

A publication of



Hemophilia Ontario
Hémophilie Ontario

BLOOD

matters

"We're all related by blood."

Volume 4 • Number 3

Fall 2013

Past, Present and Future



Hemophilia Ontario

2013- 2014 Hemophilia Ontario Board Members

Paul Wilton
Julia Sek
Mike Beck
David Neal
Jeff Beck
Rob Dinsdale
Phyllis Gray
Igor Ristevski
Raja Ammouy
Ash Kurichh
Victoria Kinniburgh
Maury Drutz
Kristen Luszka
Mojtaba Khezry
Monica Mamut
Mary Pedersen
Amy Griffith
Kevin Cruse

Editorial Committee

Tom Beer
Alex McGillivray
Sarah Wood
Terri-Lee Higgins

Staff

Terri-Lee Higgins, Executive Director
Marina Seliverstova, Senior Accountant
Susan Turner, Executive Assistant/Bookkeeper
Alexandra McGillivray
Matthew Maynard
Sarah Wood
Laura Tomkins
Stephanie Morrison
Shelly Whitney
Erika Burns

Art Direction/Design & Printing

GEPM Group (www.gepmgroup.com)

A publication of



Hemophilia Ontario
Hémophilie Ontario

Hemophilia Ontario is a certified chapter
of the Canadian Hemophilia Society.

What's in this issue?

Fall 2013 • Vol. 4, No. 3

Information from Hemophilia Ontario and its Regions

	Page
Leadership Messages	3-4
Hemophilia Ontario News	5-10
Hemophilia Ontario Youth Section	7
Bleeding Disorders News	11
Healthy Living	12
HIV/HCV News	13
Pharmaceutical News	14
Central Western Ontario Region	15-16
Northern Eastern Ontario Region	17
North Western Ontario Region	17
Ottawa and Eastern Ontario Region	18-19
South Western Ontario Region	19-21
Toronto and Central Ontario Region	22-23
Past, Present and Future	25-27

Thank you to our magazine and program sponsors:

octapharma
For the safe and optimal use of human proteins



Our program sponsors:

Baxter

octapharma
For the safe and optimal use of human proteins



CSL Behring
Biotherapies for Life™



Bayer HealthCare

Published by
Hemophilia Ontario
501 – 65 Wellesley St. E., Toronto, ON M4Y 1G7
416-972-0641 or 1-888-838-8846.
Fax: 1-888-958-0307 • www.hemophilia.on.ca

©2013, *Blood Matters*, the contents of which is subject to copy-right, is published three times a year. Reproduction in whole or in part, in written, electronic or any other format, without prior written permission, is strictly prohibited. For more information, please contact Terri-Lee Higgins, Executive Director at higgins@hemophilia.on.ca or 1-888-838-8846.

Cover photo: Courtesy of the Maynard Family and Terri Lee Higgins.

Leadership Messages



Paul Wilton

PRESIDENT'S Message

by Paul Wilton

Getting Back TO ADVOCACY

OVER THE PAST FEW YEARS Hemophilia Ontario has focused on rebuilding itself into an organization that is prepared to anticipate and respond to new challenges that the twenty first century presents. We live in an increasingly litigious society, where financial and volunteer resources are increasingly limited. It has been appropriate for Hemophilia Ontario to have this internal review to ensure we protect ourselves from financial, legal or reputational harm. During this period, we have refined our governance and staffing models, strengthened our relationships with our partners, and recruited and developed intelligent and competent volunteers and staff. While reviewing how we operate as an organization, we have simultaneously increased the quality of the services and programs we provide our members. We have made much progress.

It is now time to use our redeveloped strength to ensure we are making significant progress towards our goals. We need to ensure we are not only providing programs to our members but working to maintain and increase quality of care. This progress will only come through getting back to advocacy.

We need to ensure that comprehensive care is achieved for all people with inherited bleeding disorders. A National Standards of Care document has been developed which outlines the minimum level of

care people with inherited bleeding disorders should expect. This is a beautiful document but it is no use unless our patient organizations are working with Hemophilia Treatment Centers (HTCs) to ensure that these standards are being met. If gaps are identified, our organization should be working with our HTCs to advocate for the additional resources needed to provide this care.

We need to continue to work to ensure that individuals infected with HIV and Hepatitis C are receiving quality care, and that liver transplants are more readily available for those who need them. Patient organizations have a role to play in ensuring that women with bleeding disorders and individuals with rare inherited bleeding disorders are aware of these conditions and diagnosed.

Outside of our borders we must work to improve the quality of care for people in less developed countries.

We need to ensure that we have access to a safe, secure and adequate supply of the most advanced therapies. These therapies need to continue to be available in a timely way and at no cost to the user. We have been lucky to benefit from the great work of advocates throughout our history. We must ensure we are developing well-informed and competent leaders to carry on this tremendous legacy. As the medical

field continues to move towards more evidence based decision making models we must work to ensure that we can present the necessary data to demonstrate the cost savings of home infusion, prophylaxis, and regular visits to comprehensive care clinics.

Some may say that as an organization we should not set goals to make progress in these areas. They argue we ultimately do not have the authority to change the status quo on our own. I say, in these situations we have a responsibility to mount as much reason and pressure on decision-makers as possible to help influence their decisions. *This is advocacy.* Imagine where we would be today if throughout our history our organization did not work to influence change in areas that seemed beyond our control. We cannot be satisfied with the effort of advocating alone. We can advocate, but without success, we will have absolutely no effect on those we serve. We should set high expectations for our advocacy efforts and accept nothing less than achieving our desired goals. ♦



Terri-Lee Higgins

Past, Present, **FUTURE** TIME Perspective

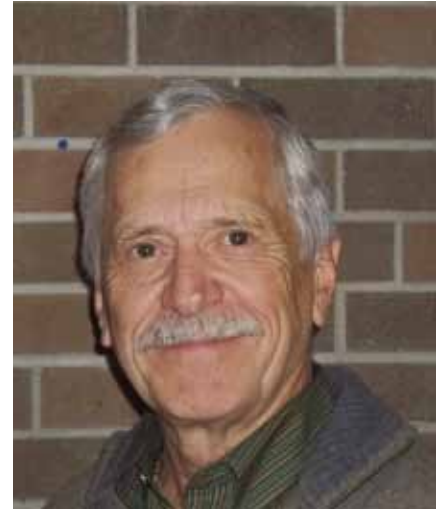
by Terri-Lee Higgins, Executive Director

I HAVE ALWAYS embraced the past as a means of living in the present and preparing for the future. I cherish my childhood memories. I can remember specific arguments, amazing family vacations and spending time with both sets of grandparents—all of which prepared me for raising my own family. School, both primary and secondary, developed lasting friendships and instilled in me the confidence to try new things even if I don't succeed. I have had key volunteer and employment situations where I learned incredible lessons that continue to benefit me today. Throughout everything there has been one constant—change.

Change is inevitable. You change—your goals change—the universe changes—something that was right for you before may not be right now. Letting go or making change is an incredible challenge we face daily. It can be painful or pleasant. For some people it is matter of fact; change happens, make it and move on. For others, change involves soul searching, considering impact or maybe even “best guessing” before deciding how to choose to move forward. I read a quotation, author unknown, that has stuck with me for many years: “You are not defined by your past; you are prepared by your past.” I believe that this reflects not only my personal mantra but also the rich history of Hemophilia Ontario.

Since its establishment in 1956 Hemophilia Ontario has experienced much growth and change. We have weathered funding challenges and continue as a viable organization. We fought for the right of self-infusion care in our homes. We have ensured that our voice has been strong and respected whether in government, regarding public policy or ensuring a safe and secure blood system. We advocated for those infected and affected by the tainted blood tragedy and continue to be fierce sentinels as we remember those who led the charge but are now lost to us.

Mahatma Ghandi said, “The future depends on what you do today.” Hemophilia Ontario has consistently focused on ensuring that those individuals living with inherited bleeding disorders have a voice and that their voice is heard. We have all benefitted from the efforts of incredibly dedicated individuals. Maynard, Woloschuk, Bishop, Terpstra, Bott, Plater, Kreppner, Duford, Mindell and Gibson are all names of individuals who boldly raised the torch that continues to be held high by those who follow. I strongly believe that as a Society we have a bright future. What that looks like I don't know, but I do know we are here today because of our past. We have a history steeped in tragedy and triumph. With the support of our members, volunteers, HTC teams and community partners, we will continue to ensure that we hold the torch for future generations. ♦



Tom Beer

TIME...

by Tom Beer, Editor

A CARD ON MY old keychain read, “Remember yesterday, dream about tomorrow, but live today!” Good advice. When I look in the mirror, I remind myself that I have more yesterdays than tomorrows, so I have to use my todays as best I know how. Lots of white hair, lots of laugh lines (gentler than saying wrinkles) and lots of twinkle in my eyes that says, “Have I got a story about that!” Let me take you back a bit.

I remember using a new invention, a ballpoint pen, back in the '50s, to write out missed notes when I was sick for a week. Little did I know that the ink would bleed through the paper so that two days later I had to rewrite them, again, this time on only one side of the paper.

I remember sitting in the back seat of my 1960 Volkswagen, with my Underwood portable typewriter on my knees, composing the last of the essay that was due that night at Western night school.

I remember that exhilarating but scary night when, for the first time, I reached into the bassinet and held my first daughter's tiny hand and marvelled at how perfect she was.

I remember going across Canada with my family, pulling a 25-foot-long

house trailer, all the way to Victoria, BC to let my family experience Canada's enchanting landscape, and to visit with my brother and sister. I remember, too, my youngest son's constant question, "Are we there yet?"

I remember the nights when my children called to tell me that my newest grandchild had been born, ... and my great granddaughter.

I remember when my first sister died—much younger than me. Loss is part of the life cycle, but it's scary when it comes close when you don't expect it.

Leaving behind yesterday, choosing today, having promise for the future. Houses, cars, pets, vacations, births, deaths; we all have memories of events, friends, gains and losses; some we smile at with fond recollection, some remind us of things we long to do again, some we wish we could redo differently, and some we wish we didn't have to remember. But

that's life. There are no "do overs."

Tomorrows fill me with hope. Hope for new cures, treatments and therapies for the illnesses that are besieging modern life (as reported on p.10, they're closer than ever). Hope for continued optimism about living well despite our individual health and/or wellness issues. (This, despite the plethora of "fad diets, as described on p.11.) Hope that the volunteers and staff who work with us and our families remain committed to service. Hope that we become universally responsible for a world that is getting smaller and smaller with new technologies and faster transport. Hope that no one gives up on the fight to make our children's and our grandchildren's lives better than ours, because we've learned from our yesterdays. As I tell anyone who'll listen. "Life. It is what it is. Accept it and get on with it." Live in the present. *Carpe Diem!* Seize the day!

Retiring, for me, meant a lateral shift to do many things I didn't have time to do when I was working full time, like editing *Blood Matters*. Now, I can take that vacation in the off-peak season and save some money. I love to dress and go out, but I don't do that nearly as often as I once did, so my clothes closet is simpler if not emptier. I walk my aging dog four or five times a day—for his benefit, and for mine. My wife and I go on a "date night" most Thursdays (avoids the weekend jam in restaurants), because it gives us a bit of time where it's "just us." That's so important in this crazy 24/7 online, wireless world in which we live. The e-mails and phone messages can wait till tomorrow. There are so many great things about living today. It's new. There's a clean slate. And, if you're an optimist like me, it is the first day of the rest of your life. We've got time. Let's make the most of it. ♦

Hemophilia Ontario News

vWD Webinar

by Laura Tomkins

ON SEPTEMBER 10, Hemophilia Ontario ran a webinar with Dr. Paula James, associate professor in the Department of Medicine, Division of Hematology, at Queen's University. Based around von Willebrand Disease, Dr. James helped educate over 20 participants on all aspects of vWD, from its history, to symptoms, and also treatment. Dr. James, we sincerely appreciate your time and commitment to this educational opportunity and thank Octapharma Canada for hosting the event. ♦

HEMOPHILIA Ontario Financial ASSISTANCE

The goal of the financial assistance policy is to provide exceptional financial support to people with bleeding disorders and their families to reduce the burden caused by their condition. To be eligible for financial assistance, these individuals must be members of Hemophilia Ontario or, if not, clients of one of the province's hemophilia treatment centres, and in financial need.

Financial support is generally provided to cover reimbursement of items including, but not limited to, tutoring, dental costs, medication, hospital parking, taxis to hospital, gas to attend clinic, assistive devices (e.g. MedicAlert bracelets, crutches, brace), equipment (e.g. protective helmets), in-hospital costs (e.g. TV, telephone) and other emergency funding. Hemophilia Ontario will pay for the first MedicAlert bracelet, first year of membership and a replacement bracelet if worn out. Lost bracelets are the responsibility of the family except under exceptional circumstances.

Hemophilia Ontario is the payer of last resort and will first of all attempt to have these costs covered by other social agencies including government. When an individual's costs are to be reimbursed by a social agency at a later date, Hemophilia Ontario can enter into an agreement whereby the funds are advanced and then later recovered.

Each year, Hemophilia Ontario allocates a set amount of money for this fund and once these funds are exhausted, no further claims will be processed in that year. For information about the new guidelines or to receive the Financial Assistance Forms to complete and submit with receipts, please contact your local Regional Service Coordinator. ♦



Hemophilia Ontario Feature: PAST, PRESENT, FUTURE

by *Matthew Maynard*

HEMOPHILIA ONTARIO has consistently been a caring, supportive community in the past and present. My diagnosis did not happen until my brother was born and for my parents that answered a lot of questions from my first year. It was the '50s which was the same time that the Ontario Chapter started. A story that is often told in our family is that when we were three and two years old we went to the first summer barbeque in Hamilton and although we were in matching shirts and shorts, many of the other children, although having fun for a hot summer day were dressed in snowsuits to protect them. As the story goes, everyone had their advice to share and my parents decided on the way home in the car that we would be growing up to know our own limits.

This did not always work out as one of us would sometimes be in the hospital. Treatment was usually a few days in the hospital and the rest of the children would be left at the front behind the iron-gate and not allowed to visit the one in hospital. In the '60s a few families got together and became the local auxiliary of the

chapter. The support offered among the parents was obvious even from a child's perspective. The treatment changed to cryoprecipitate and we learned to pool the units to give it by syringe. We went from hospital stays to emergency visits and then home infusion once we had a freezer. My brother learned to do self-infusion before I did only because he did it more often. The support of the chapter and auxiliary made it possible for families to share their successes and to work together for treatment for everyone in the region and province.

The '70s saw many changes in treatment—the advent of concentrates, the care (clinics started in many parts of the province), and the activities of the chapter such as the start of summer camps, medical meetings and still the social events in many communities. I remember a meeting in my parents' home that filled the house with probably 100 people; my brother and I gave an infusion to someone in their 60s—their first treatment outside a hospital—while everyone else met in the basement.

One of my summer positions during university was with the Canadian Hemophilia Society to complete the first census of people with bleeding disorders. With the support of the Ontario Chapter I was sent to Northern Ontario and then to Toronto to visit families, hospitals and blood banks to find those in the province with bleeding disorders. The census got done, but more important was the visit to many individuals who were living with a bleeding disorder who maybe didn't know anyone was facing the same questions other than those within their own families. The chapter was promoting the development of hemophilia centres throughout the province, working with the hospitals, government and doctors to ensure everyone had access to care. I had the privilege of participating in the start of these clinics as the first coordinator and later researcher.

In the '80s the Ontario Chapter became Hemophilia Ontario, and the role of the Regional Service Coordinators was started with a Trillium

grant. The threats to wellness from the treatment products also became apparent. Hemophilia Ontario, with the loss of so many from the tainted blood tragedy, rose to the needs of the community with compassion for members facing so many losses within their families. It also led to advocacy for the safety and security of the treatment products as well as to the support of those affected and infected during this period.

This advocacy led to many changes in the blood system, as well as in the care, mission and focus of Hemophilia Ontario. Many worked hard to get the compensation and support needed for those affected or infected by this tragedy at both the personal and community level. With the advent of recombinant products and the standards of care in the treatment centres, trust returned to the community, allowing the bleeding disorders community to explore how best to support each other in this new environment.

With the emergence of new treatment recombinant products as preventative treatment, it meant fewer and fewer emergency visits and hospital stays. The need for the caring and supporting community continues whether for women, or long term survivors, or families with young children. The advocacy, vigilance, support of the hemophilia centres, camps, and education events continue to foster a community prepared to support each other with compassion.

The future when I was first diagnosed was grim as I was expected not to reach more than my teen years. The future right now indicates that treatments will continue to improve and it seems that a cure could happen in my lifetime. Hemophilia Ontario will also look to change its programs and services, but will remain the compassionate caring community ready to support those with bleeding disorders. ♦

Hemophilia Ontario Youth Section



Amy Griffith

Past, **PRESENT**, Future

by Amy Griffith

Most people advise that it's best you don't look too deeply into your past—it's better to move forward and leave it behind. However, like many things in life, I don't agree. Even the most painful memories and heart-wrenching experiences can add great value to your life. Personally, this has been the case for me.

I've learned through extensive trial and error, to not live with any form of regret. I'm sure that doesn't make me feel any better, and I can be reassured that contrary to my feelings now, at the time it was exactly what I wanted.

When I was younger, I didn't want to be different. I didn't want to be the girl that bruised so easily that you couldn't play with her, or the one who got nosebleeds so spontaneously teachers were on the edge of their seats the day the school radiators were turned on. I just wanted to be like everyone else, a pretty common

childhood dream for many of us. I hid who I was to avoid ever being bullied, being excluded, or worst of all, being pitied. This is a good representation of my past.

However, as the years grew, so did I. Present day, I wear my MedicAlert with a sense of pride. I've not only accepted that I have a bleeding disorder, but I've embraced it as one of the largest parts of my identity. I've *chosen* to educate others, to be involved and to be even the smallest factor in making a difference. I decided that if I wanted people to see things from my perspective, to understand what I live with or went through, then it was up to me to tell them. By making the decision to open up and be actively involved, I've exposed myself to countless programs, opportunities with people all ready to listen, and even willing to help—even when they can't.

In moving from past to present, I've learned that if you want people to understand your story, you are the only one who can tell it. Accept the responsibility of becoming the change you want to see, and understanding that it won't always be easy. People will kick you when you're down, and occasionally tell you that you can't achieve what you've set your heart on. As youth with inherited bleeding disorders we have even more cards stacked against us than our peers. I found the more people that I told I wasn't giving up, and no matter how many times they said, "No," that I wasn't going away, they took a second look and wanted to hear what I had to say.

For me, the future is in awareness. The greatest tool you can give anyone, no matter their age, is education. By giving someone all the facts and a dash of personal experience, you allow people to make their own decisions, and that is a powerful gift. ♡





a standard practice in their country. As a result of this meeting, four individuals were recruited to the Board of Directors and they plan their first member education session, Hemophilia 101, for December.

With the approval of the Ontario

Board of Directors, a proposal was submitted to the World Federation of Hemophilia to engage in a four-year twinning initiative with the Tanzanian Society. WFH has approved our Tanzania Twinning, now the work begins. ♡



TWINNING

IN SEPTEMBER, Hemophilia Ontario participated in a Twinning Assessment visit with Dar es Salaam, Tanzania to determine if Hemophilia Ontario could positively partner with the Tanzanian Society. Lead volunteer Candace Terpstra spearheaded the initiative and worked with Tanzanian President Richard Minja and Dr. James to organize the many meetings, including the hospital medical team, the hospital administrator, Tanzania Blood Services and various government officials that may form the future National Hemophilia Care Committee. All individuals were very interested in enhancing not only the level of care but also the ability to accurately and quickly provide a diagnosis. The standard treatment available for a bleed is fresh frozen plasma; they do not have cryoprecipitate which would change the level of available care in the country. Without the necessary reagents to complete the testing, there are 40 samples in the freezer waiting for potential diagnosis.

Seven affected members and their families shared their heartbreaking stories. Every family noted how they have lost a minimum of three male members as the result of a bleed with one woman losing two infants following circumcision, which remains

JUST THE GUYS 2013

by Sarah Wood

THE JUST THE GUYS 2013 Weekend happened on September 20-22 and a great time was had by all. This year's theme was "Summer Olympics" so all of the fathers and sons worked together with their teams to compete for the gold medal. We had a great turn-out of participants, a wonderful group of nurses from across the province, some interesting educa-

tional speakers, and our amazing youth volunteers. A big thank you to everyone who attended, helped plan or volunteered their time at the weekend. This important event couldn't have happened without all of you. Also, a massive thanks to Bayer who sponsored this event. To you we present an unofficial gold medal. ♡



A Review of the Play, *TAINTED*

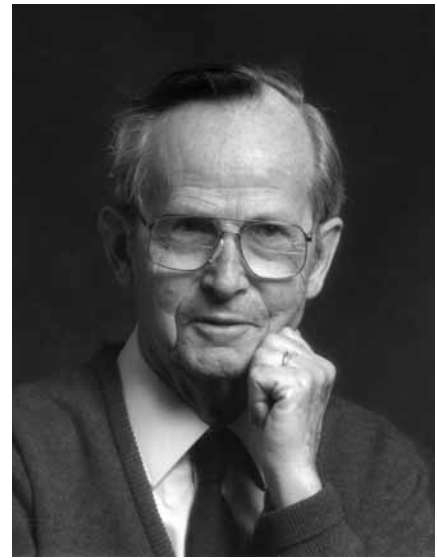
by *Laura Tomkins*

I HAD THE PRIVILEGE at the end of September of seeing Kat Lantaigne's play, *Tainted* in Toronto. The story is focused around the Steele family, a Canadian couple and their three sons. While all three sons are a bit varied in age, this lets the audience get to see them in different stages of their life, with a variety of things on their minds ranging from school, friends, careers and marriage. We also get to see, due to the fact that all three sons have hemophilia, how hemophilia treatment has changed over time. As the two older sons felt as though they were treated as fragile when they were younger, the youngest son, thanks to the miracle of at-home factor infusions, was able to not feel as different among his peers as his brothers did. However, we soon see the horrid after-effects that this miracle product had on thousands of lives.

In the 1980s in Canada the AIDS epidemic was just becoming something on people's radar, but it seemed as though everyone was still confused as to how this terrible illness was contracted. However, once many hemophiliacs started contracting HIV, it became clear that not only could HIV be spread through different methods such as blood and certain bodily fluids, but the factor that was meant to help those affected by hemophilia live a safer life, was in fact the thing that was killing and infecting them. As a result, due to their factor, all three sons in this play contract HIV, some contracting both HIV and hepatitis C.

This heartfelt yet tragic play shows how a seemingly normal Canadian family has to cope with being affected by something they never thought would occur to their family. Not only do we hear the facts about the historical Krever inquiry, along with other news associated with the tainted blood tragedy over two decades, but we also get to see into a family's day-to-day lives, and witness their own personal struggles. We see the family not only deal with the physical implications, but very much also the emotional and mental affects. We see the stigma associated with HIV, such as no one wanting to show up to the youngest son's birthday party, or the mom no longer being asked to participate in social events with her friends. We see the middle son struggle with trying to find a job and keep his HIV status a secret. We see the oldest son struggle not only when he hears how the media and government portray the tragedy, but also when he learns that he was the one who gave HIV to his wife as well. We see how a careless mistake by the Red Cross, which was fixed too late, affected and cost lives, and still affects people today.

This is a wonderfully written and presented production and is relevant and impactful for everyone. It is for any one of the tens of thousands who felt the effects of the tainted blood tragedy. It is for anyone who experienced stigma associated with their health, whether they had been affected later in life by a disorder, or were born with one. It is for anyone interested in the history of the Canadian government and the healthcare system, and the reality that sometimes things can go terribly wrong. This play not only allows the audience to mournfully remember tragedies of the past, but also allows one to educate themselves and be aware of the future of health care. ♡



Douglas Page

Remembering **DOUG PAGE**

HEMOPHILIA ONTARIO expresses its sincere condolences on the passing of Doug Page on October 20 at age 95. Doug Page was the father of David Page, Executive Director of the CHS. Doug was one of the founding fathers of the CHS along with Frank Schnabel, and was the first President of the Quebec Chapter. We extend our deepest sympathies to David, his wife Patricia, and the entire Page family and friends.

The following is the link to the obituary: www.rideaumemorial.sharingmemories.ca/siteContent/memorial.html?personId=244133&source=memlist ♡

Canadian Hemophilia Society News and World Federation of Hemophilia News

PROJECT RECOVERY turns unused blood products from **CANADIAN BLOOD DONATIONS** into **HEMOPHILIA MEDICINE** for developing countries

MONTREAL, September 26, 2013 — In what's being hailed as a world first, precious proteins left over from the manufacture of plasma products from Canadian blood donors are being turned into life- and limb-saving treatments for thousands of people living with hemophilia in developing countries.

A lifelong inherited bleeding disorder, hemophilia affects about 1 in 10,000 people worldwide. Close to seventy-five percent of them receive little or no treatment. Hemophilia is one of a number of such disorders that prevent blood from clotting properly. People with hemophilia experience prolonged internal bleeding that can result from a seemingly minor injury. Bleeding into joints and muscles causes severe pain and disability while bleeding into major organs, such as the brain, can cause death. Hemophilia A (factor VIII deficiency) is treated with factor VIII, a protein necessary for blood coagulation.

The World Federation of Hemophilia (WFH), in partnership with Canadian Blood Services (CBS) and two manufacturers of plasma products, BIOTEST AG and GRIFOLS, will officially announce the launch of Project Recovery during the WFH Global Forum on the safety and supply of treatment products for bleeding disorders in Montreal, Canada, on September 26. This humanitarian aid project, first conceived by the Canadian Hemophilia Society (CHS), now becomes a reality after a dozen years of effort.

Project Recovery will transform previously discarded cryoprecipitate

from Canadian blood donors into BIOTEST's factor VIII concentrate, called Haemoctin®, to treat people with hemophilia. It will be channeled through the WFH Humanitarian Aid Program, which focuses on providing for patients in developing countries who have little or no access to these life- and limb-saving medicines and would otherwise be at risk of death or severe disability.

"Project Recovery has the potential to improve the lives of thousands of people with hemophilia all over the world," said Alain Weill, WFH president. "It also allows the WFH to carefully plan where and when these essential medicines will be distributed thereby maximizing the benefits of this wonderful humanitarian endeavour."

It is estimated that in each year of the project at least five million International Units of factor VIII will be donated. This will allow the annual treatment of approximately 5,000 joint hemorrhages, the most common symptom of hemophilia, in children and adults. Without such treatments, the people experiencing these hemorrhages would endure weeks of excruciating pain and, over time, serious joint damage leading to crippling. In addition, early treatment or prevention of these hemorrhages will mean that caregivers—parents, spouses, siblings—will not have to miss work or school to care for the person immobilized at home or in hospital.

This is the first time anywhere in the world that such a partnership has been created to transform surplus cryoprecipitate into factor VIII



for humanitarian use. Contracts for this international cooperation were signed in July of 2013 and the first production steps have begun. The WFH will receive the first deliveries of this factor VIII in 2014.

"The CHS was at the origin of Project Recovery more than a decade ago," said Craig Upshaw,

Canadian Hemophilia Society president. "We truly appreciate how the partners were able to work through the many legal, technical, commercial and regulatory barriers to success, and hope that other countries will follow the Canadian example."

Factor VIII, a protein essential to blood clotting, is contained in cryoprecipitate, one of the components of plasma. Not all of the cryoprecipitate contained in plasma from Canadian Blood Services donors is needed to make factor VIII for Canadian patients and until now the excess was discarded. With Project Recovery, the cryoprecipitate will be harvested by GRIFOLS at its plant in the U.S., transported by BIOTEST to Germany for manufacturing. This finished


pharmaceutical product will be manufactured and released under the BIOTEST license and trademarked Haemoctin, a high purity and double virus inactivated factor VIII product for the treatment of hemophilia A. A portion will be marketed by BIOTEST and the remainder allocated to CBS for donation to the WFH. BIOTEST will also support the WFH in distributing the donated Haemoctin to recipient countries. The partnership is cost neutral for all parties. ♡

Bleeding Disorders News

Comprehensive CARE STANDARDS

THIS DOCUMENT was completed by a national multidisciplinary committee—including members of the CHS—to further the initiatives of the AHCDC (Association of Hemophilia Clinic Directors of Canada) in standardizing the care of people with bleeding disorders nationally, as recommended by the 1998 Standards of Care Conference. The document is intended for use by Hemophilia Treatment Centres, hospital administrations and provincial Ministries of Health.

The vision is to provide comprehensive care to all individuals with inherited bleeding disorders, guided by clear standards, facilitated by engagement with stakeholders, and driven by needs and best practice, resulting in best outcomes.

You can find the standards on the CHS website at: www.hemophilia.ca/en/care-and-treatment/comprehensive-care-standards/ 

Products in the Pipeline

NEVER HAVE SO MANY clotting factor concentrates been in development or “in the pipeline.” So many, in fact, that it has become difficult to keep track of them all. So the CHS is publishing three charts, one each for factor VIII, factor IX, and for inhibitor products, to help everyone stay informed of their progress through preclinical work, clinical trials and regulatory approval.

We have been able to identify 26 new therapies in development; 10 for hemophilia A and vWD, eight for hemophilia B (including two promising gene therapies) and eight bypassing therapies to treat patients with inhibitors. While some of these are still at the preclinical stage when the research is conducted on mice and other animals, many are in Phase III trials with patients, the final stage before an application is made to market the product commercially. If the results of the clinical trials are positive, we may begin to see the first of these products prescribed in Canada in 2014. That’s less than a year away, not long in terms of drug development.

Longer-acting products

The development of longer-acting products could be the first major improvement in care for hemophilia since the advent of virally safe concentrates and prophylaxis in the late 1980s. While claims need to be confirmed by clinical trials, it is possible that the half-life of factor IX could be extended three- to five-fold, factor VIII one-and-a-half times and recombinant factor VIIa eight-fold. This has the potential to reduce the frequency of infusions, an advance in convenience, or increase the trough levels in prophylaxis, a clear therapeutic advance. Currently, prophylaxis aims to maintain at least a one percent factor level at all times. Should physicians and patients be content with one percent, or is a higher trough level desirable to prevent bleeding?

More potent products

Some of the products in development are designed to be more potent and more effective in stopping bleeding. This is critically important for patients with inhibitors, for whom current treatments are not nearly as effective as conventional treatments for patients with hemophilia A and B without inhibitors.

Broader portfolios for companies

The pipeline sees the development of broader portfolios for companies so that they can market products in all three major areas—hemophilia A, hemophilia B and inhibitors—and not just one or two, as is the case today. This has the potential to increase world supply and competition. In a worldwide market growing by eight percent a year, this is a good thing.

While not all of these products will make it to market, many are very promising. We will update these charts periodically. We invite you to consult this page regularly to follow progress.

More details on these clinical trials are available on the website of the U.S. National Institutes of Health. Go to www.clinicaltrials.gov and type “hemophilia” in the search box.

Article taken from: www.hemophilia.ca/en/safe--secure-blood-supply/products-in-the-pipeline/ 

Healthy Living



GraphicStock.com/09419118b5

SAY WHAT?! Fad Diets Busted

by Sarah Wood

In keeping with the past, present and future theme of this edition, we thought we would highlight the one—and maybe only—thing that has remained consistent in the health and fitness world over the years, and that is society's love for a fad, quick fix diet. The specifics have changed over the years, and will continue to do so, but our quest for the “secret” to fitness and weight loss has remained.

Check out some of the wackiest fad diets that have come (and thankfully gone) over the years. We don't think we need to state it, but just in case; we do not promote or condone any of these practices as a safe or successful way to lose weight or be healthy.

- 1727: Thomas Short wrote that heavier people lived near swamps, so to stay thin one should avoid swampy areas.
- 1920s: Cigarette companies began linking their products to decreased hunger.
- 1930s: Slimming soap was all the rage, even though there was no facts linked to this.
- 1950s: Some began ingesting tapeworms, which would eat all the nutrients in one's intestines. This dangerous method has been linked to seizures, meningitis and dementia.
- 1960s: The Sleeping Beauty Diet, popular with stars such as Elvis, involved sedating yourself and sleeping for several days, therefore going several days without eating.
- 1980s: The Breatharian Diet believes that one can live without food, water or sleep. The side effects from this extremely dangerous diet include weakness, vomiting, dizziness, frozen hands, dehydration, kidney failure and death.
- 2000s: The Vision Diet involves wearing blue glasses to make foods look less appealing.
- 2000s: Ear stapling, in which you staple the cartilage of your inner ear and leave the staples there for six weeks - three months, as it was believed to suppress appetite. Linked to Chinese acupuncture, this fad diet has no proof of working, and in fact can lead to serious infection and permanent disfigurement.
- 2000s: The Cotton Ball Diet, a diet which has been believed to be popular in the modeling world, involves one consuming cotton balls, either dry or dipped in orange juice or gelatin.
- Popular today: Cleanses, such as the lemon juice, cayenne pepper, maple syrup and water drink (yuck!), can range in ingredients and length, but all consist of depriving the body of solid food for a period of time in order to shed pounds.

So What Does Work?

Most of us know that fad diets will not bring long-term sustainable fitness or weight loss, but many people don't know what does. There are many different ways to lose weight, tone up, and get healthy depending on your specific goals, but, if we're talking in really general terms, the key to a healthy body weight and fitness boils down to nothing more than **moving more and eating less. That's it.** It's really that simple. Beyond this you can modify your health regimen to meet your specific goals, but the foundation of any fitness and health program is to cut out all the extra food you are eating (most of which is junk) and to increase the amount of physical activity you do. Doesn't sound so hard when it's put like that does it? So skip the weird cleanses and dangerous diets and just eat healthy amounts of “good for you” foods and get yourself moving around more, and you will see long term positive health effects. ♡





EVERY LITTLE BIT COUNTS: Factor Redistribution Program

by Sarah Crymble, Hemophilia Provincial Coordinator

IN ONTARIO there is a program that redistributes clotting factor concentrates (CFC) that are soon to expire. You may have heard of this program, it's the Factor Concentrate Redistribution Program. I run this program in conjunction with a project coordinator, nurses and transfusion medicines services specialist. Together we move CFC with an expiry date of six months to hospitals that will be able to use the product for a patient with an inherited bleeding disorder. This program ensures that there is little to no wasting of CFC--an expensive resource. Over this past six months we have seen a savings of more than \$500,000 and since the program started in 2007 a savings of over \$4.7 million. We extend a special thanks to those of you who have been contacted by your nurse to assist the program by using the short dated product first. For more information about the Factor Concentrate Redistribution program, send me an e-mail at crymbles@smh.ca. ◊



HIV/HCV News



World AIDS Day

by Sarah Wood

WORLD AIDS DAY is held on December 1 each year and is an opportunity for people worldwide to unite in the fight against HIV, show their support for people living with HIV and, to commemorate people who have died.

World AIDS Day was the first ever global health day and was first held in 1988.

Globally, an estimated 34 million people have HIV. More than 25 million people between 1981 and 2007 have died from the virus, making it one of the most destructive pandemics in history.

Today, many scientific advances have been made in HIV treatment. There are laws to protect people living with HIV and we understand so much more about the condition. But despite this, people do not know the facts about how to protect themselves and others from HIV, and stigma and discrimination remain a reality for many people living with HIV.

World AIDS Day is important as it reminds the public and government that HIV has not gone away—there is still a vital need to raise money, increase awareness, fight prejudice and improve education.

- Over 90 percent of people with HIV were infected through sexual contact.
- HIV is not passed on through spitting, biting, kissing, touching or sharing utensils.
- You can get the results of an HIV test in just 15-20 minutes with Rapid Testing.
- There is no vaccine and no cure for HIV, only medications to manage the virus

www.worldaidsday.org/about-world-aids-day.php ◊

CO-INFECTION and Regular Ultrasound Checkups

by Laura Tomkins

A STUDY WAS CONDUCTED that has stated that one-third of Canadians who are co-infected by HIV and hepatitis C and who also have liver cirrhosis are not being properly screened in order to view signs of liver cancer. Those with a co-infection should have “regular ultrasound examinations.” This article can be found at: www.aids-map.com/High-proportion-of-Canadian-patients-with-HIV-HCV-co-infection-and-liver-cirrhosis-are-not-having-ultrasounds-to-check-for-liver-cancer/page/2728687 ◊



HIV/HCV and Marijuana Use

by Laura Tomkins

A STUDY HAS FOUND that “there is no apparent association between the use of marijuana and the progression of liver fibrosis (or cirrhosis) in those conected with hepatitis C virus (HCV) and HIV.” More on this article can be found at: www.aidsmeds.com/articles/pot_liver_1667_24370.shtml ◊

HEPATITIS C Diagnosis Expected to INCREASE Over the Next Decade

by Laura Tomkins

Specialists in Canada, according to an article printed in The Globe and Mail, believe that “the crisis point for hepatitis C-related diseases is about a decade away.” This is due to the fact that many people who have hepatitis C do not show symptoms for several decades. Therefore, there are predictions that while baby boomers age, diagnosis of hepatitis C will increase as symptoms begin to show. To read more about this, visit: www.cbc.ca/news/health/liver-doctors-see-hepatitis-c-screens-for-baby-boomers-1.1873202 and www.theglobeandmail.com/life/health-and-fitness/health/specialists-warn-of-a-looming-hepatitis-c-crisis/article14432504/ ◊

Pharmaceutical News

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

The HERO study Hemophilia Experiences, Results and Opportunities

Novo Nordisk Canada

WHAT HAPPENS WHEN you talk to more than 1300 people with hemophilia and their families and caregivers from countries all over the world? The result is the HERO study (Hemophilia Experiences, Results and Opportunities) conducted by Novo Nordisk, the largest study of psychosocial factors in hemophilia. By talking to people in 10 countries – including Canada – Novo Nordisk has learned a lot about what it means to live with hemophilia in 2013.

HERO focuses on the psychosocial aspects of life for people with hemophilia. The HERO study asked people with hemophilia and their families about school and work, their personal relationships, the types of activities that they like to do to stay active, and about how they talk about, learn more about and treat their hemophilia. What makes HERO different is that it captures the insights of people affected by hemophilia every day, the people who have real insights on the impact of hemophilia on day-to-day life.

The HERO study and its results provide a wide variety of insights for families and individuals affected by hemophilia as well as the healthcare professionals who care for them. For participants, HERO provided an opportunity to exchange ideas about experiences and solutions. The study results can help improve the understanding of hemophilia and reduce its stigma at the community level. The results also give healthcare providers more information about how they can provide more comprehensive hemophilia care. And at Novo Nordisk, we’re using the results of HERO to help us with our com-



Guillermo Nnicolás Pirazzini has severe hemophilia A with inhibitors.

mitment to changing possibilities in hemophilia®*.

The global HERO results are being published now, and specific Canadian results and insights will follow shortly. You may have seen some of the global results at the 2013 Rendezvous Conference. Here in Canada, local chapters of the Canadian Hemophilia Society are also helping to spread the word. If you’re interested in learning more about HERO, please contact your CHS Chapter. ◊

** Registered trademark of Novo Nordisk Health Care AG, used under license by Novo Nordisk Canada Inc.*

HERO
Hemophilia Experiences
Results Opportunities

changing possibilities
in hemophilia®*

Central Western Ontario Region

FANTASTIC Fundraising

WE'VE BEEN BUSY fundraising for the region this fall here in CWOR. On September 7, the **Big Sale on the Little Street** took place just outside the Locke Street Festival. Volunteers stuck it out in the rain to make sure this event was a success and they raised \$400 for CWOR programs and services. Many thanks to Mary Pedersen for organizing the sale, to Bob, William and Oliver Pedersen for helping with the setup, and to Jace Pedersen for helping with the take-down. We also thank Jane Dinsdale and Tyler McGillivray for helping out

during the day.

CWOR also held their **Supercrawl** Charity BBQ and Education Booth on September 14 during the James Street North Supercrawl. This event was a great success with the region raising over \$1,100 towards the cost of programs and services. We thank all of the volunteers who helped make this event such a huge success: Mary, Bob, William, Oliver and Jace Pedersen, Amy Griffith, Debbie and Meagan Bordi, Jenny Vasquez, Nola Plumb and our grill master, Tyler McGillivray. We'd also like to recog-

nize and thank those who generously sponsored items for the BBQ: the Bordi family, the Pedersen family, the McGillivray family, Starsky's Fine Foods for the sausages, and Costco Wholesale for the \$25 donation. The event was such a great success that we are looking to form a committee to organize next year's event. Contact Alex McGillivray, Regional Service Coordinator, at amcgillivray@hemophilia.on.ca for more information. ♡





2013 LIAM BARBOUR Scholarship Recipient

by Matthew D'Addario

I'M 18 YEARS OLD and living with hemophilia A. I am currently enrolled in the Automotive Power Apprenticeship Co-op Program at Niagara College. The course is all about cars and getting dirty. This is a two-year program with a College Diploma.

Once I complete the course, I intend to continue my career with cars by joining the military as a Vehicle Technician. Just knowing that I can support my country doing something I love to do, as well as being able to work on tanks and test driving them makes me excited for the future.

I have been interested in cars for a few years now since I took an automotive program through my high school, and that's what got me interested in them. I've also wanted to join the military for a long time because I was an Air Cadet during my youth. I loved being in uniform and representing the Air Cadets professionally.

I'd like to give a big shout out to CWOR, and the Liam Barbour Scholarship for allowing me the honour of being this year's award recipient. The scholarship will help me to cover the cost of my books and uniform. Without you it would have been hard for me to be able to reach my goal. Thank you for bringing it within arm's reach. ♂



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

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 offers \$500 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 to CWOR proof 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, 2014. Faxed or late applications will not be accepted. For more information or to obtain a Liam Barbour Scholarship Award application, please contact Alex McGillivray, Regional Service Coordinator. Applications can be mailed to Hemophilia Ontario CWOR, 101-King St. E, Hamilton, ON, L8N 1B2. ♂

CWOR Regional 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

North Eastern Ontario Region



Stephanie Morrison

Meet our NEW RSC

PLEASE JOIN US in welcoming Stephanie Morrison as the new Regional Service Coordinator for the North Eastern Ontario Region of Hemophilia Ontario. Stephanie joined the Hemophilia Ontario team in July, 2013. She is a mother of an affected child and previous volunteer for the Northern Ontario Region. Stephanie is excited about becoming the Regional Service Coordinator for NEOR and is dedicated to helping the members of her region affected by bleeding disorders. She looks forward to the challenge of bringing her

members together to participate in educational and bonding opportunities, in turn creating a strong voice for the north. ♡

NEOR Regional Council and Staff

Stephanie Morrison
Regional Service Coordinator
1-866-545-1647
smorrison@hemophilia.on.ca
501 - 65 Wellesley St. E.
Toronto, ON M4Y 1G7

North Western Ontario Region



Shelly Whitney

Meet our NEW RSC

PLEASE JOIN US in welcoming Shelly Whitney as the new Regional Service Coordinator for the North Western Ontario Region of Hemo-

philia Ontario.

Shelly Whitney joined the Hemophilia Team as a Regional Service Coordinator for North Western Ontario in July 2013. She graduated from Lakehead University with degrees in English/History & Education and has experience working with the homeless, the chronically ill, and the Aboriginal population. Shelly looks forward to the challenges that working at Hemophilia Ontario will bring. She also works full-time with Metis Nation Long Term Care program and is looking forward to being a strong advocate for the North Western Ontario Region. ♡

2013, seeing about 18 people during the two days. Shelly Whitney, Regional Service Coordinator was on hand to connect with everyone, as well as Karen Roberts, Nurse Coordinator, Dr. Laferrière, and various pharmaceutical reps. Thanks to everyone for your hard work. ♡

NWOR Regional Council and Staff

Shelly Whitney Regional
Service Coordinator
1-866-920-2031
swhitney@hemophilia.on.ca
501 - 65 Wellesley St. E.
Toronto, ON M4Y 1G7

FALL Clinic 2013

NWOR HAD a very successful clinic in Thunder Bay on October 7-8,

Ottawa and Eastern Ontario Region



Erika Burns

Meet our NEW RSC

PLEASE JOIN US in welcoming Erika Burns as the acting Regional Service Coordinator for the Ottawa and Eastern Ontario Region while Colin Patterson is on leave of absence. Erika is a recent graduate of Algonquin College's Social Service Worker program and also has a background in Psychology. She has worked with different marginalized populations for over a decade and has worked extensively with autistic and severely behaviourally-challenged children. We are excited to have Erika join the team. ♡

OEOR Regional Council and Staff

Raja Ammoury-Alami
Jordan Cabral
Lyanne Cabral
Ashwani Kurrichh
Nancy Sauvé
Darlene Villeneuve
Patrick Grenon

Erika Burns
Acting Regional Service Coordinator
2445 Boul. St. Laurent
Ottawa, ON K1G 6G3
613-739-3845
eburns@hemophilia.on.ca



Group of golfers at the 19th Annual Shawn Duford Hemophilia Golf Tournament

19th Annual SHAWN DUFORD Golf Tournament

by Alex McGillivray

ON A BEAUTIFUL SUNNY DAY without a rain drop in sight, 89 golfers took advantage of the weather at this year's 19th Annual Shawn Duford Golf Tournament and enjoyed taking turns on the putting green and a great round of golf on the course. In addition, participants feasted on a delicious dinner and enjoyed the prize portion of the evening. Many thanks to the OEOR Golf Committee for all their hard work throughout the year in the planning of this event, to the OEOR Council, and to The Meadows Golf and Country Club for hosting the tournament again. We'd also like to recognize all the volunteers who donated their time to make this tournament a fun one. We hope to see you next year for the 20th edition of this tournament. ♡





Most Honest Team



Winning Foursome

South Western Ontario Region

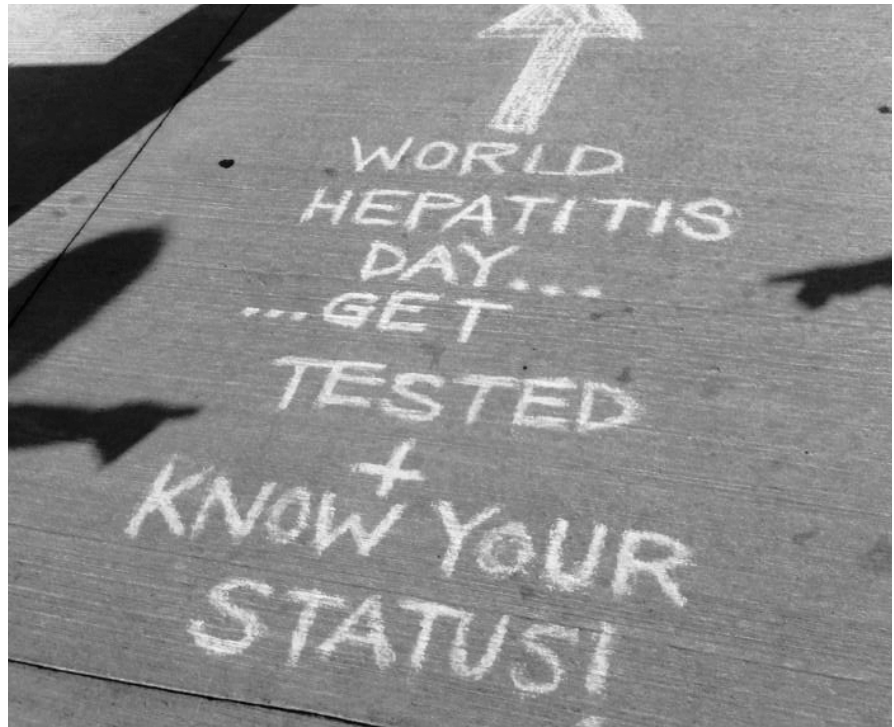
World HEPATITIS Day

by Zach Templeman, Hepatitis C Educator, Regional HIV/AIDS Connection

WORLD HEPATITIS DAY was launched in 2008 by the World Hepatitis Alliance to promote awareness about viral hepatitis on July 28 each year. Since that time, World Hepatitis Day has gotten bigger and bigger. This year in London, Regional HIV/AIDS Connection ran an awareness and testing campaign on July 23-24 in collaboration with London Intercommunity Health Centre and

Hemophilia Ontario SWOR. A booth was set up at the Central Public Library to provide information about hepatitis C transmission and testing. Sidewalk chalk on King Street directed folks from Clarence Street to Regional HIV/AIDS Connection

where testing was also available on both dates. The campaign was a success with hepatitis C information reaching more than 75 people. The contribution of volunteers added to the success of World Hepatitis Day and was greatly appreciated. ♡





PINECREST Adventures Camp: Raiders of the LOST ARTI-FACTOR

by Terri-Lee Higgins

INDY AND SALLAH led their teams of Scientists and Adventurers on an exciting journey as Pinecrest Camp took on the quest to find the lost arti-factor in this year's "Raiders of the Lost Arti-Factor." From team chants, challenges and games to leader contests, which included debates on key topics such as whether you eat the pizza crust or point first, had everyone involved from start to finish. Whether on their way to archery or the climbing wall or even the dining hall, campers were always on the lookout to find the missing treasure. In the end, the long lost message of Professor Professerson was found and camp spirit continued to shine.

Thank you to all staff for an outstanding year, with special thanks to leaders Nick, Shane, Zach, Emily, Nikki and Spencer for totally immersing yourselves in the terrific theme developed by Brittany. Sincere appreciation to the Camp Committee for your continued guidance and to the SWOR Council who understand and support Pinecrest Camp and its goals to educate, encourage and empower local youth. We hope the campers and LITs had an amazing fun-filled year, and on behalf of the staff, thank you parents for allowing us to share your amazing youth. Next year's dates are August 20-24, 2014. Save the date now so you don't miss out. ♡



Sixth Annual GOLF Tournament

by Travis Hazelwood

THE BIG DAY! On September 28 we arrive with anticipation at Ingersoll Golf Club for the Sixth Annual Golf Tournament. We are bursting with excitement because we have great sponsorship, prizes, gifts, and of course, perfect weather. The volunteers arrive and spread out across the course and into the clubhouse to get the prizes and silent auction ready.

The golfers begin arriving in time for lunch as well as for some practice time on the putting green and driving range. Some of them are also getting an advance look at the silent auction tables.

With a shotgun start, the golfers and volunteers begin having fun out there. No hole-in-ones this year for the \$10,000 hole sponsored by May-McConville Insurance or for the beautiful black Harley-Davidson motorcycle sponsored by Rocky's in London. Michelle's trivia contest stumped many of our foursome with just one group getting it perfect. Our Police Patrol volunteers, Dionne and Taylor, made a great team visiting with everyone on the course. Bob Shannon, our emcee for the dinner and auction, kept us moving with a live auction, and our speaker, Hannah Higgins, inspired everyone with her commitment to SWOR and Pinecrest Adventure Camp.

This was an inspiring event with the new level of support from our sponsors. Special mention must go to our returning Platinum Sponsors, **Source for Sports** and **Pfizer Canada**. Your commitment to the programs and services in our region is appreciated. We had two new Bronze Sponsors this year—**Cando Contracting** and **London Police Association**, both of which stepped up from being previous hole sponsorships. The support these organizations have shown in their own way was outstanding.

Special thanks to the organizing committee: Travis, Fred, Chris and Lynda (and some helpful input from many, including Charlie, Terri-Lee and Marion). Their planning brought out the sponsors, the donors and the golfers to contribute so much to this event.

To our volunteers—you help make this event a success to be remembered. To the golfers, thank you. Plan on coming to the Seventh Annual Tournament to continue to make a difference to those living with inherited bleeding disorders throughout South Western Ontario. ♡



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

SWOR'S Program Advisory Council

THE BLEEDING DISORDERS PROGRAM Advisory Council has been a part of the care in the South Western Ontario Region (SWOR) in the past and in the present, and they are committed to improving the quality of care and services to the benefit of both the patients and families and the members in the region.

This Advisory Council is a collaboration of SWOR, members and patients, the Bleeding Disorders Program Medical Team, and the administration of London Health Sciences Centre. As a group, meetings are held three times per year with opportunities to share projects and initiatives throughout the year.

It was initiated when the Comprehensive Care Centre was started in the late 1970s to ensure that the new hemophilia treatment centre had the funding, medical team resources and the community support for services in the region. There are many more patient advisory groups now throughout Ontario for many types of conditions and health and medical care services. The focus has been on how the needs of those with an inherited bleeding disorder can best be served in the region. In the past and even in the present, discussions were not always easy, but were critical when establishing the regional centre, when dealing with a shortage of treatment products, navigating the tainted blood tragedy or planning the move from one hospital to another.

This Advisory Council has led to improvements in care in many ways. In the past year a service agreement was reached between London Health Sciences Centre and Hemophilia Ontario to have the regional service coordinator available during both children's and adult clinics. The introduction of iPads for use during the clinic visit is a result of the Council's work, as was the decision to have the Medical Team doing outreach programs in Windsor and Owen Sound, both several hours drive away from London.

The benefits to the medical team and the members and patients continue as we learn about the clinical use and personal use of infusion records, planning approaches to help identify women and men who have an undiagnosed bleeding disorder before there are serious consequences, learning of the latest research or new treatments available, and exploring together the education, learning and funding opportunities to improve the care in the region. This has been a collaboration that has served those with bleeding disorders in the past and will be beneficial into the future. ♡

SWOR Regional 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

Crossword ANSWERS

1. Christmas
2. Regional Service Coordinators
8. Summer Olympics
10. World AIDS Day
11. November

Down

3. April 17
4. Canadian Blood Services
5. Hepatitis C
6. Terri-Lee Higgins
7. Lilliecap
9. CODERouge
10. WanaKITA
12. HOY
13. Facebook
14. von Willebrand Disease

Across

Toronto and Central Ontario Region



FAMILIES in Touch

by *Laura Tomkins*

TCOR'S HOLIDAY Families in Touch Party is almost here and this year we are having a bowling party! Our families will enjoy food, fun, and make some new friends in the community. It will be a perfect way to finish of 2013. Plus, it will give our members a chance to register early for Camp Wanakita. We can't wait to see everyone out at this fun event. ♡



Sarah Wood



Laura Tomkins

TCOR Regional Council and Staff

David Neal, Maury Drutz, Mike Beck, Mojtaba Khezry, Samuel Leon, Victoria Kinniburgh, Sheila Coad, Ayeh Hamidian, Maryam Najj, 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
501 - 65 Wellesley St. E.
Toronto, ON M4Y 1G7
416-972-0641
Susan ext. 21
Sarah ext. 12
Laura ext.14
Toll free: 1-888-838-8846
sturner@hemophilia.on.ca
swood@hemophilia.on.ca
ltomkins@hemophilia.on.ca

Summer FUN

by *Sarah Wood*

THE TCOR FAMILIES in Touch event (FIT) was held on August 25 on Toronto Island. With great weather and delicious food available, families were able to eat, bond with those new to the society, and those who have been members for several years, and enjoy the beauty of Toronto Island. We also were fortunate to have a dentist from Sick Kids Hospital in Toronto talk with the families about the importance of oral health care and bleeding disorders. Thank you to the more than 50 attendees, including the several volunteers who helped run the event. The next event will happen in December and we hope to see you all there. ♡

YMCA Camp Wanakita 2013

by Laura Tomkins

YMCA CAMP Wanakita, located near Haliburton, once again welcomed almost 50 campers aged 6-17 to camp this summer—all affected by an inherited bleeding disorder. Camp Wanakita provides an opportunity to participate in fun activities including kayaking, guitar lessons, sailing and archery. All activities are done in a safe environment, and involve campers meeting other children with or without bleeding disorders. With the help of several hemophilia nurses from across the province, children with bleeding disorders learned to self-infuse at camp, and successful first time infusers took home a video to show their parents, which seemed to be a highlight for many campers during their time at Wanakita.

On behalf of the campers and their families thank you to all of the nurses who dedicated their time to be available to the campers, and to Camp Wanakita, for once again warmly welcoming the campers. ♦



The Toronto and Central Ontario Regional Hemophilia Society (TCOR) would like to thank the following sponsors for their generous support of the TCOR 2013 Golf Tournament.

Premier Sponsors



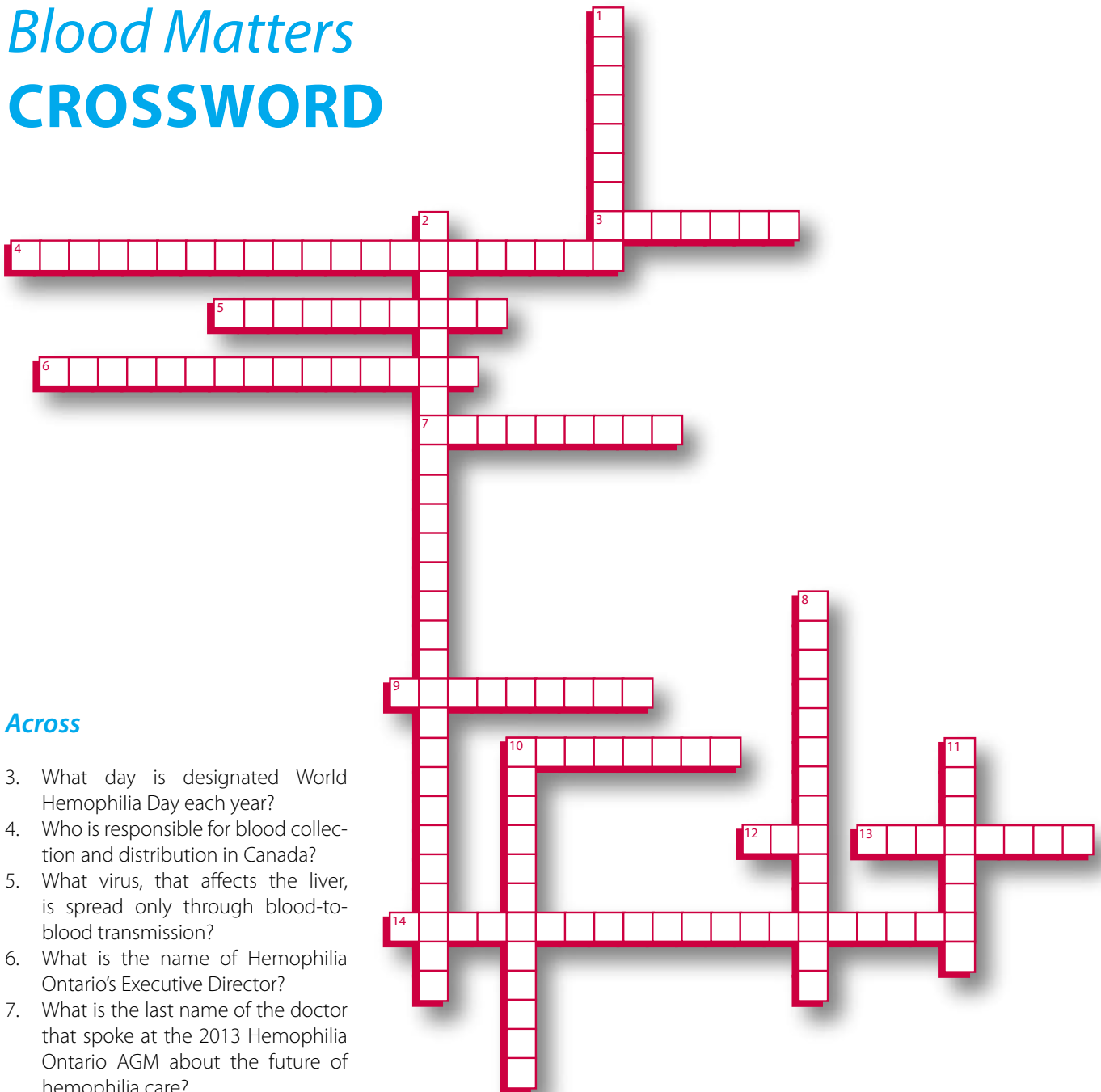
Sponsor a Camper for One Week at Wanakita



Hole Sponsors & Supporters

Arlene Atlas, Aventure Aviation, Jan Drutz, Captain Printworks, Martine Celej, Marinucci & Company, Strype Barristers, Neal and Smith Barristers & Solicitors, Av Reps, 3 Points Aviation, Octapharma and Ev Spence

Blood Matters CROSSWORD



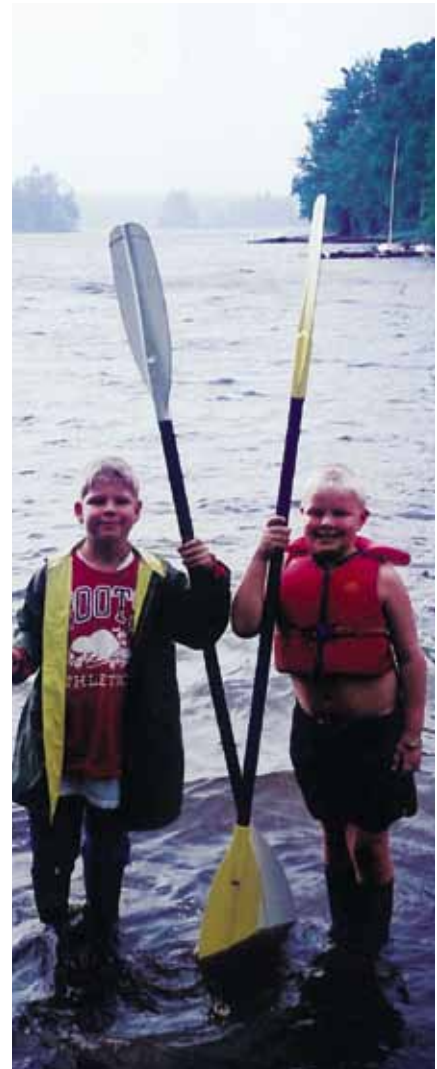
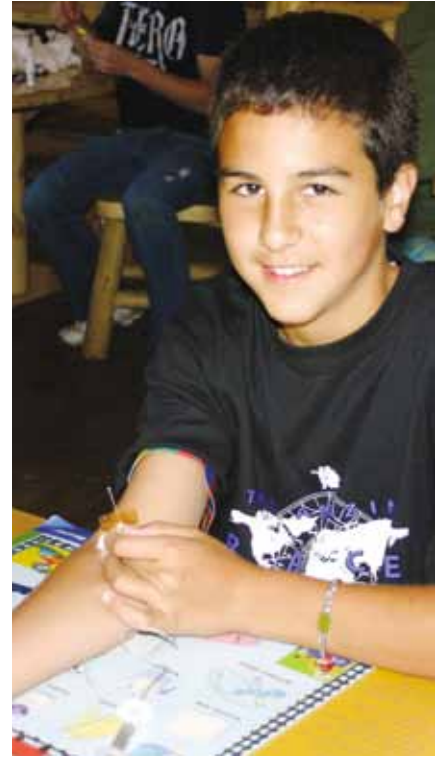
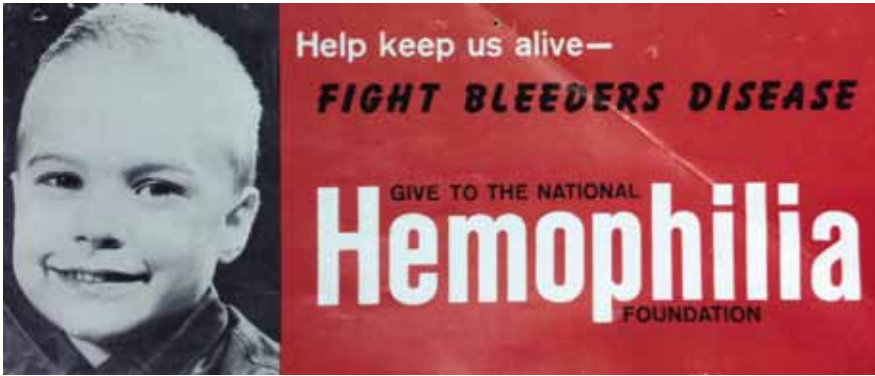
Across

3. What day is designated World Hemophilia Day each year?
4. Who is responsible for blood collection and distribution in Canada?
5. What virus, that affects the liver, is spread only through blood-to-blood transmission?
6. What is the name of Hemophilia Ontario's Executive Director?
7. What is the last name of the doctor that spoke at the 2013 Hemophilia Ontario AGM about the future of hemophilia care?
9. What is the name of the CHS program that works to promote awareness of women with bleeding disorders?
10. What is the name of the camp that Hemophilia Ontario sends children to each summer?
12. What is the acronym for the Hemophilia Ontario youth program?
13. What social network site does Hemophilia Ontario use to post information about their organization?
14. What is the most common bleeding disorder?

Down

1. What holiday shares its name with one of the nicknames for a type of hemophilia?
2. What is the name given to the staff that run programs in each region?
8. What was the theme of the 2013 Just the Guys Weekend?
10. What national awareness day is celebrated on December 1?
11. What month is bleeding disorder awareness month?

Answers on page 20





Home infusion program helps hemophiliac help himself



By Ed Hood of The Free Press

Mark Maynard, 19, left, who is a hemophiliac, helps his brother Matthew, 20, also a hemophiliac, with his home infusion of a special substance which helps restore normal clotting to the blood. About 15 Londoners are on a new home-infusion program designed to give them better control of their condition and minimize complications.

By NEIL SOUKRES

of The Free Press

For most of us a handhold does the job. But for certain, bleeding, however minor, opened sheer terror for many individuals suffering from hemophilia.

For some it meant death from uncontrolled bleeding. For others, it meant years of debilitating bleeds, agony from severe joint pain, crippling and, eventually, premature death.

This situation prevailed until modern times, but even the advent of transfusion didn't solve all the problems. All doctors could do was replace blood as fast as it leaked from the victim's body.

But a new issue — the dawn of a new lease on life for hemophiliacs — began in the 1980s with the introduction of "cryo."

Cryoprecipitate is a substance which can provide the missing element needed to stabilize and stop the runaway bleeding.

It has an ingredient known as "Factor 8," the essential component for normal clotting of human blood, which is missing or inadequate in the blood of hemophiliacs.

The disease strikes males almost exclusively but there are rare cases of it in females. It is passed on through a genetic defect which until recent years was not clearly understood. Females who inherit the defect usually become carriers and, depending on the odds of chance, can pass it on to their sons. Whether a son gets it or a daughter becomes a carrier depends on the odds. The disease strikes about 1:1 persons per 10,000.

Since the mid '80s when Factor 8 became available — it is now a done deal — the Canadian Red Cross can extract from a pint of donor blood — it has been possible to treat episodes of bleeding promptly and effectively.

But there was always the problem that the sufferer was usually well into his attack by the time he could get to hospital. And attacks don't occur simply from a cut or wound. They usually begin insidiously as bleeding into the joints which triggers painful swelling.

Thus, the sooner treatment can be started, the less the chance of immediate or long-term problems.

A major step in bringing new immediacy and on-going therapy to hemophiliacs — there are about 1,000 in Canada — is a new home-infusion program, being recently in London.

The program, backed by the provincial health ministry, brings patients to give themselves cryo treatments on a regular basis, in their homes.

Blood specialists such as Dr. Martin Rowland of St. Joseph's Hospital in London, who helped launch the local program, hope it will help prevent the crippling bleeding episodes for many. They are also optimistic that prompt therapy and control of blood cryo levels will cut the need for extensive joint replacement surgery which many hemophiliacs require.

Nobody supports the program more than one London family with three hemophiliac sons.

Matthew, Mark and Paul Maynard live normal lives because of their treatment.

Mark, who is the most severely affected, takes cryo infusions three times a week but that doesn't stop him from schooling and doing in old cars.

A business and commerce student at Wilfrid Laurier University in Waterloo, 19-year-old Mark has been taking cryoprecipitate almost as long as he can remember.

It's so good at it he has instructed his brother Matt, a 20-year-old psychology student at the University of Waterloo, how to treat himself.

"One thing about it is you realize your limitations early," said Matt, noting the boys had to educate themselves early in life from contact sports in school.

"But you're the same as any other kid, you're gonna get it . . . and usually when you hear it you're going to pay for it," said Matt, who takes home treatment once a month.

Matt earlier began flying lessons only to run into problems with the ministry of transport when he wanted to obtain his licence, but he still hopes he can get around the hangup over hemophilia.

He's heard of a hemophiliac in the west who managed to obtain his licence as a helicopter pilot.

No. 3 son Paul, 16, is hardly one to let his problems hinder his life. While he obtains cryo therapy every two or three weeks, he's managed to fit in following minor hockey for several years along with working with the University of Waterloo Ontario Blue Jay football team.

"The boys have worked out so well because we've had it (cryo) at home," said their mother, Mrs. Douglas Maynard, who prides the Red Cross for making the program possible.

"Things were not always so easy when the boys were children."

"Those days in the beginning I'd get home from 'school' and turn around and go back," Mrs. Maynard recalled.

"We lived in terror."

Even today, parents of young hemophiliacs must go through the same thing until they run out and for their children exactly when they need cryoprecipitate.

And the need for it is really just a "feeling."

A victim can walk up in the middle of the night knowing he needs an infusion. If you interfere with his sleep a bit but he can lead a normal life because he takes the time to treat himself.

"Self-treatment can be done only by a highly motivated individual," said Dr. Rowland.

"It's a serious business," he said, noting there is a rigorous screening program to select those suited for the program.

About 15 patients are now using it locally. "Give you have a 10-year course and doing jobs which, with all respect, a highly trained technological staff have done up until now," he said. In the past the patient would have had to come to the emergency department, be seen by the doctor or intravenous nurse and be given his cryo. The process could take several hours.

Dr. Rowland said patients on successful home infusion are doing "amazing" things which are lacking a tremendous effect on their welfare.

While the patients can proceed with their own care after training in keeping intravenous needles and proper infusion procedures, they are told to seek help immediately should they hemorrhage into an eye or their head. A "bulky" system is also mandatory in case of problems during infusions.

The program is having cost saving benefits as well, say officials. The cost is about a quarter what it was in the past.

In Ontario, treatment and cryo are free to patients. In some parts of the U.S., it costs a patient \$10 to \$20 a unit for cryo and he might need 10 units a week.

Dr. Rowland recalls hearing hemophiliacs called abnormal when all they have is an abnormal blood-clotting mechanism.

"They're analogous to diabetics who get insulin every day to keep their condition under control," he said.

The youngest hemophiliac undergoing home infusions in Ontario is four and the oldest is 38.





**MARK
THIS
DATE**

Hemophilia Ontario Calendar

2013-14

DATE	WHAT AND WHERE?
April 12	Hemophilia Ontario AGM, 2014 Hamilton, ON
October 3-5	Community Camp

Dates are tentative and may be subject to change



Find Hemophilia Ontario
on Facebook



www.wfh2014congress.org

Hosted by:




Organized by:



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

Hemophilia Ontario
Hémophilie Ontario

CANADA		POSTES
POST		CANADA
Postage paid		Port payé
Addressed Admail		Médiaposte avec adresse
02730391		