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This issue of *Hemophilia Today* is devoted in large part to *Rendez-vous 2019*, the flagship event of the CHS, which was held in Montreal from May 23 to 26.

You will be able to read excellent summaries by participants in the various sessions presented during the Medical and Scientific Symposium. A reminder that all of the presentations (23 videos, mostly in English, some in French) are available as webcasts on our YouTube channel at [www.youtube.com/user/CanadianHemophilia](http://www.youtube.com/user/CanadianHemophilia). Symposium participants benefitted from a simultaneous translation service that was greatly appreciated.

We took advantage of the opportunity provided by *Rendez-vous 2019* to hold our Annual General Meeting and present our 2019 National Awards to several key players in the bleeding disorder community. You can read about these exceptional people on pages 6 to 9 of this issue.

As well, as tradition would have it, our summer issue is also devoted to research. Kathy Lawday, a member of the CHS Research Advisory Committee, has written a summary of recent and upcoming studies funded through one of the CHS research programs. Brock Wilton, President of the Hemophilia Research Million Dollar Club, presents his 2018 report outlining several initiatives by members of the bleeding disorder community to directly encourage research at a time when low interest rates mean less money is available from the endowment fund to support research projects.

Enjoy your reading!
MESSAGE FROM THE PRESIDENT

by Paul Wilton

Over the past 10 years, the Canadian Hemophilia Society has experienced alarming decreases in revenue. CHS revenues support critical services including our work to ensure access to emerging therapies, our efforts to ensure treatment centres are adequately resourced, health care provider education and programs such as CodeRouge and inhibitor workshops.

In 2009, the CHS raised approximately $3 million. After a decade of declining revenue, the CHS raised $1.7 million dollars in 2018. An over reliance on pharmaceutical industry support, together with the falling prices of clotting factor concentrates have accelerated the decrease of revenues. On the one hand, the falling factor prices have helped decrease costs for governments; but on the other hand, the drops in price have led to less industry support and donations to the CHS than in previous years. Compounding this problem, some companies have left the hemophilia sector because declining factor prices have made the hemophilia market less lucrative. The CHS has made a compelling case that pharmaceutical manufacturers that profit from the sale of products used to treat medical conditions have a moral responsibility to reinvest in those communities through patient organizations. If the CHS is to continue to sustain the level of service we provide to the inherited bleeding disorder community, we must halt this downward trend in revenue.

You may be thinking: you’re only mentioning one side of the equation. If there is insufficient revenue, simply cut expenses. That’s a good point. And for the past decade the CHS has been doing just that. Did you know that our dedicated CHS staff members have selflessly reduced their hours to help us diminish expenses? We have relocated our headquarters to locations that are smaller and less expensive. Our Board of Directors and committees now do most of their work together by phone and Internet to reduce costs. We have worked to reduce expenses everywhere except for the programs and services that our community tells us are critical.

To continue providing these services, we must diversify our funding. That means we need to find other ways to raise funds. Many national organizations can conduct successful public campaigns, however, the prospects for a successful, wide-reaching fundraising campaign for us are grim. Think about it. Who does not have a family member or friend with heart disease or diabetes? Canadians can easily connect with those causes. Who has never heard of the pink ribbon campaigns for breast cancer? You can even buy a pink food mixer for your kitchen counter to support and remind you of the fight to end breast cancer. That pretty pink countertop machine even becomes a conversation piece. Your guests notice it and you end up talking about why you have it. Fundraising and awareness; brilliant. I just wish we had thought of that!

In contrast, most people in the general public have only a vague familiarity of hemophilia and rare bleeding disorders, which is oftentimes accompanied by misconceptions. Trying to raise funds from people who have no experience or knowledge of bleeding disorders has limited prospects. Fundraising is very competitive. You must connect to be successful.

We are trying something new. Our best opportunity to fundraise is within our own community. You may be saying to yourself, “Don’t I give enough already?” Maybe you give once a year. Maybe you respond to the ask from your provincial chapter, too. And let’s not forget the countless hours of your time as a volunteer. To you, we say thank you! We do not want to overstretch you, but we still need your help. When we launch our Member Engagement campaign this fall, we need you to share our message and, if you are comfortable, share your story so that those in your circle can learn what the CHS means to you and how our programs and services have helped you manage your bleeding disorder and improve your quality of life.

Maybe you are reading this and thinking “The CHS matters to me but I have never given before.” If so, please consider becoming a monthly donor. No contribution is too small. And please consider asking those in your communities to support our work.

Our hope is that by sharing our campaign and your stories in an appeal to your communities, we will together be able to increase our funding base, so that we can continue to provide advocacy, education and programs to Canadians affected by inherited bleeding disorders. In short, we need your help.
Passing of Dr. deVeber

It is with heavy hearts that we learned of the passing of Dr. L.L. “Barrie” deVeber on February 28, 2019. My family’s journey with hemophilia began with Dr. deVeber, who worked with Dr. Martin Inwood to establish the South Western Ontario Regional Hemophilia Program in London, Ontario. My parents were young, newlywed Dutch immigrants when I was diagnosed with hemophilia. With no family history of hemophilia, the diagnosis was a devastating surprise. My parents warmly recall how comforting Dr. deVeber was to them during this difficult time, and how reassuring to them it was to see the caring way in which he treated his patients, including me. For my parents, whose own parental support systems were an ocean away, Dr. deVeber assumed a father-figure role, something that came very easily to him.

Dr. deVeber was a gregarious presence, one to whom children gravitated and with whom parents immediately felt comfortable. He was the rare type of physician who did not merely practice medicine but sought to continuously improve it. Having championed advances in the treatment of childhood cancers, Dr. deVeber was excited to be treating hemophiliacs at a time when hemophilia treatment was rapidly evolving. He was passionate about improving care and treatment and preserving life, and so the events of the tainted blood tragedy, a health care system failure, would weigh heavily on his heart throughout the rest of his life. My family was fortunate enough to reconnect with Dr. deVeber two years ago, welcoming him to my parents’ home, reminiscing and introducing him to my four children. I’m grateful for Dr. deVeber’s presence in my life, and for the care and leadership he gave to the hemophilia community throughout one of its most trying times. 

– Emil Wijnker

MyCBDR/iCHIP Challenge Cup: And the winner is ...

MyCBDR (used in nine provinces) and iCHIP (used in BC) are systems used to report bleeds and infusions by patients/caregivers to their treatment centre personnel via computer and mobile devices. Their purpose is to improve the management of care.

The Canadian Hemophilia Society had a goal of reaching 95% reporting of home infusions by the end of 2018. To encourage timely and accurate reporting, and have a little competitive fun, the CHS launched the MyCBDR/iCHIP Challenge. The winning treatment centre would be the centre with the highest percentage of patients reporting well, as determined by their comprehensive care team, between September 1, 2018 and December 31, 2018.

At Rendez-vous 2019, with a score of 86%, the first MyCBDR/iCHIP Challenge Cup was proudly awarded to the Centre d’hémophilie pour l’est du Québec, CHU de Québec, Hôpital de l’Enfant-Jésus in Quebec City. Close runner-ups were the Hamilton Health Sciences Centre and the Children’s Hospital of Eastern Ontario.

Congratulations to the patients and their comprehensive care team! – C.R.
NATIONAL RECOGNITION AWARD

2019 AWARD RECIPIENTS

On May 25 in Montreal, in conjunction with Rendez-vous 2019, 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.

NOVA SCOTIA CHAPTER
Outreach to families with bleeding disorders

The Nova Scotia Chapter has dedicated tremendous effort to reach out to people with bleeding disorders in outlying communities in Nova Scotia. As care for bleeding disorders in Nova Scotia is based in Halifax, individuals and families who do not live centrally do not have the same access to programs, services and networking. To respond to this need, the chapter initiated outreach sessions which were held across the province. Approximately 15 individuals attended these sessions and the majority of them were new or unknown to the chapter. The organization of these meetings was done entirely by volunteers. Members of the chapter board were sent to each of the areas to promote these sessions. Posters were made and families in a particular area were contacted directly by e-mail or phone and invited to attend.

The Nova Scotia Chapter receiving the award from Paul Wilton. From left to right: Dianna Cunning, Paul Wilton, Rachel Wright, Emileigh Van Dusen and Katie Hines.
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.

SUE VAN OOSTEN, RN

The commitment and dedication of Sue’s service to the Nova Scotia Chapter is extraordinary. Her outstanding leadership qualities have been displayed repeatedly through the years of her volunteering with the Nova Scotia Chapter and the Canadian Association of Nurses in Hemophilia Care (CANHC). For Sue, being the Bleeding Disorder Clinical RN is more than just a job and a career.

Sue has been a long-time advocate and supporter for the NS Chapter. Sue has done it all. She sat on the Board of Directors for eight years, stepped away for two, and most recently stepped back onto the board as the new Medical Liaison. She was co-chair of the Family Weekend for eight years and assisting in fundraising.

Sue’s involvement has also been extraordinary with the children’s summer camp. Her enthusiasm for the camp to be not only successful, but to make a marked difference in the children’s lives, is outstanding. For the past 11 years, she takes time off of work, and volunteers for the entire seven days that camp runs, each year. Any camper that comes to camp is educated about their bleeding disorder and also learns how to self-infuse. Part of her motivation is to create long-lasting relationships with the campers and to assist them to become independent and educated about their bleeding disorder. She is always going above and beyond!

Sue has brought professionalism, amazing leadership, skill, passion and desire which has impacted (directly or indirectly) all of the Nova Scotia members – we are blessed to have such an individual within our organization.

KATHRYN PODREBARAC

Kathryn Podrebarac is the founder and Principal of Podrebarac Barristers Professional Corporation. Prior to founding this firm, Kathryn practiced for several years at Blakes, one of Canada’s leading national firms. Kathryn has been working with the Canadian Hemophilia Society for more than 25 years. In 1993, she and Bonnie Tough were chosen to represent the CHS during the Commission of Inquiry on the Blood System in Canada (Krever Commission). In addition to very ably representing the CHS perspective during the four-year inquiry, she travelled from coast to coast and helped many individuals with hemophilia tell their stories to the Commission.

In 1998, Kathryn again represented members of the bleeding disorder community, this time in the Hepatitis C Class Action Suit. This resulted in the 1.2-billion-dollar Hepatitis C 1986-1990 Class Action Settlement. Her legal skills were called on again in 2015 when the federal government attempted to recover a surplus in the fund. Finally, in 2017, Kathryn’s view prevailed and the Courts decided in favour of the victims of tainted blood; the surplus was redistributed to them and their families.

In 2009, the CHS obtained standing in the case of Canadian Blood Services vs. Kyle Freeman, and again called on Kathryn’s legal acumen and knowledge of blood system issues in a civil trial that lasted 35 days. The Ontario Superior Court ruled with CBS and the CHS that blood donation is not a right and that authorities can take reasonable measures to protect the blood supply, even if they discriminate.

Beyond these formal interactions, Kathryn has always been accessible to advise and guide the CHS on a wide range of issues. Moreover, she has been extremely responsive to individuals who needed help in navigating the bureaucracy of the class action settlement.

EXCEPTIONAL SERVICE AWARD

This award is presented in recognition of an individual or organization who, through exceptional service over a number of years, has contributed to the growth and development of the mission of the CHS at the national level.

KATHRYN PODREBARAC

Kathryn Podrebarac receiving her award from Dianna Cunning.

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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.

DAVID PAGE

David Page exemplifies all the qualities for which the Pierre Latreille Award is given. For years, David gave volunteer service to the bleeding disorder community both in Quebec, Canada and internationally. David joined the CHS staff as Director of Programs before being its Executive Director. David stepped down from this position to become the Director of Health Policy, enabling a fresh perspective in the two Co-Executive Directors that he is able to mentor in their new roles. David is the face of the Canadian Hemophilia Society across Canada and internationally.

No one can question his depth of knowledge of hemophilia – learned the hard way, enhanced by extensive reading and consultation. He is always ready to share his knowledge with others via a ready e-mail or phone call and the challenge of the future is that we won’t know the extent of his knowledge until we can no longer tap into it.

He has steadfastly fought for access to best care and products in Canada and has applied these advocacy skills to assist other national programs. Not just active at the national level, he has supported chapters during staff changes and has mentored volunteers to take on the challenges of leadership.

By never being limited by his inherited bleeding disorder, he “walked the talk” for young people.

DR. ROCHELLE WINIKOFF

Dr. Rochelle Winikoff is passionate for the care and treatment of all patients at the Hemostasis Centre at CHU Sainte-Justine in Montreal, but in particular her dedication is to the care and treatment of women with bleeding disorders of all ages and types. Since 2003, she has been the Clinical Director of the Women Hemostasis Multidisciplinary Program at Sainte-Justine and co-chairs the Women with Bleeding Disorders Committee of the AHCDC.

Dr. Winikoff has volunteered on several CHS projects dealing with women’s issues, both in Quebec and at the national level.

The volunteers who have worked with Dr. Winikoff have been impressed by her knowledge and the passion with which she approaches her work. She is always willing to share her skills and knowledge with patients by participating in educational and support workshops across the country. She has helped explain complex medical details, making them understandable, while respecting patients as equals. Rochelle has a warm and welcoming personality, putting her patients at ease and explaining difficult situations in the lives of women with bleeding disorders. Attending presentations by Rochelle, you can always see the passion she has for women’s issues. And the humour she brings to her presentations helps to lighten the seriousness of this challenging medical condition.

Dr. Winikoff has done presentations across Canada, as well as internationally, including at World Federation of Hemophilia congresses, along with numerous poster presentations. She is also involved in several research projects on a wide variety of hemostasis issues. She works tirelessly to improve care and treatment for all people with bleeding disorders, with a particular passion for the challenges with which women with bleeding disorders must deal.

Dr. Winikoff receiving her award from Patricia Stewart.
**INTERNATIONAL CONTRIBUTION AWARD**

This award is presented in recognition of a volunteer who, through continuing efforts over a number of years, has made a significant international contribution to the development of care and services for people with bleeding disorders.

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**MILENA PIRNAT**

Milena Pirnat, her husband and young son, fled war-torn Bosnia to come to Canada as refugees. Locating to a new country, a new language and her son’s diagnosis of hemophilia, was overwhelming. Milena came to the CHS Manitoba Chapter (CHS-MC) for support, advice and guidance. Milena’s background as a physician in Bosnia, and her Master’s Degree in Public Health from the University of Manitoba, fuels her passion for education and support for women and families managing inherited bleeding disorders. She has become a regional, national and international volunteer leader in the inherited bleeding disorder community.

In 2010, Milena created the international Facebook group, Hemophilia Mother, to provide education, information-sharing, and emotional support for women in the bleeding disorder community. Hemophilia Mother has over 7,700 members worldwide.

She recommended to the CHS-MC Board that they embark on a chapter twinning through the World Federation on Hemophilia (WFH). Milena is the chair of the CHS-MC Twinning Committee and their work in Mongolia won them the 2018 Hemophilia Twins of the Year Award from the WFH. They helped our friends in Mongolia successfully receive a grant from the World Health Organization to improve awareness and knowledge of inherited bleeding disorders in health care providers across Mongolia. Milena and the CHS-MC Twinning Committee have already applied to participate in another twinning with Serbia.

Milena joined the CHS National Twinning Committee in 2014 to help with the twinning partnership with Bangladesh. She is also part of the CHS National Twinning partnership with the Philippines that began in 2018.

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**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.

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**RICK WAINES**

Rick Waines is 53 years old with severe hemophilia A, HIV, and has been treated (and cured!!!) for hepatitis C. He credits the CHS as an important advocate and resource for his family since its inception in 1953. His uncle, Bill Rudd, was twelve in 1953, and the first in the family to have severe hemophilia A. Rick’s grandfather started the BC Chapter, and he and his parents, served on the board.

Rick is a valuable member of the CHS Blood Safety and Supply Committee (BSSC). He has mastered some of the key issues that the BSSC faces - paid plasma, MSM deferral, access to novel products. His voice in these issues has been impactful.

Rick also chairs the CHS Education Committee. As chair, Rick runs a pretty tight ship making sure the committee members are consulted on CHS programs and address issues as they surface. Rick was also involved in an informal Ageing Committee which led him to be involved in the ageing consumer workshop at Rendez-vous 2017 and then the Ageing Retreat in 2018. He chaired the Ageing Retreat planning committee taking initiatives such as the In my time project. He is a contributor to the Sage Page of Hemophilia Today. The magazine’s readership has been fortunate to read his delightful, clever and insightful texts for the past six years. His sense of humour and candid personality make him a joy to work with.

Rick uses his story and his personal life as an example, and never turns from the stigmas of HIV. While his accomplishments on CHS boards and committees are quite evident, his greatest accomplishment is just being Rick. He has a way of moving people with his gift of humour, showmanship, taking difficult moments and easing them into laughter. On a board that faces difficulties, we look to Rick for his wisdom; he lightens us up and forces us not to take ourselves too seriously. It is humbling. Simply put, we believe wholeheartedly that Rick is a gift to our world.
Saying goodbye to some great health care providers

Best wishes for a very happy retirement to nurse coordinator Sue Ann Hawes (NS); social workers, Clarke Dale (NL), Lorraine Muise (QC) and Hulda Niv (AB); and physiotherapists Gail Bellussi (NS), Cathy Walker (ON) and Nichan Zourikan (QC). 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! – R.L. ☺

The 2019 CHS Board of Directors

Front row, from left to right: Milena Pirnat, Carmen Nishiyama, Rick Waines and Brenda Godin. Middle row: Wendy Quinn, Kathy Lawday, Kristen Walsh, Bruno-Gil Breton, Cathy Wright and Dianna Cunning. Back row: Emil Wjinker, Jeff Jerrett, Paul Wilton, Doug Carr and Rachel Wright (sitting in for Erin Van Dusen).
The year 2019 marks the 60th anniversary of the CHS Quebec Chapter (CHSQ) and we are proud and delighted to have hosted Rendez-vous 2019. A warm thanks to CHS leaders and organizers for celebrating the anniversary with us by holding the conference in Montreal and offering a bilingual program with simultaneous translation. Downtown Montreal was a great location for visits and impromptu meetings around the event. We shared many wonderful moments.

Rendez-vous 2019 brought hope for the short and medium term with a host of innovative treatment alternatives either entering the market or on the verge of doing so. Beyond pharmaceutical solutions, we were also able to discuss advances in treatment methods and approaches that our bleeding disorder treatment centres will soon be introducing.

Throughout its 60-year history, the CHSQ, like the CHS and other provincial chapters, has overcome many challenges. Its leadership work remains essential to continued progress in access to quality treatment, which translates to a better quality of life for members and in turn, has an international impact.

Blood brothers and sisters, we are at a pivotal time where we must transfer our experience and expertise in patient representation and advocacy in order to face the realities of today and the challenges of tomorrow.

As in many sectors of activity, one of the issues we currently face is the passing of the torch from dedicated, long-time employees and volunteers to ensure that their roles and responsibilities are carried on and that experience and expertise continue to be developed by our organization in order to maintain and improve the quality of life of people with inherited bleeding disorders.

It was great then to see a strong curiosity and genuine desire among our younger members to learn more about the various bleeding disorders and, above all, how the CHS and its provincial chapters work. During an activity for the youth, they were invited to identify needs and learn about how they can actively contribute to the well-being of our community.

As for the 60th anniversary of the CHSQ, our staff was on hand throughout Rendez-vous 2019 to meet other members of the CHS community. In fact, Quebec was well represented over the weekend by many people with bleeding disorders and health care providers, all of them proud to host colleagues and friends in Montreal while having an opportunity to make wonderful new connections.

On behalf of the CHSQ, I would like to thank all those who participated in Rendez-vous 2019 and made it a resounding success. We hope for a future in which the members of our community enjoy good health and an optimal quality of life with minimal impact from inherited bleeding disorders.

We look forward to continuing to work together for the well-being of all.

Participants from the Quebec Chapter at Rendez-vous 2019.
Rendez-vous 2019, presented by Pfizer, was held in Montreal from May 23 to 26, and hosted by the Quebec Chapter in celebration of its 60th anniversary. The event proved to be, once again, an essential gathering of the Canadian inherited bleeding disorder community with over 270 health care providers, industry partners, patients and their families, coming 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 24, as well as from other events held throughout the Rendez-vous weekend. – C.R.

Webcasts of the symposium’s presentations are available on the CHS YouTube channel at www.youtube.com/user/CanadianHemophilia.
THANK YOU!

On behalf of the inherited bleeding disorder community, a sincere thank you to the sponsors of Rendez-vous 2019 for your invaluable support of the Canadian Hemophilia Society.

The collaborative efforts of our sponsors, health care providers and our community is vital 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.

PRESENTING SPONSOR

[Image of Pfizer]

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Promising prospects

by Wendy Quinn, Prince Albert, Saskatchewan

We all come to Rendez-vous with a common thought in mind – what is the latest, what is the greatest, what is in the future for bleeding disorders? It was fitting that the Medical and Scientific Symposium was kick started with the topic of Novel therapies – One size does not fit all. As we sat in anticipation of learning about the prospects for gene therapy, novel products that require no more IV access, and cost-effective management of inhibitors ... whatever the question, this session had many answers.

First up was Dr. Manuel Carcao who addressed EHL factors: Do they make a difference and are they here to stay? It was fitting to not get too excited to meet the new kids on the block (like Gene), but also acknowledge our present faithful friends (like EHL). Dr. Carcao did a fine job in presenting a comparison of SHL (standard half-life) and EHL (extended half-life) treatments, and how the use of EHLs has improved quality of life: fewer pokes, fewer bleeds and better trough levels. Dr. Carcao reports that 86 per cent of patients at Sick Kids in Toronto are on EHLs. So, Do EHL factors make a difference? You betcha they do!

Next up was a story that went from great despair to great triumph. The story was of an eight-year-old boy with hemophilia A and inhibitors – it was his personal story of how he bled so much once upon a time, but not so much anymore. The hero of the story: emicizumab (Hemlibra). Dr. Mark Bellettrutti presented the Clinical experience with emicizumab in patients with inhibitors, and took us through the explanation of emicizumab, how it mimics factor VIII to join activated factor IX and factor X to generate the thrombin needed for clotting in hemophilia A patients. He outlined the Haven 1, 2, 3 and 4 clinical trials that yielded very positive data showing the effectiveness of emicizumab in managing hemophilia A patients with inhibitors, as well as non-inhibitor hemophilia A patients. All boxes checked here: for inhibitors – cost-effective, convenient to give, decreased ABR (annual bleed rates). What more could you want? He then took us through the challenging life of this eight-year-old boy who did it all to manage inhibitors – FEIBA (factor eight inhibitor bypassing activity), ITT (immune tolerance induction), and immunosuppression – all of which eventually failed him and resulted in complex uncontrolled bleeds, and a family in the deepest despair. Emicizumab was made available through compassionate access, and after he received it HE HAS HAD ZERO BLEEDS. Say no more, fairy tale ending, but it is real ... oh so real.

Then followed Dr. Shannon Jackson who helped us look at our present realities and anticipate the future in her presentation What does the future hold for the management and delivery of care? With new therapies emerging, she described what clinics may look like and what new therapies will mean for patients. Will patients be so well taken care of by the new products that clinics may not be as needed, given that patient autonomy will be high? The new therapies, on the other hand, will be highly technical and need solid expertise and management. She presented the crystal ball, but unfortunately she is a stellar hematologist but not a fortune teller. The take away was this: patients need to always stay in touch with their clinics and share their data as it is relevant patient outcomes that will shape the landscape of treatment. Data systems like the Canadian Bleeding Disorders Registry and the MyCBDR app will be very important at capturing patient experiences, and these experiences will be the basis for acquiring future novel therapies.

The last presentation was the one that made us consumers really perk up and listen intensely. Gene therapy – a possible cure? Dr. Jerry Teitel helped us understand the existing gene therapy situation in his presentation simply titled Gene therapy for hemophilia. Here are a few fun facts: 1) There are no licensed gene therapies yet, only clinical trials. 2) There are 13 clinical trials currently, and the access to the trials is competitive. 3) The prospects for positive regulatory approval are expected in one to three years. Like all things, there are the positives and the negatives with gene therapy. The positives: it’s a full or partial cure, it’s a one-time dose. The negatives: success is not guaranteed, one strike and you’re out, and the long-term risks are not established yet. So the costs: a 30-year-old patient treated for 10 years with prophylaxis (3 times a week) vs. gene therapy: $1.7 million for the prophylaxis patient, and $1.0 million for the gene therapy patient. If you are considering joining a clinical trial, you would have to be more than 18 years old, with no inhibitors past or present; some trials include patients with HIV with normal immune function, whereas those with HCV or anti-capsid neutralizing antibodies are excluded. This remains very, very promising.

Many thanks to the esteemed presenters who made us walk away with new knowledge and new hopeful thoughts for our future.
Those new treatments that are changing lives
by Rick Waines, Victoria, British Columbia

Care of folks with bleeding disorders has been improving steadily since Judith Poole first discovered cryoprecipitate in 1964. Tainted blood aside (I can’t believe I just wrote that), the products we use to control bleeding are more effective than ever before, but there are still many obstacles to optimal care: intravenous (IV) infusions (every day in some cases), the terrible burden of inhibitors, trough levels that leave us vulnerable to breakthrough bleeds, adherence to prophylaxis, and the emotional toll of painful infusions in children are just a few. You likely have some of your own I have overlooked.

But for the first time, there are treatments approved, available, or in phase 3 clinical trials that will radically change the bleeding disorder landscape. In the first session of Rendez-vous 2019 in Montreal, Novel therapies - One size does not fit all, we heard two perspectives on how these advancements are changing people’s lives.

I’ll never forget the first person I met who had undergone gene therapy, it was last year at the Hemophilia World Congress in Glasgow. For me the future arrived when I met the young man who radiated with his newfound freedom. This year at Rendez-vous I met my second person who described his experience with gene therapy this way: “You walk out of the hospital and leave your hemophilia at the door. This is magical!” John Konduros is – or was? not sure, – a hemophilia B patient with factor levels around 1%. He described his childhood through to university as generally normal interspersed with injury episodes. He would miss school for a couple of weeks at a time, about twice per school year, each time needing 1-2 months for recovery. As an adult, John treated bleeds 4-8 times a year on average. John didn’t mention being on prophylaxis so we must assume that it wasn’t a good fit for him, and I think we can agree that while 4 to 8 bleeds a year might have been an amazing outcome in 1964, the year John was born, it doesn’t measure up in 2019. John doesn’t have inhibitors. In 2014, John suffered a severe leg injury while shovelling snow and spent 10 days in hospital, then one month with a walker, one month on crutches, three months with a cane, and another three months getting back to normal. This major bleed and prolonged recovery was a big reminder, he said: “Hemophilia is a very ugly disease and no matter how good I get at controlling it, it’s always there ready to pounce.”

Now, there are many reasons gene therapy will not be for everyone. For example, women are not allowed into clinical trials for existing gene therapies, so that is over half the bleeding disorder community; if you already have an immune response to the protein used in gene therapy, you will not be an eligible patient; and hepatitis C or liver damage, common in our community, can also be a barrier to access. Here, John got lucky; he is a man and he was cured of his hepatitis C in 2015. So, on June 6, 2016, John underwent gene therapy and today has 40% factor IX expression and has had “no bleeds at all, and nothing coming close to bleed.” Is gene therapy perfect for John? He explains life since treatment: “I still get panicky if I have just hurt myself and a fear washes over me...
and I need to consciously repeat, ‘My factor is 40%, I’ll be OK.’” John’s physical activity and endurance have both improved and there are no surprises the next day. And, he says, there are simple pleasures like not having stiff joints and muscles in the morning, no limping and pain getting on and off airplanes, or out of movie theatres. He doesn’t worry about how far away his fridge is and doesn’t have to bring treatments with him on out-of-town trips. I don’t know about you, but to me, this sounds like a pretty great outcome. If only it could be so for all folks with inherited bleeding disorders.

We also heard from Leanne, mother of Jace, an eight-year-old with severe hemophilia A and inhibitors. Leanne’s telling of Jace’s journey with his condition – the triumph of advocacy and advancements in Jace’s care – left very few dry eyes. It is so great to have an opportunity to be overwhelmed, in a good way for once, by a truly transformative treatment becoming available and hearing about the impacts on a family. In the hemophilia community we are no strangers to tears; what a relief to be wiping away tears that sprung from a little boy being released from the terror of living with inhibitors. The seven-year odyssey from his diagnosis with an inhibitor at 14 months until his first dose of emicizumab sounded, at times, like any parent’s nightmare, never mind how hard it must have been for Jace.

At five years old, Jace began having bleeds one after the other and often several at the same time. He was being infused up to five times per day with Wilate (VWF/FVIII concentrate) and Niastase (rFVIIa) and had to rely on a walker, wheelchair, or help from an adult to get around at school. Crutches were causing arm bleeds and the walker was causing hand bleeds. Jace’s implanted vascular access device (port) was accessed so frequently it needed replacing several times over the next few years.

Treatment after treatment failed. By the time Jace was seven years old, it seemed the only drug left for his prophylaxis was Niastase, which is an incredibly burdensome treatment with a half-life of only two hours. Jace was in and out of the hospital for months, missing many days of school, while his mother and father missed many days of work. Their older son was missing his little brother and his family all being together.

Just when they thought things were bad, they got worse. Jace was released from one of his weekly hospital stays and got to spend a nice day at home – where he innocently jumped off his bed, resulting in a right ankle bleed. Niastase was administered at home every two hours, but it was not helping. It was a long night of pain. Usually Tylenol worked but this time it was doing nothing for him. At the hospital the next day, Jace was given morphine for the pain and this still was not helping. He ended up being hospitalized for two months in excruciating pain from the bleed as Niastase was no longer effective for him. The pain team was brought in but complications kept coming. He developed a bone infection and was treated with IV antibiotics that caused him to be sick and develop a rash all over his body. There were days he did not sleep and would scream from the pain. Leanne consulted with her uncle who lived through the tainted blood tragedy, during which some people chose not to infuse rather than increase their risk of HIV infection; he advised that the bleed would stop without factor but would be painful and take time. I can only imagine how painful this would have been for both Jace and his family.

They knew emicizumab was their best and only option, but it was not yet available in Canada. Jace had been previously denied access to emicizumab because he was under 12 years old. There were no clinical trials available for him to take part in. They reached out to everyone they knew to help them get this medication for Jace. CHS National Director of Health Policy David Page, Dr. Mark Bellettrutti and nurse coordinator Heather Bauman from their HTC, and other Edmonton hematologists worked together to craft a strategic summary of Jace’s case. Jace gained access to compassionate care use of emicizumab in April of 2018.

Before being granted access to emicizumab, Jace, at only seven years old, asked his mother if he was going to die ... Today he is able to join school sports teams like handball, running, and basketball. He can go outside for recess and participate in gym class. He can play sports with friends and even go on the odd trampoline. Jace’s family has had no disruptions to their family life from hemophilia’s unpredictability since beginning emicizumab.

Thanks to the efforts of Leanne, the CHS, the treatment centre in Edmonton, and the many folks across Canada who took the time to write to ministers of Health across Canada, emicizumab is now approved and available in Canada for severe hemophilia A patients with inhibitors. Jace’s outcome would have been very different without these advancements in care and our bleeding disorder community, which pressed Canadian Blood Services and its funders to make this life-saving, cost-saving drug available.

We are very fortunate in Canada to have access to some of the best care available for people with inherited bleeding disorders. Access to new therapies like emicizumab and gene therapy must not be taken for granted; we must redouble our efforts nationally and provincially, or prepare for our access to the best care to diminish.

Great amounts of this article were lifted directly from John and Leanne’s presentations at Rendez-vous, any inaccuracies or misrepresentations are mine alone.
CBDR is the clinician portal to the Canadian Bleeding Disorders Registry and MyCBDR is the app (or portal) that patients use to update their patient records and also serves as a self-management tool. Since July 2015, MyCBDR and CBDR have gradually been integrated in HTCs across Canada. This article presents some of my thoughts on this based on Session 2 of this year’s CHS Medical Symposium in Montreal as well as my own experience using the app.

During the session, multiple perspectives intersected to highlight the effectiveness of CBDR/MyCBDR. Kay Decker, RN, of the Hamilton Health Sciences Centre, described how these two systems greatly facilitate the flow of information between all the different players of the clinic, including patients, caregivers and even learners (medical residents).

MyCBDR and CBDR are not only effective tools on their own, but they are gradually being coupled with other tools, such as the Web-Accessible Population Pharmacokinetic Service – Hemophilia (WAPPS and myWAPPS, as well as the Patient Reported Outcomes, Burdens, and Experiences (PROBE) study. Dr. Alfonso Iorio presented WAPPS, an interface in which the care team enters the patient’s pharmacokinetic data. This information is integrated and updated in real time with the bleed and infusion data entered by the patient in MyCBDR and accessible via myWAPPS, which gives the patient access to fairly precise real-time estimates of their coagulation factor level at any time. This information can be useful to better plan physical activity in accordance to one's factor level, for example.

David Page presented the PROBE study. You probably already know that PROBE is an international survey of patient-reported outcomes in hemophilia. The survey, which has many uses, notably in research and advocacy, will now be integrated within the MyCBDR interface. This will make it much easier and quicker for patients to fill in every year.

To these, I would like to add my own personal experience using MyCBDR, which had an observable impact on my health and allowed me to partner with my care team. Since 2011, my annual bleeding rate has been dropping steadily. As you can see in the following charts from MyCBDR, between 2010 and 2018, I went from 24 bleeds in multiple sites of my body to a total of 7 bleeds in 3 sites.

The graph from 2018 shows an obvious trend: 5 out of 7 bleeds were in my left ankle. The same could be observed in 2017.

During the fall of 2018, walking to work, I had a spontaneous bleed in my left ankle that gave me acute pain and made me limp for over a week. I knew right away this bleed was unusual. It seemed
to appear out of nowhere and I went from nothing to full acute pain in the space of a few minutes. I called my care team and scans subsequently showed extensive damage in my ankle. This was causing the spontaneous bleeding. My treatment plan was then modified to compensate and, so far, I have not had a bleed in my left ankle in 2019.

I had already told my care team that I “felt” something was wrong in my ankle before this event. However, this time I used the various MyCBDR graphs to communicate my concerns in a language my care team would understand immediately. This is what I call the language of health outcomes. When you say to a busy clinician that you “feel” something is wrong with a joint, they might move on to some other pressing matters. However, when you say that in the last two years, an average of 77 per cent of your bleeds occurred in your left ankle (in 2017, 83 per cent of my bleeds were in my left ankle) and that they were all spontaneous, now you’ve got their attention.

MyCBDR gave me the tools to communicate more efficiently with my care team, which led to a fast diagnosis and adaptation of my treatment plan. This in turn has led to almost immediate improvements in my quality of life. I no longer even have chronic pain in my left ankle, which turned out to be constant micro-bleeding caused by joint damage.

MyCBDR helps communication between all the players of the clinic and the patient, acts as a point of convergence for other tools such as myWAPPS and PROBE, and is becoming an invaluable lever for self-management that can enable patients to actively contribute to their care plan and enter a partnership relationship with their care team.

It is quite interesting to think of the fundamental changes an app can have on the way care is delivered, and I look forward to seeing how things evolve in the future. One thing is certain: my joints won’t complain.
I would like to start by saying how much I enjoyed all of the sessions at Rendez-vous this year, and am delighted to be reporting back on the Women and bleeding disorders presentations.

For those of you who know me, you are well aware that my #1 passion is advocating for summer camp programs, but advocating for women with bleeding disorders comes in a close second.

How many times have we all heard those words: “You’re JUST a carrier”? If only we had a dollar for each time, we would likely all be rich at this point.

Growing up I struggled with this a lot. I remember being invited to go to camp as my brother’s “buddy” and one of my very first friends in my cabin was a girl with von Willebrand disease. She was Type 1, had symptoms such as heavy menstrual cycles, easy bruising and random nose bleeds, and I thought to myself, well, that sounds like me! Maybe I have VWD? I remember talking to my mom about it when I got home and she quickly explained to me that I was “just a carrier”. And that was the start of what would soon be a trendy answer from everyone I ever talked to about my bleeding issues.

Dr. Michelle Sholzberg

In one presentation, Dr. Michelle Sholzberg quoted a doctor saying, “You’re just a carrier” to a patient and she responded, “Give me an hour and I’ll educate you on that.” And while everyone in the room chuckled, nodding their heads in agreement, I couldn’t help but reflect on my own personal experiences. How great is it that now women can actually do that? How great would it have been if I could have said that to a doctor 20 years ago? Maybe it wouldn’t have taken post-partum hemorrhaging and a couple of surgeries to get a proper diagnosis?

Dr. Sholzberg also noted that there is a general concern that women with bleeding disorders are underdiagnosed. However, we now have these great public tools such as the Let’s Talk Period website and test for women who are questioning their abnormal bleeding symptoms. I personally have promoted it to all of my family and friends who have shown interest in learning more based on their own experiences with abnormal bleeding. The struggle most face, I believe, is getting their doctors to listen to them and agree to provide a referral to hematology to follow up. I was happy to hear from Dr. Ayesha Zia from Texas, that citizens in the United States do not need referrals from their family doctors to be seen at a bleeding disorder treatment centre (HTC). Skipping that one step in the process I believe would be a huge help moving forward.

Something else that piqued my interest was learning about a study underway on bone health, particularly in hemophilia A carriers. I only wish I was 50 so I could participate. My mother (also a severe hemophilia A carrier) was not much older than I am now when a bone density scan told her she had the bones of an 80-year-old woman. Years of tests followed before she was handed diagnoses of osteo- and rheumatoid arthritis. But I wonder now if that has anything to do with her carrier status, and will I have the same fate?

We have come such a long way, and there are only better things to come I believe when it comes to the standards of care for women with bleeding disorders. We are being listened to now, and we are getting access to treatments we need to help keep our bleeding issues to a minimum. We are becoming more actively involved within our local chapters and advocating for others. Our daughters can now go to camp on their own, as opposed to being a “buddy” like I was. Cause you know what? They are not “just carriers” ... they bleed too! More change will come, but remember, change comes from research and research comes from patients. So I urge you to reach out to your HTC and participate in a study today! Help be part of the change. 📒
Informed choices make all the difference

by Adam Snow, Lewisporte, Newfoundland and Labrador

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e all have our wants and needs in life, and we all know sometimes a sacrifice may be necessary. When it comes to sports and physical activities, it can easily be both a need as well as a want with a common sacrifice being time. Now, put yourself in the shoes of a young child with a bleeding disorder. As other kids your age are playing football, hockey, rugby etc., you have to infuse because of that horrible nosebleed from earlier that morning. Your mother only lets you outside in four layers of bubble wrap, a full suit of armour, and the HTC on standby. Although this isn't a huge concern anymore, some parents still deal with the worry of injury as a sacrifice for you to play a sport you want or to continue to be physically healthy and happy. In Session 4 of the symposium, titled Choosing sports and physical activities, we heard multiple stories from patients about their accomplishments in sports and about physiotherapy and the benefits.

The session featured many interesting individuals, but the story from Tristan Mireault and his father, Pascal Mireault, was very eye-opening. Tristan is a 16-year-old from Quebec and has become a competitive swimmer. He swims 12.5 hours a week with his club, a national lifeguard, and is not letting his bleeding disorder stop him from doing the sport he loves. Tristan used to play soccer and loved it for the fierce team spirit it produced but he hurt himself so badly that after an internal hemorrhage and split lip he was told he could no longer play. He then started karate alongside his mother and brother, but swimming would become his true passion. Sometimes you have to try multiple sports before you land on the right one. For Tristan, the end result was worth it.

Colleen Jones Down, a physiotherapist for 23 years from St. John’s, Newfoundland and Labrador, mentioned how there have been many changes to our care and she hopes to make changes as to how we view physical activity. Back in the 1970s, patients were discouraged from engaging in sports and physical activities. With prophylaxis, there came a better protective approach to increasing physical activity. Many articles have been published and applications such as MyCBDR, and MyWapps allow physical activity to be better tracked and managed. Between the ages of 18 and 64, at least 150 minutes of exercise is required per week. This can be challenging for people with bleeding disorders, and as Colleen said, “It’s not so easy to tell a patient they have to be swimming.”

Jeremy Hall is a true example of someone with hemophilia who doesn’t let a factor deficiency slow him down – literally. Jeremy is a Paralympic rower, originally from Alberta, who has followed in his parents’ footsteps as they were very active. Jeremy faced recurrent issues with his knees, which eventually confined him to a wheelchair. He always dreamt of playing hockey but being in a wheelchair at an early age really limited that to just an idea. Luckily, he was able to get back on his feet at age 10, and tried anything and everything he could. His knees eventually fused together which caused more stress on his ankles. He did go on, however, to play sledge hockey for three years, finishing with a national championship.

Quickly after Jeremy began rowing, he was asked to row at Nationals. Last April, he moved to the national training centre and has since finished on the podium in two international events. “Being open and honest about bleeds, and full disclosure is key,” Jeremy said.

Jeff Jerrett is a teacher in Newfoundland and Labrador by day, but always looking for something else to accomplish by night. Jeff struggled with his ankle as his target joint, but resolved to complete the Tely 10, a 10-mile road race in the city of St. John’s. As a varsity athlete myself, I can’t express enough how tough this race would be for any individual, let alone someone with a bleeding disorder. With the help of a clinical physiotherapist by his side, Jeff started walking farther and farther after work each week. The process wasn’t easy, but his determination paid off. Completing the 10-mile trek in his goal time of under three hours, Jeff attained yet another of his ambitious goals.

Taking the time to push yourself physically is always a challenge, but with the help of our wonderful hematologists and physiotherapists, goals can be met. What used to sound scary for parents years ago, is becoming normal today. Access to the standard of care we have, as well as all other accommodations, makes choosing sports and physical activities when living with a bleeding disorder less challenging.
The patient-health care provider partnership: a model to follow

by Bruno-Gil Breton, Montreal, Quebec

I had the privilege of attending a range of sessions over the Rendez-vous 2019 weekend on a variety of topics, including Therapeutic education, patient engagement, shared decision-making.

The first panel in this session featured Claudine Amesse, RN, and Claire Longpré, M.Ps. from CHU Sainte-Justine. Their presentation, Education days devoted to patients with severe hemophilia and Type 3 von Willebrand disease, stressed the importance of not assuming patients diagnosed with a bleeding disorder are experts in their condition. These patients do not implicitly understand the impact of a diagnosis on their lives or have all the tools and knowledge needed to manage the disease and its bio-psycho-social consequences. The speakers established a program in 2010 that has shown the positive impact of providing preventive support to patients and their families to help them cope with a chronic disease and, above all, “deal with it.” This involves many changes in the routine and principles observed by the family to live a healthy life as they consider the diagnosis and the associated risks and limitations. They need to develop the knowledge and skills required to make preventive choices and intervene when complications arise. The program also addresses the parents’ need for validation, patient-therapist cooperation, family and patient autonomy and social support for everyone. The model has resulted in better adherence to treatment plans and has provided significant psychological and emotional benefits, including ease in naming emotions, finding strategies and listening to others.

In the next presentation, Thomas Sannié, from the Association française des hémophiles, spoke about therapeutic education in France, offering a rich international perspective on the subject. The patient/parent resource model, developed in France, has two objectives: improving patient adherence to treatment and supporting and accompanying people with chronic diseases. To achieve this, it is important to consider the perspective of the patients and the health care providers in charge of their treatment. This means changing the paradigm. The relationship between the patient and the health care provider must be a partnership, where the patient becomes a trained and capable resource able to support both health care professionals and other patients with a similar diagnosis. They intervene to provide support (listening and discussion) and communicate openly with health care professionals to illustrate, using concrete examples from their personal lives, what it is like to be a person with an inherited bleeding disorder. Patients receive 48 hours of training in advance to prepare them to become a resource and develop, maintain and update their skills and knowledge. Ultimately, the goal is “vivrologie,” a French term for the concept of finding the best way to live day to day. The idea is for patients to improve their quality of life by developing the ability to plan activities, take care of their health and “deal with” the diagnosis.

Here in Canada, the Centre of Excellence on Partnership with Patients and the Public has developed a therapeutic education program as part of the patient partnership vision. The program, presented by CEPPP Co-director Vincent Dumez, focuses on the individual’s life project and their access to a normal life through choices made in a free and informed manner. The patient’s choices are based on information, knowledge and skills acquired through Patient Therapeutic Education (PTE), which is for anyone with a chronic health condition. The patient of tomorrow is recognized as a full actor in their care, the owner of their own medical information (thanks to various medical technologies) and a partner in the evolution of the health system. This is a profound cultural change in the traditional treatment model currently in place. Patients and therapists are collaborators and co-leaders, forming a partnership for individual care and even comprehensive care for patients with a similar diagnosis. In this model, health care professionals are experts in the disease, while patients are experts in living with the disease. Both share common values and recognize the contribution of the other. This model does not take anything away from either party. Rather, it multiplies opportunities through the sharing of paradigms and expertise. The patient is involved at every stage of the medical process—diagnosis, choice of treatment and even the negotiation over whether to continue or change a treatment. The added value of this approach goes far beyond the case of the individual patient and health care provider. It extends to all clinical, organizational and public policy spheres, including the community, research, teaching and the care itself.

In short, the information session highlighted the progress that has been made in the therapeutic approach to benefit all parties involved. Changes in culture and protocol have already proven to increase patient adherence to treatment, improve patients’ quality of life and have a positive impact on organizations working for the well-being of citizens.
Exciting times in the world of hemophilia

by Rob J. Klaassen, FRCPC, President of the Association of Hemophilia Clinic Directors of Canada

Johnathan cautiously enters the examination room, with his parents following on his heels. “How are you doing?” is my opening line, which is met with his usual reply: “Fine.” I open up CBDR and walk him through his recorded bleeds and we go over the successes and missed opportunities. “What happened in August? You only gave half the number of infusions in your treatment plan? June, on the other hand was perfect! Notice how you only had the breakthrough bleeds in August and none in June …” Johnathan grudgingly concedes that I have a point. At this point, I proceed to go into all the many options that are potentially available to him …

RENDEZ-VOUS 2019 was a groundbreaking meeting, with many of the treatment options that were discussed in the past finally becoming available. That, and the fact that almost all of the bleeding disorder treatment centres (HTCs) are now live and connected with the Canadian Bleeding Disorders Registry (CBDR) and MyCBDR – outside of British Columbia – means that we have a much better idea of how patients with hemophilia are doing. WAPPS, a method for keeping track of how well a specific patient responds to their factor infusion, is now available through CBDR and is being widely used by HTCs.

We got to hear about the impact of extended half-life products on the lives of children with hemophilia, as well as first-hand experience of using the novel subcutaneous (under the skin) drug emicizumab in hemophilia A patients with inhibitors. The best news came shortly after the conference was over, when we found out that all of the provinces and territories across Canada have agreed to pay for this exciting new treatment for inhibitor patients!

Next, we got to hear a testimonial from a patient who successfully received gene therapy, bringing this space age technology down to earth. The next step is taking this experimental treatment and making it available to patients outside of research studies – no small feat, so we definitely need to stay tuned. Funding bodies need to grapple with the high cost of gene therapy and pharmaceutical companies need to come up with an efficient way to make it available to patients and monitor and ensure their long-term safety and efficacy.

… After going through all the options (clinic appointments are going to take much longer!), Johnathan and his parents decide that they want to check how well he is responding to his current factor therapy, using the WAPPS system, and potentially change his treatment to an extended half-life factor concentrate. They leave clinic somewhat dazed from all the new information, but certainly better informed with a clear plan of action. These are exciting times in the world of hemophilia with more to come!
Advocacy: yesterday, today and tomorrow

by Pam Wilton, London, Ontario

During Rendez-vous 2019, the CHS offered a community workshop on advocacy. Our chief historian and advocate extraordinaire, David Page, organized the workshop. He started at the beginning, in 1953, guiding us through 66 years of remarkable achievements. For many it was a good review but there was a fairly large group of youth in the room and it was a good opportunity for them to learn just how far we have come.

David facilitated a robust discussion with the participants. He asked: "How has CHS advocacy made a difference in your life?" It was interesting to hear the answers. Older patients stated that they would not be here, at all, if not for the efforts of the CHS. Younger participants said they were acutely aware that their ability to fully participate in sports and school, without any bleeds, has resulted in a very good quality of life, full of almost endless possibilities. Others said that participation in advocacy efforts with the CHS and the chapters had helped them learn new skills and increase their own knowledge and understanding of complex systems and partnerships. Some staff shared that the CHS advocacy work has been humbling and very rewarding.

David also pulled together a panel, representing youth, experience (a nice way of saying "older adults"), men, women, and provincial, national and international perspectives. He asked four of us, Rick Waines, Bojan Pirnat, Francis Mantha, and me to share our thoughts on the present and future advocacy challenges of the CHS. We did not meet to prepare before the meeting and in fact some of us had not even met each other before. In the words of Yogi Berra, "It is not easy to make predictions, especially about the future." Think about that. Maybe not so true when it comes to "advocacy." It seems that the four of us were pretty much on the same page. In fact, we are aligned with the concerns and challenges of most of the other hemophilia organizations in the developed world. We identified access to new products and therapies, choices in treatment and care, bleeding disorders clinical expertise and service delivery, and research.

I assumed David asked me to be on the panel to bring my perspective as an experienced woman with a bleeding disorder, who has volunteered for many years locally, nationally and internationally. I didn't really hold back. I encouraged those present to advocate to have representation from all of our constituents on boards, committees, panels and so on, but emphasized the importance of doing the work to earn the spot. Often for women that means working harder. I also reminded participants that often research has not included females and so we need to advocate making certain that we are not forgotten and that science guides our care and treatment options. That also means that we step up as much as possible to support research.

I was also extremely disappointed to learn that only 50 people wrote letters to their provincial officials advocating for Hemlibra. Really? Why? It was extraordinarily helpful to hear from two very articulate women in the group. One told us that she felt unsure at first, wondering if her voice would make a difference since she does not have a bleeding disorder. She then described her thought process and how she crafted her letter to be meaningful to the politician she sent it to. Another wise and experienced staff person shared with us that some in her chapter felt a bit reluctant because they were not certain of the efficacy and wanted to wait until there is more data.

We could not have done better if we planned it! These two people gave us real-life examples of how and why advocacy is hard. We have to work together sharing our knowledge and skills about the science, data, governing systems, policies, politics, economics, and ultimately what those in our community need and expect. It is never easy. We need to develop and foster the skills of our volunteers and staff to make certain we can continue our strong heritage of CHS advocacy.
The power of youth within the CHS

by Kelan Wu, Montreal, Quebec

The dynamic city of Montreal played host to Rendez-vous 2019, where patients, provincial chapter members and health care professionals united under one roof for a common mission—to stop the bleeding.

Under The dawn of a new era for people affected by bleeding disorders, Rendez-vous 2019 offered a range of presentations and activities for all participants. During the Medical and Scientific Symposium, panels of engaged speakers allowed us to explore issues related to new therapies, fostering communication and relationships between patients and health care professionals, bleeding disorders in women, the role of sports and physical activities, and patient involvement. As a patient, medical student, hemophiliac and member of the CHSQ, these issues affect me personally.

The first time I attended Rendez-vous was in 2017, in Toronto. Although I was already actively involved in the Quebec Chapter, my experience with the CHS was limited. As a participant sponsored by the youth program, I was inspired by the many young members I had an opportunity to meet at Rendez-vous 2017 and am now honoured to have as friends across Canada.

As a Montrealer, I was very excited to be introducing people to every corner of this lively city, which was gearing up for the summer music and festival season. I was even more interested, however, in the youth meeting on the agenda aimed at connecting young people and laying the foundation for a national leadership program.

The participation of young people in Rendez-vous 2019 was outstanding with a number of new faces among the familiar ones. The chemistry of this extroverted group was quickly established and we found ourselves at the youth meeting ready to engage and invest in the cause. The session began with an excellent presentation by Thomas Sannié of the Association française des hémophiles (AFH), who grabbed our attention with projects led by the AFH on the international scene. The second half of the meeting gave way to youth participation, featuring a dynamic presentation by young CHS leaders on various leadership and development programs for youth in associations working with people who have bleeding disorders. Following the presentations, we divided into teams with representatives from each province to create an initiative to develop the leaders of tomorrow. With a group ranging from 18 to 30 years of age and people already very involved in CHS projects, provincial chapters or student associations, ideas flooded the room, each more creative than the last. We discussed budget issues, the structure and content of the program and the division of labour by province. Everything moved towards a workable initiative.

The rest of the weekend went well. Workshops on various CHS issues provided a platform for discussion and collaboration among participants. It was really impressive to see the engagement of young people and the desire to share our experiences and opinions during these activities. Everyone wanted to speak and had something to say in this supportive environment surrounded by people who understood one another.

When I arrived at Rendez-vous for the first time two years ago, I never expected to meet extraordinary young people devoted to the same cause and living similar experiences no matter where they came from. Yet, I encountered the same phenomenon in Montreal. We are able to work together effectively towards a common goal even though we only meet once every two years. We are not afraid to share our stories and challenges in order to improve conditions for certain groups in our community (e.g., women with bleeding disorders or people who live far from treatment centres and need better access to resources and care). We want to bring about change in our community and involve other young people. At the same time, we know how to enjoy ourselves as a group and be inclusive when it’s time to have fun after working. We’re young!

There are exceptional individuals at the CHS, and every event is an opportunity to meet these leaders, scientists, parents, hard workers and many others. I look forward to the next opportunity to work with these wonderful people to exchange ideas, explore a city and share a meal. For young readers, I encourage you to become more involved with the CHS and your provincial chapters. Whether you participate in summer camps, volunteer in an activity or get involved with a project that’s close to your heart, there will be fantastic people to help and inspire you.

Look forward to seeing you at the next Rendez-vous! 🎉
Celebrating 10 years of PEP in Canada!
Some members of the national PEP Committee.

Youth group

Association of Hemophilia Clinic Directors of Canada | AHCDC

Canadian Association of Nurses in Hemophilia Care | CANHC

Canadian Physiotherapists in Hemophilia Care | CPHC

Canadian Social Workers in Hemophilia Care | CSWHC
Transition to adult care has traditionally been a social service area that has been overlooked and under-resourced, and often seen as an add-on to the work of youth/adult teams. However, there is a growing realization that resourcing this complex life stage transition for patients in a timely and coordinated manner is actually cost effective.

It seems that over the past few generations, the necessary level of education to meet societal standards of living has increased from minimal attendance to secondary and vocational training to today’s necessity for university degrees and continued education. The increased educational attainment expected of young adults causes many to delay marriage and family formation as they focus on education.

Concepts and expectations related to family have also changed. Marriage is delayed, divorce is common, and cohabitating couples have increased. The definition of adulthood has also changed. Many young people today are not able to clearly articulate when they became an adult or if they are an adult, and many people of older ages may have difficulty expressing this as well.

In the past, adulthood has been marked by certain role changes; the traditional markers relate to finishing school, starting a career, marriage and family, and owning a house. Parenthood was viewed by some as a definitive step in becoming an adult, given the responsibilities and role changes associated with it.

Today, people in the developed world live longer and are healthier compared to people 70 years ago. The longer life expectancy allows people's experiences between birth and death to be more varied and less homogeneous, including allowing the periods of adolescence and young adulthood to be extended. However, due to the growing influence of technology and communication in the past couple of decades, it is important to look at how youth culture has changed and to find different ways to engage with youth in transition to adulthood.

Some of my observations as a social worker working with youth in transition at the bleeding disorder treatment centre find that many youth continue to rely on their parents during these transitions, but some youth coming from less advantaged circumstances do not experience this same support. This results in very different experiences for these youth as they navigate adulthood compared to youth whose parents still contribute to their finances until they are 25 years of age or even older. Also, some youth from less advantaged circumstances may need to help their families after graduating high school as opposed to attending college or working to support themselves.

The need for transition support has given rise to a framework of duties for social work vis-à-vis young adults as social workers are trained in the understanding of life transitions, and it has brought the whole area of transitions into focus with clear roles and responsibilities. The changes in social structure have greatly impacted the transition to adulthood, including educational systems and family structure.

Therefore, given the uniqueness, the complexities and variability of youth readiness, transition to adult hemophilia care may require more than a tool kit and two to three meetings between health providers and youth to discuss the transfer of care. It requires a great understanding of the impacts of living with a chronic illness, socioeconomic variables among youth and their special circumstances and needs, their ethnic background and their understanding of the process of transition at different stages of life.
Two decisions to make Hemlibra available to patients with hemophilia A and an inhibitor

Montreal, June 1, 2019 – Authorities in both Quebec and the rest of Canada have agreed to reimburse Hemlibra for patients with hemophilia A and an inhibitor.

Héma-Québec informed the CHS on May 9 that it had signed a contract with Roche to supply Hemlibra to Quebeckers. The first patient received the therapy the following week. In the rest of Canada, the Provincial/Territorial Deputy Ministers of Health made their decision to reimburse Hemlibra via Canadian Blood Services (CBS) on May 30; however, CBS has yet to announce a date when it will be accessible.

These positive decisions come after 12 months of sustained efforts by the CHS and its members to have Hemlibra made available. Hemlibra is a monoclonal antibody that mimics factor VIII in the coagulation cascade. It was approved by Health Canada for patients with hemophilia A and inhibitors in August 2018. The drug is injected subcutaneously once a week, once every two weeks or once a month, and has proven extremely effective in preventing bleeding in both clinical trials and real-world use in people with hemophilia, both with and without an inhibitor. According to registry data, approximately 80 Canadians have an inhibitor to factor VIII.

Health Canada approves Hemlibra for patients with hemophilia A without an inhibitor

Ottawa, June 14, 2019 – Health Canada announced on June 14 that it had approved Hemlibra for patients with hemophilia A without an inhibitor. This additional indication comes almost a year after the therapy was approved for those with a FVIII inhibitor.

According to the latest approval, Hemlibra can be injected subcutaneously once weekly, once every two weeks or once a month.

“It is great news that Hemlibra has now received an indication for people with hemophilia A without inhibitors,” said Paul Wilton, President of the Canadian Hemophilia Society. “Based on the research we have seen, we are convinced that a number of Canadians may benefit from this new treatment option.”

HAVEN 3, a randomized, multicentre, open-label phase III clinical study in 152 adolescents and adults over the age of 12 with hemophilia A without FVIII inhibitors, showed a statistically significant reduction in the annual bleed rate from 4.8 treated bleeds per year on factor VIII prophylaxis to 1.5 treated bleeds with Hemlibra. Fifty-five percent (55%) of people treated with Hemlibra reported no bleeds compared to 39% of those on factor VIII prophylaxis.

Over the next several months, authorities in both Quebec and the rest of Canada will undertake health technology assessments before deciding whether or not to reimburse Hemlibra for patients without an inhibitor. The CHS will be making submissions in support of its availability based on clinical trials, real-world data, and physician and patient input.

Four hemophilia gene therapies now in Phase III clinical trial

Four gene therapies—two for the treatment of hemophilia A and two for hemophilia B—are now in Phase III clinical trials, the last phase before an application to regulatory authorities for marketing approval.

Biomarin’s valoctocogene roxaparvovec (formerly BMN 270) is expected to finish enrolling patients with hemophilia A in the third quarter of 2019. Spark Therapeutics began its Phase III trial of SPK-8011 in December 2018 with a six-month observational trial of current treatment with FVIII.

Pfizer has completed enrollment in its Phase III clinical trial of fidanacogene elaparvovec (formerly Spark Therapeutic’s SPK-9001) for hemophilia B. uniQure is moving into a Phase III trial of AMT-061, also for hemophilia B.

All four therapies have shown promising Phase I/II results with sustained factor expression very close to the lower range of normal (50%), with no serious adverse reactions.

Senate Committee unanimously recommends that Bill S-252 not proceed

April 9, 2019, Ottawa – The Standing Senate Committee on Social Affairs, Science and Technology unanimously recommended that Bill S-252, the Voluntary Blood Donations Act, “not proceed further in the Senate.” This recommendation effectively killed the Bill.

The Bill would have amended the federal Blood Regulation such that “an establishment, other than Canadian Blood Services, cannot collect allogeneic blood for remuneration or benefit for the donor unless the blood collected was of a rare phenotype.”

The recommendation came after hearing 16 witnesses over seven sessions between December 5, 2018 and March 31, 2019. Both the Canadian Immunodeficiencies Patient Organization (CIPO) and the Network of Rare Blood Disorder Organizations (NRBDO), of which the CHS is a member, presented written and oral briefs in opposition to the proposed legislation.

Chantal Petitclerc, the Committee Chair, concluded her report, saying “Members of the committee concur that Bill S-252 proposes a regulatory change that is overly simple for a complex issue and has the potential of resulting in unintended consequences.”
The value and cost of gene therapy

In April 2019, there were 372 gene therapy clinical trials in progress. As these gene therapies—not just in hemophilia but in many other disease areas—move closer to regulatory approval, the discussion is turning to the value and the cost of these treatments.

While it is more accurate to consider hemophilia gene therapy as a sustained treatment rather than a cure, there is no denying its potential value. If current research bears out, a one-shot gene therapy would mean an end to almost all factor concentrate infusions and very effective bleed control. But big questions remain. Will it work with even all those who have no pre-existing antibodies to the viral vector (about half the population)? How many years will the factor expression last? How much will it cost?

In a recent article in xconomy.com, Steven Pearson, President of the Institute for Clinical Economic Review in the U.S., said, “Hemophilia will be an important test case in several ways. From the payer perspective, it’s both good and bad. The good side is short term. They can see the healthcare expenses that might go away if the patient is successfully treated. However, if we decide the fair price for a hemophilia cure should concentrate all those downstream cost savings in a one-time price, it makes it worse.”

If hemophilia gene therapy were to cost one, two or three million dollars (these are some of the numbers being quoted), it is easy to understand health systems being reluctant to pay, especially given the uncertainty over efficacy and duration of effect. Possible solutions include installment payments—payments spread over, say, five years—and pay-on-performance conditions where payments stop if the therapy no longer works.

These are no longer questions for the distant future. Gene therapy in hemophilia is coming soon and, if the hemophilia community wants to have access to these innovations, we will have to start contributing to finding the answers.


Comparative pharmacokinetics of two extended half-life FVIII concentrates

A paper published in the Journal of Thrombosis and Haemostasis in April 2019 by Carcao et al. reported on the first head-to-head comparison of two extended half-life factor VIII concentrates, Adynovate and Eloctate. Twenty-five Canadian boys aged 12 to 18 switched from Eloctate to Adynovate prophylaxis. FVIII levels were sampled at 3, 24, 48 and 72 hours following a regular prophylactic infusion of Eloctate and then one to three months later, of Adynovate. Testing was done by the one-stage (OSA) and chromogenic (CA) assays. Pharmacokinetics were determined with the WAPPS PK tool. The mean (range) terminal half-lives with the OSA were 16.1 hrs (10.4-23.4) with Eloctate and 16.7 hrs (11-23.6) with Adynovate. With the CA, the mean (range) terminal half-lives were 18.0 hrs (12.0-25.5) with Eloctate and 16.0 hrs (10.3-22.9) with Adynovate. There were no significant differences between the two products in clearance, area-under-the-curve, or time for FVIII levels to drop to 5%, 3% and 1%. There was, however, considerable interpatient variation in PK, mainly explained by differences in blood group/VWF levels. The paper concluded that Eloctate and Adynovate have almost identical PK parameters.

April 2019, Journal of Thrombosis and Haemostasis. DOI: 10.1111/j.th.14469

CBS and Héma-Québec extend contracts for factor VIII and IX concentrates for one extra year

An April 15 Customer Letter from Canadian Blood Services said the following:

“Our contracts for recombinant factor VIII and IX were awarded until 2020-03-31 with extension options. Canadian Blood Services will be exercising one-year contract extensions for the Adynovate (Shire), Kovaltry (Bayer), Nuwiq (Octapharma) and Xyntha (Pfizer) products thereby ensuring a continuance of current access until at least 2021-03-31. Continued access to Bioverativ’s products, Eloctate and Alprolix, will be in accordance to the access criteria and the named patient program. Criteria for continued Eloctate access allows for any current immune tolerance induction (ITI) treatment in hemophilia A. Note that patients younger than 12 years of age are now required to transition from Eloctate to another product. In the case of Alprolix, patients less than 18 years of age will continue to have access until Rebinyn is approved for this patient group."

The CHS subsequently learned that the contract for Benefix was also extended to March 31, 2021.

In Quebec, Héma-Québec also extended contracts for factor VIII products Nuwiq (Octapharma) and Zonovate (Novo Nordisk) for an extra year until March 31, 2021. The contract for the factor IX product, Rixubis, is in effect until March 31, 2023.

PREVAIL study amended

The PREVAIL study, led by co-investigators Dr. Mark Bellettrutti, from the Dr. John Akabutu Comprehensive Centre for Bleeding Disorders – Pediatric Division at Stollery Children’s Hospital in Edmonton, and Dr. Paul Moorehead, clinic director at the treatment centre in St. John’s Newfoundland, has been amended so as to study immune tolerance induction (ITI) using factor VIII concentrates Wilate or Nuwiq, both manufactured by Octapharma, in combination with Hemlibra, manufactured by Roche.

ITI is a process to attempt to eradicate an inhibitor to factor VIII through repeated doses of FVIII over a long period of time.

The original PREVAIL study is a 10-year multicentre all-Canadian Phase IV (post-marketing) study investigating the efficacy of plasma-derived Wilate to eradicate inhibitors in pediatric and adult patients with hemophilia A. The inclusion of Nuwiq allows the option of attempting ITI with a recombinant factor VIII. (For more information on Nuwiq, see Hemophilia Today, Volume 52, Number 1, March 2017.)

The inclusion of Hemlibra will allow ITI to be attempted while the patient’s bleeding tendency is protected by this additional drug therapy. (For more on Hemlibra, see Hemophilia Today, Volume 53, Number 3, November 2018.)

If patients or caregivers are interested, they should contact their treatment centre.
Canadian researchers tackle new questions

by Kathy Lawday, member of the CHS Research Advisory Committee

It was exciting to hear results from research studies previously funded under the Care until Cure program at the Research Exchange at Rendez-vous 2019, hosted by Pfizer. Dr. Paul Moorehead presented preliminary data from the Canadian Hemophilia Management in the Perinatal Setting (CHiMPS) study for which funding is ongoing.

Newborns patients with hemophilia A or B or other rare bleeding disorders have been enrolled from centres across Canada (four newborn infants and five mothers). CHiMPS will investigate whether it is practical to collect data in the perinatal setting, possibly using the research module of the Canadian Bleeding Disorders Registry, and whether the care being provided to the babies and their mothers results in low rates of bleeding complications and/or low rates of exposure to unnecessary tests and medical treatments.

Dr. Michelle Sholzberg and colleagues have previously shown that men with hemophilia are more likely to have low bone strength and osteoporosis probably due to repeated bleeding into joints and muscles. Symptomatic hemophilia carriers may also bleed into joints. This study will compare bone density in women who are carriers with that of women of similar age around menopause and so better understand how this genetic state affects the health of hemophilia carriers.

Dr. Haowei (Linda) Sun identified eight outcomes including knowledge, satisfaction, self-efficacy, adherence, and clinical outcomes that can be used to assess the success of transition from pediatric to adult care. Katherine Baker, under the supervision of Dr. Vicky Breakey, will continue this approach by reviewing currently available transition tools to determine the need for adaptation or development of a hemophilia-specific transition tool to meet the needs of teens and parents as well as health care providers.

In new studies to be funded under the Care until Cure program, Dr. Sun and co-investigators will examine the relative costs associated with frequent switching of clotting factors as a result of tender changes at Canadian Blood Services (CBS) from the perspectives of society, patients/families, and public health care payers; including the extra burdens on treatment centres and laboratories and on patients and families who face worries related to safety, effectiveness, extra clinic visits and emotional distress, to provide a balanced view of the impacts of frequent tender changes.

Drs. Peter Gross and Alfonso Iorio evaluated the feasibility of using a finger-prick blood test to measure factor VIII and factor IX activity, similar to testing blood sugar before taking insulin. The individualized factor level can then be used to guide dosing and potentially save painful blood draws in younger patients. Dr. Adrienne Lee and collaborators are looking at the effect of DDAVP on platelet membranes causing an enhancement of clotting in addition to the known effects of DDAVP in releasing extra von Willebrand factor (VWF) and factor VIII from body stores to stop or prevent bleeding in von Willebrand disease (VWD) or mild/moderate hemophilia A.

Under the Dream of a Cure program, Dr. Margaret Rand and colleagues are also studying the synergy between platelets and VWF in the formation of a hemostatic plug required to stop bleeding. Patients who are missing a specific part of their DNA (22q11.2) have a platelet problem. They also have heart defects which lead to alterations in their VWF, giving them an acquired form of von Willebrand syndrome. These patients have bleeding problems so better understanding of the relative contributions of the DNA defect and the acquired defect of hemostasis may help with treatment in this special population.

Dr. Paula James continues her work on the variation in bleeding severity in patients with Type 1 VWD by studying the effects of DDAVP and exercise, and through experiments on endothelial cells cultured from patients and healthy controls.

In a new research program (ADVANCE) supported by Bayer, created to identify and study key issues in the ageing hemophilia population, Dr. Natalia Rydz and colleagues will look at the burden of having an inhibitor to factor VIII or factor IX on adult patients (ACHILLES). Inhibitors usually occur early in childhood and so there is uncertainty on the role of immune tolerance and prophylaxis using bypassing agents, and of the impact of long-standing inhibitors on joint health, chronic pain and quality of life in adult patients. Better understanding of the current state of these inhibitor patients will identify clinical and research needs of this population.

These studies are all made possible through the support from CHS members, friends and partners. Thank you!
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 2019.

**The hemostatic stress response: Do differences explain phenotypic variability in VWD?**
Dr. Paula James
Queen’s University – Kingston, Ontario

**Assessment of hemostatic abnormalities in children with 22q11.2 deletion syndrome with or without congenital heart disease**
Dr. Margaret Rand
Hospital for Sick Children – Toronto, Ontario

**STUDENTSHIP**

**Transition in hemophilia: a scoping review of transition tools**
Katherine Bailey
University of Guelph – Guelph, Ontario
Under the supervision of Dr. Vicky Breakey, McMaster University

The CHS/Bayer/ADVANCE Canada Research Program

The Canadian Hemophilia Society – Bayer – ADVANCE Canada Research Program was created to engage Canadian hemophilia treaters in activities to identify and research key issues in the ageing hemophilia population. Its goal is to support research that will help inform how management and treatment should best be adapted for people ageing with hemophilia. In order to optimize management of age-related co-morbidities, ADVANCE Canada fosters patient-centred research, and disseminates scientific information to assist physicians.

THE FOLLOWING PROJECT IS BEING FUNDED IN 2019.

**Adult Canadians with Hemophilia Living with Inhibitors Study (ACHILLES)**
Dr. Natalia Rydz
University of Calgary – Calgary, Alberta
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 2019.**

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Detailed descriptions of all the funded research projects are available at [www.hemophilia.ca/research](http://www.hemophilia.ca/research).
REPORT FROM THE CHAIR

Brock Wilton

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

The Hemophilia Research Grants Review Committee, under the chairmanship of Dr. Manuel Carcao, met earlier this year and announced the 2019 grant recipients for the CHS Dream of a Cure Research Program. Descriptions of the research projects can be found on the CHS website at www.hemophilia.ca/chs-dream-of-a-cure-research-program. These grants total $147,662 in value 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 $4.5 million in support of hemophilia research in Canada since 1991. This has made such a difference in quality of life for people with inherited bleeding disorders.

We have always depended on our bleeding disorder community – the provincial chapters, individuals, families and groups – which has provided financial support since the Club's inception in 1984. In 2018, CHS chapters and members collectively raised over $23,220 to increase the capital of the endowment fund. An additional $121,089 (including a $50,000 matching gift from the CHS) was directed towards current research.

Special thanks to 14-year-old Connor Blicker, who since 2016, has asked his friends to support the HRMDC in lieu of birthday gifts. And for the second year in a row, Ian Van Oosten, whose mother, Sue, is a nurse at the Queen Elizabeth II Health Sciences Centre in Halifax, has asked the Wellington Bakery and Café to contribute the coins they collect for charities to be directed to the HRMDC. January is now considered “hemophilia” month for them. And John Plater's friends from high school and their partners gathered on the Plater farm to celebrate their 50th birthdays while raising funds for research and remembering John and other high school friends who had passed away. It was a lovely tribute to John’s life and accomplishments. Again, just a few examples of how our community always comes through for research.

I would like to stress how important it is to fund current research. With interest rates as low as they are, the return rates alone on the endowment fund barely cover one grant and, unfortunately, each year we have no choice but to turn down many projects for lack of funding. As YOU and your family depend on RESEARCH, RESEARCH also 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 Get involved/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 Research Fund is their 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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In memory of David Poulion
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Alberta Chapter
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In honour of Juanita Pickerl
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In honour of Catherine Hordos
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In honour of Joanna Halliday
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Dr. and Mrs. Ron George
In honour of their “Angels”
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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 Kinniburgh
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Kevin Bryar
In honour of his “Angel” Manny Bryar

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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.
The Canadian Hemophilia Society (CHS) relies on the generosity of our donors to fulfill our mission and vision. To recognize an exceptional 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.