Hemophilia Today

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Canadian Hemophilia Society

Serving the Bleeding Disorder Community

Working together for the future

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Canadian Hemophilia Society
Help Stop the Bleeding

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The CHS is on Facebook
Go to the CHS website **www.hemophilia.ca** to be directed to our Facebook page.

Word from the editor

François Laroche

I had the opportunity to attend the 9th WFH Global Forum on Research and Treatment Products for Bleeding Disorders, held in Montreal at the end of last October. Organized by the World Federation of Hemophilia (WFH), this conference saw record attendance with 179 participants from 37 countries. It provided the opportunity for interactions among medical experts in hemostasis, researchers, representatives from the pharmaceutical industry, as well as volunteers and staff from WFH national member organizations.

Many presentations caught my attention, particularly those on new treatment products and on gene therapy.

Dr. Manuel Carcao, co-director of the Hemophilia Treatment Centre at Toronto's Hospital for Sick Children, spoke about clinical practices pertaining to products with extended half-life. He noted that prophylaxis regimens with these new products could improve quality of life for patients with hemophilia A and hemophilia B alike. With conventional recombinant factor VIII concentrate with a "normal" half-life (about 12 hours), a school-age child with severe hemophilia A on prophylaxis at proper dosage receives therapy every other day – on average three infusions per week. With a product with extended half-life (about 19 hours), two infusions per week, at equivalent dose, are sufficient to provide equal and substantial protection against bleeds.

For a child with severe hemophilia B on prophylaxis with factor IX concentrate with a "normal" half-life (about 18 hours), the standard prophylaxis regimen is two infusions per week. Whereas with a factor IX product with extended half-life (about 45 hours), just one infusion is sufficient to provide equivalent or even superior protection. With the extended half-life products, in both hemophilia A and B, this represents one less infusion per week – in other words, 52 less infusions per year – allowing improved quality of life as well as the possibility of individualized prophylaxis to optimize protection. Dr. Carcao concluded with two questions: Are factor dosages comparable between these two types of products? Do the products with extended half-life present greater or lesser immunogenic (i.e., inhibitor development) risk? Only time will provide the answers.

Dr. Edward Tuddenham, of the Katharine Dormandy Haemophilia Centre at Royal Free Hospital and University College London in England, described the long-term follow-up of 10 patients with severe hemophilia B enrolled in his ongoing gene therapy clinical trial using type 8 adeno-associated virus vector (AAV8), with parenteral administration to the liver. Key investigative questions focus on stable long-term factor IX expression, safety and efficacy. Results to date have been very encouraging, with evidence of sustained factor IX expression levels in all patients. Four patients in the high-dose cohort who had been on prophylaxis prior to participating in the clinical trial have been able to stop prophylaxis therapy; they have had no spontaneous bleeds, with significant improvement to their quality of life. However, in four other patients in the cohort, perturbation of liver enzymes occurred at levels requiring treatment with steroids. This promising gene therapy approach remains under investigation. Furthermore, recruitment for a gene therapy clinical trial for hemophilia A was initiated in fall 2015. Stay tuned.

Next, Dr. Glenn Pierce of Global Blood Therapeutics based in San Francisco discussed the costs associated with gene therapy for hemophilia and the possibility of a cure. There are a number of key questions. What price is the health system ready to pay to cure a patient with hemophilia? What is considered a cure? Is it sustained factor levels above 1%, 2%, 5%, 10%, or even 50%? The scientific literature suggests that acute bleeds occur less frequently if patient plasma levels are maintained above 5% trough levels, with very few or no joint bleeds reported with trough levels above 10-15%. Is converting a patient with severe hemophilia to mild hemophilia part of the answer? This remains to be seen.

According to Dr. Pierce, the lifetime cost of factor concentrate treatment for a patient with hemophilia living until age 80, in the absence of inhibitors, is $20 million. Will health systems be able to pay just 5% of this amount to convert a patient with severe hemophilia to mild hemophilia? The key considerations are efficacy and safety, savings to the health system, and quality of life. In addition, price should be adjusted in proportion to the results achieved in terms of factor expression levels (from 5% to 50%).

In conclusion, Dr. Pierce noted, "Three quarters of the world have no access to effective bleeding disorder therapies. For the one quarter who do have access, disruptive innovation occurs at a startling pace."

Message from the president

Craig Upshaw

After almost a year's work by the strategic planning committee and the largest consultation ever undertaken by the Canadian Hemophilia Society, I am pleased to say that on January 17 the CHS Board of Directors unanimously adopted the 2016-2020 strategic plan for the national organization and its ten chapters.

A solid strategic plan is essential to all organizations as it sets priorities, focuses energy and resources, strengthens operations, ensures that volunteers, staff and other stakeholders are working toward common goals, establishes agreement around desired outcomes, and assesses and adjusts the organization's direction in response to a changing environment.

To arrive at the final plan, the following activities took place over the last ten months:

- Formation of a strategic planning steering committee with broad representation;
- A synthesis of all recent information related to the CHS and its work;
- In-depth conversations between our external consultant and each one of our partners at Canadian Blood Services, Héma-Québec and in the pharmaceutical industry;
- An online survey that gathered the detailed opinions of more than 250 people with bleeding disorders, some of whom are members and some not, as well as health care providers in the network of treatment centres;
- A half-day focus group, facilitated by our consultant, regrouping more than 75 people, held at *Rendez-vous 2015* in May, in Halifax;
- Consultations at chapters' member and board meetings;
- A second online consultation that gathered over 75 detailed comments on the last draft of the plan;
- A final day-and-a-half, face-to-face meeting in Toronto in January involving the national Board of Directors, chapter presidents and Hemophilia Ontario board members to review the plan in detail and adopt it.

Considering the evolving needs of our community and the decreasing financial resources available, and based on the valuable input and feedback received, the plan reduces the number of goals from nine in the 2011-2015 plan to four in the 2016-2020 plan. These four goals reflect the priorities of all those who participated in the surveys and discussions. They are:

Care and Treatment – Achieve standards and evidence-based comprehensive care for all people with inherited bleeding disorders throughout their lifespans.

Research – Promote, fund, facilitate and conduct fundamental, clinical and quality-of-life research to improve health and quality of life and ultimately find cures.

Education and Support – Deliver evidence-based information and support to patients, their families, health care providers and the general public across Canada in both official languages, English and French.

A Cohesive Organization – Build a cohesive organization through good governance, member engagement, effective communications and fundraising to support our strategic goals.

In the plan, each of the goals is linked to a series of desired outcomes and key strategies to achieve those desired outcomes. For a quick look at the plan, see the strategic map on pages 8-9 of this issue. To read the full plan, including the results of the environmental scan, please see the CHS website at **www.hemophilia.ca/en/about-the-chs/our-strategic-plan**.

The work to turn the plan into action is just starting. At the January meeting, the board members and chapter presidents explored how to use the strategic plan to develop detailed annual action plans at the chapter level. It is now the job of each chapter board to take this plan and then develop and deliver programs and services that align with these four goals and are seen as particularly valuable to the province's members with bleeding disorders.

It is my hope that this strategic plan will prove instrumental in helping us to achieve our mission: *improving the health and quality of life of all people in Canada with inherited bleeding disorders and ultimately finding cures*. The members of the strategic planning committee are available to support each of you, in the chapters across Canada, in beginning the process of developing your action plans to align with the organization's overall strategic plan.

Finally, thank you to all who contributed to this important work.

CHAPTER SPOTLIGHT

Wonderful summer camps. For thousands of kids from everywhere, summer camps mean great outdoor adventures, unique friendships and memories that last through the year until they all meet again. Summer camps in the hemophilia community are all that but so much more. They facilitate the learning experience of self-infusing for the first time. They allow kids to meet other kids who have the same bleeding disorder, sometimes for the first time ever. They are one of the most important programs offerred to members by the chapters of the Canadian Hemophilia Society.

Like everything else, camps have evolved immensely over the decades. The following articles feature camps offered by three chapters and how they have managed to bring summer camps to a different level. – C.R.

Leaders in training at Ontario summer camps

by Terri-Lee Higgins

Executive Director of Hemophilia Ontario

Hemophilia Ontario is in the unique position of offering two very distinct camp opportunities for our youth. The Southwestern Ontario Region offers Pinecrest Adventure Camp, while Hemophilia Ontario offers provincial youth an integrated camp experience at YMCA Camp Wanakita. Both camps have operated for more than 20 years and both provide much more than just the opportunity to learn to self-infuse. Camp is a way to build strong community as youth return year after year, making connections and friendships that last a lifetime.

Few people are born to be leaders. Most of us need to practice to become a good leader, and that is why leadership development is so important. Both camps have strong Leader-In-Training/Student Counsellor (LIT/SC) programs focused on enhancing youth leadership skills through a variety of education-based learning opportunities. Peer mentoring has been a key component of our success. The youths who complete the LIT/SC program and return as staff set the bar for those campers who are coming up the ranks behind them, and this is a goal many youths strive for. These individuals are motivated to get involved, giving back and inspiring the younger campers to get involved. Names like Sean, MJ, Jordan and Amy are often heard as the ones who led the way and inspired other youths to want to be leaders – to them we will be forever thankful.

I believe that hemophilia camps have a huge impact on the person you are, and the person you become. The ability to meet with other children who share the same or similar bleeding disorder and the experiences that come with that is an incredible opportunity. You learn and grow together to become more independent, knowledgeable, and make lifelong friendships along the way. We do a lot of leadership activities with our senior campers at Maritime Adventures Camp and I believe that they are the future leaders of our organization.

– **Katie Hines**, vice president of the Nova Scotia Chapter and founder of the Maritime Adventures Camp

Hemophilia Ontario has benefitted from the leadership that our youth have developed through their camp involvement; in fact it has been one of the strongest recruitment resources for committees, councils and Hemophilia Ontario's Board of Directors. By observing their older peers, the number of youths involved at the regional level has increased and this is now benefitting the province as our dedicated youth step up and get involved in provincial programs such as *Wellness for Women*, *Just the Guys* and *Community Camp*. Good leaders see potential opportunities and take advantage of them to benefit themselves and influence others. By developing the attributes needed for success in the workplace and their communities, these youths are taking advantage of the volunteer leadership opportunities that not only foster personal development but also strengthen our organization.

John Quincy Adams said, "If your actions inspire others to dream more, learn more, do more and become more, you are a leader." Hemophilia camp provides the stepping stones to strive for success.

Manitoba summer camp: a family camp where learning is for everybody

by Christine Keilback
Executive Director of the Manitoba Chapter

This year marks the 24th year that the CHS Manitoba Chapter (CHS-MC) families return to Luther Village, on beautiful Dogtooth Lake, to enjoy a week full of bonding, education and fun. Family camp offers Manitoba Chapter children with bleeding disorders and their families a chance to experience camp with the safety and security of having a nurse, Rose Jacobson, from the Manitoba Bleeding Disorders Program accompanying them. There have been some changes to the camp program over the years but the core goals remain the same: providing an opportunity for families to learn more about their bleeding disorder and spend a week together sharing struggles and triumphs. Our families value spending time in an environment where *everyone* understands what it is like to live with a bleeding disorder.

Beaver Lodge is where kids get their treatments in the morning. It is wonderful to witness the small ones, as young as two years old, watching very closely as the older kids sit for their treatment. Often the older kids coach and encourage the little ones when they are treated. Modelling and mentoring happens very naturally and is so important for the parents, too. For some siblings, this may be the first time they have seen another child get a treatment. Like all other hemophilia summer camps, children who are ready to embark on self-infusion receive training from a nurse.

> Family summer camps here in Newfoundland are great times when everybody gets to interact with each other and truly build the relationships that have become our extended family. It is personally the highlight of each year for me in the hemophilia community. Families feel comfortable in their surroundings and let their kids run and play around campgrounds. It's like a giant family reunion each year. I feel very blessed to have such awesomeness in my life.
>
> – **Jeff Jerrett**, president of the Newfoundland and Labrador Chapter

But what is different from other camps is that training is also provided to parents who are ready to start home management and learn about venous access and the steps to prepare and infuse factor concentrate. In other words, children learn to self-infuse and mothers and fathers learn to access their sons' veins in a week! It's a great time for all our families to work on any issues surrounding infusions. The children also attend one to two education sessions designed for their age group.

Families have full access to all the programming at Luther Village. The children spend the morning in activities (parents *love* the break!). Afternoons and evenings offer a choice of family activities. Good weather days are often spent at the beach, hiking or fishing. Many children catch their first fish at Luther Village! Rose leads the annual Frog Hunt and chapter member Ron Silver hosts the fish fry. Beaver Lodge is always full of people! A rite of passage for the teenagers is canoeing to the island for the overnight camping trip.

Living with other bleeding disorder families offers some unique perspectives that are beneficial and important for new families. Our experience of having a peer group to help parents through the different stages and changes in a child's life is invaluable. Parents can see how other families manage bleeding episodes and how other families manage their child's behaviour related to the bleeding disorder. It is always interesting to learn what other families allow their children to do in terms of activities and learn about their strategies for success. Our new parents often spend time talking to the teenagers asking questions about how they feel about their bleeding disorder and are often surprised to learn about the sports they participate in.

"Once you go you'll be hooked! It's a great experience for everyone. The kids get to be around other kids just like them. Even the siblings get to hang out with others that deal with having a brother with hemophilia. And it's a great safe place to talk about everything that goes along with hemophilia. You can see you're not alone and someone else had dealt with the exact same stuff." – 2015 CHS-MC family camper

Summer camp in Alberta – a nurse's perspective

by Sheri vanGunst, RN, BN
Alberta Children's Hospital

Hemophilia summer camp is an excellent setting for children with bleeding disorders to learn about their condition and how to self-manage age-appropriate issues related to their medical care. Camp allows children to learn self-infusion together and also be mentored by older children who have previously mastered this skill.

The hemophilia nurse plays a key role in facilitating this learning. There is a high level of responsibility and a special skill set that a nurse develops for camp. In my first year as a nurse at camp, I was mentored by longtime hemophilia nurse Wilma McClure (now retired). This mentorship was invaluable as she taught me the skills and demonstrated the trusting relationship needed to be a hemophilia camp nurse.

Hemophilia summer camp is held in Alberta for five days each summer at Camp Kindle, which is owned and operated by the Kids Cancer Care Foundation of Alberta. Camp Kindle is a small camp designed for campers with medical needs. This camp was chosen by me and the CHS Alberta Chapter because it provides a safe, nurturing and accepting environment for children with bleeding disorders to experience recreation, camaraderie and education.

The camp staff and volunteers are very reliable as they all receive bleeding disorder education in their training. Anytime there is concern about a possible bleed, campers are brought to the clinic to be assessed by the hemophilia nurse. Sometimes, they are just a little homesick and need a few minutes to hang out with their familiar nurse. If they do have a bleed, they are encouraged to help figure out how to best treat and manage their bleed. Rest is always the most difficult thing to accomplish at camp but kids are always excited to be shuttled around camp in the "Gator" UTV (utility task vehicle).

Our hemophilia campers attend camp along with children who are currently being treated for cancer, children who are cancer survivors, children with other blood disorders, and siblings of these children. The bleeding disorder campers are fully integrated with these campers and grouped with children in their same age range. Campers participate in most of their recreational activities within this group. Some of these activities include hiking, rafting, wall climbing, swimming, archery, the high ropes and the giant swing.

Infusions and educational sessions are times when the hemophilia campers are brought together. Morning infusions occur in the clinic after breakfast. Younger children are able to observe the older children doing self-infusions, which is highly motivational. The younger campers work on doing their own infusions. They are so proud when they get their first poke!

Each day, after lunch, the hemophilia campers come together to have an educational session with the hemophilia nurses. The older campers become mentors as they teach younger campers how to use the infusion training kit. They all learn to become advocates for themselves as they are taught to state their condition and their treatment. They practice what they would say if they went to the emergency department with a bleed. They also get a chance to play the hemophilia board game *Don't Push Your Luck!*, which is designed to spur discussion about hemophilia and help them learn how to make decisions that are in their best interests.

The mentorship and camaraderie, the independence and confidence that are gained at camp simply do not happen anywhere else. I have a passion for camp because I find it so rewarding to see how much they grow and learn in just five days each summer. I truly consider it a privilege to be a hemophilia camp nurse.

> Our camp which is a *Just the Guys* event may not be unique, but it is really enjoyable and fits the boys of all ages. The activities are authentic to what boys really like to do. Our guys are simply being at a totally outfitted camp having the time of their lives and just doing regular guy things!
>
> – **Wendy Quinn**, president of Hemophilia Saskatchewan

Canadian Hemophilia Society

Our Mission

The Canadian Hemophilia Society is committed to improving the health and quality of life of all people in Canada with inherited bleeding disorders and ultimately finding cures.

Our Vision

A world free from the pain and suffering of inherited bleeding disorders.

Our Values

INCLUSIVENESS
By providing information, programs and services to all people with inherited bleeding disorders of all ages and their families in both English and French and, where possible, in other languages.

INTEGRITY
By acting honestly, responsibly, transparently and accountably.

RESPECT
By treating the people with whom we interact with dignity, fairness and compassion.

ENGAGEMENT
By being well connected to our grassroots community.

COLLABORATION
By fostering meaningful and collegial relations, and strong partnerships among our diverse stakeholders.

Our Goals

CARE AND TREATMENT
Achieve standards and evidence-based comprehensive care for all people with inherited bleeding disorders throughout their lifespans.

RESEARCH
Promote, fund, facilitate and conduct fundamental, clinical and quality-of-life research to improve health and quality of life and ultimately find cures.

EDUCATION AND SUPPORT
Deliver evidence-based information and support to patients, their families, health care providers and the general public across Canada in both official languages, English and French.

A COHESIVE ORGANIZATION
Build a cohesive organization through good governance, member engagement, effective communications and fundraising to support our strategic goals.

2016-2020 Strategic Plan

Target Populations: Who We Serve

The Canadian Hemophilia Society provides information, programs and services to …

- people with hemophilia, von Willebrand disease, rare factor deficiencies and inherited platelet disorders;
- carriers of these conditions;
- their families;
- the patients' communities (friends, co-workers, daycare workers, teachers, employers…);
- health care providers in the Canadian network of inherited bleeding disorder comprehensive care clinics;
- other health care providers (primary care practitioners, dentists, specialists…) who may provide care for people with inherited bleeding disorders.

Our Global Responsibility

While the primary mission of the Canadian Hemophilia Society is to work within our own borders on behalf of Canadians, this strategic plan recognizes our responsibility to the global bleeding disorder community.

Canadians with inherited bleeding disorders enjoy access to advanced therapies. Our comprehensive care clinics provide a high standard of care. Such is not the case around the world where 75% of people with hemophilia do not have access to safe and efficacious treatments and highly trained health care providers. Life expectancy remains less than 20 years and these short lives are filled with pain and suffering.

The national organization and its chapters, as well-developed patient associations, acknowledge their responsibility to work with the World Federation of Hemophilia (WFH) to further its mission of TREATMENT FOR ALL.

chs@hemophilia.ca ▪ www.hemophilia.ca

MyCBDR virtual holding centre open for registration

by David Page
CHS National Executive Director

Patients and/or their caregivers can now register in MyCBDR through the virtual holding centre while awaiting their centre to join the Canadian Bleeding Disorders Registry (CBDR).

In May 2015, the CBDR was launched by the Association of Hemophilia Clinic Directors of Canada (AHCDC), in collaboration with McMaster University and the Australian National Blood Authority, and with the support of the Canadian Hemophilia Society. At the same time, MyCBDR, the home infusion reporting module, went live.

As of early 2016, five treatment centres—CHU Sainte-Justine in Montreal, Hôpital de l'Enfant-Jésus in Quebec City, CHUS-Hôpital Fleurimont in Sherbrooke, Hamilton Health Sciences Corporation and the Kingston General Hospital—had successfully navigated all their legal and ethical requirements, and were thus able to make MyCBDR available to their patients on home infusion. The vast majority of the patients in those centres promptly registered and have been sending their home treatment data on bleeds and infusions to their care providers quickly and efficiently. Comments from patients have been extremely positive. MyCBDR is described as "user-friendly", "intuitive" and "fast". Reports are entered and uploaded in less than a minute.

At least nine other Canadian centres are currently in the process of obtaining legal and ethical approvals to register their patients. The AHCDC's goal is to have all 23 treatment centres up-and-running by the end of the year. (Note that the two British Columbia centres use a similar system called iCHIP. The plan is that the BC data will be merged with CBDR to create a truly national registry and database.)

For those patients in the 18 centres not yet fully operational, there is a way you can start using MyCBDR and reporting your infusions quickly and easily. McMaster University, which is mandated by AHCDC to manage CBDR, has set up a "virtual holding centre" where you can register in MyCBDR.

All you need to do is go to the MyCBDR website (**mycbdr.ca**) and register. Please be sure to select "Holding Centre for MyCBDR" from the drop down list for Hemophilia Treatment Centres. Once registered you will receive an e-mail from **help@cbdr.ca** with a fillable PDF form requesting your basic clinical and demographic information. The CBDR team at McMaster will use that information to register you in the CBDR and approve you for MyCBDR use. You may now log in to MyCBDR using the temporary password that will be sent to you at your registered e-mail address. You'll be connected! You are welcome to contact the CBDR help desk at any time during the process.

While the providers in your treatment centre will not have access to your records until the hospital's ethics approval is received and they gear up for CBDR, you will receive reports of your treatment log from CBDR's virtual holding centre via e-mail every two months, or whenever you request. You will be able to provide these records to your treatment centre whenever needed. In summer 2016, MyCBDR will add a "print" function so you can print your own treatment records any time you want.

When your centre joins CBDR, your stored MyCBDR data will be automatically transferred and become available to your providers at all times.

Note that while registration in MyCBDR is **highly** recommended, it is entirely optional for patients/caregivers.

The CHS believes use of CBDR and MyCBDR will improve patient care and health outcomes. In its 2016-2020 strategic plan, the CHS has adopted a goal of having 95% of patients on home infusion registered and using MyCBDR by the end of 2018. Get connected! Help yourself! Help others in our community!

Five benefits of using MyCBDR

1. No more paper bleed logs!
2. Fast and easy transmission of your bleed and infusion data via computer or smartphone interfaces. Most infusion reports take less than one minute!
3. Reports on all locations of bleeds and product use that you can view and print. You'll be able to better manage your own care.
4. Accurate and timely information about your bleeds and your infusions for your health care providers. They will be better able to guide you in your own individual care.
5. More complete information on health outcomes for all patients on home infusion. This will help clinicians and researchers improve clinical care for all.

CBDR and MyCBDR ...

- provide patients, caregivers and providers with a complete clinical picture;
- facilitate health outcome research;
- allow fast, easy and accurate reporting of bleeds and infusions;
- work on any modern browser;
- use the latest web and app technologies (Android and iOS);
- offer users five days/week e-mail and phone support;
- are built on the code of the Australian Bleeding Disorders Registry and are customized for Canada following patient and provider input;
- are available in English and French;
- are designed with business level safeguards designed to satisfy federal and provincial privacy requirements (role-based access, encryption at rest and transmission, electronic audit trails, password authentication ...).

The **Annual General Meeting of the Canadian Hemophilia Society**

will be held on **Saturday, June 4, 2016 – 8:30 a.m.**
at the Hilton Toronto Airport Hotel & Suites, 5875 Airport Road, Mississauga, Ontario

If you are in the area, you are more than welcome to join us!

The Canadian Hemophilia Society (CHS) and the Hemophilia Society of Bangladesh (HSB) receive the WFH 2015 *Hemophilia Organization Twins of the Year Award*

The World Federation of Hemophilia Organization Twinning Committee was very impressed by the scope of the activities undertaken in 2015 by the CHS-HSB twinning including the successful execution and analysis of the first bleeding disorder survey in Bangladesh, the development of a three-year strategic plan for HSB, a successful action planning workshop for lay and medical members of HSB, a webinar to help HSB develop a communications and marketing plan, and the participation of HSB President Nurul Islam at *Rendez-vous 2015* held in Halifax which included a presentation on the survey exercise.

Kudos to all who made this twinning such a success both in Bangladesh and Canada. – C.R.

CHS James Kreppner Memorial Scholarship and Bursary Program

The deadline to submit applications for this year is **April 30, 2016**. The criteria and application forms are available on the CHS website at **www.hemophilia.ca/en/support-and-education/scholarship-program**. – J.A.

Some of our past recipients ... Will you be next?

Rick Waines
Vancouver, British Columbia

A letter to Rory and Quinn, my cousin's boys

Part 1. Normal.

Dear Rory and Quinn,

Normal used to look like your grandfather, my uncle, but I couldn't see that at the time. Hemophilia was hard on him. I would be surprised if he had one joint that was free of arthropathy. My first memories are of his wooden crutches: worn, used every day, dark brown with age. That was how he got around. Both legs would swing through at once as neither had the flexibility nor the strength needed to support his body on its own. I couldn't have known it at the time but looking back I would say that his ankles, knees, hips, elbows and probably other joints were all locked and fused, the old-fashioned way, due to a lifetime of bleeding into the joints with little effective treatment. When I looked at him I didn't see myself. I certainly didn't see normal. I saw someone from a different era. Someone who had had no access to effective care until he was an adult. My life, my opportunities, my joints, would be different. Your grandfather, my uncle, never had the opportunity to pretend he was like everyone else – I did and it was a mistake.

My quest for normal reached fever pitch in high school when I fell in with the wrong crowd. No, they weren't drug-addled teenagers. It was worse, they played basketball and I fell in love with basketball. I fell in love with watching it, playing it, spending hours and hours tearing up and down the court each and every day. I got bleed after bleed, after bleed, after bleed into both my ankles; and still I played basketball. How could I not? My two best friends were playing it. I loved it. I wanted to be normal. I wasn't going to ever end up like your grandfather after all. Things were different.

Four-year-old Rory and his six-year-old brother Quinn, practicing self-infusion on their toys.

My uncle Bill (Rudd), past president of the CHS (1982-1984).

Uncle Bill with his son Eric.

I'm almost 50 years old now and my mobility has been pretty severely compromised. I have recently had one ankle fusion which has helped a lot, but I will likely need another. Looking back, I can't help but wonder whether it might have been more prudent to find activities that suited me better. Hindsight is never a great crutch to lean too heavily upon. But I ask you now, to lean in close and consider this one thing as you grow up. Normal is exactly what you are, period; whether or not you go with the class onto the court, rink or field. Your bleeding disorder, however, will never be normal.

You might be tempted to feel excluded if there are activities you can't take part in. I know you will not want to be left out. Your parents, if they are anything at all like mine, will want you to be afforded all the opportunities that your classmates will have. But please allow your almost old "uncle" (apologies to all over 50) to pull the "old wise one" card just this once. Normal doesn't mean doing everything everyone else is able or allowed to do. A truly old friend of mine (much older and therefore much wiser) once described these kinds of limitations as beautiful fences – while they may keep you from certain places, they will also lead you where others would never think to go and it is in these places that you will thrive, where you will flourish.

Things will be better for you. You will have fewer major bleeds, we hope, and fewer target joints – maybe none at all? But do we really understand the role of micro-bleeds on the long-term health of joints? You will look at photographs of your grandfather and you may not recognize his disease as your own. You will look at me like I looked at him and know that your life with hemophilia will be different, better. All this is true. And it is also true that hemophilia is not normal – you are.

Me: A period flow assessment app signed CODEROUGE

by Chantal Raymond
CHS National Communications Manager

For many years, the Canadian Hemophilia Society (CHS) has promoted the use of a menstrual assessment chart in its publications and on its website, based on the Pictorial Blood Loss Assessment Chart developed by Dr. Jenny Higham et al. In 2015, the CHS chart was revised to include interpretation of menstrual scores and to refer women to their doctor or to a bleeding disorder treatment centre if concerns were raised about their menstrual cycle.

As part of its awareness program for women and bleeding disorders, the CHS attends various medical conferences, such as the Annual Clinical and Scientific Conference of the Society of Gynaecologists and Obstetricians of Canada (SOGC) or the Annual Family Medicine Forum, in order to increase knowledge among other health care providers beyond HTCs about the diagnosis and management of inherited bleeding disorders, notably von Willebrand disease. Health care professionals at these conferences have been very interested in our menstrual assessment chart but many asked if a mobile version might be available.

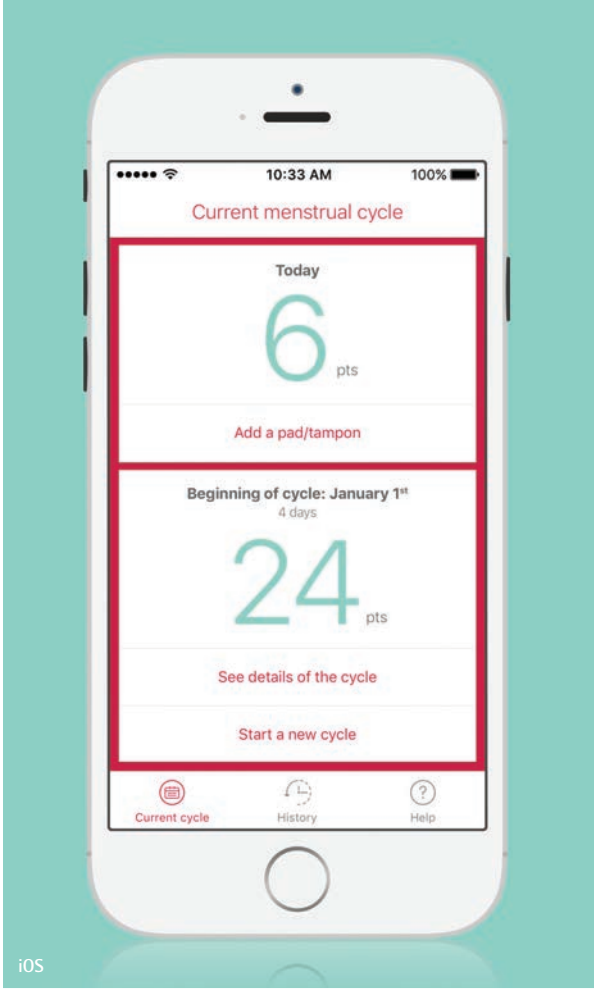
And so we developed the first, but certainly not the last, CHS mobile application, called *Me*. It is a very simple app available, free of charge, on both Apple and Android platforms. The *Me* app features the same components as our current menstrual assessment chart, which allows the assessment of blood saturation level of pads and tampons, augmented with the benefit of calculating automatically your menstrual scores. It will warn women if and when their score represents a risk of possible menorrhagia. It then advises them to communicate with their doctor for further assessment.

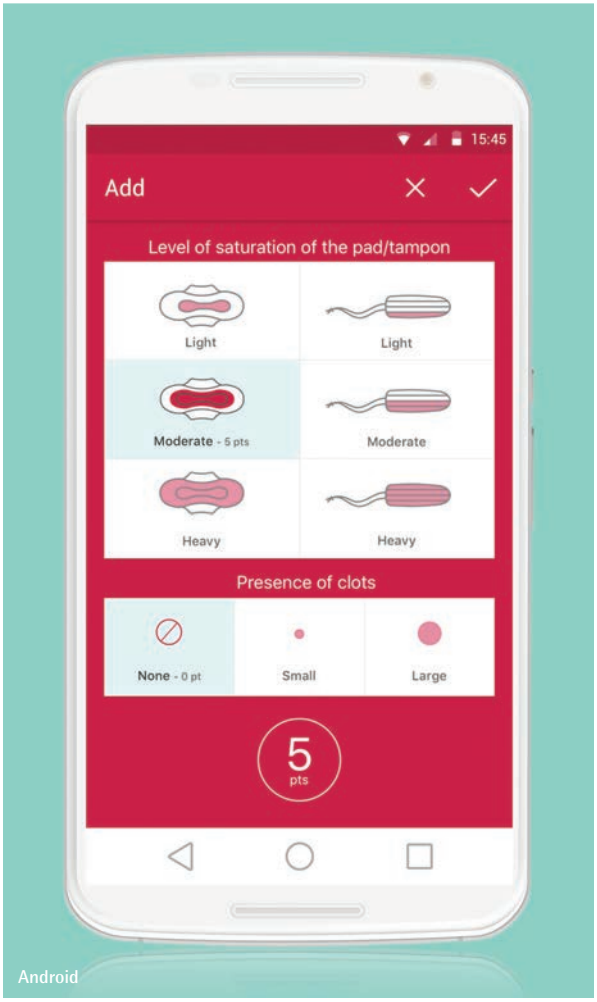
It is important to understand that this is not a menstrual calendar; there are plenty already on the market. We developed an application that is very specific to women who have bleeding issues.

This tool, part of the CHS CODEROUGE program, is a perfect fit to one of the CHS 2016-2020 strategic plan's desired outcomes: *The number of women diagnosed with inherited bleeding disorders will increase by 5 percent per year.* Increasing the number of women receiving a proper diagnosis starts with empowering the women themselves. With *Me*, they will have a reliable tool for assessing their menstrual flow and then can talk to their doctor with more quantified evidence.

The application can be found in the Apple Store and Google Play Store under the name *Me – Period Flow Assessment*. For discretion, only *Me* is displayed on mobile devices.

Don't be shy to promote it among your network; the more women who know about it, the more they can finally find answers to their monthly struggles.





It is now or never ...

by Deborah Franz Currie
CHS National Director of Resource Development

Over the past twenty years people with bleeding disorders have seen a dramatic increase in the quality of care we are privileged to receive in Canada. This includes increased prophylaxis, advances in care for patients with inhibitors, greater access to care for women with bleeding disorders, better surgery to correct joint damage, and cures for hepatitis C. Additionally, the CHS has been able to maintain support of research in excess of $500,000 annually, a level that is unheard of among health charities of our size. We have been able to do all of this because of the dedicated work of the CHS and its volunteers, and through a strong corporate funding base.

While our work in treatment advocacy continues to excel, behind the scenes human and financial resources available to the CHS are declining. This could have serious repercussions down the road. We cannot take for granted the excellent care and treatment the CHS has advocated for on behalf of its members since 1953. Without a strong patient voice, it would not take long for all of this to be jeopardized.

Over the past five years, the collective budgets of the CHS national and its chapters have decreased by more than one million dollars. In the last eight years, funding from the pharmaceutical industry to the national organization has decreased by 29%. In 2016, the CHS also faces the added challenge of all national staff being reduced to a four-day workweek because of financial constraints, the impact of which we have yet to fully realize.

We have been fortunate to maintain strong corporate support from our pharmaceutical partners in excess of $1.5 million dollars. However, in our environmental scan for the 2016-2020 strategic plan we were urged by our pharmaceutical partners to diversify our funding, as they will not always be able to contribute in the amounts we have been privileged to receive. Their support may continue to decline.

So what can we do to change this?

If we look at other health charities of comparable size, the single largest differentiating factor is that our revenues are, in a word, backward. While many of our members give generously of their time and talent, member support of the CHS is less than 1.5% of our total national budget; the majority of those funds directed towards research. The situation is similar for our chapters, who rely largely on pharmaceutical support, revenue-sharing funds transferred from the national organization and fundraising events. Not member support. Most charities of our size provide member support at a level of 38-52% to the national organization, not including individual giving from the general public!

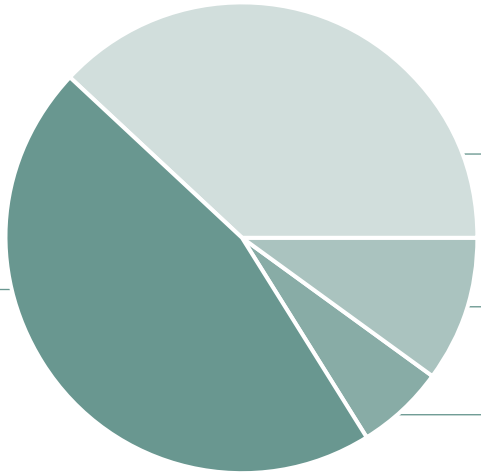
> "In the 21st century, health care charities like the CHS are funded by the grassroots membership at both the local and national levels. We're not. This has to change."
>
> – David Page
> CHS National Executive Director

The community MUST begin to seek greater support from within to survive. This has been on the horizon and discussed for the past seven years with much reluctance, but is now a necessity. We cannot rely only on pharmaceutical funding nor do we have a strong case for support among the general public, or the private sector. Since the Krever Commission 20 years ago, our relevance to the general public has diminished as the blood system reformed and blood products became incredibly safe. We are in competition with all other health charities, many of whose members do not have access to efficacious treatments nor as much hope for the future. Our only option is to seek support for programs and services from the people we serve and their networks, which is how all other leading health charities in Canada are able to survive.

Our decline in revenue can be seen as a crisis. Or it can be seen as an opportunity. In the spirit of this organization and its ability to face adversity, we can rise to meet this challenge and ensure the CHS is able to continue to provide the programs, services and access to high quality care for generations to come. **But we cannot do it without YOU!** It is now or never.

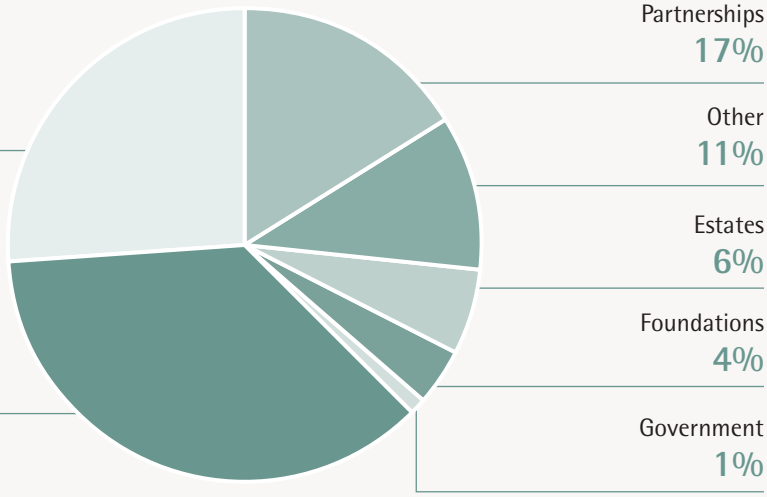
SOURCES OF REVENUE

Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada



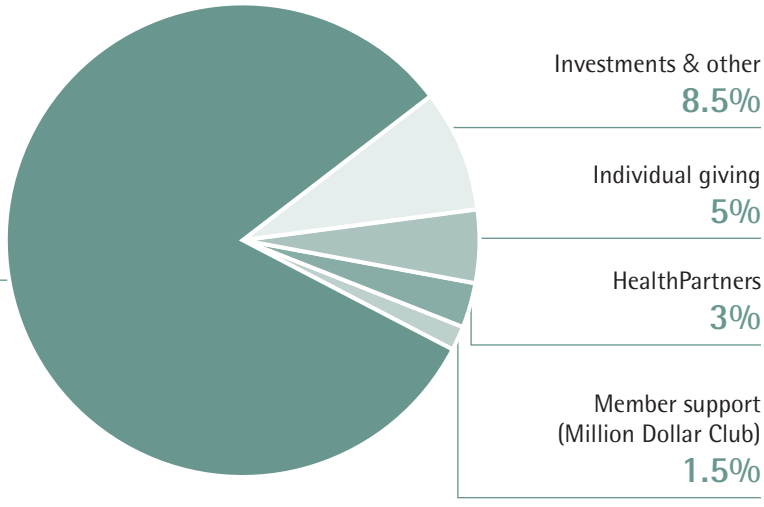
(source: 2015 Annual Report)

liver.ca
Canadian Liver Foundation
Fondation canadienne du foie



(source: 2014 Annual Report)

Canadian Hemophilia Society
Help Stop the Bleeding



(source: 2014 Financial Statements)

The Blood Factor

David Page

CHS National Executive Director

Eloctate and Alprolix now available

OTTAWA, February 3, 2016 – Canadian Blood Services (CBS) announced that extended half-life factor concentrates, Eloctate® to treat hemophilia A, and Alprolix® to treat hemophilia B, have been approved for reimbursement and are now distributed through CBS in all provinces and territories (except Quebec). Both products are manufactured by Biogen.

The decision comes 22 months after approval of Alprolix by Health Canada in March 2014 and 16 months after approval of Eloctate in August 2014 and lengthy reviews involving the National Advisory Committee on Blood and Blood Products (NAC) and the Canadian Agency for Drugs and Technologies in Health (CADTH).

"We are really happy to finally see the introduction of Eloctate and Alprolix for Canadian patients," said CHS President, Craig Upshaw. "They represent the first in a new class of extended half-life factor concentrates."

According to access criteria developed by NAC, Eloctate and Alprolix will be available to patients with moderate or severe hemophilia A or B, 12 years of age and older, who meet one or more of the following criteria:

- are currently on a prophylaxis regimen;
- have frequent bleeding episodes while on their current on-demand or prophylactic regimens;
- have venous access difficulties and could avoid use of a central venous access device with these potentially lower-frequency products;
- have shorter than normal half-lives;
- could improve adherence to a prophylactic regimen because of the lower frequency of infusions needed; or
- would experience improved quality of life.

Based on physician recommendation, other access criteria could be considered. For the original list of access criteria, see the NAC website at **www.nacblood.ca** and select "Criteria for Use - Alprolix and Eloctate."

Meanwhile, the Quebec access criteria put in place in April 2015 remain much more restrictive. They include:

1. shorter than normal half-life;
2. venous access difficulties; or
3. other justifiable reasons, as determined by the treating physician and subsequently approved.

The CHS and its Quebec Chapter are working to broaden criteria #3 to include some of the criteria identified by NAC for the rest of Canada.

CHS Board of Directors supports shortening of MSM deferral

MONTREAL, November 29, 2015 – The CHS Board of Directors, based on a recommendation from its Blood Safety and Supply Committee, voted unanimously to support shortening of the blood donation deferral for men who have had sex with other men (MSM) from five years to one year without MSM activity.

Both Canadian Blood Services and Héma-Québec will make formal submissions to Health Canada early in 2016. These submissions are based on evidence from Canada and from other countries that have already made the change that the shortened deferral would not result in any increased risk to recipients.

SIPPET study results on inhibitor risk released

MONTREAL, November 11, 2015 – The CHS Blood Safety and Supply Committee is closely monitoring developments following release of some results of the SIPPET study (Survey of Inhibitors in Plasma-Products Exposed Toddlers) that suggests that the risks of developing an inhibitor in previously untreated patients (PUPs) are almost twice as high with recombinant factor VIII compared to plasma-derived factor VIII.

A statement from the World Federation of Hemophilia said: "Some results of the SIPPET (Survey of Inhibitors in Plasma-Products Exposed Toddlers) study were published as a conference abstract in advance of the American Society of Hematology (ASH) Annual Meeting this December. The abstract suggests that, in previously untreated patients, the risk of developing an inhibitor when using recombinant factors is significantly higher than when using plasma-derived factor concentrates. This is an important study and the results may prove to be significant."

A link to the abstract is available on the CHS website.

The full results of the study are expected to be published in a major medical journal early in 2016 and are eagerly anticipated.

Provinces and territories decline the CHS' request to extend survivor MPTAP benefits to spouses and dependants of claimants post September 15, 1993

After hearing from CHS members covered by the Multi-Provincial and Territorial Assistance Plan (MPTAP) expressing worry for spouses and children who entered their lives after September 15, 1993 and therefore were not eligible to receive survivor benefits, the CHS undertook to lobby P/T health ministers to have these benefits extended to ALL MPTAP members' spouses and children, including those who became part of the claimants' lives after they had applied and been accepted under the plan. After two years of follow-up, we were finally informed on February 11, 2016 that all provinces and territories unanimously agreed to maintain MPTAP's current eligibility criteria, thus rejecting the CHS' request. More information is available at **www.hemophilia.ca/en/hcv-hiv/hepatitis-c-and-hiv-compensation/i-am-a-survivor**.

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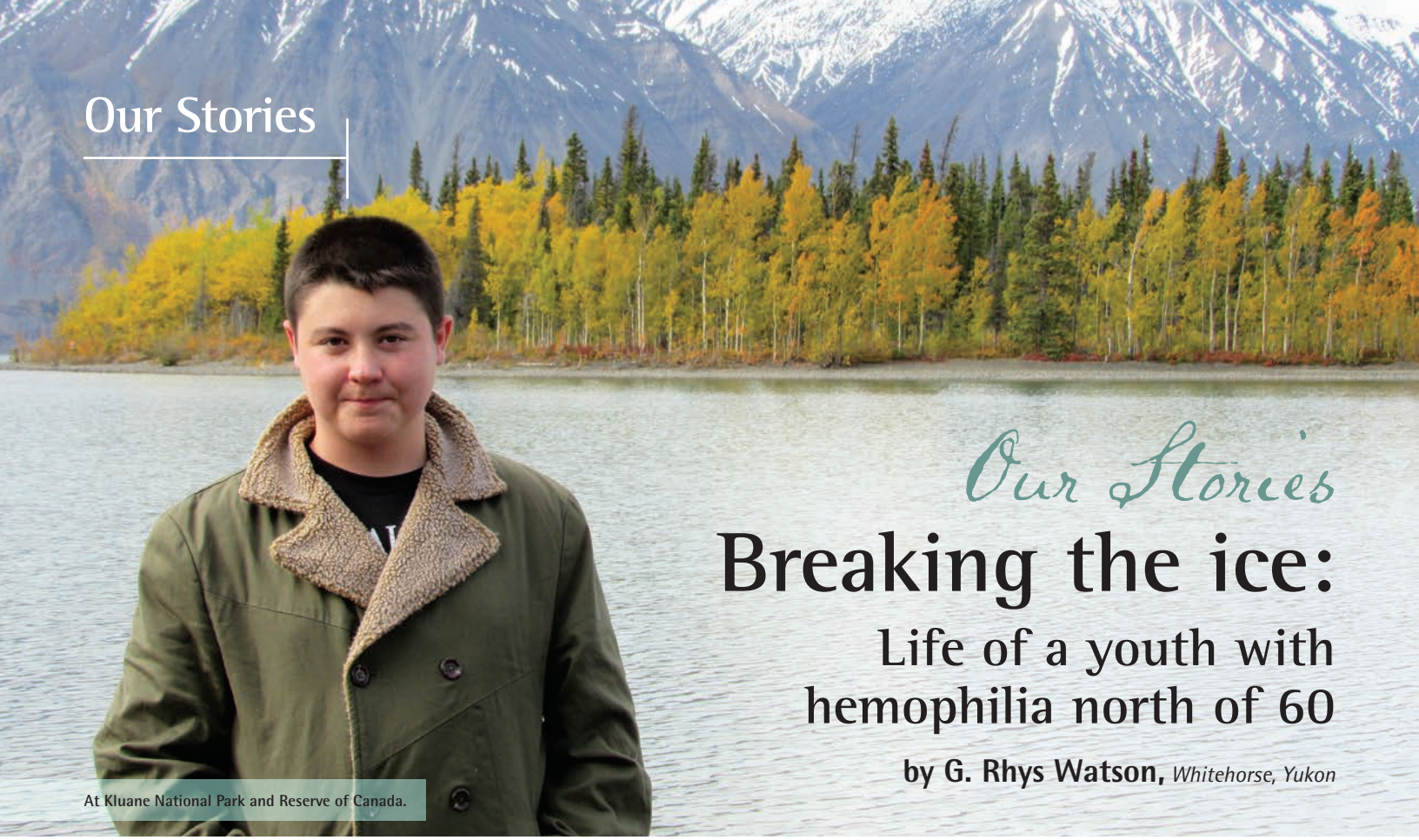
FEDERACIÓN MUNDIAL DE HEMOFILIA



At Kluane National Park and Reserve of Canada.

Our Stories

Breaking the ice:

Life of a youth with hemophilia north of 60

by G. Rhys Watson, *Whitehorse, Yukon*

In January 2014, my mom and dad decided that they wanted to fulfill a lifelong dream to experience more of Canada and move to the Great White North. After a lot of consideration, my parents decided that we would move to the Yukon, a territory where the Watson side of my family has been living since the 1940s. This move came with its own opportunities and challenges, especially for me. My dad transferred from the Department of National Defence to the Royal Canadian Mounted Police and my mom accepted the position of manager of accounting at the Yukon Hospital Corporation, both jobs in Whitehorse.

Wildlife in the Yukon.

By July, my mom and baby sister Ariana had moved and were living in Whitehorse. By August, my dad brought my sister Teaghen and I for a house-hunting trip. It was a long journey, but worth it. We arrived in Whitehorse just past midnight and a bright green aurora borealis filled the sky. We checked into our hotel and went to bed right away. Teaghen and I knew that in six hours we would have to get up for school. It was August 27, 2014, and Teaghen and I had already missed the first two days of school! Though we complained about it at the time, we now appreciate the early start of the school year – it allows Yukoners a two-week March Break and the school year is over by June 15, two weeks earlier than what we were used to. My dad returned to Nova Scotia after 10 days to finish moving arrangements and Ariana, Teaghen, Mom and I were on our own, until Dad returned in November.

This is where I started to realize that I must start advocating for myself much more than before about my bleeding disorder. My parents have always typically looked after informing and educating others about my hemophilia. This time was different, with my mom busy at her new job and my dad away. I was 14 years old and knew I had to start taking more responsibility for my bleeding disorder and be more mature about my choices. It was time for me to grow up. Now was as good a time as any.

The Yukon is a rugged and beautiful place, with 482,000 sq. km of land and emerald lakes, and only 37,000 people inhabiting the entire territory. About 75 per cent of the population live in the capital, Whitehorse. Moose outnumber people 2:1 and there are as many grizzly bears and black bears as there are people in the entire territory. There are also mountain lions (cougars), bison, lynx, fox, coyotes, mule deer, elk, caribou, porcupine, beaver, squirrels, wolves, and mountain goats, all of which are easily spotted and sometimes in large groups. Needless to say, Dad is taking me on my Hunters Safety and Firearms Courses so that we'll have added protection and comfort while outdoors. On top of the usual risks that I had before and the new animal risks, I now have to deal with a far different climate than I did in Atlantic Canada.

My family and I have travelled by car several times to Alaska, USA. On these long trips over mountainous terrain, I carry extra factor just in case. Driving in Canada's North, for eight months or more of the year, there is snow and ice on the roads. It also gets very cold, down to -40° to -50° C; frostbite can happen before you know it, so I bundle myself up and my medication if it's very cold. Communities are on average

two to five hours' drive away from each other, have small populations and have only nursing stations. Added to this, 9-1-1 service doesn't exist in between communities, let alone cellular phone coverage. An accident due to bad weather, animals crossing the road or otherwise means that you're likely on your own for a while. I really have to be self-sufficient, wear my tag, have factor in the vehicle along with the roadside emergency kit, carry my *FactorFirst* card in my wallet, have satellite communications, and make a travel plan so that people know where I am going and ensure that I make it there.

Living in this isolated part of the country also means that I have to have more factor on hand. Prior to my arrival, my medication wasn't stocked in the Whitehorse General Hospital's pharmacy. I'm thankful this was arranged for me by the BC Children's Hospital in Vancouver. Heck, I'm a teenager now and have grown taller, stronger and more active than ever before. I also travel by air more than I did before – over long stretches to other provinces such as Alberta, British Columbia and Ontario for Cadets, band and my six-month check-ups at the BC Children's Hospital. I always keep a copy of the letter from the HTC with my identification so I can carry my factor on flights.

Living "North of 60" means that I have to be much more responsible, mature and self-sufficient. I am literally the only pediatric hemophiliac in the entire territory. What does this mean to me and the people I meet? It means that I have been continually teaching people about what I have and what I do not. In many cases, there's almost no knowledge of hemophilia here beyond my parents, sister and family doctor. At times there is a sense of fear of the unknown amongst the groups and activities that I engage in from Cadets to band, school, church and snowboarding. I had to educate each group, most of whom took a lot of interest, asked many questions and were very positive.

Award I received from the Yukon Minister of Justice for Outstanding Youth Volunteer at the Community Safety Awards.

I have been very impressed with two people in particular who are involved in my physical activities, both of whom brought me into their groups without any hesitation due to hemophilia. They knew nothing about hemophilia but were ready and eager to learn. The first is my physical education instructor at Porter Creek Secondary School, Mr. MacDonald (aka Mr. Mack), who makes me feel confident every day that I can achieve many things and be included in many physical activities as long as I remain aware of the risks and take my medication when needed. I have shifted my prophylactic treatments to the mornings instead of the evenings to make sure I am prepared for his classes. The second person is the president of Snowboard Yukon, Sergeant Yule, an RCMP officer who has previously worked with people with different challenges including Paralympians. He simply listened to me, asked how to treat my bleeds and injuries, and makes sure I am always safe. He even donated to me boots, a snowboard and, most importantly, a quality helmet.

My new friends are into the same interests as me such as collectible cards and video games; however, they are also involved in many outdoor activities that pose new risks. They also know about my bleeding disorder and have welcomed me into their group. Everybody either mountain bikes, skis, skates or snowboards. During the winter, most activities are on hills and trails much higher, steeper and longer than back out East. I have joined the Yukon's snowboard team, the Shredders, to learn how to engage in this sport safely and responsibly. As this was a new challenge for me, I knew that I had to have the right equipment and lots of training, and take it easy on the hills until I build my skills and confidence. My goal is to become Snowboard Bunny Hill Champion of Mount Sima! I am fully aware of the risks and have weighed them against the benefits; I always have medication nearby (and on me) and people know what to do in an emergency.

When I look back over this past year and our move to the Yukon, I don't believe I would have been as successful in teaching others about my bleeding disorder if it wasn't for the efforts of many people over the years. My family, nurses, social workers, physiotherapists, doctors and all the staff at the hemophilia treatment centres, along with training at Canadian Hemophilia Society summer camps and family weekends, have made me stronger. I have met others with hemophilia and have learned how to self-infuse. All of these people continue to be important in my life and provide ongoing education, training and guidance that enhance my knowledge, confidence and skills to better manage my condition. I know I have a whole lot more to learn and share with others. For now, living in this beautiful part of our country rife with opportunities, challenges and risks has been good. Though I am sure that I will face challenges in the future, with continued support from my family, the HTC and the CHS, I will be ready when that time comes.

The BeneFACTORs Club

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 all of their tremendous effort.

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