Past, Present and Future
What’s in this issue?
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Information from Hemophilia Ontario and its Regions

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

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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 Victo-
ria, 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
to-day, 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 recollec-
tion, some remind us of things we
wish we didn’t have to remember. But
that’s life. There are no “do overs.”

Carpe Diem! Seize the day!

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 park-
ing, 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 On-
tario 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 pro-
cessed 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. ♦
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.
**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 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.

**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 educational 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 Lanteigne’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 learns 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 themself and be aware of the future of health care.
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 trade-marked 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

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.

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 range, 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 Bretharian 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.

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.
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.aidsmap.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

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.
**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 commitment 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.

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**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-seek-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/
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 recognize 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 able to reach my goal. Thank you for bringing it within arm’s reach.

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.
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

Meet our **NEW RSC**

**PLEASE JOIN US** in welcoming Shelly Whitney as the new Regional Service Coordinator for the North Western Ontario Region of Hemophilia 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.

**FALL Clinic 2013**

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

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**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.

---

**OEO 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
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.  

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.  

**Crossword ANSWERS**

Across

1. Christmas  
2. Regional Service Coordinator  
8. Summer Olympics  
10. World AIDS Day  
11. November  
13. Facebook  
14. von Willebrand Disease

Down

1. Czech Republic  
2. HOY  
3. Canadian Blood Services  
4. Terminology  
6. Terri-Lee Higgins  
7. Bloodstream  
9. CODErouge  
10. Wanakita  
12. HOY  
13. Facebook
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.
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

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.
**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?
8. What is the name of the CHS program that works to promote awareness of women with bleeding disorders?
9. What is the name of the camp that Hemophilia Ontario sends children to each summer?
10. What is the acronym for the Hemophilia Ontario youth program?
11. What social network site does Hemophilia Ontario use to post information about their organization?
12. 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?
3. What national awareness day is celebrated on December 1?
4. What month is bleeding disorder awareness month?

Answers on page 20
Home infusion program helps hemophilic help himself

Mark Naynard, 19, left, who is a hemophiliac, helps his brother Nathan, 20, also a hemophiliac, with his home infusion of a special substance which helps restore normal clotting to the blood. About 1500 Canadians are on a new home-infusion program designed to give them better control of their condition and minimize complications.

By NEL MORRIS
The Free Press
For Mark Naynard, 19, home is where the blood is.

But he wasn't born with it. He was born with hemophilia, a bleeding disorder. For almost two decades, Mark has been fighting to replace the blood that his body failed to produce.

In addition, people with severe hemophilia have a reduced ability to stop bleeding because the blood does not clot properly.

The program, funded by the provincial health authority, has enabled hemophiliacs to receive their own drug locally. It is helping many young men enter adulthood and lead normal lives.

Mark and his older brother Nathan, 20, are on the home-infusion program. They receive their drug at home, once a day.

The drug, Factor VIII, is given intravenously. It helps the blood to clot and the body to heal.

The program was developed in response to the needs of people with hemophilia who were unable to travel to hospital for regular infusions.

The program has had a significant impact on the lives of people with hemophilia, allowing them to lead normal lives. The program is a major milestone in the treatment of hemophilia in Canada.
Hemophilia Ontario Calendar

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<th>DATE</th>
<th>WHAT AND WHERE?</th>
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<tr>
<td>April 12</td>
<td>Hemophilia Ontario AGM, 2014 Hamilton, ON</td>
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<tr>
<td>October 3-5</td>
<td>Community Camp</td>
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*Dates are tentative and may be subject to change*

Find Hemophilia Ontario on Facebook

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

Hemophilia Ontario
Hémophilie Ontario

WFH 2014 WORLD CONGRESS
THE LARGEST INTERNATIONAL MEETING FOR THE GLOBAL BLEEDING DISORDERS COMMUNITY
MELBOURNE, AUSTRALIA - MAY 11-15

www.wfh2014congress.org