REMARKABLE FIRSTS AT THE WFH 2014 WORLD CONGRESS!

• First vial of factor VIII for *Project Recovery*!

• First long-acting products on the market or soon to be!

• First e-novella featuring bleeding disorders → 100,000 readers so far!
The Canadian Hemophilia Society (CHS) relies on the generosity of our donors to fulfill our mission and vision. We are fortunate to count on a group of exceptional donors who have committed to making an annual investment to support the CHS and its core programming needs.

To recognize this special group of donors we have created the BeneFACTORS Club, the CHS’ highest philanthropic recognition, which symbolizes the critical bond between our organization, the donor and every person we serve with an inherited bleeding disorder. Corporations that make annual gifts of $10,000 or more to support our organization and its core programming needs are recognized as members of the BeneFACTORS Club.

The Canadian Hemophilia Society acknowledges their tremendous effort.
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Despite the long voyage this represented for most people – for us Canadians, at least – this country and continent with undeniable tourist attractions succeeded in bringing together just over 4,000 delegates including people from 128 national member organizations. Attendance was lower than the 2012 Congress in Paris but still satisfactory since this time it was held Down Under. After all, doesn’t everyone want, some day, to see kangaroos living freely in their natural habitat, caress koalas… and blow a didgeridoo!

The main sessions that interested me this year dealt with the medical, musculoskeletal and multidisciplinary aspects of inherited bleeding disorders care.

I really appreciated the session on pain management, which presented points of view from two physiotherapists, a nurse, and a psychologist. There was discussion on how pain is an unpleasant sensory and emotional experience, and also subjective, which means that everyone responds to pain in different ways. However, when pain becomes chronic, it affects the sufferer’s energy, mood and quality of life. What can they do to feel better and function properly? Some people with chronic pain take analgesic pain medications, sometimes excessively, or even opioid drugs which can cause numerous side effects and often addiction that is difficult to break later on. An approach that combines the use of pain medication (which may include opioids prescribed for a short period in cases of acute pain), physiotherapy, individualized exercises and complementary treatments can provide good results. In any case, the panelists said it is important to be well informed about the type of pain one is experiencing in order to better understand and control it; and if chronic pain cannot be resolved completely, there are pharmacological and non-pharmacological interventions that can improve well-being.

In addition, there was one session I made sure not to miss – the plenary session on new products for bleeding disorders and the new prophylaxis regimens to come. Dr. Johannes Oldenburg, director of the hemophilia centre at the University Clinic in Bonn, Germany, gave a comprehensive presentation on factor VIIa, VIII, IX and X concentrates under development, particularly the longer-acting products that will soon be on the market. He explained the different techniques used to extend the half-life of these factor proteins. In closing he emphasized that with several of the new products, depending on the test used (one-stage or chromogenic assay) to determine potency, circulating factor level in a person following infusion, be it a product with normal or extended half-life, the results can vary considerably. It is therefore necessary to continue to work on more trustworthy tests that would more closely reflect the pharmacodynamic reality of these products.

Dr. Manuel Carcao, co-director of the pediatric comprehensive care hemophilia program at the Hospital for Sick Children in Toronto, described the progress made in the treatment of bleeding disorders in recent years. He highlighted the fact that there has been no real change in the pharmacokinetics of coagulation products (cryoprecipitate, plasma-derived factor concentrates, and recombinant factor concentrates) in the past 40 years. The advent of prophylactic treatment though has reduced the number of hospitalizations and invasive surgeries and improved quality of life for people with bleeding disorders. However, prophylaxis presents certain challenges, such as cost of treatment, venous access, and adherence to treatment; missed doses are a problem – in fact, the adherence rate for prophylaxis varies from 60 to 80%, according to studies. Dr. Carcao suggested that the longer-acting products could lead to higher adherence to treatment, which would lead to better long-term clinical outcomes. Furthermore, with these products it may be possible to reduce the frequency of infusions or to maintain higher factor trough levels, or both, to provide improved protection against bleeds. This will require a more individualized treatment approach, he added. Dr. Carcao raised an important issue as to the per unit cost of these new products. He pondered the reasons that would drive health care regulators/payers to reimburse more expensive treatment products. He was skeptical that convenience for patients actually works as a powerful argument. If it is shown, however, that quality of life would be improved, regulators/payers
may allow themselves to be convinced. In conclusion, Dr. Carcao underlined that the new products are in the early stages and close post-marketing surveillance is essential.

In general, there appears to be a consensus forming among hemostasis specialists: current recombinant products are considered similar in terms of composition, efficacy, and safety and, for all practical purposes, are interchangeable.

The longer-acting products consist of molecules that are very different from current recombinant factors because the factor protein (truncated or whole) is combined with something else (polyethylene glycol/PEG, albumin, Fc receptor, etc.), using diverse techniques (fusion, single chain, amino acid sequence modification, etc.). The extended half-life molecule is a lot larger and, due to the new techniques, presents a greater potential risk of immunogenicity, that is, it can induce an immune reaction and the development of inhibitors.

In summary, the extended half-life factor VIII products, which have a 1.5-fold increased half-life, may be particularly significant for children with hemophilia A with difficult venous access since these products can reduce the frequency of infusions. The extended half-life factor IX products, which have a 3- to 6-fold increase, may be used in a large number of people with hemophilia B with the goal of reducing the frequency of infusions or raising trough factor levels, or even both at the same time, depending on the prophylaxis regimen used. Nevertheless the advice of specialists studying the half-life of these different coagulation proteins must be considered in the development of a treatment plan for patients using these new molecules. Again, as mentioned, close post-marketing surveillance will be of paramount importance to ensure that the benefits of these new therapies outweigh possible disadvantages related to their use.

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At the WFH Awards Ceremony on May 15 in Melbourne, CHS Executive Director David Page was recognized, along with Irish Haemophilia Society Chief Executive Brian O’Mahony, with the International Frank Schnabel Volunteer Award. This award, given every two years, is the most prestigious award bestowed by the WFH. It is awarded to a person with hemophilia or other inherited bleeding disorder (in this case two people) or a family member, who has contributed significantly to advancing the WFH’s mission and goals.

Both good and close friends, I found it very apropos to give this award to David and Brian in the same year, a truly well-deserved honour which they accepted with emotion.

Congratulations to both!

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Message from the president

Craig Upshaw

CHS membership unanimously approves by-laws

At the Canadian Hemophilia Society Annual General Meeting, held in Mississauga on June 8, the three classes of members – regular members, associate members and honorary life members – unanimously approved a Special Resolution to apply for a continuance of the Corporation under the new Canada Not-for-Profit Corporations Act (CNCA).

By-law No. 1 was also unanimously approved. The major change to the previous by-law is that the members of the CHS will be its ten chapters, not individuals. This clarifies the federal structure of the CHS as being made up of ten chapters and reflects the way the organization has in fact been operating for many years. Individuals are members by virtue of becoming members of their chapters. Other changes to the by-law bring it into line with the new CNCA.

One small change from the proposed text distributed to members in May was unanimously approved by those present. The process to remove a member, that is, a chapter, was revised to make it a two-step process. In addition to a motion from the board, a members’ meeting must be held at which any resolution to remove a member must be approved by 75 per cent of those members voting. In both steps of the process, there is opportunity for the member to be heard. The key documents are posted at www.hemophilia.ca/en/about-the-chs/governance/by-laws.

The Special Resolution referring to the revised Articles of Continuance and By-law No. 1 will be submitted to Industry Canada before the deadline of October 17 and will take effect soon thereafter.
Community news

Chapter Spotlight

British Columbia Chapter

For World Hemophilia Day, British Columbia Chapter member Danielle Allen set up an information booth at the downtown library in Victoria and Board member Marla Gibbs (pictured here with her sons) set one up at a mall in her community of Chilliwack, B.C. Many flyers, Stop the Bleeding bandage dispensers and magnets were handed out with information about bleeding disorders. The BC Chapter is looking for more members to help spread awareness next April. If you are interested in helping out, please contact the chapter at chsbc@shaw.ca.

The BC Chapter also held a well-attended bowling event earlier in the year. People of all ages came to share laughs, cheer others on and exchange information. Families met or got reacquainted over a game of bowling. The BC Chapter is aiming to change up the activity each year to accommodate the broad range of ages, preferences and abilities. Please contact us with ideas – your chapter really wants to hear from you!

South Western Ontario Region (SWOR)

For World Hepatitis Day on July 28, in collaboration with the Regional HIV/AIDS Connection (an AIDS service organization in London serving the region), we promoted testing at the London Central Public Library. There was an art component using chalk and a regional toolkit was provided to service organizations in the region.

Prelude to Pinecrest was held June 13–15. Our volunteer staff were onsite at Camp Menesetung for staff training in preparation for Pinecrest Adventure Camp in August. This was also an opportunity for potential new campers to stay at camp with their families and find out for themselves what camp will be like. Special thanks to our camp director Ryan, the Hazelwoods—the mentor family—and all the other volunteers.
Toronto and Central Ontario Region (TCOR)

The TCOR Regional General Meeting took place on March 1st. TCOR members networked over lunch and learned about what Hemophilia Ontario has been up to this past year, including upcoming events and twinning, and there was also a fabulous presentation by John Schmitke from Manitoba.

On March 23, nearly 40 TCOR members braved the cold and came out to the annual Polar Bear Dip. Woodbine Beach was full of superheroes, with 10 of them plunging into the cold waters of Lake Ontario! A great warm-up was led by Lolë Ambassador Angela Donovan Jackson, and there was music, food and socializing. Over $9,500 was raised for research and TCOR programs and events!

For World Hemophilia Day, TCOR was at both SickKids and St. Michael’s Hospital to spread the word about bleeding disorders. The booths were popular attractions!

On May 4, the 2nd annual Ageing with a Bleeding Disorder event was held. Like last year’s very popular inaugural event, this year’s event once again drew out a crowd. A fabulous lunch was accompanied by four amazing speakers: hematologist Dr. Michelle Scholzberg, physiotherapist Laurence Boma-Fisher, naturopath Dr. Jean-Jacques Dugoua and TCOR regional service coordinator Sarah Wood, who spoke about accessing home care.

On May 25, the annual Men’s Event took place. Several guys came together to have lunch, play pool, and talk about their bleeding disorders as a group. Social worker Jordan Lewis was onsite to help lead the discussion.

A Negative, greatest awareness outreach ever for the CHS!

In May 2014, the CHS launched A Negative, a first-of-its-kind awareness initiative targeted at young women ages 16-24. This campaign leverages social media and the online story sharing platform Wattpad, to develop and launch an e-novella about a woman with an undiagnosed bleeding disorder. Only one month after its launch, A Negative had reached an audience of 96,000 readers and has now been read by more than 100,000 people! The awareness efforts surrounding the e-novella continue to be developed and implemented. Don’t be shy… please read it and invite your social media network to do the same.

To read A Negative by author L.D. Crichton, please go to www.wattpad.com/story/16049004-a-negative. – C.R.

And the winners are...

The 2014 Pfizer Take a Happy Break, hosted on the CHS Facebook page, made many people very happy indeed. In first place was Laura Young and her entry titled Always Young. Laura won $3,000 for a personal improvement project and matched funds for the Alberta Chapter. Finishing in second place was Jenny Jacobs and her entry titled Caleb Taking a Break. Jenny won $1,000 for a personal improvement project and matched funds for the Newfoundland and Labrador Chapter. The contest generated nearly 6,500 votes. It also helped us increase the number of likes for the CHS Facebook pages, with now more than 1,700 likes for both the English and French pages. – C.R.
Canadian Hemophilia Society

- **October 2–5, 2014** – The 2014 CHS Youth Workshop will take place at the Me to We Leadership Centre in Bethany, Ontario. Only 25 candidates will be able to take advantage of this opportunity. Make sure to be one of them! The workshop will provide you with the tips you need to improve your communication skills. You will better understand the reality of people living with a bleeding disorder in emerging countries. You will learn the smart choices to make about sports, the importance of taking ownership of your bleeding disorder and much more.

For more information or to request a registration form, please contact Hélène Bourgaize at 1-800-668-2686 or by e-mail at hbourgaize@hemophilia.ca.

**Alaska Chapter**

- **September 12–14, 2014** – Goldeye Family Camp and AGM in Nordegg, Alberta.


**Hemophilia Ontario**

- **September 19–21, 2014** – Just the Guys weekend is happening at YMCA Camp Ki-Wa-Y in St. Clements. The Just the Guys weekend is a residential camp for boys ages 4–17 who are affected by an inherited bleeding disorder and their accompanying fathers/ male role models ages 19 and above. For more information or to register please contact Alex McGillivray at 905-522-2545 or amc@hemophilia.on.ca.

- **October 3–5, 2014** – This year we will be once again running our biannual Community Camp at Camp Wanakita in Haliburton! This residential camping experience is for individuals, adults or children living with a bleeding disorder and their support persons. For more information or to register please contact Susan Turner at 416-972-0641 ext. 21 or sturner@hemophilia.on.ca.

**Toronto and Central Ontario Region (TCOR)**

- **September 12, 2014** – TCOR Golf Tournament will be held once again at the beautiful Nobleton Lakes Golf Club in Nobleton. Take a day off work and come enjoy great company, food and golfing, all for a good cause! Please contact Susan Turner at sturner@hemophilia.on.ca or 1-888-838-8846 ext. 21 for more information or to register.

- **September 18, 2014** – Dr. Paula James will once again be hosting the annual VWD Webinar. This year’s Webinar will focus on women with inherited bleeding disorders and iron loss. To participate, make sure to contact Laura Tomkins at ltomkins@hemophilia.on.ca or 416-972-0641 ext.14 for login info!

- **October 2014** – The biannual Women in Touch event again invites carriers, mothers, spouses, women with bleeding disorders, and all other affected women to come and share their experiences. Please contact Laura Tomkins at ltomkins@hemophilia.on.ca or 416-972-0641 ext.14 for more information.

- **November 9, 2014** – This year’s Commemorative Event for TCOR will be held on November 9. Please contact Laura Tomkins at ltomkins@hemophilia.on.ca or 416-972-0641 ext.14 if you have any ideas you would like to share for this event or to register.

**South Western Ontario Region (SWOR)**

- **August 21–24, 2014** – Pinecrest Adventures Camp, Camp Menesetung Goderich, Ontario. This five-day residential camping experience for children with bleeding disorders and their siblings (ages 5–15) offers knowledgeable and specially trained volunteer staff (health care professionals, camp co-directors and counsellors) onsite 24 hours per day.


- **October 2014** – Speakers Bureau, Telling Your Story Your Way. Date and location to be confirmed.

- **November 28, 2014** – Delivery of Festive Wreaths, Swags and Pots throughout SWOR.

**Quebec Chapter (CHSQ)**

- **August 10–17, 2014** – 44th Summer Camp for young boys with hemophilia, ages 5–15. New this year: Joint camp for children with or without inhibitors.

- **October, 2014** – Just the Guys weekend. Date and location to be confirmed.

- **November 15, 2014** – 8th Dance for Life benefit show at the Corona Theatre. Once again, be charmed by captivating and talented professional and semi-professional dancers. For more information, visit the event’s Web site at www.dansezpourlavie.ca or contact the CHSQ office at 1-877-870-0666.

**Nova Scotia Chapter**

- **August 2014** – Maritime Adventures Camp.

- **September 2014** – Family Weekend and AGM.

- **October 2014** – Annual Pumpkin Regatta.
Hemophilia Ontario twins with Tanzania

Candace Terpstra, Stratford, Ontario
with the collaboration of Terri-Lee Higgins, Hemophilia Ontario executive director

In September 2013, Hemophilia Ontario representatives travelled to East Africa to meet with the Hemophilia Society of Tanzania in order to assess the possibility of an organizational twinning. Our flight took us to Dar es Salaam, a city of over three million people, the largest city in Tanzania and its unofficial capital. The country’s population of 45 million is spread over a large expanse of land where many are reliant on a subsistence agricultural economy. Known for its political stability, this African country is able to attract both aid and investment in its natural resources.

On the first day, we met with two hematologists, hematology nurses, laboratory personnel and a trained physiotherapist at the Muhimbili National Referral Hospital. To date only 29 people with hemophilia have been diagnosed and 40 additional blood samples are waiting in storage to be analyzed. Diagnostic capacity is limited by the lack of funds required for the purchase of reagents and service contracts to operate and maintain the specialized laboratory equipment.

Treatment is also a major issue in that the hospital relies on fresh frozen plasma to treat all patients with inherited bleeding disorders except when small amounts of nearly expired factor become available through the WFH Humanitarian Aid Program.

We were also able to tour the National Blood Transfusion Service facility. This facility is part of a relatively new infrastructure for blood collection and processing. Operators report that they have been able to increase the number of voluntary donors every year over the past five years. Each unit of blood is screened for HIV, hepatitis B and C, and syphilis. The institution of an external quality control system is currently underway.

With Ministry of Health and Social Welfare officials, the discussion was broad, including such issues as the limited diagnostic capacity, the lack of treatment, the number of deaths, the need for awareness among medical personnel in rural regions, and the treatment guidelines which await government approval. The discussion around the possible production of cryoprecipitate, purchase of necessary equipment and training of laboratory personnel was encouraging as was the plan to augment hemophilia care and treatment at Muhimbili Hospital.

A meeting with patients and families provided a powerful overview of the harsh reality faced by people with hemophilia and inherited bleeding disorders in Tanzania. Treatment is lacking and it can be costly for families if they are not able to obtain the waivers needed to avoid paying medical fees. Transportation is also a serious undertaking for those living at any distance from a hospital. Most challenging and heartbreaking was that many relatives present described the loss of loved ones. A young woman reported that she had lost two baby brothers as a result of bleeding due to circumcision; an older woman reported losing two brothers; two teens had reportedly died in the two months prior to our visit.

I can’t help but think of the early days of the CHS and how families came together to bring awareness, to fundraise, to see what could be done, but also to comfort each other in times of loss. In my family, I never had the chance to meet my husband’s brother who died at the early age of 17 as a result of gastrointestinal bleeding. We are so very fortunate here in Canada that times have changed and that hemophilia care and treatment have so dramatically improved as a result of medical advances but also as a result of the Society’s advocacy efforts over the years. And we are confident and hopeful that hemophilia care and treatment will change for the better in Tanzania.

In May, representatives from Hemophilia Ontario had the chance to meet with Tanzania volunteers at World Congress to map out this year’s activities. Zach Adams (Ontario) and Dominic Seye (Tanzania), both strong youth leaders, had the opportunity to talk and better understand the unique challenges youth leaders face. This inspired Dominic to hold his first youth group meetings upon his return.

The Hemophilia Society of Tanzania and Hemophilia Ontario were officially recognized as twinning partners in October and the action plan is now in place. We are excited with the doors opening on both sides of the ocean this year through sharing governance knowledge and working together to build a stronger future.

Mission accomplished in Nicaragua

Geneviève Beauregard, CHSO operation and program manager

Last April, the second visit by a Quebec Chapter delegation to Nicaragua took place. The action plan for this year consisted specifically of offering the Nicaraguan Association’s Board of Directors suggestions to help improve their lobbying skills with government ministries. We also offered management tools for planning activities, information about the creation of a patient registry as well as holding a strategic planning exercise.

On a more social note, we were able to meet many members and partners of the organization at an event to inaugurate their new office.

We can say “Mission accomplished!” The Nicaraguan Association now has a clear mission, a vision, and well-established values, as well as practical tools to move forward and grow stronger! ©
The ABC’s of a hemophilia world congress

Hélène Bourgaize, CHS national director of chapter relations and human resources

A world hemophilia congress brings together over 4,000 people from over 125 countries every two years to share, network, get informed on the latest developments in care and research, and learn about the different challenges encountered by the global bleeding disorder community. An estimated 6.9 million people worldwide have bleeding disorders. Three-quarters of them have not been diagnosed or receive inadequate care, or have no access to care at all.

Organizing a world congress is an enormous task. Over the course of four years, different committees made up of representatives from the World Federation of Hemophilia (WFH), the host country and the medical community work to put everything in motion. To meet the needs of everyone, the program consists of two tracks, multidisciplinary and medical, and counts on more than 200 speakers in 60 different sessions presented over four days.

In addition to the sessions, more than 250 posters by health care providers and volunteers are exhibited throughout the week. These posters summarize research projects and programs offered by different bleeding disorder organizations and treatment centres. The posters address topics such as the different types of hemophilia, women with bleeding disorders, clinical trials underway, factor concentrates, inhibitors, von Willebrand disease, prophylactic therapies, ageing, youth leadership, and many other topics of interest to the bleeding disorder community. The posters in the exhibition hall allow participants to learn more about topics of common interest.

Participants can also benefit from the opportunity to visit dozens of onsite information booths set up by pharmaceutical companies and patient organizations such as the Canadian Hemophilia Society. The strong representation of the pharmaceutical industry gives participants access to a wealth of documents and information on treatment products and the treatment of their bleeding disorder. The CHS booth allows us to share with the global community the educational materials that we produce to meet the needs of our community. Many organizations in different countries reproduce our publications in their own languages.

Social activities are also held throughout the week to foster connections among participants. Whether it’s the opening ceremonies, a cultural event or the closing banquet, there are many occasions to meet, interact and network.

To ensure a smooth-running congress, more than 80 volunteers work hard from dawn to dusk to meet the different needs of participants. From the nurses in the Treatment Room, physiotherapists in the physiotherapy room, volunteers who give directions onsite and distribute and gather evaluation forms, and those who drive buggies or push wheelchairs for people with reduced mobility, all these initiatives are supported by dedicated volunteers who are an essential component to ensuring the success of such a congress.

Helping organize a world congress is a unique and unforgettable experience. I encourage readers of Hemophilia Today to take the opportunity presented by the next WFH Congress, which will be held in North America, in Orlando, Florida, in July 2016, to attend in large numbers.
NMO training at World Congress: A fabulous experience

Jennifer Ruklic, Airdrie, Alberta

When I was notified that I would be attending the 2014 WFH World Congress in Melbourne, I was a little caught off guard and in disbelief. That was back in November of last year. Fast forward to May 5. On the trip over I had a lot of anxiety, being away from my family for two weeks. How would my son do without me administering his factor? Who would rush the kids around? That all disappeared when I stepped off the bus that brought us to Creswick, Australia, for the National Member Organization (NMO) training.

Every two years before its World Congress, the WFH holds a three-day Global NMO training that includes a variety of information-sharing sessions and capacity-building workshops. Each NMO is invited to send one participant and the WFH makes 16 youth fellowships available.

Stepping off the bus was so overwhelming; all I kept thinking was “I'm in Australia.” I was ready to open up my mind to the experience. NMO training was a great way to spend an intimate time with over 100 people. During these days we attended interactive workshops by international experts on the topics of psychosocial support, pharmaceutical funding, data and the economics of bleeding disorder care, and youth leadership training. Plenaries highlighted best practices by NMOs, women with bleeding disorders, and clinical research in hemophilia.

I was fortunate enough to have been chosen as one of eight people to share best practices and, although extremely nervous, I was happy to share a little insight into my abilities to fundraise. After my brief 20 minutes, I spent roughly two hours helping several countries look at ways they could utilize my ideas. I was able to speak to each of the participants through this special part of the plenary session. By gathering details on how they run their associations, engage with their communities and also how they deal with the ongoing issues with hemophilia, I came to the realization that in Canada there is really great care for our community. It made me think of all the things I take for granted like having factor at my fingertips.

After the time spent at the NMO training, we headed off to Congress itself. It hit us all that we had experienced a unique part of the conference and that we had forged relationships and networks that many would not have the chance to do. Congress was a life-changer for me; it made me step out of my comfort zone and understand a different way of life with hemophilia through the eyes of people from different nationalities.

When asked to write about my experience at Congress, I had planned to write about the sessions, the education, and these were great ideas. However, the experience was complete in my mind because of all the people I met. I came to the realization that hemophilia touches many lives and even though there is a world of education to learn from all of these seminars, taking time to make friendships and connections is just as important. I feel so blessed that I was given the opportunity to attend World Congress so I could embrace all that it had to offer.

Presenting CO2ERouge at World Congress

Shelley Mountain, Cornwall, Prince Edward Island

I had been invited by the WFH to attend the 2014 World Congress in Melbourne, Australia, as a speaker in a session titled We should talk: Sharing information with carriers and those who care for them, held on May 12.

The objective of this session was to share new information and science about issues related to carriers; to identify potential resources in the bleeding disorder community for carriers; to increase recognition of possible signs and symptoms of trouble for carriers; and to stimulate discussion amongst health care providers and carriers.

There were approximately 150 people attending the session to hear our presentations (a four-member panel and chair Pam Wilton from Ontario). It was very warmly received and I was extremely proud about how I presented. It was very rewarding.

My presentation talked about the CO2ERouge ambassadors being the key to the success of CO2ERouge, the training elements, and the importance of ongoing support to the ambassadors. Included in the talk was a full list of the events held across Canada. I ended the presentation with the e-novella launch (see page 7).

The Congress gave me an opportunity to share and learn from others around the world and participate in a wide range of networking opportunities with peers. It also gave me a chance to meet with many women from numerous countries and discuss CO2ERouge and possible implementation in other countries.

Thank you to the WFH and the CHS for this unique opportunity.
Global embrace: Powerful connections at Hemophilia World Congress

Justin Smrz, North Vancouver, British Columbia

The World Federation of Hemophilia Congress, as advertised, is a venue to bring patients, physicians, researchers, volunteers, caregivers, and loved ones of the inherited bleeding disorder community together from around the world. This year, over 128 countries were represented at Congress. Topics ranged from new ideas to deal with chronic pain, fine-tuning physical exercise as a preventative measure against bleeds, through to gene therapy advancements for the future.

Of these 128 countries, the majority of people worldwide (75%) do not have access to treatment and, unfortunately, in many countries being diagnosed with a bleeding disorder has very poor outcomes. It was absolutely heartbreaking to hear that the oldest hemophilic in one country is nine years old. Due to lack of technology, medication and resources, in many countries those affected with a bleeding disorder succumb to a major bleed early in life.

As Canadians with inherited bleeding disorders, we are lucky to receive the treatment that we have. However, even though we have access to treatment, are there ways to improve our care? The answer is yes, but it is not just about receiving care, it is also about going forth and taking charge for ourselves. The best way to control a bleed is to not have one in the first place. Building strong muscles and staying flexible is a very good treatment approach for those of us affected with a bleeding disorder. There are many ways to accomplish this, but the best way is to find out what you like to do in terms of exercise and talk to your health care team about building a regimen that will work for you. It is also very important to keep up-to-date records and medical information, and stay in touch with the medical care team as this gives important data necessary to further care and treatment of your bleeding disorder. The World Congress is embraced by the bleeding disorder community because it gives hope to the countries in need, and guidance for the more fortunate countries.

Congress, for those who attend, means much more than just a week full of educational sessions and social events. For me, meeting participants in Australia did not feel like meeting strangers. There was an immediate connection and the usual uncomfortable zone that people have when meeting new people did not exist. It might be the fact that even though we are all from different parts of the world, we all share similar stories in our upbringing dealing with our bleeding disorder.

There were those at Congress who felt isolated most of their lives. For many, by the end of Congress, they no longer felt this way because they were now connected to a community greater than themselves. Many farewell hugs were exchanged on the final day of Congress, but they were more than just hugs; they were powerful embraces that made the distances across the world obsolete because, in that week, in that moment, we had made connections that would stay with us forever. We embraced the knowledge that Congress had to offer and furthermore, we embraced ourselves, each other, and the days to come.

EDITOR’S NOTE: Justin was this year’s recipient of the Karttik Shah Youth Fellowship. He is co-chair of the CHS National Youth Committee and the contributor of the YOUTH FILE for Hemophilia Today.
It was such a great privilege to attend the WFH 2014 World Congress in Melbourne and have incredible and inspiring learning experiences with hemophilias from around the world. I would never have imagined travelling so far away from home but I am so humbled and grateful for this opportunity of a lifetime.

My first day started with a cup of Melbourne’s famous coffee, then browsing the Exhibition Hall booths and presentations, and chatting with the national CHS team. I encountered many incredible people and stories, such as one hemophiliac who overcame his physical disability with bravery and resilience and coped with his central blindness (caused by cerebral hematoma during delivery) through musical education. He and his family made a powerful impression on me.

During the conference, most of my time was spent attending psychosocial and multidisciplinary research sessions, and particularly sessions regarding women and bleeding disorders. To name a few: Embracing women’s sexuality, Ageing gracefully with hemophilia, Education and employment issues living with a bleeding disorder, and Strengthening multidisciplinary teams to provide inter-professional care.

I learned about many approaches and strategies used in different countries but one presentation struck a chord with me: What will I be when I grow up? by Frederica Cassis, psychologist at a hemophilia centre in São Paulo, Brazil. As the mother of a hemophiliac son, I was impressed with how much it resonated with my own experiences and beliefs about the need for reliable, long-term psychosocial support for families living with hemophilia. It showed how with a strong and dedicated care team to guide and nurture them through developmental changes, children can learn to be resilient and thrive with their chronic condition, and parents gradually overcome negative emotions associated with hemophilia and gain acceptance. The presentation focused on parents: common reactions and needs at the time of a child’s diagnosis, the initial psychosocial assessment, psychosocial strategies and support, and the benefits of ongoing psychosocial assessment and intervention to identify and address parent needs throughout a child’s stages of development. Dr. Cassis’ knowledge and understanding were impressively holistic. After the presentation, I introduced myself and thanked her for her insight. To my surprise, she hugged and kissed me and said it meant the world to her that a mother of a hemophiliac showed appreciation for her efforts to improve the lives of families affected by hemophilia.

In the halls of the congress I met many new friends from all over the world: India, Bangladesh, the Philippines and Mongolia. We talked about the lack of treatment all over the world and about the conditions in some countries. A remarkable feature of the congress was the Treatment Room next to the Exhibition Hall, where participants with bleeding disorders were able to access free treatment onsite. Specialized physicians and nurses were available to assess emergency and semi-urgent situations and to provide infusions. I met a young man from the Philippines who was thankful just for the possibility to be treated with the optimal dosage every day. It breaks my heart that many patients don’t get adequate treatment in their home countries and I left this congress with the realization that more work must be done to make treatment available for all.

The conference was also an exciting opportunity for me to meet up and chat with many of the friends and advocates I have met through the Facebook group, Hemophilia Mother, which I created as a space for mothers affected by hemophilia and other inherited bleeding disorders to share information and support each other. There are over 1,500 members and it was an overwhelming privilege to experience the group’s truly international connection in person. I was also privileged to have the opportunity to meet up with Cheryl Nineff D’Ambrosio (USA), founder of MyGirlsBlood, a group dedicated to supporting women with bleeding disorders; Marelle Hart (Luxembourg), an advocate for access to affordable treatment in developing countries; and hemophilia society leader Megan Acediran (Nigeria), who gave an incredible introductory speech at the Congress. I was excited to meet with the Bangladesh–CHS Twinning Committee and have the opportunity to spend some time meeting the Mongolian delegation in order to make twinning with the CHS Manitoba Chapter a reality. The meetings were productive and the CHS Manitoba Chapter Twinning Committee and the WFH are organizing an assessment visit to Mongolia for this summer.

It is hard to put into words the enthusiasm, friendship and knowledge that was gained through this conference but I hope I was able to give you a small glimpse.
Inspiration, passion, commitment, excitement

Zach Adams, Pickering, Ontario

Inspiration, passion, commitment and excitement. These four words are the only way I can begin to describe the sentiment and atmosphere exuded by all participants during the 2014 World Federation of Hemophilia World Congress. Gratefully having been selected to represent Hemophilia Ontario in Melbourne, Australia, the host city for this year’s WFH World Congress, I was privileged enough to be among the over 4,000 participants.

As kangaroos were bounding through the Australian outback, researchers and health care professionals were showing us how they are now bounding into a new era for the care and treatment of bleeding disorders around the world. The opening ceremony gave us the opportunity to hear stories of multiple individuals from around the globe who have been affected by the WFH and its initiatives. For example, Megan Adediran, a mother of two boys with hemophilia and the founder and president of the Hemophilia Foundation of Nigeria, gave an inspiring talk on her involvement with the Cornerstone Initiative. This program provides much needed assistance and essential education that will help to identify those with bleeding disorders who have yet to be discovered, thus continuing the momentum towards the goal of Treatment for All, the vision of the WFH.

The week continued with a multitude of both plenary and concurrent sessions, which covered both medical and multidisciplinary aspects of bleeding disorders. It was very exciting to see such a large contingent of speakers from Canada, who led talks during numerous sessions and provided insight into their novel research and the current understanding. Dr. David Lillicrap, from Kingston General Hospital, spoke during a session on rare bleeding disorders and discussed the process of next generation sequencing and how it will begin to play a significant role in the molecular diagnosis of von Willebrand disease and rare bleeding disorders.

Furthermore, Kathy Mulder, physiotherapist from Winnipeg’s Health Sciences Centre, put aside, for a moment, her strong beliefs regarding the many positive benefits of exercise and rehabilitation to engage the audience in an animated and often humourous crossfire session that attempted to consider reasons why individuals with bleeding disorders might avoid engaging in exercise and rehabilitation.

Also, Dr. Alfonso Iorio, from McMaster University, discussed issues surrounding adherence and non-adherence, and the effect it can have on treatment efficacy.

These are just a few of the many Canadian speakers who were able to share their research and insights with the worldwide bleeding disorder community. It is truly inspiring to see how Canadians have taken a leading role into continually striving to improve the care and treatment for those with bleeding disorders in Canada and around the world.

Finally, the World Congress allowed me to speak with individuals from across the globe and gain insight into the large differences in care and treatment. Our meeting with two individuals from the Hemophilia Society of Tanzania, involved in the current twinning with Hemophilia Ontario, offered optimism and hope that projects such as these are the key to one day ensuring treatment for all.

I would like to thank Hemophilia Ontario for providing me with this incredible opportunity, as well as all of the individuals who spent countless hours organizing and volunteering throughout the week to provide a wonderful World Congress. ©
Building on the experiences of others

John Schmitke, Morris, Manitoba

My name is John Schmitke and I’m currently vice president of the CHS Manitoba Chapter and chair of our provincial Youth Committee. As a young man living with hemophilia, I recently participated in a program that gave me the opportunity to be a Hemophilia Champion.

One of the most exciting parts of the program was that I was to represent Canada at the World Hemophilia Congress in Melbourne, Australia. Once in Melbourne, I touched base with my friend Justin (Smrz), who is co-chair of the CHS National Youth Committee with me. He was already at the Convention Centre and had managed to find an organized youth event.

This is where I initially met a lot of the people with whom I would form the strongest relationships. One of the things that I looked forward to the most was to meet people from around the world with the same but different challenges. Health care in Canada is among the top tier systems in the world, which means that there is a lot to be learned from my peers in the tiers below the one that I have been privy to.

When people meet me they would never think that I have a disorder of any kind, never mind one that typically manifests in physical symptoms. This was not the case for everyone I met at Congress. I should say that I have always tried to be acutely aware of what hemophilia is like for the majority of people suffering from it globally, but that awareness is much different when those people surround you.

At this youth event there were people with arms that could not straighten, with knee replacements, in wheelchairs, suffering from inhibitors, and just living with daily reminders of what it is we have. There were also others like me, people who have been lucky in their lives. People with no outward symptoms of having a bleeding disorder. I use the word luck, because luck it would seem is a big part of it. We have also become very good at managing our bleeding disorders. Either consciously or in some cases instinctively, finding a way to minimize the effects by staying ahead of them.

Andrew, Chris and Adam were the three people I met who had the greatest impact on me and made lasting impressions.

Andrew is living with an inhibitor. He also struggled with target joints. As a result he had a complete knee replacement and had both of his ankles fused. Like me, he is in his twenties. He has the exact same type of hemophilia as I but has had an inarguably much more difficult set of challenges. Andrew went through a lot of his life accepting his limitations, but at some point, he stopped accepting things for what they were and decided to make them what he wanted. He lost a lot of weight, began fitness training, and now lives his life the way he wants to live it.

The next inspiring person I would meet was Chris. Chris is currently in better shape than I am. I know that sounds conceited, but this level of physical ability is not something that is seen in people with severe hemophilia. I was surprised, and I admired Chris for what he has achieved, knowing the dedication it takes to achieve it. I never had the experience of having another hemophiliac come near my physical ability, never mind surpass it. The experience was both humbling and immensely satisfying.

Adam is a young man who relies on a wheelchair to get around because he is paralyzed from the waist down. This is a result of a bleed near his spine caused by an epidural, shortly after he was born. He doesn’t want sympathy; no one with a mental fortitude as strong as his does. He is as accomplished as anyone else. It is people who are this remarkable that inspire the most. They are the true role models among us. To go through life with a severe bleeding disorder and being unable to walk, yet accomplishing as much or more than most people, he shows that with effort and the willingness to adapt, these things are no handicap.

People with bleeding disorders from the 128 countries represented at this conference embodied the best knowledge to be gained. There were all kinds of sessions on treatment methods, medications, complications, challenges, etc. But it’s witnessing the culmination of life experiences that make up the “patient population” that you gain the most.

I went to Melbourne because some people see me as someone that has experience worth sharing. While I understand this, it is the experiences of others that drive me to continue living in an exemplary way.
Abdulaziz’s journey: WFH’s phenomenal impact in the world

Kathy Mulder, physiotherapist, Health Sciences Centre, Winnipeg, Manitoba

The highlight of World Congress in Melbourne for me was seeing the effectiveness of several programs of the World Federation of Hemophilia (WFH) embodied in one courageous young man.

In 2003, I had the opportunity to participate in a WFH twinning project between the Jordanian Hemophilia Society and Hemophilia Ontario’s Toronto Central Ontario Region. At one of the musculoskeletal workshops, I met Abdulaziz Al-Sharif... and his knee!

Dr. Jerome Weidel (orthopedic surgeon from Denver, Colorado, USA) and I knew that this knee required a surgical synovectomy, as soon as possible.

Fast forward to 2006: at another WFH-sponsored workshop in Amman, I met Abdulaziz again. This time with Dr. Adolfo Llinás (orthopedic surgeon from Bogotá, Colombia). For many reasons that Canadians would find difficult to understand but are common in other parts of the hemophilia world, the surgery had not been possible and the knee was now destroyed. Abdulaziz was unable to walk without crutches and was in constant, considerable pain.

Imagine my delight during the opening ceremonies of WFH Congress in Melbourne when Abdulaziz WALKED onto the stage – without crutches – to describe how the WFH Humanitarian Aid Program had provided the factor required to allow him to undergo knee replacement surgery! And then to have the chance to talk to him later in the week and hear about how Dr. Llinás had coached the Jordanian surgeons from a distance, and how several sectors of the Jordanian health system (which did not communicate with one another in 2003) had collaborated to ensure a successful outcome.

Abdulaziz has grown from a shy teenager to a successful high school teacher. This is a great example of how the WFH has made a huge difference and I am so proud to be involved in this organization.
Focus on research

REPORT FROM THE CHAIR

Norman Locke
Chair of the Hemophilia Research Million Dollar Club, on behalf of the Administrators

The Hemophilia Research Grants Review Committee, under the chairmanship of Dr. Nancy A. Dower, met earlier this year and announced the 2014 grant recipients for the CHS Dream of a Cure Research Program. Summaries of the projects can be found on pages 19 and 20. These grants total $236,926 and were made possible by funding provided by the Hemophilia Research Million Dollar Club (HRMDC) and the Canadian Hemophilia Society (CHS). The HRMDC and the CHS have provided over $4 million in support of hemophilia research in Canada since 1991. This has made such a difference in the quality of life of people living with an inherited bleeding disorder.

It has been 30 years since Ken Poyser, a person with severe hemophilia who passed away in 2010, had a dream. He dreamed of an endowment of at least $1,000,000 to provide funding for inherited bleeding disorder research in Canada. In 1984, with the help of Richard O’Shaunessey, Ed Kubin and many other committed people in the hemophilia community, his dream was brought into reality with the creation of the Hemophilia Research Million Dollar Club (HRMDC). In less than six years, the HRMDC reached that goal! In 2000, Frank Bott, the father of two sons who had hemophilia, also had a vision. His dream was to increase the endowment of the Club to $1,600,000 and he spearheaded an ambitious fundraising campaign to which the Club will be forever grateful. Thanks to his efforts and the support of the CHS, its chapters and regions, and individuals, this goal was reached at the end of 2004. Today the fund stands at over $2,000,000!

We have always depended on our hemophilia community – the chapters and regions, individuals, families and groups – which has provided financial support since the Club’s inception in 1984. And each year this caring and committed community understands that supporting the Million Dollar Club is the most effective way in which they can support bleeding disorder research in Canada. In 2013, the chapters and members collectively raised over $96,926 to increase the capital of the endowment fund. An additional $77,507 (including a $50,000 matching gift from the CHS) was directed towards current research.

As is our custom, we are pleased to acknowledge in Hemophilia Today our members and donors who truly understand that the Hemophilia Research Fund is “our” fund. The complete list of Voting Members, Non-Voting Members, Honorary Members and Honorees who have supported the HRMDC since 1984 appears below and on the next page. We express our heartfelt thanks to all of you for your generosity!

If you would like to support and/or receive our information brochure, please contact Joyce Argall at the CHS national office (1-800-668-2686 | jargall@hemophilia.ca) or visit the TO SUPPORT US section of our Web site.

We would like to thank all those who made donations:

In honour of David Auld, Rashpal Bhogal, Manny Bryar, Marjorie Calderwood, Dan Doran, Alexander Mark Ernst, Dr. Ron George, Benjamin Gray, Nathan Gray, Phyllis Gray, David Gray, Darryl Gray, Joan Kinniburgh, Murray Kinniburgh, Victoria Kinniburgh, Carrie Ku, Mary MacLeod, Alden Mueller, Carter Ruklic, John Schmitke.


We would also like to thank our numerous additional donors who each year express their confidence by contributing to our yearly appeals or supporting activities organized by individuals, chapters and regions.
In honour of his "Angel" Gayle
Achyrmichuk
James Kreppner
In honour of his "Angel" Antonio Swann
Tony Niskic
In honour of his "Angel" Loretta Niskic
Dr. and Mrs. Ron George
In honour of their "Angels"
Dr. Martin Inwood, Dr. Irwin Walker, Dr. J. Cranby, and the hemophilia nurse coordinators
Blanchette-D'Fana Family
In honour of their "Angel" Kevin
Can-Ital Ladies Society
In memory of Martin and Gregory bott
David Page
In memory of his "Angel" Julia Page
Maureen Griffith
In honour of her "Angel" Amy Griffith
Catherine Bartlett and Dave Halliday
In honour of their "Angels"
Joppy Marie Halliday
Joan and Murray Kinniburgh
In honour of Benjamin and Nathan Gray
Ottawa and Eastern Ontario Region
In memory of John Wilson
Newfoundland and Labrador Chapter
In memory of Michel Frank bottleneck
In memory of Mike and William Frank
Dr. and Mrs. Ron George
In honour of his "Angel" Manny Bryar
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Dr. Ron and Leni George
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Alberta Chapter
Carter's Quest for a Cure

HONORARIES
Dr. Agathe Barry
Giselle Belanger and her team
Lorraine Bernier and her team
Helen and Hunter Bishop
In memory of Martin bott
In memory of Ann Lois Brown
Dr. Robert Card, Caryl Bell and Elena
Kanigan
Comprehensive Care Team of Southern Alberta
Kathy Coniffe
In memory of Clifford Ray Crook
Ray and Pat Daniel
In memory of Ken Daniel
In memory of Ray Daniel
Dr. Barry L. DeLebe
Bill Featherstone
In memory of Raymond Joseph Fontaine
For persons with hemophilia who have died from "We Never Forget"
Pierre Fournier
In memory of Robert Gibson
Muriel Girard and her team
Dr. Gerry Growe
In memory of Frank Haslam
Ann Harrington
In memory of Glen Michael Hofer
Dr. Marcie Inwood
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In memory of Stuart Johnson
Family of David Joy
Martha James
In memory of Kelly King and John Akabutu
In memory of James Kreppner
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In memory of Charles Joseph C. J. Kubin
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In memory of Edward Kubin
Normand Landry Family
In memory of Pierre Latrelle
In memory of Bill Laxdal
Dr. Mariette Lepine and her Team
In memory of James "Jimbo" Alan Love
In memory of Gary Maclean
In memory of Douglass, Mark, Paul and Nuria Maynard
In memory of Art Olson
In memory of Ray O'Meara
Bub O'Neill
Ottawa and Eastern Ontario Region
Dr. Mohan Pai
John Peach
Persons with hemophilia from South Western Ontario Region
Paulien Peters and Duncan Conrad
Gary N. Petrick
In memory of John Poole
Ken Poyser
Ray Poyser
In memory of Allan E. Quartermain
In memory of Brian Rebeiro
In memory of Darryl Rebeiro
Dr. Georges-Etienne Rivard
Joyce Rosenthal and Lois Bedard
Carter's Quest
In memory of Howard Sayant
Dr. Brent Schacter
In memory of Kenneth Shewchuk
In memory of Frank Schnabel
Marthe Schnabel
In memory of Glen Sprenger
In memory of John Strawa
Dr. Hanna Stawczynski
Frank and Candy Terpstra
In memory of Frank Terpstra
In memory of Troy Christian Trépanier
Dr. Chris Tsoukas
In memory of Neil Kerr Van Dusen
Dr. Irwin Walker
Barbara Webber
Glen Webster
CHS Dream of a Cure Research Program

Supporting research towards improving the quality of life for people with inherited bleeding disorders and finding a cure have been goals of the Canadian Hemophilia Society (CHS) since it was founded in 1953. Since 1990, through funds provided by the Hemophilia Research Million Dollar Club and the CHS, the CHS provides basic scientific research grants and studentships aimed at developing treatments for inherited bleeding disorders and finding a cure.

THE FOLLOWING PROJECTS ARE BEING FUNDED IN 2014.

DREAM OF A CURE

Characterization of common inherited platelet function disorders

Dr. Catherine Hayward
McMaster University – Hamilton, Ontario

This research will involve testing of samples from people in families with increased bleeding due to platelet disorders. The goals are to better understand what causes these disorders, develop better tests and improve patient care.

DREAM OF A CURE

Understanding angiodysplasia in von Willebrand disease: Studies using BOEC (Blood Outgrowth Endothelial Cells)

Dr. Paula James
Queens University – Kingston, Ontario

This study aims to better understand the causes of angiodysplasia, small vascular malformations like varicose veins on the inside of the bowel, a common cause of gastro-intestinal bleeding in von Willebrand disease. It will also study the available treatments including concentrates of von Willebrand factor, estrogen, thalidomide and atorvastatin.

DREAM OF A CURE

Incorporation of rFVIII into platelets as a potential therapy in patients with inhibitory antibodies to factor VIII

Dr. Walter Kahr
The Hospital for Sick Children – Toronto, Ontario

The goal of the project is to improve methods for making rFVIII-loaded platelets and to demonstrate their potential for use in hemophilia patients with inhibitors. The rFVIII in these platelets would be longer lasting and limit the effects of inhibitors.

More detailed descriptions of all the funded research projects are available at www.hemophilia.ca/en/research.
FOCUS ON RESEARCH

LAB WORK STUDENTSHIPS

DREAM OF A CURE

What are the short-term effects of physical activity on the cartilage of hemophilic and age-matched boys? Functional imaging perspective

Humayun Ahmed
Hospital for Sick Children – Toronto, Ontario

This research will apply a short-term exercise protocol (knee squats) to hemophilic and age-matched healthy boys to determine whether a change in the organization of collagen fibers can be detected in their maturing cartilage pre- and post-exercise. This information is critical for the development of future guidelines on safety and effectiveness of physical activity for people with hemophilia.

DREAM OF A CURE

Effects of FEIBA on FXa generation in factor VIII and factor IX deficient plasma

Alice Kun Yi
McMaster University – Hamilton, Ontario

This research will use a lab assay to compare the differences in plasma from people both with and without hemophilia. The results will provide important information regarding how FEIBA (Factor Eight Inhibitor Bypassing Activity) functions so that its use can be optimized in various clinical settings.
The CHS/Pfizer Care Until Cure Research Program

The Care until Cure Research Program, established in the year 2000 and funded by Pfizer, allows Canadian investigators to conduct research on various medical and psychosocial aspects of bleeding disorders. Grants are given for clinical research, including outcome evaluation, in fields relevant to improving the quality of life of people with hemophilia, von Willebrand disease or other inherited bleeding disorders, people with related conditions such as HIV or hepatitis C, as well as carriers of an inherited bleeding disorder.

THE FOLLOWING PROJECTS ARE BEING FUNDED IN 2014

CARE UNTIL CURE

HR-pQCT: a novel imaging technology detects microarchitectural skeletal pathology in hemophilia patients

Dr. Adrienne Lee  
University of Calgary – Calgary, Alberta

Several studies have shown that people with hemophilia develop osteoporosis at an early age. The goal of this project is to utilize new imaging technology called HR-pQCT (high resolution peripheral quantitative computed tomography) to visualize the bone structure in 3D so as to identify individuals at higher risk of bone fracture.

CARE UNTIL CURE

Living with and managing hemophilia from diagnosis and through key care transitions: the journey for families of children with hemophilia

Dr. Roberta Woodgate  
University of Manitoba – Winnipeg, Manitoba

This study will improve understanding of the experiences and needs of families of children with hemophilia. Children and their parents play an active role in defining issues, considering solutions and identifying priorities. Results will inform and improve existing services and programs.
FOCUS ON RESEARCH

The CHS/AHCDC/CSL Behring Hemostasis Fellowship Program

The Hemostasis Fellowship Program, a fellowship in congenital and acquired bleeding disorders, was established in the fall of 2001. Since 2010, the Fellowship has been made possible thanks to the generous financial support of CSL Behring Canada.

The goal of this ongoing annual research program that encompasses a one-year fellowship appointment is to provide fellows in hematology or other relevant fields the opportunity to acquire clinical or research skills necessary to improve the care, treatment and quality of the life of patients with hemophilia and other congenital or acquired bleeding disorders.

THE FOLLOWING PROJECT IS BEING FUNDED IN 2014.

HEMOSTASIS FELLOWSHIP PROGRAM

Mechanisms associated with hyper-responsive platelet GPIbα cause alterations in platelet activation and function leading to a bleeding phenotype

Dr. Harmanpreet Kaur
Queen’s University – Kingston, Ontario

This research will look at various aspects of platelet activation and clot formation using a mouse model for platelet-type von Willebrand disease (PT-VWD). It will also study the effect on bleeding of inhibiting hyper-response GPIbα, a protein present on the membrane of platelets. This study seeks to better understand this rare disease and to develop strategies to treat bleeding in PT-VWD patients.

The CHS/Novo Nordisk Canada Psychosocial Research Program

The CHS/Novo Nordisk Canada Psychosocial Research Program was created to engage hemophilia program professionals/graduate students from the allied health disciplines (i.e. nursing, physiotherapy and social work) in research activities addressed to understanding the psychosocial impact of hemophilia and other inherited bleeding disorders and to improve the quality of life of people and families whose lives are affected by these disorders.

The research grants are made possible thanks to generous financial support from Novo Nordisk Canada.

THE FOLLOWING PROJECT IS BEING FUNDED IN 2014.

PSYCHOSOCIAL RESEARCH PROGRAM

How is quality of life impacted by vocational experiences and opportunities among males (≥16) with moderate and severe hemophilia throughout the lifecycle?

Claude Bartholomew, RSW
St-Paul’s Hospital – Vancouver, British Columbia

This research seeks to answer the above question using questionnaires and focus groups with people with hemophilia in centres in four provinces: British Columbia, Manitoba, Ontario and Saskatchewan.
CHS/Baxter Canada Inherited Bleeding Disorders Fellowship Program for Nurses and Allied Health Care Professionals

The Canadian Hemophilia Society – Baxter Canada Inherited Bleeding Disorders Fellowship Program for Nurses and Allied Health Care Professionals was created to engage hemophilia program professionals/graduate students from the disciplines of nursing, physiotherapy, social work and other related allied health disciplines in research focused on improving services and quality of life for people and families whose lives are affected by bleeding disorders.

The fellowship is made possible thanks to the generous financial support from Baxter Canada, and the CHS is proud to be in a partnership with Baxter in order to offer this important fellowship program.

THE FOLLOWING PROJECTS ARE BEING FUNDED IN 2014.

INHERITED BLEEDING DISORDERS FELLOWSHIP PROGRAM

Implementation, utilization and effectiveness of an electronic application developed specifically for young men with mild hemophilia

JoAnn Nilson, PT
University of Saskatchewan – Saskatoon, Saskatchewan

This study will spread the use of a Smartphone App, called HIRT? throughout Canada and test its effectiveness over a period of 12 months in helping young men with mild hemophilia better assess musculoskeletal injuries. The goal is to contribute to earlier treatment decisions by these young men and better communication with the health care workers.

INHERITED BLEEDING DISORDERS FELLOWSHIP PROGRAM

After 12 months of individualized treatment plans, what is the long-term impact on physical activity and quality of life in a single treatment centre?

Sandra Squire, BScPT
St-Paul’s Hospital – Vancouver, British Columbia

This research will look at the long term impact on patients of an individualized prophylaxis plan, developed based on motivational interviewing philosophy. Over the 12 months, the study will measure how physical activity, quality of life and bleeds/infusions are influenced by the individualized plan.
Social Workers Face-to-Face

Pride and inspiration at World Congress

Claude Bartholomew, MSW, Hemophilia Program – Adult Division, St. Paul’s Hospital, Vancouver, British Columbia

If there was a pinnacle in hemophilia-related conferences for me, it would be the 2014 WFH World Congress, held in Melbourne last May. The WFH had invited me to be a speaker within a multidisciplinary session on Education and employment. I was thrilled and nervous but prior work completed with Michelle Sims from Saskatoon shaped the basis for much of my presentation. I found the Congress to have an immediate international flavour with acquaintances and newfound connections from Europe, Africa, North America, Asia, Australia, New Zealand, and other places.

At this time I must thank and honour Frederica Cassis, psychologist from Brazil, for guiding and gently encouraging me and the other professionals on the panel (Werner Kalnis from Germany, Haluk Zulfikar from Turkey). We all salute you! The Wednesday session in which I spoke on Rights, duties, challenges, and tips for employable people with hemophilia, was well attended by colleagues, international youth, and professionals from the other disciplines who formulate and deliver interdisciplinary comprehensive care.

Some highlights from our session included the need for more research on vocations and bleeding disorders, for example, the generally higher levels of education among people with bleeding disorders do not translate to higher income levels. Why not? What are women’s experiences in the workplace? What are the effects of limited interdisciplinary comprehensive care teams globally? What is the role of social work in guiding disclosure to employers? What are the roles of NGOs (outreach, education, advocacy, etc.) locally and internationally?

I attended many sessions on the latest research in hemophilia. Each of these sessions was core to patients, family members and practitioners, and attempted to push forward the science, psychosocial, and general practice areas. ***

Michelle Sims, SW, Saskatchewan Bleeding Disorders Program (SBDP), Saskatoon

Psychosocial issues had many venues at the 2014 Congress. I had a poster presentation titled Pain management: Do we offer appropriate care for men with pain due to hemophilic arthropathy? which was based on the first of a series of focus groups on men and pain that are being held at the SBDP.

The work of the CHS and the care system provided by the Canadian network of HTCs were referenced in many of the presentations I attended. I was proud and grateful to be Canadian, and delighted to hear the excellent work being recognized. Congress is always a source of reflection, inspiration and new learnings. ☺

Request to include survivor benefits for all spouses and dependents of MPTAP claimants under study

In 1993, the Multi-Provincial and Territorial Assistance Program (MPTAP) was created in order to address the needs of individuals infected with HIV as a result of contamination of the Canadian blood supply. At the time, it was not foreseen that many of the claimants might survive decades, get married and perhaps even have children. The provisions for survivor benefits were therefore limited with a deadline of September 15, 1993, for the inclusion of a spouse or dependents.

Some claimants subsequently married or entered into common-law relationships after September 15, 1993, and some also had children. These spouses and children, who became part of the claimants’ lives after the timeframe for applying and being accepted under the plan, are not entitled to survivor benefits. With a view to correct this mistake, the CHS decided to approach the provincial and territorial Health Ministers with a request to extend survivors benefits to ALL spouses and children of directly infected claimants covered by the MPTAP. We have recently been told that our request is being considered and that Canadian Blood Services and the Province of British Columbia are currently leading a legal review of the impact of an adjustment to the agreement, with a decision expected by the fall of 2014. – M.L. ☺

HCV treatment support for 1986-1990 claimants

If you are a patient who received tainted blood or blood products and a registered claimant of the Hepatitis C (HCV) 1986-1990 Class Actions Settlement (www.hepc8690.ca), now is a good time to speak to your doctor about new treatments for HCV. Treatment has progressed significantly, and now may be the right time for you to seek a cure.

Recently, new therapies have been approved by Health Canada that shorten the duration of treatment, achieve a cure rate of more than 90%, minimize side effects compared to past treatments, and are interferon free for HCV genotypes 2 and 3. To complement your commitment to treatment, there is a new resource in Canada that can help you start your journey. The Momentum Support Program, which is Gilead Sciences Canada’s patient support program, puts you in touch with a case manager who can support you to access therapy, help you seek financial assistance to pay for treatment, and provide education and support throughout the treatment. Upfront payments for these high-cost treatments while waiting for a reimbursement from the 1986-1990 plan are among the assistance options offered to those eligible. In Canada, Momentum can be reached at 1-855-447-7977.

Whether or not you are a claimant, the CHS advises you to speak to your specialist about the current evolution in hepatitis C therapy. – M.L. ☺
Introduction of innovative factor products may be delayed

Alprolix™, an innovative factor IX concentrate with extended half-life manufactured by Biogen Idec (see next page), received its Notice of Compliance from Health Canada in March 2014. Eloctate™, a factor VIII product also with extended half-life manufactured by Biogen Idec, was approved by the FDA in June 2014 and a Canadian license is expected this summer. Introduction of these products to the Canadian market, however, may be delayed several months or longer.

In the past, in the provinces and territories served by Canadian Blood Services (CBS), newly approved factor concentrates were evaluated by an expert CBS committee. Recommendations were approved by CBS management. The process was quick and efficient. The patient organization perspective was taken into account. With these new products, the Provincial/Territorial Blood Liaison Committee (P/TBLC), representing the Ministers of Health on CBS budget and policy issues, wants the Canadian Agency for Drugs and Technologies in Health (CADTH) to manage the review and make recommendations. CADTH is known to be under-resourced, well behind in its review of other new drugs, and has little or no experience with blood products and their alternatives. In the only two evaluations it has conducted of blood products – solvent detergent treated plasma and subcutaneous immune globulin – CADTH took between 18 and 29 months to make its recommendations to the provinces and territories. What’s more, their track record of including patient input has been criticized.

As of this writing, CBS, CADTH and the P/TBLC have not been able to even agree on a process for evaluating these promising therapies.

The portrait is more encouraging in Quebec where the review process remains unchanged. The province’s advisory committee on transfusion medicine (Comité consultatif national en médecine transfusionnelle) has completed its evaluation of Alprolix and made a recommendation to the Deputy Minister of Health. A decision is expected shortly. This could lead to a situation where the product is available in Quebec while the rest of the country has yet to agree on a review process.

In early 2014, the Association of Hemophilia Clinic Directors of Canada recommended to both CBS and Héma-Québec that extended half-life factor VIII and IX products be introduced in Canada as soon as possible after regulatory approval. The Canadian Hemophilia Society has taken a similar position.

The CHS Blood Safety and Supply Committee is following developments closely and is in regular contact with the key players. Watch the CHS Web site for upcoming news.

Project Recovery launched at WFH Congress

World Federation of Hemophilia President Alain Weill launched Project Recovery by holding up the first vial of factor VIII made from surplus Canadian cryoprecipitate during his plenary address on Day 1 of the Melbourne Congress. This success comes after more than a dozen years of effort.

The vial of Haemoctin® was manufactured by Biotest from Canadian Blood Services (CBS) plasma fractionated by Grifols. CBS donated the FVIII to the WFH for distribution through its Humanitarian Aid Program.
Alprolix™, a recombinant factor IX concentrate manufactured by Biogen Idec, was approved by Health Canada March 21, 2014, and by the U.S. FDA a week later. It is indicated in adults and children (≥12 years) with hemophilia B for routine prophylactic treatment to prevent or reduce the frequency of bleeding episodes and for control of bleeding episodes.

Alprolix is the first in a new class of extended half-life coagulation products for hemophilia. Half-life is defined as the time it takes for half the clotting factor to be eliminated from circulation. Alprolix is currently being reviewed by health authorities in the provinces and territories. Decisions are expected soon as to when it will be approved for distribution by Canadian Blood Services and Héma-Québec. Hemophilia Today (HT) interviewed two physicians who were closely involved with the development and clinical trials of Alprolix. – D.P.

Alprolix, a longer half-life factor IX, approved by Health Canada

Hemophilia Today: Dr. Pierce, can you tell us about Biogen’s history, especially as regards biological therapies?

Dr. Pierce: Biogen Idec has been manufacturing recombinant therapeutics for more than 30 years. It has developed an extensive portfolio in multiple sclerosis as well as in other autoimmune diseases. We have facilities in Cambridge, Massachusetts, in Research Triangle Park, North Carolina, and in Hillerød, Denmark. Biogen has a very large production capability, one of the largest in the pharmaceutical industry.

HT: Could you describe the Fc fusion technology behind Alprolix?

Dr. Pierce: Fc fusion is the same technology that other companies have used to develop long-lasting versions of other drugs over the past 15 to 20 years. The Fc-receptor system, which has evolved in mammals over a period of many hundreds of millions of years, is responsible for keeping immunoglobulins in the bloodstream for a prolonged period of time. This is done by recycling immunoglobulins, taking them out from the intracellular compartments where they would be destroyed, and putting them back into the circulation.

By attaching the back end of an immunoglobulin molecule to factor IX, one can take advantage of the recycling pathway. Instead of the protein getting destroyed, much of it comes back out of the cell and gets recycled.

HT: Dr. Pierce, is this modified, larger molecule equally efficacious in stopping bleeding?

Dr. Pierce: We needed to make sure the factor IX molecule with an Fc was as effective in functioning as native factor IX. We did this in the laboratory with a variety of clotting factor assays as well as in factor IX-deficient animals. In these preclinical studies, we demonstrated that the factor IX Fc, or Alprolix, could stop bleeding equally well compared to BeneFIX®. And we showed that it lasted two to three times longer.

HT: That leads to the key question with extended half-life factor IX: how much is it extended over current products?

Dr. Pierce: For Alprolix, we’ve been able to achieve a half-life of about 82 hours, or about three and a half days.

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Dr. Glenn Pierce is the senior vice-president for Global Medical Affairs and the chief medical officer for hemophilia at Biogen Idec, a biotechnology company based in Cambridge, Massachusetts.

Dr. Jerry Powell is professor of medicine at the University of California and since 1990 has been centre director of the hemophilia treatment centre at the Davis Medical Center. He was involved in the Phase I/II and III clinical trials of Biogen Idec’s longer half-life factors VIII and IX and was lead author of the Phase 3 Study of Recombinant Factor IX Fc Fusion Protein in Hemophilia B.

Dr. Glenn Pierce
HT: This is a little confusing. In the Phase III studies, as you’ve just said, you report a half-life of 82 hours compared to 33 hours for BeneFIX while Pfizer’s own package insert claims 19 hours as the BeneFIX half-life. Do you have different ways of measuring?

Dr. Pierce: We do. One needs to go out a certain amount of time, based on that protein’s half-life, in order to get an accurate measurement. BeneFIX measurements go out 48 hours. That’s not a sufficient time. When one measures BeneFIX over a more scientifically appropriate time period, such as 96 hours, the half-life is 33 hours. When we do the same with Alprolix, its half-life is 82 hours.

HT: But half-life is not a straight line; it’s a curve with a quick drop in factor IX activity in the first few hours and days and a slower drop as the days go by. Isn’t the first 50% loss in activity much quicker than 82 hours?

Dr. Pierce: Yes. In the first six to nine hours, the factor IX activity is lost much more quickly. So if you don’t measure far enough out in time, you won’t get an accurate measurement of half-life. We’ve measured Alprolix over 14 days and, if you average it out, there’s one half-life decrease every three and a half days.

HT: Another way to think about this is to look at time to 1% or time to 3% factor level. Would that give a better idea on the frequency of infusions needed?

Dr. Pierce: If you give a dose of 50 IU per kilogram, after seven days, models predict about 95% of patients will be above 1% with Alprolix. That contrasts with 31% of those treated with BeneFIX. If you receive 100 IU per kilogram of Alprolix every 14 days, about 53% of patients will end the period at 1% or higher, compared to 1.5% of patients treated with BeneFIX.

Dr. Powell: From a patient’s perspective, what he really wants to know is how long it will take before he is at risk of bleeding again. This depends on his activity level. If a person is going to be engaged in activities that have a higher risk of bleeding, he clearly needs a higher factor IX level. If he’s at a desk job or going to school, he doesn’t have to worry so much about maintaining a high factor IX level. In the study, it looked like a number of patients could go 12 or 14 days between doses and maintain a factor IX level of above 1% and have no breakthrough bleeds.

HT: Dr. Powell, could you describe the clinical trial and the key results?

Dr. Powell: This Phase III clinical trial was international with over 100 patients enrolled at multiple sites. A first group of patients was followed using on-demand therapy. A second group was followed on a once-a-week regimen and a third group of patients had variable intervals between doses of 100 IU with the objective to maintain the factor IX level above 1%. There was a fourth arm for surgery with over 10 patients. The efficacy was equal compared to the standard factor IX products in stopping bleeding and reducing pain from a bleed.

HT: How did you measure this?

Dr. Powell: In two ways. One was to define efficacy by the factor IX level. But, more importantly, patients reported that Alprolix stopped the pain from an acute bleed as quickly as any of the other factor IX products they had used. That was important. The efficacy in stopping bleeding with Alprolix was as expected.

HT: Were there any adverse reactions?

Dr. Powell: Both those on on-demand therapy and those on prophylaxis were studied for over 50 exposure days or one year or more, and there is an extension study in addition to the Phase III study. There were no inhibitors. And there were no unexpected problems. All of the medical problems that we saw in the study population were problems we would expect to see in a hemophilia population. That, too, was very reassuring.

HT: What do you see as the principal benefits of Alprolix compared to the current factor IX preparations?

Dr. Powell: I see two benefits. The first is the decreased burden of dosing. We have all moved into the era where we try to keep the factor IX level above 1%. Most patients require infusions every three or four days to achieve that. With this longer half-life product, at a dose of 50 to 100 IU per kilogram, they should be able to achieve that with less frequent infusions. Clearly, infusions once a week kept their levels much higher than 1%. And some of the patients got by with infusions every 10 or 14 days. The second is a little more subtle. The major problem with hemophilia is that patients bleed into joints and there is joint damage. But the more important problem is internal bleeding, such as a retroperitoneal bleed with organ damage or an intracranial bleed with neurological damage. The prediction is that with this longer-acting drug we’ll see many fewer of those devastating bleeds.

However, after all my enthusiasm, I have to say the proof is in the pudding. This was a Phase III study with a little over 100 patients. We need to see what happens over the next few years with a couple of thousand patients with many thousands of infusions. I don’t expect any problems but we always have to be vigilant and follow up with good post-marketing surveillance.


To read the unabridged version of the interviews, see the CHS Web site at www.hemophilia.ca/en/bleeding-disorders/clotting-factor-concentrates.
Period survival for not so beginners - Part 2 of our discussion on menstruation

The response to November's Female Factor article Period survival guide for beginners was fantastic! Thank you all for your feedback. I was asked by several women to continue with a Not so beginners guide and expand on a few topics surrounding menstruation and bleeding disorders.

I will begin by encouraging all women to be in close contact with your bleeding disorder treatment centre team, especially if you are having issues with your period or bleeding disorder. You may be embarrassed, think you are alone, or think because other relatives have not sought out treatment that you should not either. I want you to know there is a whole team who wants to help you to find the correct course of action to ensure that your bleeding disorder is managed in an appropriate way.

A favorite quip of bleeders is how they should own stocks in Procter & Gamble, one of the largest companies producing tampons and pads, because of how many products they buy! While buying up stocks might not be the answer, there are many alternatives on the market such as Luna Pads and the Diva Cup. These products are reusable and promote being earth and budget friendly, with the added benefit that you will never have an emergency shortage of supplies. These products are now widely available in drug and health food stores. Be sure to research any products before buying and pay close attention to cleaning and sterilizing while in use.

I was quite impressed to hear about a new service in the United States called helloflo.com which mails, directly to your door, monthly care packages filled with supplies for your period, and includes candy of course! While a service like this may be impractical for a woman who has trouble with menorrhagia (heavy and prolonged periods), it does show how companies and the market are changing to make products more available and better suited to women's needs.

Low iron and anemia is something that every woman with menstrual trouble needs to have closely monitored. Hemoglobin, ferritin and iron study levels are all base level tests that can determine if you are anemic or have low iron. Fatigue, shortness of breath, dizziness, headaches, coldness in your hands and feet, pale skin, chest pain, weakness or restless legs can all be symptoms of low iron and anemia. Be especially mindful if you are breastfeeding and are having menorrhagia issues, as your body will be more prone to becoming anemic. There is treatment that can drastically improve your health, but it does require close monitoring by your physician.

Endometrial ablation is quickly becoming the most popular choice for many women who suffer from menorrhagia. This one-day procedure performed at a hospital has a very quick recovery time and does not have many of the complications or complexity of a hysterectomy. The procedure destroys the endometrial lining which will then scar. This scarring will usually reduce or prevent uterine bleeding. It should be noted that this procedure is only an option for women who are finished with child bearing, it cannot be reversed, and it is not a form of birth control.

Being your own health advocate is the best weapon in your arsenal to keep your bleeding disorder in check. The CHS Passport to well-being program includes an informative session on how to navigate the emergency department. This program has some wonderful tips on being your own advocate, which can be adapted to outside the emergency department. This program is accessible on the CHS Web site at www.hemophilia.ca/en/support-and-education/passport-to-well-being/navigating-the-emergency-department.

Why not plan a women's morning out for your chapter and review this session? Talking with your health care team, researching products and treatments, and asking for help from other women in our community are all positive ways to move toward gaining relief from menorrhagia.

EDITOR'S NOTE: A Negative, our e-novella featured on the cover and on page 7 mentions a fictional Web site similar to helloflo.com. At the time of printing, HelloFlo indicated they will feature A Negative on their blog! To read their blog and learn more about HelloFlo, please visit: http://helloflo.com/blog.