A BRAVE NEW WORLD
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As tradition would have it, the August issue of alternate years sees a quite fully stocked *Hemophilia Today* since it is the one that includes the various reports from *Rendez-vous*, the biennial flagship event of the Canadian Hemophilia Society.

Held this year from May 25-28 in Toronto, this meeting is a landmark in many ways. First, in its number of participants: 135 health care providers from across the country, as well as 150 people affected by inherited bleeding disorders. There is also the esteemed Medical and Scientific Symposium, which allows us to hear updates on various subjects or to discover what’s on the horizon, be it new treatments or new tools to ensure optimal care for people with bleeding disorders. As an aside, I would like to take this opportunity to point out that all of the symposium’s webcasts are now available on the CHS YouTube channel.

But there is much more happening at *Rendez-vous*. In addition to the Friday symposium, workshops, developed with and for patients and their families, are offered throughout the day on Saturday. Again, we are pleased to present reports on these workshops in this issue. Concurrently, on Saturday, the Association of Hemophilia Clinic Directors of Canada holds its own annual Scientific and Educational Symposium to highlight and report on the most significant advances in treatment. Finally, we cannot conclude our weekend overview without telling you about the National Recognition Awards ceremony held during the Saturday evening banquet. You will find the winners presented in our Community News section.

The August issue is also the time for our special section Focus on Research. I would like to bring your attention to the excellent article introducing the section, which asks the simple question: *Research – what’s in it for me?*

Finally, factor XIII deficiency is very rare; one in a million people is affected in Canada. We have the privilege of publishing the touching story of one of them, the dynamic Miranda, 14 years old. Do not miss her account in the Our Stories section.

Enjoy!

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**Letter to the editor**

**Tainted blood full compensation**

My name is Jim Moauro and I am a hemophiliac. I am also living with HIV and I had hepatitis C that I received from tainted blood like so many of you.

In the early 1980s we received blood products as a treatment to help stop a bleed and maybe even to save our lives. We trusted the Red Cross. We trusted that the blood we received was safe and it was not. It was contaminated with two deadly viruses: HIV and HCV. The Red Cross and the health system in which we trusted failed us. Many fellow Canadians, not just people with hemophilia, were issued a death sentence. We have lost loved ones and we have had to endure endless suffering.

Years have passed. Thousands have died, families have been destroyed and children have had to grow up without their parents. Mothers have had to stand by the graves of their children and cry. I’ve lost my brother and my beloved wife.

I am asking you for your support. Many who were compensated under the Red Cross plan were not compensated as they had been promised. The Past Economic Loss and Dependents (PELD) Fund in the pre-86, post-90 settlement has run out of money. Join me in demanding the Government of Canada to come forward and fully compensate all victims who were infected with tainted blood, and their families, as promised. In order to raise awareness about the issue, I’ve recently had my story published in *The Windsor Star*, and on CTV News. Please write to your member of Parliament and demand full compensation as promised for all tainted blood victims.


Jim Moauro
Message from the past president

Craig Upshaw

It is very hard to believe that I have served the bleeding disorder community as president of the CHS for seven years! The achievements during this time are the result of significant dedication by staff and volunteers across the country, all focused on improving the lives of people with inherited bleeding disorders.

During this time, we have seen dramatic improvements in care, notably in dealing with the treatment-related complications of HIV and hepatitis C. Together, we worked so that the surplus funds in the 1986-90 HCV compensation settlement went to the people affected and not back to the federal government. We completed treatment centre audits in order to help ensure that everyone in the country, no matter where they live, receives care that meets comprehensive evidence-based standards. We collaborated closely with the physician, nursing, physiotherapy and social work teams and their associated organizations, resulting in the sharing of best practices, high-quality symposia for our members, and the development and launch of the Canadian Bleeding Disorders Registry. We placed great importance on ensuring that our community gain access to extended half-life factor concentrates. We continue to focus our efforts on making sure that future innovative drugs that have the potential to significantly alter the quality of life for people with bleeding disorders will be available in a timely way and at no cost to patients.

Yes, we have great care and access to coagulation products. However, perhaps more than at any time in the recent past, we must be determined in our advocacy efforts as provincial budgets are constrained and there are competing priorities for health care dollars.

It has been an absolute honour to be given the opportunity to lead the organization, to be able to create long-lasting friendships and to be inspired by the courage and tenacity of the whole community. I stepped into this role having big shoes to fill and built upon the great accomplishments of those who came before me. I now leave this role to Paul Wilton. I have full confidence he will steward the organization so that the CHS will continue to be seen as a leader and respected authority in bleeding disorders in Canada and around the world.

Message from the president

Paul Wilton

Some people with inherited bleeding disorders no longer see the relevance of the Canadian Hemophilia Society to their lives. They recognize our past successes: advocating for a safer blood system, fighting for compensation for those affected by tainted blood and helping to advance care. They argue we are a “victim of our own success” – we have been able to improve the level of care so much that there is little reason left for people to engage. However, such thinking minimizes the challenges facing individuals in our community and the continued vigilance required to protect and improve our quality of care. On the contrary, this supposed “organization of yesterday” is full of smart, compassionate community members doing their absolute best to make things better for those we serve. For the truth is there are many good reasons to join this team by constructively participating in the work of the CHS.

Perhaps the best reason is to ensure all people with inherited bleeding disorders in Canada have access to evidence-based standards of care. Currently our clinics face funding crunches, with 23 of 25 bleeding disorder treatment centres lacking human resources in one of the core disciplines: hematology, nursing, physiotherapy, social work, and data entry. In nine of 25 programs, there are no resources allocated at all to certain physiotherapy and/or social work. To governments and hospital administrators, our clinics are just another budget line in funding battles. It takes a strong patient voice to make the case for why properly resourcing clinics now is a wise investment in improving our health and reducing long-term costs to the health care system. Another reason to engage is to help us ensure access to longer-lasting factor products, which are here for some people now, as well as non-factor products and gene therapies which are coming soon and promise a better life for many in our community.

In this magazine we strive to share with you the latest issues in inherited bleeding disorder care, the services we provide and how you can get involved to help us achieve our mission. I encourage you to join us in our work to improve the health and quality of life of all people with inherited bleeding disorders and find cures.

Finally, a huge thank you to Craig for his service to the CHS and the community over the last seven years.

Craig Upshaw

Paul Wilton
Hemophilia Ontario was thrilled to host Rendez-vous 2017, welcoming the rest of the country to a fun weekend in Toronto. With our new president, Maia Meier, and myself as new executive director, it was the perfect opportunity to make connections, celebrate the community's successes, and cap off our 60th anniversary celebrations.

One benefit of hosting the conference in our home province was the ability to send so many of our board and staff. All five Hemophilia Ontario employees were in attendance, participating in the symposium and workshops, and meeting in person for the first time some of the individuals they have been communicating with for years. Six Hemophilia Ontario board members and many more volunteers were also part of the contingency, broadening our reach within the sector, increasing our overall capacity, and strengthening the entire Hemophilia Ontario network.

The organization is in the middle of an engagement strategy: talking to our membership, doing outreach with the broader community, and rethinking the way we design and deliver services. Rendez-vous provided additional opportunities to spread the word and learn about what other chapters are doing. Hemophilia Ontario is excited to share the learnings and results with everyone later this year. As the chapter considers its priorities and how to capitalize on existing strengths, a reimagined fundraising strategy and focus on sustainable revenues will follow.

In other chapter priorities, the Rendez-vous advocacy workshop was an excellent opportunity to revisit the topics we addressed in April with the chapter advocacy workshop. Hemophilia Ontario has launched an operational committee to establish priorities based on the results of the clinic assessments, develop an action plan to address short-, medium-, and long-term goals, and focus on the need to ensure all nine provincial HTCs have the resources required to meet the Standards of Care.

As 2017 continues, Hemophilia Ontario still has a lot of work to do. Our webinar series has upcoming presentations by David Page, Dr. Manuel Carcao, and Dr. Alfonso Iorio on a variety of topics. The Wellness for Women (W2) conference is being held in Kingston, Ont., this fall featuring medical keynote speakers, Dr. Paula James and Dr. Mary Anne Jamieson. Our annual Just the Guys weekend will have its first-ever presentation by a pediatric hematologist, Dr. Anthony Chan, as well as a busy slate of activities for the boys and male role models in attendance. We are sending a record number of campers to Camp Wanakita this year and celebrating the 25th anniversary of Pinecrest Adventure Camp.

This is an exciting time for the chapter, full of energy and forward momentum. We send a sincere thank you to the CHS for the hard work that went into planning such a successful Rendez-vous event and the opportunity to celebrate our 60th anniversary milestone in such great company. We look forward to a very bright future working together.
On May 27 in Toronto, in conjunction with Rendez-vous 2017, the CHS recognized dedicated volunteers, staff and health care providers who made a significant contribution to the bleeding disorder community.

CHAPTER RECOGNITION AWARD

This award is designed to recognize chapters and regions who have demonstrated a significant achievement over the preceding year or years in one or more specific areas such as fundraising, communications, peer support/education, advocacy or chapter development.

HEMOPHILIA SASKATCHEWAN | AWARENESS AND ADVOCACY

Every year, Hemophilia Saskatchewan volunteers have manned a booth in shopping centres in support of World Hemophilia Day. In addition to this awareness initiative, the chapter organized a conference on Women and Bleeding Disorders. At this event, 38 women from both Saskatchewan and Manitoba gathered in Saskatoon to discuss von Willebrand disease challenges for women, new treatments and approaches, the psychosocial impact of having a bleeding disorder, the genetics of bleeding disorders and much more.

One of the biggest achievements of the chapter was, without a doubt, their success in obtaining funding for a second pediatric hematologist. In May 2015, the chapter approached the Saskatchewan Health Minister regarding the lack of coverage in pediatric hematology. The Ministry was quick to realize that the workload was too much for one pediatric hematologist in Saskatchewan. This was also reflected in the HTC audit conducted by the CHS. In their letter, the chapter urged the Health Minister to provide funding for a second hematologist. A few months later, the hematology team at the clinic posted for a second pediatric hematologist and credited this success to the advocacy role of Hemophilia Saskatchewan.
CHAPTER LEADERSHIP AWARD

This award is given to an individual who merits special national recognition for outstanding efforts to further the growth and development of a particular chapter or region.

PAUL WILTON | Hemophilia Ontario

Paul Wilton is a past president of Hemophilia Ontario. He served as vice-president of the Canadian Hemophilia Society and was chair of its Governance Committee. His advocacy in Blood Safety led to his appointment on the World Federation of Hemophilia’s Treatment Product Safety, Supply and Access Committee. In 2009, he was awarded the Canadian Blood Services’ Honouring our Lifeblood Award and previously served on their Southern Ontario Regional Liaison Committee. He also served as director of Hemophilia Ontario’s Pinecrest Adventures Camp, and was awarded the John Meyers Award.

Paul has been a committed volunteer with a significant history of leadership, participation and involvement since being diagnosed in 1986. Paul’s early contributions to Pinecrest revealed his leadership qualities. He was instrumental in fostering a true leadership development program for the camp, encouraging young campers to take on progressively more demanding responsibilities. Many have gone on to make significant contributions to the community as board members and valuable volunteers. Paul has a unique ability to identify individuals with the necessary strategic skills and successfully encourage them to use those skills in service to the community and the organization.

He received the Alumni Student of the Year award at King’s University in 2013, recognizing his volunteering in the community, including his work in the hemophilia community. Paul’s contributions to Hemophilia Ontario are significant. He has served on many boards and committees at both the regional, provincial and national levels. During his presidency, Paul was instrumental in updating and changing Hemophilia Ontario’s governance and by-laws. His efforts to improve the chapter’s governance helped ensure a smooth transition at a time when the chapter was facing funding cutbacks. Today, thanks to his work, Hemophilia Ontario continues to be a strong, vital chapter, making a difference in the lives of Ontarians with bleeding disorders.

AWARD OF APPRECIATION

This award honours an individual who has demonstrated outstanding service to the care of people with inherited bleeding disorders over and above their responsibilities as a member of the bleeding disorder health care team.

ANNE VAUGHAN, RSW

Anne Vaughan has been an integral member of the bleeding disorder clinic team at the IWK Health Centre in Halifax for the past nine years. As a social worker, she is dedicated and committed to the care of children and their families affected by bleeding disorders both in the Maritimes and nationally. Two of her most significant achievements include introducing the Parents Empowering Parents Program (PEP) and facilitating transition of care from pediatric to adult bleeding disorder clinics.

As a member of the national PEP Steering Committee, she has been the driving force in bringing and sustaining this valuable program in Canada. Anne’s vision has always been to offer access to PEP to ALL Canadians. After nine years of effort, she will see the first French-speaking workshop delivered in the fall of 2017.

Anne is a dynamic leader who is present in current activities but also looking forward to what should come next. Members of the PEP Committee have learned so much, both professionally and personally, from the time they have spent with Anne. Under her leadership, the committee has developed tools to help her colleagues and the chapters deliver the PEP program in various formats and ensure the program endures. Anne brings a level of enthusiasm and dedication to her work that inspires the members of the committee to work hard and dream big.

Anne’s dedication and volunteer work come from a deep respect for the families she serves. Anne’s tireless volunteer work with the PEP Program is motivated by her desire to give families the tools they need to manage the job of parenting with the added challenges of a bleeding disorder. There is no doubt that her work, and her volunteer work, come directly from her heart.
PIERRE LATREILLE AWARD

This award was initiated in memory of Pierre Latreille who was the CHS finance manager for many years. This award for excellence is given to an employee of the CHS who has worked at the national, provincial or regional level for a minimum of five years.

ROBERT SHEARER

Robert (Bob) Shearer was the CHS executive director from 1987 to 1992. During these very difficult times, Bob was able to provide the leadership at the board level that brought balance to HIV and non-HIV issues.

His support and caring extended to provincial matters. He was always professional but full of fun at a time when it was most needed. His visits across the country helped cement chapter/national relationships.

With his encouragement and support the CHS was successful in advocating for HIV-positive hemophiliacs on both the provincial and national levels. This was not particularly popular as hemophiliacs at that time did not want to be assumed HIV-positive simply by association. Others put the human face on the HIV issue and helped bring a resolution to compensation but the groundwork was done at the national board level under his direction.

None of these accomplishments would have been possible without the strong and capable leadership of Bob. His dedication and tireless efforts gave the CHS the stature we enjoy to this day. His good humour and ready smile helped both staff and volunteers as they fought battle after battle for the rights and welfare of all Canadians affected by a bleeding disorder.

FRANK SCHNABEL AWARD

This award was initiated to honour the outstanding service of Frank Schnabel, the founder of the Canadian Hemophilia Society, for his valued role in the growth and development of the CHS, the education and care of people with hemophilia and other bleeding disorders, and the education of the public regarding the needs of the bleeding disorder community. The award is presented in his name to honour a volunteer at the national level of the CHS, who, over a number of years, has rendered distinguished services and noteworthy contributions to the mission and objectives of the CHS.

CRAIG UPSHAW

Craig is the longest serving president of the CHS with the exception of our founder, Frank Schnabel. He volunteered in his home chapter of Alberta for many years before serving on various CHS committees, working groups and the Board of Directors.

He was a member of several committees but is especially respected for his work on the Blood Safety and Supply Committee where due to his scientific background and extensive knowledge of blood products and pharmaceuticals, he contributed to the committee’s expertise. He has maintained a focus on access to a safe supply of coagulation products for all people with bleeding disorders. He has participated in product tender processes and been a strong voice on national and international advisory boards.

Craig was a key player in advocacy which led to the indexation of the Multi-Provincial Territorial Assistance Program in 2006. He also lobbied successfully with provincial/territorial governments for access to extended half-life products throughout 2014-16. He helped to push the Canadian Bleeding Disorders Registry project to successful completion in 2015.

Craig became president of the CHS in 2010, a time of tremendous change. His business experience helped guide the board to make critical decisions regarding financial and human resources so that the CHS could remain focused on its mission. During his term, the CHS aligned its board structure and by-laws to conform with the new Canada Not-for-Profit Corporations Act and completed a strategic planning process that resulted in our current Strategic Plan.

Craig has fostered strong relationships with key stakeholders such as the World Federation of Hemophilia and other patient organizations. Craig is available to staff and volunteers daily to provide advice, encouragement and support. He is a well-respected friend and mentor to many across our national and global hemophilia communities.
DR. PAULA JAMES

Dr. James obtained her MD and subsequent training in internal medicine at the University of Saskatchewan. During her training she had developed an interest in hematology, and specifically in the care of inherited bleeding disorders. Later, Dr. James settled in Kingston to complete her clinical hematology fellowship. It was very quickly obvious to everyone at Queen’s that she was a bright, committed and highly motivated physician with outstanding clinical skills.

After completing an excellent clinical hematology fellowship, Dr. James entered a 30-month training in basic laboratory research in the Department of Pathology and Molecular Medicine at Queen’s. During this time, she published first authored manuscripts on a novel therapy for hemophilia, and was also the first author and prime mover of the landmark Canadian type 1 von Willebrand disease mutational landscape manuscript, published in Blood.

Dr. James has been very successful in developing a productive independent research program at the same time as establishing a clinical program for the care of inherited bleeding disorder patients that is second to none.

In the clinic, Dr. James provides outstanding direction to the Kingston Regional Bleeding Disorder Program and has established a superb Women’s Bleeding Disorder Clinic that is a model of multidisciplinary efficiency. Her clinical acumen and excellent communication skills make her a favourite with her patients, and she is regularly asked to provide advice from all over Canada.

Dr. James’ clinical expertise in the care of von Willebrand disease has also been recognized internationally. She is often solicited to give talks, and has very recently been invited to be a senior author for the next international clinical guidelines document being generated in a project supported by the World Federation of Hemophilia, the American Society of Hematology and the International Society on Thrombosis and Haemostasis.

As a complement to her exceptional clinical contributions, Dr. James leads a highly successful research program that has reported novel and important information relating to the molecular pathogenesis of von Willebrand disease, the development and utility of bleeding assessment tools and the bleeding profile and causation of bleeding in carriers of hemophilia.

In closing, there is not the slightest doubt that Dr. James is an international star in the inherited bleeding disorder community. Her clinical and research contributions to the field of von Willebrand disease have been highly significant, and her work on the development and initial validation of bleeding assessment tools has been immensely influential. She appears to effortlessly blend the skills and attributes of clinician and researcher in a manner that is a model of efficiency and success.
Important award given to one of our community physiotherapists

Congratulations to Pam Hilliard, physiotherapist at Sick Kids in Toronto, who was awarded the 2017 Pietrogrande Prize at the 15th World Federation of Hemophilia International Musculoskeletal Congress. The WFH’s Pietrogrande Prize honours a health care provider having made significant contributions in promoting the WFH Musculoskeletal Committee’s mission and goals. With 35 years of experience in hemophilia care, important research accomplishments (at home and internationally) and her dedication to teaching, mentoring and her patients, Pam is more than deserving of this award.

The CHS would also like to wish Pam all the best as she looks forward to retirement at the end of September. – R.L.

Saying goodbye to three wonderful nurses

Best wishes for a very happy retirement to Dorine Belliveau, RN, and Charlotte Sheppard, RN, respectively from the treatments centres in Moncton, NB, and Saint John’s, NL. We also salute Sherry Purcell, who will be transitioning from the South Eastern Ontario Regional Inherited Bleeding Disorders Program to work full time in the emergency department.

With decades of experience between them, the bleeding disorder community across the country will miss their knowledge, skill, professionalism, enthusiasm and commitment. We wish them all the best in their new adventures! – R.L.

Congratulating two deserving staff

This year, the CHS recognizes two valued staff members for their years of service. First, our hats off to David Page for fifteen years of outstanding service. His accomplishments would be too long to list but we are truly grateful for his tremendous work in advocacy, his guidance and leadership in care and treatment and his tireless effort to maintain a safe blood system.

And to Michel Long, for ten years of professional management of diverse files, including services to our population affected by HIV and/or HCV, administration of our research programs and support to the International Projects Committee. A sincere thanks to each of you for your continued dedication and commitment to the CHS! – C.R.

PROBE launches website

The Patient Reported Outcomes, Burdens, and Experiences (PROBE) study explores patient perspectives on life and care and is working to develop a comprehensive tool to improve advocacy, treatment and available data for both in-country and cross-country comparison. Check out www.probestudy.org for information on the PROBE study including presentations, posters and more. – R.L. 6
Recognizing retiring Board members

We would like to acknowledge the outstanding contributions of three individuals who concluded their terms on the CHS Board of Directors at the last Annual General Meeting after long and distinguished service. Pam Wilton (Ontario), who served as CHS president from 2007 to 2010, past president for the last seven years as well as member of many committees of the Board; Mylene D’Fana (Quebec), secretary of the Board and chair of the Program Committee from 2011 to 2016; and Justin Smrz (British Columbia), youth representative on the Board from 2012 to 2017. Thank you for your dedication and invaluable contributions.

Front row, from left to right: Wendy Quinn, Maia Meier, Dianna Cunning, Betty Anne Hines, Kathy Lawday, Ben Glazebrook and Carmen Nishiyama. Back row: John Schmitke, Rick Waines, Monica Mamut, Mathieu Jackson, Joe Doran, Craig Upshaw, Paul Wilton and Jeff Jerrett.
Rendez-vous 2017, presented by Pfizer, was held in Toronto from May 25 to 28, and hosted by Hemophilia Ontario in celebration of its 60th anniversary. The event proved to be, once again, the finest gathering of the Canadian inherited bleeding disorder community. Over 320 health care providers, industry partners, patients and their families, came together to learn, share, network, question, reflect and educate. The following pages will provide an overview of what was heard and learned at Rendez-vous. You will find reports on the presentations from the Medical and Scientific Symposium held on May 25, as well as from other events held throughout the Rendez-vous weekend.

Please note that links to watch the symposium’s presentations are available as webcasts on the CHS website at [www.hemophilia.ca/en/webcasts/rendez-vous-2017](http://www.hemophilia.ca/en/webcasts/rendez-vous-2017) or directly on the CHS YouTube channel at [www.youtube.com/user/CanadianHemophilia](http://www.youtube.com/user/CanadianHemophilia). – C.R.
On behalf of the inherited bleeding disorder community, a sincere thank you to the sponsors of Rendez-vous 2017 for your invaluable support of the Canadian Hemophilia Society.

The collaborative efforts of our sponsors, health care providers and our community is central to the achievement of our mission of improving the health and quality of life of all people in Canada with inherited bleeding disorders and ultimately finding cures.
As a patient with hemophilia, one of the most impressive features that strikes me about the hemophilia community is the almost natural inclusion of patients alongside health care providers at conferences. In the context of my work at the Centre of Excellence on Partnership with Patients and the Public, within the Research Centre of the Centre hospitalier de l’Université de Montréal, I have the opportunity to encounter patients with other medical conditions and I can say that such inclusion is far from the norm for most patient groups.

The Canadian Hemophilia Society’s biennial Rendez-vous is an excellent example of collaboration, bringing together health care providers and patients from across the country as well as representatives from the pharmaceutical industry. The event is the occasion for all stakeholders in the hemophilia community to exchange knowledge, learn from one another and strengthen their connections in order to ensure good management of care and the advancement of research. It is therefore a pleasure to share my summary and impressions of the first session of the Rendez-vous 2017 Medical and Scientific Symposium, A brave new world in coagulation therapies.

In this session chaired by Dr. Jayson Stoffman, we had the privilege of hearing presentations by four leading experts in the field of hemophilia: Dr. Shannon Jackson of St. Paul’s Hospital in Vancouver, Dr. Manuel Carcao of the Hospital for Sick Children in Toronto, Dr. David Lilliecrap of the Kingston General Hospital and Queen’s University, and Dr. Jerry Teitel of St. Michael’s Hospital in Toronto. In this article, I will briefly summarize the presentations and highlight the main points that I retained as a patient. I encourage readers who would like more information to view the conference recordings, which are available online on the CHS YouTube channel and via the home page of the CHS website.

The presentation by Dr. Jackson dealt with factor concentrates with extended half-lives. She began with a portrait of the extended half-life products in Canada, then described the observations that have been made on their use. Extended half-life concentrates work by protecting the factor molecules from elimination by connecting them to immune globulin, albumin or glycoproteins. This enables recycling of the clotting factor proteins that otherwise would be more quickly removed from the bloodstream. As with standard half-life concentrates, half-life varies from person to person. More research is needed to understand how these novel products can improve adherence to prophylactic protocols and health outcomes.

Dr. Carcao talked about the management of inhibitors. I was quite surprised to learn that the rate of inhibitor development among people with severe hemophilia A is between 25 to 40 per cent. Unfortunately,
it is complex and very difficult to predict if one person is at greater risk of developing inhibitors than another. However, numerous studies have shown that inhibitor development is more likely to occur with recombinant products than with plasma-derived products, particularly among patients with few exposures to clotting factor concentrates. In terms of treatment of patients with inhibitors, Dr. Carcao presented a long list of new products under development or awaiting approval, which is good news given the limited efficacy associated with the two products currently in use, FEIBA® and Niastase®.

Dr. Lillicrap described two alternative therapies on the horizon. Emicizumab, previously referred to as ACE910, is a monoclonal antibody that mimics the role of factor VIII in the coagulation cascade, linking to factor IXa and factor X, and making hemostasis possible. While emicizumab is less effective than factor VIII in patients without inhibitors, its most significant benefit is its efficacy in patients with inhibitors. Moreover, it does not cause inhibitor development. Dr. Lillicrap also gave an overview of rebalanced hemostasis therapy, which aims to restore the equilibrium between coagulant and anticoagulant agents in the body. Two products under development (fitusiran and concizumab) have shown promising results, including among patients with inhibitors. These alternative therapies are very promising, particularly for patients with inhibitors, and offer a glimpse of a future in which treatment for hemophilia will be tailored to the specific needs of individual patients.

The last speaker described the advances in gene therapy, a topic that has always appealed to me. In fact, as Dr. Teitel noted in his opening, we have been promised miraculous gene therapies since the 1980s, which have never seen the light of day. Hearing this, I recalled that when I was little, as she pricked me with the infusion needle, my mother tried to comfort me by saying someday there would be a genetic cure and I would not have to live with hemophilia all my life. During Dr. Teitel’s presentation, I learned that the emergence of gene therapy was delayed and research put on hold following the death of two clinical trial patients (not with hemophilia) in 2003. To date, only three gene therapy products have been approved worldwide.

One of the major challenges to overcome in gene therapy relates to the administration of DNA to patients. To address this issue, researchers use viral vectors engineered with the desired DNA. The viral vector then delivers the DNA into cells in the body. In hemophilia, gene therapy is administered by intravenous injection into a vein, just like a factor concentrate. The vector carrying the gene makes its way to the liver, where it produces factor VIII or factor IX. There are still challenges in the development of effective gene therapies. These include the risk of developing cancer, risk of transmitting undesirable genes to the patient’s offspring, and the rate of immune reactions to the viral vector. Despite these obstacles, there are many clinical trials going on, some of which are very promising.

This fascinating panel outlined the latest developments and results in treatment advances in hemophilia. Extended half-life products and gene therapies offer us a world in which, even if hemophilia always exists, patient quality of life will be vastly improved and the associated complications will greatly diminished. Now it’s up to us, as the association representing patients, to ensure that these innovative treatments become accessible, to create a brave new world in coagulation therapies.
We were excited to attend the second session of the Rendez-vous 2017 Medical and Scientific Symposium. This session was entirely dedicated to the Canadian Bleeding Disorders Registry (CBDR), which is now the database for Canadian patients with bleeding disorders. Launched in 2015, the system is gradually being implemented in the bleeding disorder treatment centres across the country. The CBDR was created to support the treatment centres in providing care to patients, but also to help patients in managing their own health condition. In other words, this is the best way to report treatments and bleeds to your health care team.

The first part of the presentation was given by Arun Keepanasseril, from McMaster University—a snapshot of the current situation as of May 26, 2017. At that time, the CBDR was "live" in 16 of the 23 treatment centres (69.5%) across the country. Four other centres are planning to implement it within the next six months. More than 300 infusions are recorded every single day in the online database and with the MyCBDR app! Currently, 3,731 users are registered in the system.

The second part of the presentation was given by Dr. Georges-Étienne Rivard, from CHU Sainte-Justine, who spoke of the challenges and implementation steps of the CBDR in Quebec. Unlike other provinces, the system was relatively easy to implement in Quebec due to the specificity of the system. Indeed, in Quebec, patients need to directly contact their treatment centre to access their factor concentrate products. This direct link helped the set-up in the province. Needless to say, the cooperation between the four provincial university hospitals was also a key factor in the success of the whole process. Dr. Rivard closed his presentation by highlighting the long-term impact that the CBDR database may have. Not only does the system allow for a uniform approach to patient data collection across the country, it may also help in standardizing treatment. Ultimately, the CBDR enables health care providers to improve care for the patients with bleeding disorders.

The third part of the presentation was given by Nancy Hodgson, nurse coordinator at the treatment centre of the Saskatoon Royal University Hospital. She talked about the real-life experience during the CBDR implementation in Saskatchewan. She indicated that, unfortunately, the project could not be set up in the short-term due to complications migrating data from the older CHARMS database to the CBDR one. The training necessary for the treatment centre team and the patients is another factor slowing down the system implementation.

Finally, we heard and understood from the perspective of a user, thanks to Mathieu Jackson, a young man with hemophilia B. Based on his experience, the transition from the paper registry to MyCBDR was easy. The multiplatform aspect of the system, making it accessible from computers or mobile devices, is one of the many benefits Mathieu noted. Ease of use, charts and visual representations have become tools that help him better manage his health and his treatment regimen.

In conclusion, the CBDR and MyCBDR are excellent tools to easily update the inventory of factor concentrates and manage treatment. It is also extremely reassuring to know that health care providers can follow bleeds and infusions in real-time. Overall, the tools appear to facilitate the process for all involved. From the patient’s perspective, it is difficult to assess the impact of this database, but it is clear that the effort made for its creation and implementation is beginning to show results.
The Female Factor

Not “just” a carrier

by Erin Van Dusen, Halifax, Nova Scotia

A highlight of my experience at Rendez-vous 2017 was the presentations by Dr. Paula James and Dr. Michelle Sholzberg. I am an obligate carrier of hemophilia B and I have recently been coming to terms with the fact that my carrier status is more than just a status – it is an important part of my day-to-day life.

I used to explain my bleeding disorder to friends and co-workers as only a genetic condition with no visible symptoms. I would assure everyone that I was clinically unaffected by any significant expression of the disorder. I now know that to be untrue, and I appreciate the work of doctors such as Dr. James and Dr. Sholzberg in creating awareness of women’s bleeding disorders by providing evidence-based research.

I long resented the idea of attending clinic at my local hospital as my thought process was that being “just a carrier” meant I did not need to go to clinic. I believed that my relatively normal factor levels meant I could not experience any clinical symptoms. I appreciated Sholzberg’s description that bleeding can occur even with normal factor levels. I had not been to clinic nor had my factor tested since I was a small child, and I was shocked to discover my levels were much lower than I had previously thought. The idea of labels posing barriers resonated with me as an important piece of the puzzle in providing adequate medical care for carriers. I had been stuck on my own label as “just a carrier” for years, which resulted in denial of my symptoms.

Confusion over terminology, lack of research and potential skepticism amongst medical care providers can result in negative experiences and reduced quality of care for carriers. Dr. Sholzberg spoke about an evolving understanding of bleeding in hemophilia carriers. It is fascinating as a carrier to hear that science is pushing forward with new ways of thinking and creating potential changes in the way women identify as bleeders.

The work of Dr. James and Dr. Sholzberg is not only impressive but also empowering to the bleeding disorder community. Dr. James’ team has reached out to women with bleeding disorders globally through social media platforms and the development of a user-friendly self-administered bleeding assessment tool (Self-BAT). In my experience, women will often share intimate stories about abnormal bleeding and concerns about undiagnosed bleeding disorders when they discover I have a bleeding disorder. I have recommended the Self-BAT available on the “Let’s Talk Period” website to women expressing suspicions of abnormal bleeding. I can only hope there will be additional research and information sharing on women’s bleeding disorders, carriers, and abnormal bleeding in order to create awareness and improve understanding.
A lifelong journey

by Rick Waines, Victoria, British Columbia

Managing hemophilia online: the development, testing and implementation of a transition program for teens

Dr. Vicky Breakey of McMaster University presented a trial and a qualitative needs assessment, both aimed at helping with the challenges facing teens with bleeding disorders.

She noted that the transition from being dependent on others for your hemophilia care to being independent is difficult. Researchers have identified two important factors that lead to more successful transitions from pediatric care to adult care: knowledge and skill.

A team out of the University of Toronto and McMaster University developed an eight-module online tool for teens with hemophilia-specific and general topics relevant to the transition from pediatric to adult care. The pilot participants were randomized into two arms. One arm used the online tool and had weekly calls from a coach while the other arm only had the weekly call. Significant improvements in hemophilia knowledge, self-efficacy and transition preparedness were found in the arm that used the online tool.

One important limitation of the trial was the contribution of the coach to the success of the pilot. Was it the coaching itself that provided the gains in knowledge, and if so, is there a role for peer support?


The success of coaching within the trial led to the next part of Dr. Breakey’s talk, which was a review of Online Peer-to-Peer Mentoring Support for Youth with Hemophilia: A Qualitative Needs Assessment.

The results from this assessment were qualitative. Twenty-three youth were interviewed. Generally, the participants felt that peer support was important and wanted to know how it would be delivered. Would it be online, in-person, or by text? Would the content be structured or unstructured? What would be the frequency of sessions and length of the program? The participants identified possible challenges as well including: scheduling, comfort level for discussion, training and support, and finding the right mentor fit.

The next steps, according to Dr. Breakey, will be to develop a peer support program for youth with hemophilia and design a pilot study to determine the feasibility and effectiveness of the program.

A new approach to choosing sports and activities

The next presentation, A new approach to choosing sports and activities, was given by Julia Brooks, physiotherapist from Alberta, and Jeremy Hall, a young adult with hemophilia and inhibitors whose Alberta sledge hockey team had just won nationals.

Jeremy and Julia’s task was to review with us previous ways in which activities were selected, provide examples of individualized decision-making related to sports and other activities, and introduce a new resource.

Previous methods we have relied on in the hemophilia community were limited to the familiar green, yellow, red light concept, classifying sports and activities into green light (think once) activities, yellow light (think twice) activities, and red light (think again) activities.

This approach doesn’t work for everyone, and Jeremy’s story was a perfect example of this. Born with hemophilia, Jeremy developed inhibitors and severe joint damage in both knees at a very early age. Not many of us with two naturally fused knees would get the itch to take up hockey, but, that is the beauty of us humans, we all have different needs, knees and desires. The green-yellow-red approach was never going to work for Jeremy. My guess is, it stems from the fact that it is more of a top down approach. The answers are provided; self-determination is removed.

A new resource was needed that put people with bleeding disorders “in the driver’s seat” and could be used by patients, with or without their HTC, allowing for self-reflection/evaluation, and activity selection/evaluation. In the Driver’s Seat, developed by Canadian Physiotherapists in Hemophilia Care (CPHC) members Elia Fong, Erin McCabe, Kathy Mulder, Julia Brooks, Colleen Jones and Karen Strike, in collaboration with the CHS, is divided into four sections: Assessing yourself, Choosing physical activities that work for you, Reducing risks, and Making an activity plan. It looks to me poised to help people with bleeding disorders make informed decisions about the activities they undertake.

Point-of-care ultrasound in hemophilia: building a strong foundation for clinical implementation

Wendy Lawson of Mohawk College reviewed the strengths and weaknesses of point-of-care ultrasound (POC-US) implementation into hemophilia care. First, its strengths. POC-US is fast, portable, has high resolution, and an ability to show many of the changes that occur during a bleed. It also has limitations, however. It can’t see all structural changes, it is highly user dependent, it requires regular use, and professional development.

Despite these limitations, POC-US has improved patient health, has a positive impact on clinical decision-making, and allows data collection on joint health.

With opportunities come liabilities including: improper use of POC-US, barriers to implementation, a lack of formal training opportunities, and dependence on user competence. Some of the strategies to overcome these obstacles include important training and competency evaluation, appropriate use including consultations, and having a clear and precise definition of POC-US.
She also discussed community and industry partners enabling evidence-based research in the areas of POC-US training and impact on patient outcomes.

As POC-US is increasingly used by our health care providers, it will be important to take advantage of its strengths and mitigate its weaknesses. Wendy’s talk laid the groundwork to help make this possible.

Moving Ahead with Hemophilia: feedback from Canadians ageing with hemophilia

The last presentation of the day was made by Yola Zdanowicz of Ensemble Strategies, on research she conducted on ageing with a bleeding disorder on behalf of Pfizer, in collaboration with the CHS.

Her qualitative research, to help develop resources for people ageing with a bleeding disorder, was conducted through one-hour phone interviews with 17 men over 40. These men were a fairly representative group of hemophilia A and B, but not of von Willebrand disease or other rare inherited bleeding disorders.

Here is what they had to say:

- Treatment advances have dramatically changed the realities of hemophilia. Products are more convenient. Prophylaxis and longer lasting products mean fewer bleeds and healthier joints. The risk of blood-borne infection has all but disappeared. There is also a “cure” for hepatitis C and more effective suppression of HIV.
- Joint damage is the most pressing health issue that leads to reduced mobility. Joint replacements can be difficult to access due to wait times and require long recovery.
- Pain is ever present, even after joint replacement. There is also a lack of knowledge about how to manage it and little access to pain specialists. There are concerns about long-term opioid use and little knowledge about alternative therapies such as naturopathic medicine and acupuncture.
- When mobility is reduced, the world becomes smaller, leading to less social engagement, premature retirement, financial difficulties, weight gain, and low self-esteem.
- Ageing patients often endure pain and hardships with a pragmatic, “power through it” attitude, seeing little need for emotional support services.
- They divulge hemophilia and/or HIV and hepatitis C status on a need-to-know basis due to fear of discrimination and challenges to health coverage. They spend more time dealing medically with hemophilia, but more time emotionally with HIV. HIV is seen to have had a huge emotional impact including isolation, loneliness and depression. The “cure” of hepatitis C was difficult leaving physical and emotional scars.
- The CHS is seen as being a crucial support providing a sense of community.
- Hemophilia clinics have gone beyond the provision of direct care and ultimately have kept men alive. Unfortunately, other health care providers know little about hemophilia so treatment of urgent health issues, particularly in emergency departments, seems riskier.
- Hemophilia is seen as a family illness leading to a great reliance on family (particularly one’s spouse). If there is no family, isolation increases.
- A few programs were proposed but when asked if they could make use of them the answer was “not now.” The men felt these programs were not for them, they were for others, or for later.
- Most of these patients have a sense of distrust and feel they are living on borrowed time. They have lost so many peers and feel the system failed them.

This study has sparked ideas and provided direction on the needs and mindset of the community. The CHS, Pfizer and its collaborators are now building concrete solutions to address these needs.

Finally, that last session featured a panel discussion on ageing.

Tim Ireland has severe hemophilia A and, when asked about the emotional impacts of pain, replied that he copes well, with very little pain medication. He did, however, note that he relies on anti-inflammatory drugs to keep himself on the tennis court.

Pam Wilton, a carrier with symptoms, stated that not having a specific diagnosis as she ages causes her some concern about future health decisions.

Patricia Stewart, a caregiver and partner of someone ageing with a bleeding disorder, shared what some of the challenges have been on a lifelong journey with her partner.

And Greig Blamey, a physiotherapist, helped us wrestle with the difficulties, from the health care perspective, of managing the disciplines associated with ageing and bleeding disorders. Gone are the days when we could just drop in to clinic once a year and get all our needs met. And that, folks, is a lifelong journey.
Advocating for comprehensive care – a Rendez-vous workshop

by Kimberly Kroll-Goodwin, director, Hemophilia Saskatchewan, and “hemo-mom”

Let me preface this article by stating this was my first Rendez-vous conference and a first for me attending any type of advocacy workshop. Although I came in very aware of how passionate we all are about hemophilia and bleeding disorders in general, I was amazed and proud of the high level of professionalism of this diverse group of people.

The advocacy training was well laid out and each session was abundant in providing many takeaways and tools for the attendees. For a newbie like myself, I walked away with a sense of confidence and a toolkit full of standards, guidelines, and a “how to” manual when it comes to lobbying and advocating for comprehensive care.

The Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders, authored by the Canadian Hemophilia Standards Group, was presented during the advocacy training. This is one of the many tools that were provided to us during the training session and is a great starting point for anyone looking to do any kind of advocacy work. The document outlines nicely what the desired standards are for bleeding disorder health care providers and centres, and can be used as a reference when establishing future needs for patients and their health care centres. It will be your best friend when trying to make a case for any advocacy work!

A highlight for me was listening to all of the experiential stories, not only from the presenters themselves, but also from others in the room who have “been there, done that.” Brian O’Mahony, chief executive of the Irish Haemophilia Society, was not only wise, experienced and witty, he also provided a safe place for people to discuss their own experiences in advocacy work. The discussions were always timely, relevant and honest. Mr. O’Mahony started the day by providing a great overview of what one should expect when lobbying, who to meet with, tips on dealing with the media, and just a general “how to” when advocating and lobbying.

The simulated meeting was a great way to end the day. The facilitators laid out the scenario well for us, and as a spectator I could truly imagine myself in that hot seat. Kudos goes out to the brave souls who were advocating for the additional physiotherapy resources. The simulation really provided us with a sense of what it would actually be like to have to research, plan and present to a CEO and their team to advocate for health care needs. My only “reproach” would be that it left me wanting to try out the simulation myself, however, there was not any time allotted for that. A consideration in the future might be to have the advocacy training be 1.5 days instead of one day so we can all try our hand at being “in the hot seat”, or to break out into groups to role play. All in all, the simulation was not only educational, but entertaining as well!

I want to send a huge thank you out to the advocacy team and presenters at Rendez-vous 2017 as I truly learned a lot and feel much more equipped should there ever come a time that I need to advocate – it’s comforting to know there are many resources available to assist us along the way.
Chapter development workshop at *Rendez-vous*

**by Christine Keilback, executive director, CHS Manitoba Chapter**

One of the most valuable parts of *Rendez-vous* is the opportunity for CHS chapter members to come together to see speakers and presentations that help build capacity in our own chapters. Meeting face-to-face gave us the venue to discuss the challenges that we all share and to learn from chapters who have had successes in different areas. The workshop has motivated the CHS and its chapters to consider reintroducing quarterly teleconferences to continue the discussions!

Finding the right volunteer for the job can be a struggle for chapters. Building an effective Board or working committee in the bleeding disorder community can be challenging if the pool of volunteers is small. CHS new president, Paul Wilton, gave a hockey-inspired presentation that highlighted the benefits of strategy in volunteer recruitment in the building of an effective team. Paul reminded us to scout the "rookies" in our chapters to look for the skill sets we are missing and invest in developing our young adults to be future leaders.

How we engage with our membership to deliver education and build community is rapidly changing. Social media is firmly ingrained in our society as a communication tool, even if the delivery tools change. L.A. Aguayo gave an inspirational presentation about how he turned around his life and met the challenges he faced from his bleeding disorder. L.A. has inspired many others though his #HemoLife social media feeds.

Matthew Radford followed L.A. with a presentation on the different social media tools and the steps needed to build a better social strategy. Matthew reviewed the different social media feeds, who is using them and the best times that work for posting messages. The CHS and many chapters have Facebook pages, Twitter, YouTube channels and Instagram feeds. Search for them and follow!

Deborah Franz Currie, CHS national director of resource development, spoke to the group about the trends in not-for-profit fundraising and the importance of measuring the amount of dollars and human resources it takes to raise a dollar. Deborah spoke to the success of peer-to-peer fundraisers and the value of sharing our stories with the general public: people give to people. She reinforced the importance of using positive messaging to inspire and involve people in our organization. The social media training we received will help with that.

The chapter development workshop allowed time for us to share our challenges and successes. The topic we discussed the most was youth (ages 15 to 25) programming. What does relevant and meaningful programming for them look like? In recognition that these young people are the future leaders of our organization and that we need their skills, energy and ideas, how do we engage them? We can perhaps look to some chapters with youth groups for some answers.

The learnings from the chapter development workshop have certainly touched on topics that are important to all of us. Hopefully, more regular contact between us can help us all move forward in volunteer development, fundraising, program development and community building. *Rendez-vous 2017* did not disappoint.
Ageing with a bleeding disorder: a new reality

by Rick Waines, Victoria, British Columbia

Wow, already over two months since Rendez-vous. The time has allowed me to reflect on our ageing with a bleeding disorder workshop and some of what we learned. For those who weren’t at the workshop, led by Yola Zdanowiec of Ensemble Strategies, we split the workshop up into three groups. Our task was to identify some key issues facing people who are ageing with a bleeding disorder and their caregivers, and hopefully identify some strategies to address them.

Our three groups focused on emotional impacts, pain and joint damage, and communication between patients, their HTC and allied specialists.

We are still in the process of digging through the notes from the session so I am not yet able to share the whole picture, but I will share some things that stood out for me. First of all, everyone came with their sleeves rolled up. There is a great amount of passion for understanding this new reality that so many of us are facing. We are the first generation to be expected to live a normal lifespan. Given what we have faced and how far we have come, from no effective treatment options in the 1950s to plasma fractionation and the development of life-saving clotting factor concentrates in the late 1960s and early 1970s, followed by the tragedy and costs of HIV and HCV infection for many, this is quite an achievement, but it has come with some great challenges.

People are dealing with a lot of chronic pain, and very few of us have a clue how to deal with it. We have mostly been using mind over matter along with wee fistfuls of analgesics. Most of us have not had much in the way of guidance on dealing with, what can be, sometimes, debilitating pain related to ageing. The good news is there are resources that can provide some help. The CHS publication *Pain: The Fifth Vital Sign* is a good example. The bad news is that almost no one in the room knew it existed. This resource is not a panacea, it will not solve all of your pain problems, but it certainly won’t solve our pain issues if we don’t have ready access to it. Ask your clinic about this resource and others that might help address your pain issues; many clinics keep such resources handy for people who need some guidance.

Caregivers, significant others and family members are also under tremendous burdens when faced with the many challenges of ageing. The people closest to us shoulder and share in our difficulties with mobility, our anxieties and work-related stress, and the emotional turmoil that accompany ageing with hemophilia. Our caregivers need to be supported by our organizations through workshops, gatherings and peer support. We need to learn more about the challenges they face so we can try to support them as they support us.

Finally, there is a very long list of complications that can arise when we have a bleeding disorder and get older. Patient education is crucial. It is my opinion that it is too much to expect our hemophilia treatment centres to take it all on. We already lean too heavily on them for treatment that isn’t specifically bleeding disorder related. So, as we age, it is going to be super important, more than ever, to have a general physician who can communicate with our HTC and with the many other specialists we are bound to have appointments with – someone who can keep an eye on the big picture and help ensure that the necessary information gets to the necessary personnel. I asked my own doctor about the problem of keeping everyone in the loop, and he had no easy answer. The only way to make sure our health needs get met is to become empowered. To be the custodian of our health, to ask questions, to become our own expert – which we already are in many ways – and share this knowledge whenever we are dealing with health care professionals beyond HTCs. Easier said than done sometimes, I know, but for the time being there is no other way.

Stay tuned for a more thorough reporting of our findings from the ageing workshop at Rendez-vous 2017.
It was called a Brave New World and for individuals with inherited bleeding disorders, it truly was. People with inherited bleeding disorders came together from far and wide and had the opportunity to learn about the new developments in the world of hemophilia. The three-day event covered conventional and new treatment plans for hemophilia and other bleeding disorders.

As in past years, I was fortunate enough to once again be involved with the youth group. I always look forward to attending this biennial event as it gives me the chance to catch up with lifelong friends, and create new memories with new acquaintances with similar disorders. This year we had the chance to attend medical sessions and focus groups, where we learned about new and possible future treatment plans, and improvements that have been made. My eyes were not only opened to new developments in hemophilia treatment, but also the experiences that others have with different bleeding disorders.

I was diagnosed with severe hemophilia A with an inhibitor when I was two days old, so I am already very familiar with many current topics in hemophilia. For me, Rendez-vous 2017 was a chance to interact and empathize with others who have journeys similar to mine. I also learned about the day-to-day struggles encountered with other bleeding disorders. This was humbling for me and it sincerely made me realize that even though we struggle, we continue to live strongly and well with the bleeding disorders we were born with.

For me, the most inspiring session was given by a fellow hemophiliac and my lifelong friend, Jeremy Hall. Jeremy shared his life story about the challenges that he has overcome, and where he is today. We have all had our moments in the dark – the ones where we felt there is no hope. We have asked ourselves, “Why me?” or “What did I do to deserve this?” Jeremy’s story was both powerful and humbling because he made me relive my past and re-ask myself the many unanswerable lifelong questions I’ve never received an answer for. Jeremy’s session reminded me that no matter what we have or continue to go through, there is always someone somewhere going through something much worse.

Jeremy also showed that no walls could keep him contained. He has a life and he wants to live it to the fullest – and he does just that. Jeremy’s hunger for life brought up new questions such as, “How will I live my life to the fullest?” and “How can I overcome the walls that have trapped me and my hemophilia for decades?” I was left with a lot to think about; Jeremy’s session was the alarm clock that I needed. Over the years, the most consistent value that has supported me on my journey has been hope. Hope has kept me going through my dark times, and even my brightest of times. But hope is not just for me. It is also for the parents of hemophiliacs and for our doctors who continue to develop treatment plans to help us live life to the fullest. Hope reaffirms that we have made it this far, and that we will continue to strive for our goals to live life to its fullest.

While our families and doctors can all benefit from this event, it is invaluable for patients – there is no greater support system for hemophiliacs than other hemophiliacs because no one knows what we go through better than others with bleeding disorders. We have been there, we have done that. For those who have not “been there” or who still need to “do that”, we are here to show them that we truly live in a Brave New World.

Rendez-vous 2017 was a reminder that it is so important for youths to come together and support each other. Together, we are the future of the organization. Together, we can get through anything.
The Annual Meeting of the Association of Hemophilia Clinic Directors of Canada (AHCDC) is always an exciting event to connect with colleagues and friends, discuss exciting trends and changes in bleeding disorders, and encourage new clinicians and trainees to join this rapidly evolving field.

The biennial Rendez-vous adds to that excitement, providing an opportunity to directly interact with both our patients and our allied health care partners at a level rarely seen in other areas of medicine. The ongoing and effective collaborative efforts by everyone involved in improving the care of people with inherited and acquired bleeding disorders remain an inspiration.

The CHS Rendez-vous Medical and Scientific Symposium sessions always highlight this cooperation between health care providers, patients and caregivers, and the incredibly positive results made possible when we work as a true multidisciplinary team. From the initial session exploring the new approaches to hemophilia care, which have the potential to revolutionize how we look at bleeding disorders, we moved into a review of the Canadian Bleeding Disorders Registry (CBDR), which serves as a means to monitor both treatments and outcomes. Beyond the update on the wonderful pace of implementation across the country, I especially valued hearing the experiences of the Montreal team as we prepare to bring the system online in Winnipeg. In addition, updates on the important issue of women with bleeding disorders and the final sessions and panel presentation on lifespan and lifestyle issues for people with bleeding disorders illustrate the enormous scope of what we do. This in turn reinforces the importance of true multidisciplinary and patient-focused collaboration to provide the best possible care.

On Saturday, we moved on to the annual Scientific and Educational Symposium of the AHCDC. In my 11 years as a member of the organization, I have happily seen this meeting transform from a venue for delivering reports and committee updates to an opportunity to learn about the scientific and clinical advances being made by Canadian health care providers in bleeding disorders.

The meeting started with an implementation update and technical demonstration of the CBDR, which we had heard about the previous day and would see again in light of its research and clinical potential. This was a fitting lead-in to the abstract presentations, which started with the rapid-fire presentations of our posters; each presenter had one minute to entice us to view their work during the breaks. The clinical case studies followed; as a pediatric treater, I was particularly struck by the young boy with hemophilia B and orbital complications of a subgaleal bleed, and reminded of the unique challenges of our Canadian population with its often distant geography. We also heard about a case of Obizur used in a patient with congenital hemophilia with inhibitors. This was a great opportunity to reflect on past experiences with porcine products, and I’m sure we will see much more about recombinant porcine factor VIII in future meetings.

After lunch, the scientists took to the stage, and we heard from two members of the Kingston Genotyping laboratory about new aspects in the genetics and analysis of von Willebrand disease and hemophilia. This was followed by clinical research in refining the approach to coagulation testing in the emergency department and evaluating desmopressin response in carriers of hemophilia A, a fitting counterpoint to the previous day’s session on women with bleeding disorders. The research session was appropriately concluded by a presentation from Drs. David Lillicrap and Paula James on the past, present and future of research within the AHCDC. It is always inspiring to see the quality of scientific work that comes from our Canadian investigators and through our national collaborations.

The afternoon concluded with the introduction of the ADVANCE Canada program focusing on hemophilia care in older patients, and a special presentation by Dr. Pål André Holme from Norway. While I joked that, as a pediatrician, my idea of care of older patients is transitioning them to the adult clinic, I recognize the importance of focusing on the unique issues of older patients with bleeding disorders. Ageing with hemophilia is the happy consequence of the improvements in therapies and care that we continue to see, and I expect that this Canadian collaboration will bear the same fruit I was able to witness over these two packed days.

The Annual Meeting of the Association of Hemophilia Clinic Directors of Canada (AHCDC) is always an exciting event to connect with colleagues and friends, discuss exciting trends and changes in bleeding disorders, and encourage new clinicians and trainees to join this rapidly evolving field.
Tapping your way to better emotional health

by Mandeep Toor, MSW, RSW, Adult Hemophilia Clinic, St Paul’s Hospital, Vancouver

“Your emotional health, your success in the world, and your level of joy can all be dramatically enhanced by shifting the energies that regulate them” – Clinical psychologist David Feinstein in his book The Promise of Energy Psychology.

Living with a chronic condition such as hemophilia can greatly impact a person’s energy system. Energy is seen as the blueprint of our bodies and our bodies are composed of energy pathways that are constantly working in flow along with our organs, cells, moods and thoughts. At the Adult Hemophilia Centre at St Paul’s Hospital, many patients experience chronic pain which can lead to stress and this can impact the flow of energy in the body. I wanted to be able to offer coping strategies which were different from the conventional therapeutic route, and which patients could do at home to help alleviate their stress. We cannot underestimate the psychological and emotional impact of having a bleeding disorder.

I had the opportunity to attend the Energy Psychology Conference in Halifax last year in November, where I was able to learn from various experts about energy psychology and how we can improve our overall well-being by taking control and healing our own bodies. Energy psychology has been referred to as “acupressure for the emotions” and builds upon conventional therapy principles. However it focuses on stimulating energy points on the skin, paired with specific mental activities, which can instantly shift your brain chemistry. Energy healing has been used in many cultures around the world for thousands of years and includes acupuncture, reiki and reflexology.

One particular method called tapping, is also known as the Emotion Freedom Technique, and it is similar to acupuncture – but without the needles! Tapping can help people manage a wide range of issues including pain relief, alleviating anxiety, and healing childhood traumas, fears and phobias. When we experience a flight or fight situation, our body’s defense system goes on alert and various changes happen in order to help us meet the challenge of the impending danger – our adrenaline goes into overdrive, our heart rate and blood pressure rise and our muscles get tense. Tapping on specific meridian points on the body can help to put the brakes on the flight or fight response and re-program the body and brain to react differently. With regards to chronic pain, as we continue to experience the pain, the emotional toll it brings with increases and can make the pain feel even worse.

I was able to experience first-hand the positive impact of tapping during the completion of the Clinical Fast Track program at the conference. You begin by stating two affirmations about a problem that you are trying to address. Using the example of pain, an affirmation would be Even though I have this pain in my ankle, I deeply love and accept myself. This affirmation is repeated as you tap, with your fingertips, on various meridian points on the body which can include, but are not limited to: above the eyebrows, the side of the eye, under the eye, under the nose, under the lower lip, and under the armpits. You move through this tapping sequence several times, eventually working through the problem you are addressing by changing the affirmation which can lead to reducing, or even eliminating, the problem.

Tapping is an option that I have presented to many patients and I have heard positive feedback on how well it has helped them to alleviate many symptoms that they are struggling with. A simple Internet search for tapping will yield several articles and videos that will guide you more in depth through this practice. This is only one approach as there are a wide range of counselling and therapeutic options available for managing pain. It is worth exploring to determine which approach works best for you.

Different strategies work for different people and it is worth exploring to determine if this approach works for you.

For more information on tapping and energy psychology, the following resources can help get you started:

The Promise of Energy Psychology by David Feinstein;
Novo's EHL FIX approved in Europe and U.S.

London – June 7, 2017 – Novo Nordisk’s extended half-life factor IX concentrate, branded Refixia®, has been approved for use by the European Medicines Agency for prophylaxis, on-demand treatment of bleeding and surgical procedures in adults and adolescents. Just ten days earlier, the U.S. Food and Drug Administration (FDA) approved the same drug, branded Rebinyn® in the U.S., for the treatment of adults and children with hemophilia B.

This factor concentrate, also called nonacog beta pegol or N9-GP when in clinical trials, is a glycopegylated recombinant factor IX molecule that has a five-times longer half-life than standard forms of factor IX. In the Phase III trials, once-weekly administration of Refixia maintained factor IX activity levels above 15 percent, and reduced the annualized bleed rate to 1.0.

While N9-GP has been tested in clinical trials in Canada, it has not yet been approved by Health Canada.

FDA fast tracks Sangamo/Pfizer’s FVIII gene therapy

Washington – May 15, 2017 – The U.S. FDA has granted Fast Track designation to SB-525, Sangamo’s clinical stage cDNA gene therapy candidate for hemophilia A. It is being developed through collaboration and a license agreement with Pfizer.

The FDA’s Fast Track designation facilitates the development and expedites the review of drugs and biologics to treat serious conditions that fill an unmet medical need.

SB-525 uses a recombinant adeno-associated virus (rAAV) to deliver a human factor VIII cDNA construct to the nucleus of liver cells with a single infusion, providing continuous therapeutic expression of factor VIII.

Preclinical studies report that SB-525 is significantly more potent than equivalent constructs being evaluated for hemophilia A. This treatment has the potential to produce clinically relevant levels of factor VIII protein using considerably lower doses.

Not all drug developments make it to the finish line

Montreal – June 22, 2017 – Not all promising drug developments make it through clinical trials, regulatory approval and commercialization. Overall, it is reported that 9 out of 10 fail somewhere along the line. Below are a few examples.

In May, Xenetic Biosciences reported on a Phase I/II clinical study conducted by its partner Shire, evaluating SHP656 (PSA-recombinant factor VIII). This is an extended half-life molecule intended for the treatment for patients with hemophilia A using Xenetic’s PolyXen™ technology to join polysialic acid to factor proteins. While there were no drug-related adverse events or FVIII inhibitors reported, predefined once-weekly dosing criteria and FVIII expression levels were not met.

Also in May, Dimension Therapeutics announced it had discontinued development of its experimental gene therapy treatment for hemophilia B, dtx101, based on aavrh10-based vector. Early study data revealed it would not meet the minimum target objectives for continued development.

In April, uniQure announced that it will not seek renewal in Europe of its marketing authorization for Glybera, the world’s first gene therapy. Glybera was not approved by the U.S. FDA. Glybera was first approved in October 2012 for hereditary lipoprotein lipase deficiency (LPLD), an ultra-rare genetic disorder. Glybera introduces copies of the relevant gene to produce the deficient lipase indefinitely; the longest term study has proven its efficacy for at least six years. Despite this, the company acknowledges that “Glybera’s usage has been extremely limited, and we do not envision patient demand increasing materially in the years ahead.” Moreover, uniQure was required by the European Commission to monitor patients over a long period of time, conduct a Phase IV clinical trial, undergo annual regulatory inspections and increase risk management precautions. Glybera will still be available to patients approved for the treatment before the withdrawal date.

uniQure plans to focus its gene therapy research on other programs in Huntington’s disease, hemophilia B, and congestive heart failure.
Focus on research

Research – what’s in it for me?

by Kathy Lawday, member of the CHS Research Advisory Committee

Research isn’t just for researchers, it is key to improving the lives of people with inherited bleeding disorders.

With a goal as big as a Dream of a Cure, it is often necessary to proceed one step at a time and nibble away at uncovering knowledge. Results from each of the projects funded in 2017 will add crucial information to our understanding of inherited bleeding disorders, how to diagnose and treat them or how to better manage therapy.

Understanding the bleeding disorder

Von Willebrand disease varies widely in severity between people and even within the same person at different times, making it difficult to diagnose accurately. In one type of VWD patients may lack von Willebrand factor in their plasma but have sufficient in their platelets to reduce bleeding severity. So studying such platelets and the role of platelet-VWF may help patients with severe VWD (Dr. Kahr study). Platelets are important in many inherited bleeding disorders including many characterized by low numbers of platelets. Using a mouse model that mimics platelet deficiency, Dr. Möröy’s research looks at how a gene (Gfi1b) is involved in platelet formation in the bone marrow and how this may lead to new treatments for platelet deficiency disorders.

It is easy to assume that a person with a bleeding disorder would not have problems with blood clots, but that is not always true. As the person ages, treatment of concomitant diseases may require use of a blood thinner which could put the patient at risk of major bleeding. Rachelle Li will study the structure of blood clots from a person with hemophilia with the addition of a blood thinner. The knowledge gained may help clinicians balance the opposing sides of the clotting process in difficult clinical situations.

Complications of therapy

Factor VIII inhibitor development is a major complication of hemophilia A treatment. Whether plasma derived or recombinant DNA factor VIII products are better is widely debated. A number of predisposing factors to inhibitor development have been proposed such as genetic factors and intensity of therapy but the question is: what triggers the immune system to react against the administered coagulation factor? Studying the effect on immune cells of different sugar molecules or different positioning will help in the development of new, modified factor VIII products (analogues) to reduce the risk of inhibitor development. Using a novel “humanized” mouse model of hemophilia, it might be possible to screen future new products for risk of inhibitor development prior to testing in patients (Dr. Lillicrap study). Gut bacteria can influence the immune response and Matt Cormier’s work in mice will seek to establish whether altering the gut flora affects the development of inhibitors and potentially development of tolerance too.

Improving health outcomes

As teens take greater responsibility for managing their hemophilia themselves, they face many challenges. Transition between pediatric to adult care clinics occurs at a stressful time of life. Identification of the education and support needed as they take on these challenges will guide development of a peer-mentoring program offering meaningful social support which in turn can improve health outcomes (Claudia Nguyen). Social media can be used to advantage in supporting such initiatives. Dr. Sun will identify what factors contribute to a successful transition between clinics as measured by clinical and patient-reported outcomes.

Guidelines for the care mothers and babies with hemophilia and other bleeding disorders receive during pregnancy, childbirth and the newborn period should minimize bleeding complications while preventing exposure to unnecessary tests and medical treatments (Dr. Moorehead study).

People with hemophilia and physiotherapists are partners in managing the effects of joint damage on daily activities and a good working relationship means better outcomes and satisfaction with care (Erin McCabe study).

Managing treatments

A tool is only useful if it is used. By exploring the ease of use and acceptability of the web-based reporting tool CBDR/MyCBDR, training can be optimized and the system improved to meet users needs which will encourage effective participation in bleed reporting (Prof. Heddle study).

These are research projects ongoing or commenced this year. For several of the investigators, the projects are just pieces of a larger study as knowledge from these research initiatives leads to the next question, to new research and applications to improve care and treatment, and quality of life in ways that were not evident at the outset.

Research – what’s in it for me?
Detailed descriptions of all the funded research projects are available at www.hemophilia.ca/en/research

**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 2017.**

**studentships**

**VWF in megakaryocytes and the role of platelet-VWF in VWD**

**Dr. Walter Khar**  
Hospital for Sick Children – Toronto, Ontario

**The role of FVIII glycans on the immunogenic potential of FVIII concentrates**

**Dr. David Lillicrap**  
Queen’s University – Kingston, Ontario

**Role of Gfi1b in the formation of platelets and in inherited bleeding disorders**

**Dr. Tarik Möröy**  
Institut de recherches cliniques de Montréal (IRCM), Department of Hematopoiesis and Cancer

**The link between the gut microbiome and inhibitor development in hemophilia A mice**

**Matt Cormier**  
Queen’s University – Kingston, Ontario  
Under the supervision of Dr. David Lillicrap and Julie Tarrant, Queen’s University

**A study of the clot ultrastructure when factor VIII deficient-plasma is coagulated in the presence of anticoagulants**

**Rachelle Li**  
University of Western Ontario – London, Ontario  
Under the supervision of Dr. Anthony Chan, Dr. Howard Chan and Jorell Gantioqui, McMaster University – Hamilton, Ontario

**Developing an evidence-based training program for mentors for a virtual peer-to-peer hemophilia mentoring program for teens**

**Claudia Nguyen**  
Ryerson University – Toronto, Ontario  
Under the supervision of Dr. Vicky Breakey, McMaster University – Hamilton, Ontario
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 2017.

Assessing the usability and user experience of the Canadian Bleeding Disorders Registry (CBDR) and MyCBDR

Prof. Nancy Heddle
McMaster University – Hamilton, Ontario

Canadian Hemophilia Management in the Perinatal Setting (CHiMPS)

Dr. Paul Moorehead
Janeway Children’s Health and Rehabilitation Centre – St-John’s, Newfoundland and Labrador

Outcomes indicators of transitional care in adolescents with hemophilia: a Delphi survey of Canadian hemophilia care providers and patient focus groups

Dr. Haowei (Linda) Sun
University of British Columbia – Vancouver, British Columbia

The CHS/Shire Fellowship Program

The Canadian Hemophilia Society – Shire Fellowship 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 inherited bleeding disorders. The fellowship is made possible thanks to generous financial support from Shire. The CHS is proud to be in a partnership with Shire in order to offer this important fellowship program.

THE FOLLOWING PROJECT IS BEING FUNDED IN 2017.

The assessment of therapeutic relationships in hemophilia care

Erin McCabe, PT
University of Alberta – Edmonton, Alberta
The Hemophilia Research Grants Review Committee, under the chairmanship of Dr. Manuel Carcao, met earlier this year and announced the 2017 grant recipients for the CHS Dream of a Cure Research Program. Descriptions of the projects can be found on the CHS website at www.hemophilia.ca/en/research/chs-dream-of-a-cure-research-program. These grants total $216,000 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 $4.3 million in support of hemophilia research in Canada since 1991 by supporting over 40 research projects and 30 studentships. This has made such a difference in quality of life for people with inherited bleeding disorders.

We have always depended on our hemophilia community – the provincial chapters, individuals, families and groups – which has provided financial support since the Club's inception in 1984. In 2016, CHS chapters and members collectively raised over $63,810 to increase the capital of the endowment fund. An additional $88,056 (including a $50,000 matching gift from the CHS) was directed towards current research.

You and your family depend on research, and research depends on you. The most effective way you can help bleeding disorder research in Canada is by supporting the HRMDC. To make a contribution, please contact Joyce Argall at the CHS national office (1-800-668-2686 | jargall@hemophilia.ca) or visit the TO SUPPORT US section of the CHS website.

As is our custom, we are pleased to acknowledge in Hemophilia Today our members and donors who truly understand that the Hemophilia Million Dollar Club 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 on the following pages. Our heartfelt thanks to all of you for your generosity!
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Ken, Darlene and Tony Poyser
Terry Douglas
Lyne Kubin and Family
C. Kang Tan
Mr. and Mrs. Joe Laxdal
Audrey Irene Saigeon
Poyser, Schultz and Glass
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Manitoba Chapter
The Isaacs
Northern Alberta Region
Toronto and Central Ontario Region
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Nova Scotia Chapter
Central West Ontario Region
British Columbia Chapter
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Susan Anderson

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Northern Alberta Region

In memory of Frank Schnabel
Art and Leona Olson
O'Shaughnessy-Molina
Ian and Gail Austin (Jeff and Tim Austin)
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Clam Chops II (Dr. Gerry Growse, Lois Lindner, Diane Rudd, George Stephenson, Cheong K. Tan)

Frank Bott and Family

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Scott MacDonald and Noise Solutions
In honour of Carter Ruklic
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In honour of Jack Spady
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In honour of Wilma McClure
Ian Austen
In memory of Jeff Austen
Tony, Jennifer, Jordan and Dylan Poyser
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In memory of Irene and Martin McPherson
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Plot to Clot 2013
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In honour of Catherine Hordas
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Dr. David Lillicrap
Margaret Cracknell
In memory of George Forbes-Bentley
Godin Family; Fernande, Donald and Guy-Henri
Northern Alberta Region
British Columbia Chapter
In memory of Captain Dick Rudd
Catherine Hordas
In memory of Andras J. Hordos
In memory of Captain Dick Rudd
Catherine Hordas

Volunteers from the 1st Annual Road Hockey Tournament
Dr. Martin Inwood, Dr. Irwin Walker,
Dr. J. Cranby, and the hemophilia nurse coordinators

Blanchette-D’Fana Family
In honour of their “Angel” Kevin Blanchette
Can-Ital Ladies Society
Ottawa and Eastern Ontario Region
In memory of Michel Frank

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 “Angel” Iris Halliday
In honour of their “Angel” Poppy Marie Halliday
Joan and Murray Kinlin
In honour of Benjamin and Nathan Gray
Ottawa and Eastern Ontario Region
In memory of John Wilson

Newfoundland and Labrador Chapter
Dimart Foundation
In honour of Alexander Mark Ernst
Elaine Dorothy Archibald and Guy-Henri Godin
We would like to thank all those who made donations:


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.
M y story begins a few days after my birth in British Columbia, when my umbilical cord fell off and then refused to heal. At every diaper change, my parents repeatedly put Band-Aids on my belly button and each time they soaked up blood. After two weeks, almost as if by magic, my wound finally stopped bleeding! The pediatrician asked for a blood test, but nothing out of the ordinary was detected.

During the summer after I turned two, I fell on the cement and busted my knee. I had a big scratch the size of a quarter that took almost a month to heal. Throughout that same summer, I had so many bruises on my legs that I looked like a child who’d been beaten.

Several months later, still worried about all my symptoms, my parents met with another pediatrician. More in-depth blood tests were performed and all the factors were checked to finally arrive at a diagnosis — I had a deficit of factor XIII. Worse, I had a severe deficiency of factor XIII. They found only .05% of factor XIII in my blood. And you know what? I am lucky in my unluckiness; only one in three million people are factor XIII deficient ... I always have a playful smile when someone says, “what are the chances that ...!”

So, here’s the million-dollar question I’ve heard hundreds of times now in my life: “But what is factor XIII deficiency?”

The short version I tell my friends is this: There are 13 factors necessary for your blood to clot. The 13th factor is like glue that holds your scab in place so the bleeding will stop. Without this 13th factor, the chain breaks down and the bleeding starts up again. So, I get infusions that boost my factor XIII level to protect me from spontaneous bleeding. I find this is a simple way to explain my condition and much easier for people to understand than the clinical version!

During that fateful meeting with the pediatrician, he explained to my parents that it was imperative that I receive infusions of factor XIII concentrate to prevent bleeding in my brain. My parents asked, “what’s the worst-case scenario if we chose not to proceed with treatment?” And the doctor replied, “If she does not have the infusions of factor XIII and is in a car accident, she will never make it to the hospital.” The decision was made instantly: I would start infusions in the coming weeks.

Ever since I was little, my parents made me aware of my health issues and whenever someone would ask me what could happen if I bumped my head, I would respond without missing a beat: “Bleed and die.”

A few months later, a three-year-old in pig-tails, I got my first infusion of factor XIII. I looked at my mom and beamed: “Look mommy, I didn’t cry!”
In the following weeks, my family and I moved to Yellowknife in the Northwest Territories. My new pediatrician, Dr. Sam Wong, had to familiarize himself with my bleeding disorder, not having known about it before. So, it was an educational experience for him. As resources were limited in Yellowknife, and we needed to be closer to a large urban centre, we moved to the South shore of Montreal. This is how I came to meet Dr. Georges-Étienne Rivard, a leader in the field of hematology-oncology in Canada.

After several visits to CHU Sainte-Justine, my parents had to learn to do my infusions, and naturally had a few issues at the beginning. I remember several years ago, after my mom had blown a couple of my veins and was almost in tears, I gently told her, “It’s ok mom, take your time, start again!” It didn’t stress me out or make me angry! Now, I’ll let you in on a little secret — I am trying to stretch out for as long as possible the day when my parents will pass the torch and I will self-infuse twice a week. I know … I should be doing it myself, but it’s my little quiet moment with my mom or my dad and I’m in no rush to take over that job!

I’ve been very lucky since birth to have no complications or internal bleeds and I’m crossing my fingers that it stays that way. On the other hand, any surgery comes with its own precautions, whether it be a simple dental extraction (I’ve had seven teeth pulled) or a major operation like the one I underwent six months ago. I was at Sainte-Justine February 6 of this year, for Dr. Stephen Parent to perform scoliosis surgery and repair my spine 50 degrees. Leading up to my operation, many consultations were held to ensure that everything was in place for “D-day.” It was the first time that Dr. Rivard had a patient with factor XIII deficiency undergoing surgery for scoliosis. He planned ahead and increased my factor XIII dose before and after my procedure to ensure that coagulation and healing went well. I was like his guinea pig!

To be honest this operation was no fun for me … or my parents, or my brother, or for the wonderful nurses who heard me groaning or yelling in pain! My big brother Josh had the hardest time seeing me like this. But it’s all over now. My surgery was extremely successful; I had no complications during or after and now I have an amazing straight back! The cherry on top is I no longer hear my mom saying: “Mimi, stand up straight!”

In short, I am a little bit special ... I have factor XIII deficiency, ADHD with hyperactivity, braces (for now), a 45cm scar covering two metal bars and 28 screws in my spine. Even though there are always risks related to my health condition, I don’t let them stop me and I take the necessary precautions. Let’s just say my early years were full of uncertainty and maybe some slightly exaggerated protections, right Mom and Dad?

At the end of the day, I’m a normal teenager with her joys and her struggles. I’ve just finished Secondary 2, I love my boyfriend Marwan, I frequently fight with my brother, I’m a motorcycle enthusiast and I give my parents a little bit of a hard time! I dream of becoming a pathologist and having children. I’m lucky to be surrounded by amazing people and I can’t wait to see what the future has in store!
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.