www.justtheguys.ca.

CWOR, NOR, OEOR, SWOR and TCOR—September 20-22, 2013 at YMCA Camp Ki-Way-Y

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 aged 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 their diagnoses, as well as to connect with other families through a series of education sessions, activities, group events and network opportunities. This year's theme is Summer Olympics.

Please note that four-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. ♡

Changes to the **CAMP WANAKITA** Student Counselor (SC) Process

by Terri-Lee Higgins

IN 2013 all potential SCs participated in an interview process to help ensure suitability for the program. As part of this process, former campers and staff Amy Griffith and Dan Ignas comprised the interview panel alongside Terri-Lee Higgins. With their comprehensive knowledge of Camp Wanakita, Amy and Dan were able to ask insightful questions and explore each candidate's answers to ensure they understood the program and that they would make great SCs. Amy and Dan, thank you once again for volunteering your time and enthusiasm to this process. Best of luck to all the selected SCs this summer. ♡

Bleeding Disorders News

NEW Withholding Requirements **FOR THOSE WITH a RDSP**

by Jeenetha Kulasingam

EFFECTIVE JANUARY, 2014 financial institutions will start to deduct income tax from your Registered Disability Savings Plan payments instead of individuals paying this tax up front. This means that you will start to see a difference in the net amount you receive. The payment will be less, but theoretically your tax return will now be larger (if there are no other contributing factors).

Some of you may already know that there are two types of payments made out of an RDSP. One is called the Lifetime Disability Assistance Payment (LDAP), and the other is the Disability Assistance Payment (DAP). The LDAP is a continuous payment that must be paid until the plan ends, the DAP is a singular payment one can make for grand purchases (i.e., buying a car, travelling, etc.). Both payments can be made individually or at the same time within a calendar year.

When payments are withdrawn from the plan, the following amounts are taxable income:

- Canada Disability Savings Grant
- Canada Disability Savings Bond
- Investment Income earned in the plan

Please note, individual contributions made by third parties are not taxable.

The Financial Institution (FI) will issue a yearly T4A slip to beneficiaries for the taxable portion of any RDSP withdrawal. Beneficiaries must include the amount reported on the T4A as income on their income tax and benefit return.

There are benefits to withholding at source. One is that beneficiaries may not have a tax liability, as well as reducing the financial burden on them. The rate established will ensure withholding is as close as possible to the tax liability.

The rates are determined based on the taxable portion of the RDSP payments (bonds, grants and earned investment).

Withholding Rates
10 percent on amounts up to and including \$5,000
20 percent on amounts over \$5,000 and up to and including \$15,000
30 percent on amounts over \$15,000

These rates will be applied to the taxable portion of your payments minus the basic personal amount (BPA which is \$11,038) and the Disability Amount (DA which is \$7,697). Non-residents can also be RDSP beneficiaries as long as they have a valid SIN card; for these individuals there is a 25 percent withholding rate to the taxable portion. They in turn will get an NR4 slip.

Here's How it Works

Let's say you purchase one DAP for \$65,000, and you have no Bonds, \$10,000 in grants, and \$40,000 received from contributions. In addition to this, your earned investment is \$15,000. To find out how much tax is withheld, this is what FIs will do:

Example: Scenario 1

1 DAP	\$65 000
Subtract the contributions	-40, 000
This equals the taxable amount	25, 000

Taxable Amount	\$25, 000
Minus the BPA and DA	-18, 735
Equals the amount subject to withholding	6, 265

Because the taxable portion of your RDSP is above \$15, 000, the applicable withholding rate is 30 percent.

Tax withheld at 30 percent	\$1, 880
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The taxable portion is between \$5,000 and \$15, 000, therefore the withholding rate is 20 percent in this case.

Example: Scenario 2

Let's say now that you purchased 12 LDAPs of \$1 850. In total, that is \$22, 000. Again you have no Bonds, \$3,000 in grants, \$15, 000 in contributions and your earned investment is \$4,200.

Follow this example below to find out what the taxable amount is and how much is withheld.

12 LDAPs X 1,850	\$22, 200
Subtract the contributions	-15, 000
Equals the taxable amount	7, 200

Taxable Amount	\$7, 200
Minus the BPA and DA	-18, 735
Equals the amount subject to withholding	\$0 (This person's payment did not exceed the \$18,735)

Tax withheld at 20 percent	\$0
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Another item that should be noted is that these calculations are done every month and therefore there will be several months where you will not see a change in what you receive. You will only start noticing the change when the payment exceeds \$18,735. Therefore, you do not have to worry about a one lump sum payment; the tax will be taken out gradually.

More information about RDSPs is available at www.cra.gc.ca/rdsp and/or www.disabilitysavings.gc.ca.



Healthy Living

How to **KEEP YOUR BODY MOVING** Every Day

by *Laura Tomkins*

EVEN WHEN WE get super busy with life, incorporating exercise into every day is important to keep all aspects of ourselves, physically, mentally and emotionally healthy. Here are some easy ways to sneak exercise into everyday life.

- Take the stairs instead of the elevator.
- When in a parking lot, park farther away from your destination to get extra walking in.
- Even if it's just to a farther transit station, walk.
- Walking with friends is also an inexpensive way to get together, explore your neighbourhood, and get fresh air.
- Bad weather? That's no excuse, Walk around a mall or grocery store to get that extra bit of exercise.

Listed below are some simple stretches one can do daily to increase flexibility and movement

Remember to breathe and be conscious

- **When you wake up:** lift your arms up and stretch as tall as possible. Follow this by continuing that stretch, but by reaching to your toes, knees, thighs or whatever works best for you. Roll yourself up slowly after a minute.
- **Standing poses to strengthen legs and knees:**
 - Mountain: A simple but effective pose. Stand with your toes spread apart, and your weight distributed evenly on all four corners of your feet. Lift your arches, pull the pelvic bones up, roll the shoulder blades down your back, and breathe.
 - Tree: Standing tall, put all your weight onto one foot. Slowly lift your other foot, and place your heel on your thigh or calf, or keep your toes on the floor and have your heel touching just above your ankle, anywhere but your knee. Balance. Breathe.
- **While Sitting (at work, on the bus, at home)**
 - Stretch your legs out in front of you and reach your toes.
 - To stretch out your neck, drop your left ear to your left shoulder, then your right ear to your right shoulder. Do this a few times, and then follow this by dropping your chin to your chest and back up a few times.
 - On an inhale bring your shoulders up to your ears. On the next exhale roll your shoulders down your back. Do this three to five times.
 - Sit on your bed, chair, couch or floor. Bring the soles of your feet together, legs open. If this feels uncomfortable, try doing this pose while lying down. Wish to go further into the pose? Round your back and fold over your legs, resting your hands on the ground. ◊

**Disclaimer: Exercise and physical activity are based on an individual's condition. Be sure to always consult with your clinic team before starting a new exercise program.*



Photo Credit: BigStock.com/19161146



EATING HEALTHY During the Summer Months

by Laura Tomkins

ONE OF THE BEST THINGS about summer is the abundance of fresh, local produce that is available. Stocking up on fruits and veggies while they are in season is cheaper than doing so in the off season, and by buying a bunch of fresh produce and freezing it, it's a great way to incorporate fruits and veggies into your diet all year long. Here's what is in season from June – September:

- | | | |
|------------|----------------|----------------|
| • Corn | • Apricots | • Peas |
| • Cucumber | • Arugula | • Plums |
| • Eggplant | • Beets | • Radishes |
| • Figs | • Bell Peppers | • Rhubarb |
| • Lemons | • Blackberries | • Strawberries |
| • Limes | • Blueberries | • Tomatoes |
| • Melons | • Carrots | • Zucchini |
| • Peaches | • Cherries | |

Farmer's markets will have these available over the next few months, and there are also several farms where you can pick your own fruits and vegetables, which is a great way to spend the afternoon with your friends or family. A lot of these products can also be mixed with other healthy add-ons, such as nuts, seeds, olive or coconut oil, ginger, cinnamon or garlic.

Here are some quick and easy ways to incorporate the produce listed above:

- Add blackberries, blueberries or strawberries to cereal and yogurt, or make a smoothie out of them.
- Load up salads with different items such as radishes, beets, cherries or figs.
- Mix your pastas with carrots, corn, peas, zucchini or eggplant.
- Top your sandwiches with arugula, bell peppers, cucumber and tomatoes.
- When on the run, grab an apricot, peach or plum for a snack. ♡



HIV/HCV News

Knowledge of HIV/AIDS and HCV is Decreasing in CANADA

by Laura Tomkins

ACCORDING TO the Public Health Agency of Canada, only 37 percent of Canadians have ever been tested for HIV, and HIV/AIDS and hepatitis C knowledge among Canadians is decreasing. Recently, Dalhousie University researchers were envisioning ways to encourage people to get tested for HIV, but found scientific publications have confirmed that people have refused testing due to anxiety or fear, mostly linked to the test results.

In response, these researchers asked volunteers at a sexual health clinic in Halifax if they would be more willing to be tested for HIV if they had access to POC, or rapid point of care HIV testing. POC testing, which is more than 99 percent effective, involves testing a few drops of blood taken from the finger. Tentative results are processed within several minutes, versus typical HIV testing which can take one to two weeks. The results from this study were that over 90 percent of the volunteers favoured the test, which are comparable results of similar studies done in Toronto, New York City and Chicago.

Resources:

www.catie.ca/en/catieneews/2013-05-28/halifax-researchers-find-high-acceptability-rapid-hiv-testing

www.catie.ca/en/catieneews/2013-03-26/canadian-s-awareness-attitudes-knowledge-and-behaviours-related-hiv-and-hepatit ♡

Changes to **BLOOD DONOR** Guidelines in **CANADA**

by Laura Tomkins

IN MAY, 2013 Canadian Blood Services confirmed that men who have had sexual relations with other men are eligible to donate blood if they have not engaged in sexual interactions with another male for a minimum of five years. Previously, no male who had ever been intimate with another male was eligible to donate blood in Canada.

Resources:

www.blood.ca/CentreApps/Internet/UW_V502_MainEngine.nsf/page/MSM?OpenDocument&CloseMenu ◊

TAINTED – THE PLAY by Moyo Theatre in Association with **GROMKAT** **PRODUCTIONS**

TAINTED tells the story of the Steele family and their fight to stay intact when the unimaginable happens. Set against the backdrop of the devastating tainted blood crisis, *Tainted* is a story about love, grief, justice and the enduring power of forgiveness.

Tainted will run from September 26 to October 12 at the new premier arts venue in Toronto, **The Aki Studio Theatre, Daniels Spectrum**. Under the direction of multi-Dora winning director Vikki Anderson, this stellar cast and design team bring the story to life.

Source: www.indiegogo.com/projects/tainted-be-a-valiant-voice ◊

Pharmaceutical News

Brand names of treatment products are provided for information only. Their inclusion is not an endorsement of a particular product or company

Saluting **CANADIAN INNOVATORS** Who Embody **BAYER'S** Philosophy: **SCIENCE** for a Better Life

Bayer Celebrates 150-year Anniversary by Honouring Canadians Who Have Made a Mark on Society Through Science and Innovation

A news release developed by Bayer Inc

TORONTO, ON, MAY 7, 2013 – Scientists and innovators have guided every step in Bayer's 150-year journey to becoming a global leader in healthcare, crop and material sciences. As it marks its 150th anniversary this year, Bayer also celebrates Canadian innovation and individuals who exemplify the curiosity and commitment to help shape a better future. Bayer is recognizing a number of Canadians for their individual contributions in the areas highlighted in its anniversary exhibit, and who live by its mission, *Science For A Better Life*.

These Canadians, ranging from educators and research scientists, to leaders in business and philanthropy, were honoured at a special ceremony on Tuesday, May 28, hosted by physician and television personality Dr. Marla Shapiro, herself an honoree for her work in women's health.

"I spend much of my time counseling and educating my patients and the public on ways to live healthy and fulfilling lives," says Dr. Shapiro. "Although we may not always stop to think about how innovation and science affect us, it's important to recognize the people behind the research that make it all happen."

One of the Canadians honoured included the hemophilia community's very own Dr. David Lillicrap for the category of *Effective Hemophilia Treatment*. To see a full list of all those who were honoured, visit www.bayer.ca. ◊

Enhancing the Quality of Life of **VON WILLEBRAND** Disease Patients: **STOP & THINK** – Should **YOU** be on **TREATMENT** to Help Prevent Bleeds?

A new educational piece developed by Octapharma Canada

USING INPUT FROM the von Willebrand Disease (VWD) focus group held in January of this year, Octapharma has developed a simple to use awareness piece highlighting signs of bleeding that is focused on individuals with von Willebrand Disease. In the form of a convenient postcard, it describes "10 Red Flags" of bleeding that may encourage individuals or their caregivers to speak to their healthcare team regarding treatment to help control and

prevent bleeding. If you can identify with these “Red Flags,” then perhaps prophylaxis treatment is something that you and your healthcare team need to consider. Prophylaxis refers to treatment that is given in anticipation of bleeding, to help prevent bleeds from occurring. There are two very important points about this preventative approach to treatment. First, treatment is given before bleeding has occurred and secondly, the aim of treatment is to help prevent bleeding. The ultimate goal is to prevent and control bleeding. Prophylaxis

helps individuals with VWD be active, attend work/school regularly and participate in life as fully as possible. Many families that attended the VWD focus group found that prophylaxis improved their quality of life and decreased the number of visits to the hospital. They all affirmed the benefit of prophylaxis treatment.

Octapharma would like to acknowledge the Canadian Association of Nurses in Hemophilia Care and Ann Marie Stain of Kiddies Health-Care Inc. for their leadership in the creation of this awareness tool.

We were also fortunate to have Dr. Paula James, Associate Professor and Hematologist, Queen’s University, Kingston, a world renowned expert in von Willebrand Disease, review this piece as it was being developed. Please contact your healthcare team to receive your *Stop & Think... 10 Red Flags* postcard. ♡

von Willebrand Disease Patients

STOP & THINK...

Should you be on treatment to help prevent bleeds?

10 Red Flags

If you experience any of the below, effective treatment options may be available.

- Frequent Nosebleeds (5 or more per year)
- Heavy menstrual periods lasting more than 7 days (or requiring a change of sanitary protection more often than every 2 hours)
- Bleeding into joints (one or more per year)
- Bleeding into muscles (one or more per year)
- Bleeding into the brain
- Bleeding into or around the spinal cord
- Recurrent, unexplained GI bleeding (from the stomach or bowels)
- Anemia/iron deficiency/need for blood transfusion
- Frequent visits to the hospital or clinic for bleeding
- Poor Quality of Life because of bleeding



Please discuss all treatment decisions with your doctor and nurse.

We would like to acknowledge the CANHC nurses and Ann Marie Stain of Kiddies HealthCare Inc. for their leadership in the creation of this awareness tool. Edited and reviewed by Dr. Paula James, MB, FRCPC, Associate Professor & Hematologist, Queen's University, Kingston, Canada. Provided a medical information source to patients with von Willebrand Disease by Octapharma Canada. Roman et al., J Thromb Haemostasis 2006; 6: 2002-6.



Central Western Ontario Region

50 Fabulous YEARS

2013 MARKS THE 50th anniversary for the CWOR region, so it was only fitting when 50 participants (the most we've ever had) attended our 50th Anniversary and Regional General Meeting on Saturday, March 2 at Dundurn Castle.

The event was a tremendous success as families and individuals gathered to listen to presentations on upcoming research from Carrie Ku, Medical/Scientific Advisor with Bayer Inc; Lucie Gringas, BioPharmaceutical Medical Manager with NovoNordisk Canada Inc; Dr. Hany Elgendy, Medical Science Liaison for Baxter Bioscience; and Dr. Alfonso Iorio, Clinic Director for the Hamilton-Niagara Regional Hemophilia Centre. As always, the presentations were engaging and highly informative.

Participants also gained knowledge of the region's rich 50-year history with a presentation by Alex McGillivray, Regional Service Coordinator, that highlighted the regions' journeys and triumphs. During this presentation, a slideshow showcasing photos from as far back as 1963 were displayed for all to enjoy.

The children in attendance also enjoyed their share of fun. It was a pizza, popcorn and movie kind of night. The kids had a blast playing games and watching Dr. Seuss', *The Lorax*, while eating freshly popped popcorn. Many thanks go to our organizer and entertainer for the evening, Amy Griffith.

Not only did this event celebrate the region's 50th anniversary, but it also reinstated an old tradition; the CWOR Honour Roll and Volunteer Recognition.

Congratulations to all the recipients of this year's awards. We are truly grateful for all that you do for this region and for the passion you share with the inherited bleeding disorders community.

Many thanks to Debbie Bordi, Mary Pedersen, and Jane Dinsdale for all of their hard work in organizing and setting up the venue. Thanks to Tyler McGillivray for his photographic skills and capturing the events moments. Thank you to all the speakers for your skills and your time. Lastly, thank you to all those who attended and made this event such a great success. We can't wait to see you next year. ☺

CWOR Honour Roll and Volunteer Recognition recipients

CWOR Honour Roll	Kay Decker , Hemophilia Nurse Coordinator
CWOR Honour Roll	Jace Pedersen , CWOR Council Member
CWOR Honour Roll	Alan Sutton , Past CWOR Council Member
CWOR Honour Roll	Theresa Almonte , Program Administrator
CWOR Honour Roll	Igor Ristevski , CWOR Council Member
Volunteer of the Year	Rob Dinsdale , CWOR Council Member
Leader of Tomorrow Award	Meagan Bordi , CWOR Council Member
Member of the Year Award	Leslie Bauman , CWOR Member



Members of CWOR enjoying the 50 Year Celebration slideshow and history.



Some of the kids enjoying their fun activities!



Alex McGillivray presenting Meagan Bordi with her Leaders of Tomorrow award



Youth leader Amy Griffith having a ball while entertaining the kids



Kay Decker, Nurse Coordinator and Theresa Almonte, Program Administrator with their CWOR Honour Roll awards



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

Regional Board/Council and Staff

Rob Dinsdale, Mary Pedersen
 Igor Risteovski, Debbie Bordi
 and Meagan Bordi
 Alexandra McGillivray –
 Regional Service Coordinator
 101-140 King St. E
 Hamilton, ON
 L8N 1B2
 905-522-2545
 amcgillivray@hemophilia.on.ca

DATE	WHAT AND WHERE?	Events Calendar
September 7	Big Sale on the Little Street	
September 20-22	Just the Guys Weekend	



Save the Dates!

BIG SALE on the Little Street FUNDRAISER

IT'S BACK! Save the date of Saturday, September 7 for the *Big Sale on the Little Street*. Remember, this fundraiser takes place during the Locke Street Festival, so come on down and show your support while enjoying live music and entertainment on Locke Street.

If you would like to donate any items to the sale, contact Alex McGillivray, Regional Service Coordinator at 905-522-2545 or amcgillivray@hemophilia.on.ca for more information. Please note that clothing and electrical items will not be accepted at this time. ♡

CWOR at Buskerfest

ON SATURDAY, JUNE 8, CWOR represented the inherited bleeding disorders community by having an education booth at The Dundas International Buskerfest. We partnered with our neighbouring agency, The AIDS Network of Hamilton to provide education and awareness to the community.

CWOR's table displayed a large infographic poster which highlighted some of the basic but key points about inherited bleeding disorders and the work that Hemophilia Ontario does. This poster generated discussion from the crowd and a few donations and we learned that you're never too young to start supporting Hemophilia Ontario.

Our table also focused on the upcoming World Hepatitis Day, which takes place globally on Sunday, July 28. Posters and information were on display and available for the taking that captured this year's theme of "This is Hepatitis. Know it. Confront it."

Thanks to Rob and Jane Dinsdale, Mary Pedersen and Tyler McGillivray for all of their help during the event, and thank you to The AIDS Network of Hamilton's Kaitlyn Walsh and Dane Griffiths for sharing the educational booth with us. ♡



Three-and-a-half-year-old Emma MacLeod shows her support for Hemophilia Ontario at Buskerfest.

Supercrawl BBQ FUNDRAISER and EDUCATION Booth

COME OUT AND SUPPORT CWOR at their BBQ Fundraiser and Education Booth at the James Street Supercrawl in downtown Hamilton (www.supercrawl.ca). This year CWOR will hold a BBQ on Friday, September 13 to raise funds for local programs and services, as well as participating in the festival with an education booth on Saturday, September 14.

The James Street Supercrawl is the largest FREE Art Festival in Southern Ontario and boasts approximately 80,000 visitors. If you are in the Hamilton area during this weekend, you will not want to miss this festival, so be sure to come down and visit Hemophilia Ontario CWOR at their BBQ and education booth. We hope to see you there.

To help volunteer or for more information, contact Alex McGillivray, Regional Service Coordinator at 905-522-2545 or amcgillivray@hemophilia.on.ca. ♡

LIAM BARBOUR Scholarship Award

The Central Western Region of Hemophilia Ontario (CWOR) is proud to present the Liam Barbour Scholarship Award. This scholarship is made possible through the generosity of the Barbour family. The Liam Barbour Scholarship Award will offer a \$500 award to any affected member for their first year of post-secondary education. This amount is to be evaluated on an annual basis, and based

on the amount of funds raised by the Liam Barbour Charity Golf Classic.

Scholarship Requirements:

- To qualify for this award, the applicant must reside in the Central Western Ontario Region, be an active member of CWOR, and have a bleeding disorder.
- The applicant must provide proof to CWOR of their enrolment at a post-secondary institution.
- CWOR has been empowered with the selection of the award on an annual basis. The award will be

paid in/around the first week of October of the first year the student is enrolled in post-secondary education.

The deadline for receipt of scholarship applications is August 1, 2013. Faxed or late applications will not be accepted. For more information or to obtain a Liam Barbour Scholarship Award application, contact Alex McGillivray, Regional Service Coordinator. Applications can be mailed to Hemophilia Ontario CWOR, 101-King St. E, Hamilton, ON, L8N 1B2. ♡

Northern Ontario Region

Welcome **STEPHANIE**
and **SHELLY**

WITH THE HIRE of Stephanie as the NEOR RSC and Shelly as the NWOR RSC, members can expect new programs and events sometime in the fall / early winter months. Be watching the mail and e-mail for further details. Not on our e-mail or mailing list? Please contact the appropriate RSC by e-mail as noted below to be added.

Hemophilia Ontario will invite members from NEOR and NWOR regions to participate in the 2013 Southern Just The Guys event scheduled for September 20–22 at Camp Ki-Wa-Y in St. Clemens, ON. By mentoring the staff and participants this year it will better prepare the regions to run their own events in 2014. If you are interested in attending the event, please contact your RSC for further details.

The Wellness for Women Conference (W2) is a provincial event taking place in October (see flyer at back of *Blood Matters*). Women from NEOR and NWOR regions interested in attending should contact your RSC as below:

Stephanie and Shelly will be available by e-mail July 10 and will then provide full contact details.

Stephanie Morrison smorrison@hemophilia.on.ca

North West Ontario Region

Shelly Whitney swhitney@hemophilia.on.ca ♡



Stephanie Morrison, the new NEOR RSC.



Shelly Whitney, the new NWOR RSC.

NORTHERN ONTARIO held two very successful clinics recently, one in Thunder Bay and one in Sudbury. TCOR Regional Service Coordinator Sarah Wood travelled to the North to assist nurses Karen Roberts and Betty-Ann Paradis with these clinics. The Thunder Bay clinic saw about 12 people throughout the day and the Sudbury clinic saw almost 40 people. At the Sudbury clinic families got the opportunity to connect with each other, check-in with their HTC, speak with the Hemophilia Ontario RSC and a number of the pharmaceutical representatives, and enjoy some good food. A big thanks to both of the nurses for their hard work on these clinics. ☺

DATE	WHAT AND WHERE?	Events Calendar
September 20-22	Just the Guys	

Ottawa and Eastern Ontario Region

Ontario Regions



Regional Board/Council and Staff
 Raja Ammoury-Alami
 Jordan Cabral
 Lyanne Cabral
 Ashwani Kurrichh
 Nancy Sauvé
 Darlene Villeneuve
 Patrick Grenon

Colin Patterson
 Regional Service Coordinator
 2445 Boul. St. Laurent
 Ottawa, ON K1G 6G3
 613-739-3845
 cpatterson@hemophilia.on.ca



Colin Patterson presenting Diane Bissonnette, Nurse Coordinator with her years of service award

All articles in this section, unless otherwise indicated, are by Colin Patterson.



2013-2014 OEOR Council Members



Colin Patterson presenting Dr. Klaassen with his years of service award



OEOR's World Hemophilia Table at Gloucester Shopping Centre



SAVE the DATE!

19th Annual Shawn Duford Golf Tournament for Hemophilia

MAKE SURE to save the date of Saturday, August 10, 2013 and join OEOR for the 19th Annual Shawn Duford Golf Tournament for Hemophilia. This tournament features a shotgun start at 1:00pm at the Meadows Golf and Country Club in Ottawa. Registration, as always, is on a first-registered basis, so don't delay.

For more information on the tournament, contact Aleksandra McGilivray, Regional Service Coordinator at 905-522-2545 or amcgilivray@hemophilia.on.ca.

DATE	WHAT AND WHERE?	Events Calendar
Aug 10	18th Annual Shawn Duford Golf Tournament The Meadows Golf & Country Club, Ottawa, ON	
Sept 20-22	Just the Guys	
Oct TBA	Bowl-a-thon	

South Western Ontario Region



**YOUTH VOLUNTEERS
– Each Contributing
IN THEIR OWN WAY**

MARION STOLTE, Chair of SWOR, recognized the contribution of some of our youth volunteers in the London area at the Pillar Nonprofit Network's Youth Volunteer Appreciation Night. The youth in the region have found so many ways to contribute, whether by stuffing envelopes, being the keynote speaker at a golf tournament or being part of the Pincrest Adventure Camp leadership program, just to name a few. Each one of these youths makes a difference. ♡

SWOR volunteer Marion Stolte with three of the youth volunteers who were recognized at the event: Hannah Higgins, Paul Travaglini, Ryan Kleefman. Absent: Jason Kleefman, Tyse Burrows.

THANKS to our VOLUNTEERS

THERE ARE SO MANY volunteers who contribute in their own way to the success of South Western Ontario Region. How each individual contributes their time and efforts for the region's programs and services makes a difference in so many ways.

At our Education Day and Regional General Meeting, SWOR welcomed three new council members: Monica Mamut, Leigh McFadden and Moutasem Zakkar.

SWOR's Volunteer of the Year was Travis Hazelwood who has been a Council Member, three year Chair of the Golf Tournament, and on the Bleeding Disorders Program Advisory Council as a parent. Travis' commitment and accomplishments as a volunteer for SWOR were also recognized when he was selected to receive a Queen's Jubilee Medallion. Congratulations Travis. ♡

Pinecrest ADVENTURES CAMP – RAIDERS of THE LOST Arti-Factor

by Nick Higgins

URGENT HELP REQUIRED! This is a call for all SWOR youth ages 5-16!

Indiana Jones needs your help to find the Lost Arti-Factor at Pinecrest Adventures Camp this summer. Indy urges that you tell no one about this message, remain calm and await further instructions that will be provided once he gets back from his latest mission.

Camp takes place from Wednesday, August 21 – Sunday, August 25, 2013 at Camp Menesetung in Goderich, ON. For registration information, contact Terri-Lee Higgins at thiggins@hemophilia.on.ca or call 519-432-2365. ♡



GRRRR, BRRRR, GREAT!

THE WATER WAS COLD, the air was cold, but the Spartan costumes and support were great for the support of the Polar Bear Dip in Port Stanley on April 14. What a great way to recognize World Hemophilia Day with the help of volunteers Leigh (organizer), Marion, Dave (first responder), Terri-Lee (photographer), and everyone who collected sponsorships for their plunge! The support and encouragement of so many that came out to cheer us into the water, and to wrap us up in towels afterwards, was amazing. This has become an event to look forward to each year. Next year's plan – SUPERHEROES! ♡



Regional Board/Council and Staff

Dawn Harman
Kathleen Hazelwood
Travis Hazelwood
Ryan Kleefman
Michelle Lepera
Maureen Schaus
Marion Stolte
Holly Valenta
Paul Wilton
Moutasem Zakkar
Leigh McFadden
Monica Mamut

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



SAVE the DATE

Saturday, September, 28th, 2013

SWOR 6th Annual Tournament for Hemophilia and Inherited Bleeding Disorders



Ingersoll Golf Club
51 Holcroft Street
Ingersoll, ON N5C 3K1

To qualify for Early Bird Prizes
Register by July 28th 2013
(World Hepatitis Day)

Hemophilia Ontario
South Western Ontario Region
186 King Street, Suite 30
London ON N6A 1C7
519.432.2365



swor@hemophilia.on.ca

www.sworgolftournament.com



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

SAVE the DATE!

ON SATURDAY, OCTOBER 5, join SWOR for their Youth Speakers Bureau—an event where you can learn to tell your story in person or through a video.

For more information, contact Matthew Maynard at mmaynard@hemophilia.on.ca, or 519-432-2365.

DATE	WHAT AND WHERE?	Events Calendar
August 21 - 25	Pinecrest Adventure Camp , Goderich, Ontario	
September 14	6th Annual Golf Tournament for Hemophilia and Inherited Bleeding Disorders , Bear Creek Golf Club, Strathroy, Ontario	
September 20-22	Just the Guys Weekend	

Toronto and Central Ontario Region

End the SUMMER at the TORONTO ISLANDS

by Jeenetha Kulasingam



Sarah Wood

CAN YOU THINK of a better way to spend your last days of summer than hanging out with your fellow TCOR friends at the Toronto Islands? We certainly can't. Come out on Sunday, August 25, from 11:00am – 3:00pm for some great food, fun activities led by our enthusiastic volunteers and a worthwhile educational session on dental care

We know you want to come, so register now with Sarah Wood at 416-972-0641 Ext. 12. See you there! ☺



Laura Tomkins

DATE	WHAT AND WHERE?	Events Calendar
August 25	Families In Touch Summer Picnic	
September 6	TCOR Golf Tournament	
September 20-22	Just the Guys Weekend	



Celebrating our Volunteers

ALL in the FAMILY

by Terri-Lee Higgins

What a PLUNGE!

by Jeenetha Kulasingam

SEVERAL TCOR MEMBERS plunged into Lake Ontario on a very frigid Saturday morning and together collected donations close to \$11,000. This was beyond what we expected. Prizes were awarded for best adult costume to Lara Oulahen, best kid costumes to Jenna and Trevor Reid, longest dipper to Mark Oulahen and Maryam Naji and most collected pledges to the Shock and Thaw team (Victoria Kinniburgh, Jeff Kinniburgh, Suzanne Bevan, Kelly McCurrach). Thank you to all the dippers for your commitment, devotion and enthusiasm. Can't wait for next year's dip. 💧

AS A TEENAGER I began following my parents' examples of being involved in the community as a volunteer; it was what you did if you really wanted to make a difference. I believe this, in part, guided me to a career in the not-for-profit sector, and that it is with the support of my family that I have been able to continue working in this community. So, for me, it made sense that *my* family should become involved in my passion. Because of them, I have the flexibility to do what I need to do. Meet my terrific family, all actively involved or volunteers for the society:

- Jim, my husband—helps within administration and mailings, takes vacation days to help transport supplies to camp, participates in fundraisers such as the golf tournament, provides donations for fundraisers and overall helps me keep my sanity day to day.
- Nick, my son—is completing his fifth (and final) year as Director of SWOR's Pinecrest Adventures Camp and was involved in the SWOR Council for a year.
- Hannah, my daughter—a six-year volunteer, is a first-year staff at Pinecrest, participates in fundraisers such as the polar bear dip, provides child care/activities at member programs, assists with mailings/office and storage area clean-ups and helps with just about anything asked.
- Tom, my dad—is one of the editors of *Blood Matters* and sponsors Hannah.
- Bonnie, my mom—engaged her sorority to help collect items for camp supplies/craft items, shares fundraisers among her community and sponsors Hannah.

JC Penney said, "How can we expect our children to know and experience the joy of giving unless we teach them that the greater pleasure in life lies in the art of giving rather than receiving." I am fortunate that my family learned this lesson well, thank you from the bottom of my heart for always being there. 💧

Regional Board/Council and Staff

David Neal, Maury Drutz, Mike Beck, Mojtaba Khezry, Samuel Leon, Victoria Kinniburgh, Sheila Coad, AyeH Hamidian, Maryam Naji, Zachary Adams, Lara Oulahen, and Michael Kwadwo Bosompra

Staff

Susan Turner, Executive Assistant/Bookkeeper
 Laura Tomkins, 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



Nick Higgins



Hannah Higgins



Meagan Bordi

CWOR Volunteer

by Alex McGillivray

JOINING THE CWOR COUNCIL only a year ago, CWOR volunteer Meagan Bordi has been a great asset to our group. Over the past year, we have seen Meagan grow into an amazing volunteer as she willingly takes the lead to share the duty of chairing our meetings.

Meagan can be found helping out at CWOR programs, or more recently, getting sunburnt while canoeing during a Hemophilia Ontario Youth (HOY) event. She is passionate about helping the community and plans to organize a bottle drive to help raise funds for HOY programming.

Not only does Meagan volunteer for CWOR, but also she volunteers for other community organizations, and she does this all while juggling a full course load in the sciences program at McMaster University.

Meagan, we just want to say that is truly an honour and a privilege to have you as part of our group, and that our meetings just wouldn't be as fun without you. Thank you for all you do—including singing “It's so Cold in the D” to entertain us. ♦

Retiring HEMOPHILIA ONTARIO Board Volunteers

by Alex McGillivray

EVERY YEAR, Hemophilia Ontario elects a new Board of Directors at the Annual General Meeting. These individuals direct their support and unique talents at the provincial level while ensuring the best interest of their local region. This process brings new members to the Board while others step down to embark on new ventures. We would like to thank and recognize the following retiring Board members for their countless hours of hard work and dedication.

Paul MacNeil (NOR) – Paul is best known for being a former staff of Hemophilia Ontario and a marathon man who raised money for the organization.

Steve VanDusen (OEOR) – A central figure of the Ottawa Region, Steve has always been involved in making life better for future generations growing up with an inherited bleeding disorder. With his community as his focus, he was always a fearless advocate for what he believed was right.

Kiran Gopie (TCOR) – Kiran possessed an MBA background and

tackled every task with a professional approach during her time on our provincial Board of Directors. As a favourite among her peers, her professionalism and talents will be greatly missed.

Samuel Leon (TCOR) – As an affected person with an inherited bleeding disorder, Samuel's focus was geared towards youth as well as practical implications.

Travis Hazelwood (SWOR) – As a father of two boys, and with his heart always in the right place, he was focused on making things better for his kids and others in the inherited bleeding disorders community. Known as a straight shooter, Travis will be missed for his honesty and integrity.

Again, words are often not enough to capture all of the qualities each volunteer brings to the table, but we ask that each of you accept our sincere thanks for all that you have done, and will continue to do. Best of luck with your future endeavours. ♦

JOIN US ON Facebook

by Alex McGillivray

IN NOVEMBER OF 2012, Hemophilia Ontario launched the new look of its Facebook page. Since that time, the page has increased by 100 fans. We definitely want to keep our numbers rising, so we've decided to make some amazing changes to our posting schedule.

Fans can still enjoy Mission Monday, Trivia Tuesday, and Fan Friday, but our Wednesday and Thursday themes are changing to incorporate a more diverse style of posting. Wednesday will be “Webisode” Wednesday where we will post videos about interesting topics. Thursdays will be “Throwback” Thursday where we will focus our posts on the organization's rich history.

We are still going to award one lucky fan with the title of “Fan of the Month,” so make sure to leave us comments and like our posts for your chance to win. If you're not a fan yet—what are you waiting for? Come out and join our community. We look forward to connecting with you.

You can find our page using the following link: www.facebook.com/pages/Hemophilia-Ontario/192391854132304?ref=hl ♦



From STUFF to DONATION

by Phyllis Gray

HAVE YOU EVER LOOKED in your closets, in your cupboards, in your basement, and around your living room and wondered, “Why am I keeping all this stuff?”

For 40 years we lived in a house built in the 1800s, and during that time I collected many antiques, including vintage toasters, apple peelers, bottles, barn lanterns and even mouse traps. On moving to a newer home 10 years ago, we packed all those antiques into boxes and bins and most of them began to reside in our closets, cupboards and basement. A few made it into our kitchen and living room.

One day last year, trying to think of different ways Hemophilia Ontario (HO) could raise funds, I looked in one of our closets and came up with an idea. Why not sell all this “stuff” and donate the proceeds to HO. What better way to help our

grandsons Benjamin and Nathan and others affected with hemophilia, and also help our three sons, who would have been stuck with getting rid of everything someday. And the accountant in me liked the idea of a tax credit on next year’s income tax return.

There were several options for selling. I could have rented a booth at an antique mall, rented a table at an antique show, had a yard sale or sent everything on consignment to an auction house. Since I was looking for the easiest and least time-consuming way, and the one that brought the best return, I chose an auction house.

I contacted one in our area that I thought would be most appropriate. It was easy from there on. I sent them a photo of each item, which they posted on their website, and a few days before the auction I loaded everything up and delivered it to them. They did the rest—all the advertising, the displaying, the cataloguing, the selling, the final reporting, and finally issuing the cheque to me. For all of that, they took a 30 percent commission.

Although I would like to have received \$1,000,000 for my antiques (just joking), that wasn’t the case. Some of the items sold for less than what I expected, but some sold for much more. My vintage toasters were a good example. I put in about 25 of them, and they didn’t sell well, but I did meet a collector who potentially could be the purchaser of some of my remaining collection, hopefully at better prices. I didn’t consign all of my surplus antiques, but I will consider selling more in the same way—possibly in another area of Ontario, perhaps around London or Owen Sound, just to see how the results are there.

In the end, I had the satisfaction of being able to make a donation to HO, I am now able to look in my closets and see some empty shelves, I save time on dusting, and our house feels a little bit bigger. Hopefully the purchasers enjoy the antiques they bought, so it’s a win-win situation for everyone.

If anyone is interested in doing the same and would like more information, feel free to contact me at pgray@saybuck.com. ♦

WORLD HEMOPHILIA Day Reflection

by David Neal

WORLD HEMOPHILIA DAY is obviously an important day for our community. It is a day of reflection, to remember where we have come from as a community and where we are going. It is also an opportunity to raise awareness of all inherited bleeding disorders and to learn about new medical advances. After recently speaking with TCOR staff, I accepted an invitation to speak to the staff at Biogen Idec to share my story and to educate staff about the history of hemophilia.

I attended this luncheon with Jeenetha Kulasingam, one of our Regional Service Coordinators, and really enjoyed the experience. We

met some great people who are very passionate about developing longer-lasting factor replacement treatments. After learning about these treatments, I am confident that all pharmaceutical companies are committed to ensuring that these products are available in the future.

Whenever I have an opportunity to educate the public about hemophilia, I try to take the opportunity to do so. I was always taught that knowledge is power, and the more aware of hemophilia the public is, the more willing they may be to contribute to our goal of finding a cure. I was very impressed with the questions that the audience asked about my personal experiences,

and was more than happy to answer their questions.

When lunch was finished, I thanked the staff at Biogen for inviting me to celebrate with them, and proceeded downtown later that day to take in the view of the CN Tower. I felt very proud to see the Tower lit up in red to celebrate World Hemophilia Day. The World Federation, the CHS and Hemophilia Ontario has definitely come a long way from its beginnings 50 – 60 years ago. With all the positive news that I read about new treatments, I firmly believe that a cure for hemophilia (and all other inherited bleeding disorders) is not far off. ♦

Board of Directors 2013

WE WOULD LIKE to officially introduce this year's Hemophilia Ontario Board of Directors for the 2013-2014 term. These members were voted in at the Annual General meeting. Welcome and thank you in advance for all your hard work!

President

Paul Wilton

Vice-President Care & Treatment

Julia Sek

Vice-President Nominations

Mike Beck

Vice-President Board Development

David Neal

Past President

Jeff Beck

Secretary

Rob Dinsdale

Treasurer

Phyllis Gray

Directors

Igor Ristevski

Raja Ammoury

Ash Kurichh

Victoria Kinniburgh

Maury Drutz

Kristen Luszka

Mojtaba Khezry

Monica Mamut

Mary Pedersen

Amy Griffith

Kevin Cruse

Delegate to the CHS

Paul Wilton ♦

ALL welcome!

All provincial and regional Hemophilia offices, programs, and events are safe and supportive environments for members of the LGBT community. We welcome members of all communities. ♦

Hemophilia Ontario Youth Section



Reflections of a VOLUNTEER

by Zachary Adams

A QUICK SEARCH of the word *volunteer* turns up this definition: "A person who freely offers to take part in an organization or undertake a task." After having been a volunteer with Hemophilia Ontario for the past two years I can attest to this definition being grossly inaccurate.

Being a volunteer has meant so much to me, more than I could put into words, and definitely more than that simple definition. First, it has taught me an incredible amount about myself, along with being fundamental in developing my leadership skills. I know my time as a volunteer has helped me towards pursuing my goal of entering medical school, by helping me become proficient in balancing my time and learning new skills.

My time spent volunteering at Just the Guys and Pinecrest has made me consider becoming a pediatrician, as I really enjoy the time spent with all of the amazing kids. Second, I have been fortunate enough as a volunteer to be given the opportunity to travel and participate in several amazing conferences. These conferences include two visits to Arizona to participate in the North American Camp Conference for Hemophilia Organizations (NACCHO) as well as just recently returning from Winnipeg where I attended CHS' *Rendez-Vous*. At both of these amazing events I was able to learn tons of new information, helping me become a better and more knowledgeable volunteer.

Finally, my experience as a volunteer would not be the same without the people involved. Being a volunteer has allowed me the opportunity to meet lots of incredible people who are so friendly and welcoming. Volunteering becomes a community, everyone working together to achieve a common goal, and once you start, you'll never turn back. I hope that after reading this I have been able to convince you that the simple definition of a volunteer does no justice to the real life rewards of doing something you love. ♦



Hemophilia Ontario is a safe space environment.

Save the Date!

Southern Ontario Just the Guys 2013

Friday September 20—Sunday September 22

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 aged 19 and above. 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 (one volunteer position per region).

OCTOBER 25-27, 2013

**YMCA Geneva Park
6604 Rama Rd, Orillia, ON
L3V 6H6**

Save the Date!



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

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

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

W2 brings together dynamic guest speakers, provides practical tips, lessons, and advice. Conference topics may include raising a child with a bleeding disorder, living well with a chronic illness, navigating the ER and much more.

Come build your skills and knowledge and meet others who know what you're going through!

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

Set aside October 25 -27 to take part.



**MARK
THIS
DATE**

Hemophilia Ontario Calendar 2013

DATE	WHAT AND WHERE?
September 20-22	Ontario JTG (CWOR, NOR, OEOR, SWOR, TCOR)
October 26-27	Wellness for Women: W2 Conference

Dates are tentative and may be subject to change



Find Hemophilia Ontario on Facebook



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Hemophilia Ontario
Hémophilie Ontario

