



Hemophilia Ontario
Hémophilie Ontario

BLOOD *matters*

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Community Focused

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Hemophilia Ontario
Hémophilie Ontario

Hemophilia Ontario is a certified chapter of the Canadian Hemophilia Society

President's Message



Dear Friends,

I am writing to wish you a relaxing and enjoyable holiday season, and to let you know some of the key priorities and programs of Hemophilia Ontario in 2019.

WE ARE RUNNING THE PROGRAMS THAT YOU WANT

I am very pleased to announce that, in 2019, Hemophilia Ontario will be running the following major programs:

- Camp Wanakita
- Just the Guys
- A weekend for women who are affected by inherited bleeding disorders
- Pinecrest Camp in Goderich
- Family camp in Northern Ontario
- Community Camp Days in every region

Over the past few months, our new Executive Director, Byron James, and I, have heard from many of you about how important these programs are to our community. We heard that the potential loss of these programs would be devastating. We heard this message loud and clear, and, along with the Board of Directors, have taken steps to preserve these critical programs.

Rest assured that talking with you, and understanding the needs of our community, is central to work of Hemophilia Ontario. Finding the resources necessary to deliver programs, services, education and advocacy to address those needs is the number one priority for the staff and Board of Directors of Hemophilia Ontario.

WE ARE GOING BACK TO A REGIONAL STAFFING MODEL

We have re-organized our staff model to align with our regions and clinics. This regional model served us well for many years, and will ensure that the organization has a consistent presence in your region. Serving people in their community is the basis upon which our organization has developed, and we are committed to making this a top priority moving forward.

As you know, Byron James was hired as our permanent Executive Director in October. Byron has spent decades in senior management for several charities, most recently with the Canadian Cancer Society in Ottawa. You can reach him by email at bjames@hemophilia.on.ca or phone at 705-690-4605.

With Byron joining us, Bojan Pirnat will step down as interim Executive Director at the end of December, to take on the role of provincial coordinator starting in January 2019. On behalf of the Board of Directors, I would like to thank Bojan, as well as Susan Turner, Natalie Philbert and Alex McGillivray for their hard work in 2018.

As many of you are aware, Matthew Maynard left us at the end of November to take a position with the Grand Bend Area Community Health Centre. On behalf of everyone with an inherited bleeding disorder in Ontario, I would like to thank Matthew for his dedication and service to our community. I am delighted to advise that, true to his character, Matthew has already rejoined our organization as a volunteer with our Pots and Wreathes fundraiser.

WE ARE BREATHING NEW LIFE INTO REGIONAL COUNCILS

The Board of Directors and staff at Hemophilia Ontario understand the commitment and passion that exists in our province to bring people together and make positive change for everyone living with inherited bleeding disorders. Over the past several years, the unity and contact between the councils, the community, and Hemophilia Ontario has waned. We are going to change that.

We encourage all of you get involved with your regional council. To that end, you will be hearing from your regional council in the coming weeks and months asking you to get involved and commit to contributing locally. If you are new to the organization, please consider joining your regional council and finding out ways that you can connect with people, and help your community. This is an important time of transition for Hemophilia Ontario, and the time is now for you to be a part of this positive change.

What's in this Issue?

Fall 2018 Volume 9, Number 2

- 02 Leadership Messages
- 04 Hemophilia Ontario News
- 08 Bleeding Disorders & Research News
- 12 HIV/HCV News
- 12 BleedHERS
- XX Thank You
- XX Hemophilia Ontario Calendar

Want to continue receiving a hard copy of Blood Matters by mail?

Please contact Susan Turner at 1-888-838-8846 ext 11 or sturner@hemophilia.on.ca

Thank You

Thank you to our pharmaceutical partners, whose support makes Blood Matters and our many other programs possible.



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I have included a chart below listing our regions, assigned staff, as well as your representative on the Board of Directors. If you require contact information for the people involved, or wish to engage with your regional council and are not sure how to proceed, I can help. Please email me if you have questions at president@hemophilia.on.ca.

REGION	STAFF	BOARD MEMBER
South West Ontario Region	Natalie Philbert	Emil Wjinker
Central West Ontario Region	Natalie Philbert	Meagan Bordi
Toronto and Central Ontario Region	Bojan Pirnat	Michael Bosomptra
Ottawa and Eastern Ontario Region	Byron James	Dar Villeneuve
Northern Ontario Region	Bojan Pirnat (Thunder Bay region) & Alex McGillivray (Sudbury region)	Shelley Hewett

WE ARE COMMITTED TO SERVING EVERYONE WHO NEEDS HELP

Despite advances in care over the past three decades, there remain groups within our community that need help, and many others for which our services and programs are an important part of their lives. While many of the basic pillars of our health care have been solidified, we understand that our task is to investigate and deliver on the following:

- Work to determine who is not being served,
- Identify and work toward addressing gaps that exist in the health-care system,
- Provide more opportunities for members of our community to participate in our programs and education events, especially camps, and
- Advocate aggressively for access to new and developing treatments until a cure for all bleeding disorders is secured.

We firmly believe that there exists an overwhelming need to address the above areas, and that the work we need to do now is as important as ever. In that regard, our priorities for 2019 include:

1. Addressing the needs of women with bleeding disorders by investigating where the challenges lie, and securing the resources necessary to provide programs, services, education and advocacy for these women.
2. Ensuring that those who continue to suffer from the impact of the tainted blood tragedy in this province are recognized and supported.
3. Developing more opportunities to educate children and bring people together, including expanding Wanakita and Pinecrest.
4. Serving the health, emotional and financial needs of the people in our community, with a particular emphasis on helping people who are aging with inherited bleeding disorders.
5. Understanding ways that we can help people with inherited bleeding disorders in the rest of Canada and around the world, and ultimately developing and executing a plan to meet those needs.

I trust that everything set out above, and what you have seen from our organization in the past few months, demonstrates that we are committed to supporting our community members and are focused on what matters to everyone affected by inherited bleeding disorders in Ontario. You can expect a high level of transparency, direction and energy from myself, the Board of Directors and staff. It is going to take some time in early 2019 to organize ourselves and to carry out everything that we are setting out to do. At this point, we are asking for your patience, cooperation and assistance in fulfilling our plan. You can contact me directly at president@hemophilia.on.ca if you have any questions or want to help with our plans for 2019.

Cameron Peters 
President
Hemophilia Ontario

Executive Director's Message Byron James Executive Director Hemophilia Ontario

I am writing this at the end of my tenth week with Hemophilia Ontario and what a ride it has been.

My first three days on the job were spent at Community Camp at Camp Wanakita. There could not have been a better environment to be introduced to this organization. I was able to meet and interact with staff, board members, volunteers and, most importantly, our members. I learned more about this organization and bleeding disorders in three days than I could have in nine weeks of reading and meetings.

My takeaways three weeks in:

- An organization in transition
- A board of directors wanting to move forward, not look back
- A tenured, experienced and extremely dedicated staff who have our members as their top priority, and strive to fulfill their needs no matter the odds
- Members who appreciate the supports we provide, but more importantly have provided feedback through various forums that tells us where we need to go in 2019 and beyond

2019 and Beyond:

My mantra for this organization going forward and the question I will continuously ask "what difference does it make?". If it is not making a difference and having a quantitative impact for our members, then why are we doing it?

At Camp Wanakita I told the members that what I saw with this organization was opportunity. We have a rich heritage, a cause more than worth fighting for and a membership who has offered to step forward and help us move in the direction we need to go. I will take you up on that offer. We will provide you with support, materials, plans and the focus to help us move this organization forward to meet the needs of members across the province.

I will promise you this, we may not always move as far forward as we want in a given year, but we will not be taking any steps back. To quote our editor Tom Beer (summer edition 2017) it's time to "get 'er done". ♦

Moving Ahead Tom Beer Editor Hemophilia Ontario

"Yesterday is not ours to recover, but tomorrow is ours to win or lose"
Lyndon B. Johnson

When I'm supervising pickleball games, and a game on Court 3 ends, the players on Courts 1 and 2 shift over. Often, I sing out, as did Michael Jackson in the musical, "The Wiz", "Ease on down, ease on down the road."

Think about it. When something is done, you move on, you ease on to the next game, the next challenge, the next goal.

As articulated by President Cameron and, and by the new Executive Director Byron, Hemophilia Ontario is moving ahead, by using and developing what has worked well in the past, by implementing new initiatives, and, keeping those affected by inherited bleeding disorders aware of what's happening and why it's happening. Paraphrasing the lyric, they're helping Hemophilia Ontario "move on down the road" to serving the inherited blood disorders community.

As President Cameron states, Hemophilia Ontario is committed to moving forward, as expressed by Michael Jackson's lyric, "easing down the road", making sure that what's attempted is making a difference. Be patient.

We should be encouraged by Executive Director Byron's mantra, "What difference does it make?"

I remember collaborating with other teachers and our students to ask 4 questions of any project. What is your plan? How will you complete it? What will be the impact of your project? What will you learn? These are key to the Hemophilia Ontario plans.

See the relevance of moving on in the feature on David Quinn, coach of the NHL's New York Rangers.

See the impacts of Hemophilia Ontario programs. Read the reports and insights about Camps Wanakita and Pinecrest, the Golf tournament and the Zoo Walk, all designed not only to inform you, but also to confirm the impact of these programs on our community and to educate others on the importance of these programs to the community.

Read the article about Hemlibra, and, more importantly, get involved and write letters.

I'm encouraged. I'm excited.

The road ahead will be bumpy. It will be challenging. But, with your help, Hemophilia Ontario is ready to start on the next part of their journey.

Read on.... ♦

Best Wishes & Thank You Matthew Maynard

I hope this finds you well! I am writing to share some news with you.

I have recently accepted a position as Community Developer with Grand Bend Area Community Health Centre. You can learn more here:

<http://gbachc.ca/connected-communities/>.

It does not seem that long ago that I was asked if I might be able to help out (just a few hours a week) in South Western Ontario Region. There have been many changes, opportunities to learn, share and support since then. I will truly miss working with all of you!

As for me, I have continuously been amazed and grateful for your willingness to share your concerns and support for the care and well-

being of those impacted by bleeding disorders in Ontario. I know you will continue this important work together to expand and contribute to the circle of care. As our mission states "until a cure for all" I hope you will join me in finding new ways to support the bleeding disorder community.

Lastly whether you are personally impacted by a bleeding disorder, a caregiver or family member, staff, volunteer, medical team member or donor I know you will continue this important work together. And you will have another ally out there – me! ♦

Aging Well with a Bleeding Disorder: What Women Should Know by Sydney MacLeod



Having a bleeding disorder means you need to pay closer attention to your lifestyle and self-care as you grow older. “We want you to live well as you age,” says Tammuella Chrisentery Singleton, MD, a hematologist at the Louisiana Center for Bleeding and Clotting Disorders at Tulane University School of Medicine who is passionate about women and girls with bleeding disorders. “It’s especially important to be informed and aware of additional complications to make good decisions.”

While there hasn’t been ample research focused on how aging affects women with bleeding disorders, Singleton says it’s good news that the issue is a matter of discussion today. “Ten years ago, we didn’t have this topic,” she says. And she expects the conversations to push researchers to address the issue. “I think we will see a paradigm shift. Hematologists and gynecologists are coming together to look specifically at women with bleeding disorders.”

Three common issues facing women with bleeding disorders.

Menopause and bleeding disorders

Singleton suggests talking with your gynecologist and hematologist about options to make the transition through menopause smoother. After an overall health evaluation, hormone therapy or birth control pills might be considerations, she adds. “It’s a different conversation than for a woman who doesn’t have a bleeding disorder,” Singleton says.

It’s also important to continue to see a gynecologist even when menses ends, says Jeanette Cesta, 54, a national bleeding disorders educator who has von Willebrand disease. “Just because monthly menstrual bleeding is no longer an issue, we need to remember there are other reasons to see a gynecologist regularly,” Cesta says. “Pap smears, mammograms and other gynecological health monitoring is still critical and shouldn’t be ignored.”

Concerns about osteoporosis

Loss of bone density and increased risk of fractures are a concern for all women as they age. However, there is an additional risk for women with bleeding disorders if surgery is necessary as a result of a fracture, says Singleton.

Typically, preventive measures include weight-bearing exercises, spending time outdoors in sunshine and taking oral vitamin D supplements. However, it’s important to talk with your doctor before you take any supplements, as they may affect your bleeding disorder.

Grace defined

Along with regular exercise and eating a well-balanced diet, a positive mental outlook is critical. “I believe attitude has a major impact on our health,” says Cesta. “By continuing to work toward personal goals and being supportive to the people in our lives, we will thrive.”

Questions remain regarding typical recommendations for aging women and how they might affect those with bleeding disorders. For example, “natural remedies such as antioxidants might be heart-healthy for others, but will they interfere with bleeding or platelets?” says Cesta.

Despite such lingering uncertainties, Cesta says she is encouraged by the progress so far. “I love watching the next generations of women coming up and seeing them have better-quality healthcare for their bleeding disorder,” she says. And alongside hope for the next generation is an admiration for her own. “I feel pride for my generation of women, who have endured so many challenges yet have succeeded in lighting the path for women coming behind them.”

Annual Zoo Walk Fundraiser by Susan Turner

Hemophilia Ontario hosted its Annual Zoo Walk fundraiser on Saturday June 26 at the Toronto Zoo. This year was our biggest year yet with 60 people in attendance and you raised a whopping \$7800!

Thank you so much to all of our all of our donors and especially to the Reid Family and friends who contributed over \$5000 of the money raised. We are truly grateful for all of your support and generosity. We hope to see you all again next year!



Hemophilia Ontario Camps!

Pinecrest Adventures Camp

by Emily McCormack

To Pinecrest and Beyond! For the 26th year of Pinecrest campers went through our Astronaut training program, working in two groups, Team Golden Stars and Team Groot. Throughout the week campers collected moon-rocks and worked with team leaders, such as Chewbacca and Wall-E, trying to decide what planet we should explore next. At the end of the week the teams decided that Earth was the best planet for us to live on and that we should stay here.

Activities at camp this year included creating unique UFOs in the craft hut, playing Jugs and Capture the Flag during game time, and singing our favourite campfire songs at night. It was so exciting to see all the creative costumes the campers wore this year as they embraced this theme, Pinecrest Adventures Camp Space Odyssey.

I had the opportunity to attend Pinecrest as a camper for 3 years and, to also, be a volunteer staff for 7 years. Pinecrest has always been one of my favourite weeks of the year and I was very excited to take on the task of being the Camp Coordinator this year. As my first year as Camp Coordinator, I had the opportunity to work with Hannah Higgins and Julia Lepera-Adams in their role as Co-Directors. They worked together to create fantastic staff training and camper programming. It was great to work with our returning staff and to welcome new staff who fit in perfectly with our Pinecrest team.

A big thank you to Lori Laudenbach for her many years of attending Pinecrest as our nurse and to Mary Jo DeCourcy. This year's Noitacude (education session) was one of the best yet! 💎



My Pinecrest

by Aidan Catton

My name is Aidan Catton. I have been going to Pinecrest Adventures Camp since I was 4 years old, and I am now 15. My first few years of camp I was a very quiet kid and didn't really want to get involved. As I got older, I became less shy and started to participate more. The counselors really helped by telling me not to be afraid and to just go out and play a game or make a craft. We were all there to have fun and support each other. They encouraged me to always be myself no matter what happens in life and not change for anyone.

This year was my first year as an LIT (leader in training). The point of the LIT program is to build future leaders not just at camp but in other communities too. I have already applied my leadership skills at school by leading a mentorship program for grade nine students.

Pinecrest is where I have made some of my best friends. We talk to each other not only at camp but also through text and social media. I know these friendships will stay with me for the rest of my life.

My camp experience has become the highlight of my years and I always wish the five days would never end. There are not enough words to explain how amazing Pinecrest is and the positive impact it has had on my life. Whether it's the staff every year or the friends that I make, it is great and I always look forward to it. 💎



Pinecrest Camp

by Andrew Valdez

Pinecrest adventures camp is a camp where people who have or are affected by hemophilia may go to learn about this bleeding disorder. I have gone to this camp ever since I was 4 and I have had many amazing experiences with it. I believe and have witnessed many times that the kids who go always leave with more knowledge, friends, and memories which they can really use in the future.

Every year I have gone to camp I have witnessed the extraordinary hard work the counselors and staff put into this camp and planning all the events and games for the short week there. Every year I have gone out thinking that "this was the best year" as it has been so enjoyable with all the games and even friendly pranks which are played. However, the next year always manages to be even better. As a Leader in Training (LIT), I have learned many skills and I go every year to give back

to the amazing opportunity which is camp because of the great thing's kids have there. This camp is a truly remarkable sum of many people's hard work and is a masterpiece for children, LITs, and even counselors to go to have a good time and make new relationships with the people around them and form great memories and is often seen as a "home away from home". At camp we do games such as capture the flag, gaga ball, and obstacle courses. We also make crafts like UFOs, or name tags, and finally the food is great as well. Pinecrest offers something I have never seen before which is an excellent learning environment for kids to realize that despite their hemophilia they are a regular kid after all, and they are just like everyone else. I hope to see this camp prosper for many years to come. 💎

YMCA CAMP WANKITA SUMMER CAMP 2018

Camper Diagnosis	Camper Session Time at Camp Breakdown	Infusions and Independence Infusion Breakdown
Camper Diagnosis Breakdown Hemophilia A: 35 Hemophilia B: 9 Factor XIII: 1 vWD: 11 Other: 1	Camper Session Time at Camp Breakdown # of 1 week campers: 23 # of 2 week campers: 30 # of 4 week campers: 4	Infusions and Independence Infusion Breakdown Total # of infusions: 177 Total # of independent infusions: 19 Total # of new infusers: 1

Hemophilia Ontario sponsored 57 campers to attend YMCA Camp Wanakita in 2018. Of those campers, 23 attended camp for 1 week, 30 attended camp for 2 weeks, and 4 participated at the Student Counselor level for 4 weeks.

2018 Hemophilia Golf Classic

by Susan Turner

The 19th Hemophilia Golf Classic was held at the beautiful Nobleton Lakes Golf Club on September 7, 2018. The day was a true success with 70 golfers joining in and helping to raise \$15,000 for our services and programs! Our sponsors were Barrick Gold Corporation, Pfizer, Sam Marinucci, Martine Celej, Neal and Smith Barristers & Solicitors, Fitzpatrick Electrical, Perry Bitterman, R&R Staffing, Cross Filtration, Cambridge Filter Management, Bob MacDonald, MRM Consulting, Zeno & Norma Fernandes and Gluskin Sheff. Congratulations to our winning foursome; Gavan, Carson, Mike and Ryan!

Thank you to Dante Veloce for speaking on behalf of the community and letting those in attendance know how his time spent at programs like our summer camp YMCA Camp Wanakita has helped him gain independence!

Thank you to our 2018 Golf committee: David Neal, Maury Drutz and Paul Golding. Your time and dedication to making this event a success are truly appreciated!

And finally, the day wouldn't run so well without the help of the tournament volunteers: James Beckwith, David Goodman, Kathy Lawday, Rick Griffith, Renee Laviolette, Pam Charbonneau and Colette Laviolette! Thank you!



Hemophilia Ontario Financial Assistance Program

Hemophilia Ontario has a long history of providing financial support to members in need through a variety of programs or funds. With decreasing revenues and a health care landscape that continues to evolve, Hemophilia Ontario has rewritten its policies to ensure it can continue to support those most in need.

To receive the complete policy in your preferred format, contact Byron James at 888-838-8846, ext. 17 or bjames@hemophilia.on.ca. An overview of the changes included in the new Financial Assistance policy include:

- The elimination of the Now Experience Wellness (NEW) program funding, which previously supported physical activity opportunities for youth;
- All applicants must now seek approval prior to purchase in order to be considered for funding. Hemophilia Ontario will not reimburse for expenses already incurred;
- All transportation and parking assistance will be funded directly to the clinics and patients may inquire with their clinic team for support as required;
- Assistance is limited to two grants per calendar year per household with a combined maximum of \$750 being available for financial assistance;
- In an effort to respond to requests more quickly, all applications will be handled directly by the Executive Director and decisions made in no more than three business days

Hemophilia Ontario continues to provide financial support, based on availability of funding, to help defray the costs of:

- Expenses incurred in bleeding disorder care, including treatment or prevention of bleeds;
- Emergency transportation services to HTC's;
- First-time MedicAlert products and registrations; and
- Other related expenses determined to be appropriate by Hemophilia Ontario.

Applications can be made by email, fax, or online at:

<https://hemophiliaontario.typeform.com/to/XIQ45m>

Other Ontario Financial Assistance Programs

Ontario Health Insurance Plan (OHIP) - Ontario residents are eligible to access healthcare services provided by the Ministry of Health and Long-Term Care. **1 866 532-3161 (Service Ontario INFOline)**

Ontario Public Drug Programs - Ontario residents receive drug benefits from Ontario's drug programs. The province has six different programs. **1 866 532-3161 (Service Ontario INFOline)**

The Trillium Drug Program - This program helps people who have high prescription drug costs relative to their household income. **1 800 575-5386**

OHIP+ - Beginning on January 1, 2018, OHIP+ will provide free prescription medications for children in Ontario under the age of 25. Beyond the most common prescriptions, OHIP+ will give children and young people access to more than 4,400 drugs reimbursed under the Ontario Drug Benefit Program, including medications funded through the Exceptional Access Program, at no cost.

Drugcoverage.ca - This website offers information on reimbursement for prescription medications by providing information on the various types of private insurance plans, provincial/ territorial drug benefit programs, drug funding by provincial cancer agencies, and federal drug plans available in Canada.

Canada Revenue Agency – Medical Expenses - Individuals or a spouse or common-law partner may be able to claim the total eligible medical expenses incurred on their annual income tax return. Keep all receipts. **1 800 959-8281 (Income Tax Enquiries)**

Ontario Disability Support Program - This program helps people with disabilities who are in financial need pay for living expenses, like food and housing. **1 888 789-4199**

Ontario Works - If you are in temporary financial need, Ontario Works can provide you with money, and help you find a job. Call your local Ontario Works Office or find them at - <http://www.mcscs.gov.on.ca/en/mcscs/programs/social/ow/>

Canada Pension Plan – Disability Benefits - Canada Pension Plan (CPP) Disability Benefits provide a monthly taxable benefit to contributors who are disabled and to their dependent children. **1-800-277-9914 (Service Canada)**

90-90-90: Treatment for All by Alex McGillivray

The 90-90-90 UNAIDS initiative is an ambitious treatment target aimed at ending the AIDS epidemic globally by the year 2030. While previous global initiatives were focused on access to treatment, the 90-90-90 initiative focuses on achieving the following global objectives by 2020:

1. 90% of all people living with HIV will know their HIV status.
2. 90% of all people with diagnosed HIV infection will receive sustained.
3. antiretroviral therapy.
4. 90% of all people receiving antiretroviral therapy will have viral suppression.

The Canadian Government has created a framework titled. "Reducing the Health Impact of Sexually-Transmitted Blood-Borne Infections by 2030" to help guide HIV prevention and care work to reach the UNAIDS targets.

As of the end of 2016, Canada's progress on meeting the 90-90-90 HIV targets is estimated at:

1. 86% of the estimated 63,110 persons living with HIV were diagnosed and know their HIV status.
2. Of those diagnosed, 81% were estimated to be on treatment.
3. Of those on treatment, 91% were estimated to have a suppressed viral load.

For more information on the 90-90-90 initiative and to access the Canadian Government's summary on meeting the 90-90-90 targets, please visit:

<https://www.canada.ca/en/public-health/services/publications/diseases-conditions/summary-estimates-hiv-incidence-prevalence-canadas-progress-90-90-90.html>

We are happy to announce that myWAPPS is now available for download from the App store and Google Play. Your support in testing and providing feedback has been essential in the development and release of this app.

Please note that updating or downloading the official version of myWAPPS will remove access to your test account. Your current myWAPPS login is only associated with the test version of the app and will not work on version 1.0.0.

You may still access the test version of myWAPPS for a short time, however please be aware that this will expire. Activation for myWAPPS is now available on the WAPPS-Hemo website and can be done by a healthcare professional at your hemophilia treatment centre.

Please see our website for more information: www.mywapps.org.

If you would like assistance with activating a new myWAPPS account, please let me know and I would be happy to facilitate.

We are already working on incorporating much of your feedback into the next version of myWAPPS, and look forward to bringing out these updates within the next few months!

Best regards,
Sydney MacLeod
(maclesd@mcmaster.ca)

Jivi approved by Health Canada

Bayer Inc. announced today that Health Canada has approved Jivi® (Antihemophilic Factor [Recombinant, B-domain deleted, PEGylated]) for routine prophylactic treatment to prevent or reduce the frequency of bleeding episodes in previously treated adults and adolescents 12 years of age or older. Health Canada also approved Jivi for control and prevention of episodic bleeding, and peri-operative management of bleeding (surgical prophylaxis.)

The recommended initial prophylactic regimen for Jivi is twice weekly, with the ability to dose every five days and further individually adjust to less or more frequent dosing based on bleeding episodes. This approval is based on results from the PROTECT VIII trial.

"In Canada, approximately 2,500 people live with hemophilia A2. It is a rare disease where one of the proteins needed to form blood

clots is missing or reduced and patients struggle to manage bleeds," said Dr. Alfonso Iorio, professor and researcher of the Department of Health Research Methods, Evidence, and Impact and the Department of Medicine at McMaster University. "Research shows Jivi's novel structural design produces very predictable pharmacokinetics (the way the drug moves through the body). This makes it simpler to build effective treatment regimens and minimize the infusion frequency."

"We welcome the approval of Jivi by Health Canada," said Paul Wilton, president, Canadian Hemophilia Society. "This will add another option for patients with hemophilia A in selecting the factor VIII replacement therapy that is right for them."

HEMLIBRA (Emicizumab) approved by Health Canada

Hoffmann-La Roche Limited (Roche Canada) announced today that Health Canada has approved HEMLIBRA® (emicizumab injection) for hemophilia A (congenital factor VIII deficiency) patients with factor VIII inhibitors as routine prophylaxis to prevent bleeding or reduce the frequency of bleeding episodes.

In two of the largest clinical studies for people with hemophilia A with inhibitors (HAVEN 1 and HAVEN 2), HEMLIBRA was shown to substantially reduce bleeds in adults and children compared to prior episodic (on demand) treatment with bypassing agents.

"Preventing bleeds in patients with hemophilia A can be extremely challenging, usually requiring patients to self-infuse medications multiple times a week, or even daily," says Dr. Jayson Stoffman, Associate Professor, Department of Pediatrics and Child Health, University of Manitoba, and Medical Director of the Manitoba Bleeding Disorders Program. "The development of inhibitors adds a significant challenge, with more demanding treatments that are often less effective. Hemlibra offers these patients the chance to effectively reduce the frequency of their bleeds with a once weekly injection at

home. This could significantly improve the quality of life for inhibitor patients, and particularly children and their families."

Hemophilia A is a rare bleeding disorder affecting approximately 3,000 Canadian males. Five people with hemophilia A have significantly lower than normal levels of factor VIII (FVIII) in their blood, which lowers the ability of their blood to clot. Nearly one-in-three people with severe hemophilia A can develop inhibitors to factor VIII replacement therapies, putting them at greater risk of life-threatening bleeds or repeated bleeding episodes that can cause long-term joint damage.

"Many people with severe hemophilia A face an ongoing struggle to control their bleeds, live with pain caused by joint damage and their lives revolve around treatment infusions. Until now, treatment options have been limited for those with inhibitors to factor VIII and there hasn't been a new medicine in the past 20 years," says Paul Wilton, President, Canadian Hemophilia Society. "Hemlibra is a significant innovation for people with inhibitors and we are pleased that it is now approved for Canadian patients."

New York Rangers Head Coach David Quinn on Hockey & Hemophilia

by Caitlin Kelly

Ice as unyielding as concrete. Razor-sharp blades whizzing past with abandon. Slap-shot pucks flying through the air. Boards dented and dinged from bodies slammed hard into them during every game. Ice hockey and hemophilia are not a good match. But for David Quinn, an ice hockey rink is where he feels most at ease. On one hand, this is no surprise. Quinn, 52, is the new head coach of the New York Rangers, one of the National Hockey League's most storied franchises. On the other hand, it's a bit startling, because the rookie NHL head coach and former hockey player has hemophilia B.

On a steamy August afternoon a few weeks before the Rangers began preseason training for the 2018-19 season, Quinn was still moving into his office at the team's practice facility in Tarrytown, New York, just north of New York City. Tables were stacked with plaques and awards, accolades from a nearly 25-year coaching career.

Before coaching, Quinn was a lauded player, a tough and skilled defenseman. He won hockey scholarships to a prestigious prep school and to Boston University, was a first-round NHL draft pick and had a realistic shot at the 1988 Olympics. Needless to say, this is not the expected athletic resume of someone with mild hemophilia B. But that's because Quinn wasn't diagnosed until he was 20, when his college team doctor noticed his internal injuries were blood-related and suggested Quinn be tested for hemophilia.

During an interview at the Rangers practice center, Quinn is persistently modest. He often starts sentences with the phrase, "I'm lucky that..." In some ways he is, but he's also made a long, hard climb. And few challenges tested him more than the hemophilia diagnosis that ended his promising on-ice career. It was a complete shock, although in hindsight there had been signs.

Quinn was born July 30, 1966, and raised in Cranston, Rhode Island, a town he characterized in an open letter introducing himself to Rangers fans as being "as blue collar as they come." His late father, Bill, was a narcotics detective. His mother, Janice, was a school bus driver. Quinn, the oldest of three kids, grew up a jock. Unaware of his hemophilia, he played just about every sport, no matter how rough-and-tumble. "Right near our house there were three baseball fields, four basketball courts, a pool and a pond," he recalls of his childhood. He started hockey at 4. He bruised a lot, but no one questioned it. "That's just sports played hard," everyone figured.

Quinn excelled at ice hockey. His sophomore year of high school, he transferred to the Kent School, a prestigious boarding school in Kent, Connecticut. The school's hockey coach had seen him playing on an opposing team and offered him a full scholarship—a major win for someone whose family could never have afforded it. "I had never heard of any of these prep schools, but I was excited," he recalls. "I wanted to go. I looked at the opportunity academically and as a way to get into that world."

Not that it was easy at first. "I was probably the poorest kid on campus," Quinn says. "I vividly remember lying there in bed thinking, 'What am I doing?' But I said, 'In one month, everything's going to be OK.' I've always been optimistic." Easing the adjustment was the known quantity of sports. Quinn played hockey and football. At 6 feet tall and 215 pounds, he was a dominating physical presence. He was also frequently in pain.



The shadow of his hemophilia, still unsuspected, began to grow as Quinn ramped up his athletic activity and the intensity of every game—and his injuries—became more severe. "I started getting hurt more often," he recalls. "I missed some hockey and some football because of it. My ankle would swell up at the end of the game." He played running back in football, and the day after games he would have bruises up his arm. "I couldn't hold a pen. I just thought, 'Well, I'm playing sports at a higher level, so of course I'm getting hurt.'"

Just how high a level Quinn was at athletically was evident when he was picked 13th in the first round of the 1984 NHL Entry Draft. He had just graduated from Kent and was not yet 18 years old. Opting to forgo signing a professional contract right away, Quinn accepted a hockey scholarship at Boston University, having been recruited by celebrated BU assistant coach Ben Smith. In Boston, Quinn's life would be forever altered.

At BU, Quinn struggled to stay healthy. He missed half of his first season when he needed surgery to stop internal bleeding in his right shin, a long, deep scar a reminder of that injury, which kept him bedridden for weeks. An award-winning second season was still marked by painful aches and bruising.

After his sophomore season, in March 1986, the BU team doctor suggested Quinn be screened for hemophilia. The tests came back showing he had factor IX deficiency. Quinn had no idea what had just hit him. "I knew zero about hemophilia," he says. "I thought I could take a pill and I could be cured. Once they told me what it was, it was scary. I'd already played two years of college hockey!"

His family was equally surprised. Of the three Quinn siblings, only David is affected. The Quinns later discovered Janice's father had hemophilia, and she was a carrier.

Shaken, Quinn wasn't ready to give up. His sights set on making the USA hockey team for the Calgary Winter Olympics in February 1988, he signed a waiver releasing BU from any liability. "My theory was I'd already survived 15 years of playing high-level sports," he says. "As far as treatment, there really wasn't much you could do," he says of that time. Back on the ice, he started the Terriers season but promptly got a thigh bleed that landed him in the hospital and forced him to miss half the season—again. Despite all this, he won an invite to the US Olympic hockey trials in 1987.

Three weeks before the trials, Quinn sprained his ankle. The injury spiraled into a massive leg bleed. In what was now a painfully familiar scenario, he faced surgery and an extended hospital stay. Finally, Quinn acknowledged what was all too clear: His body couldn't cope with the demands of hockey. His playing career had to stop. "The realization led to some dark days," he says. "I was definitely a pissed and rattled and depressed human being. I tried to put up a good front, but it wasn't easy. The only thing that helps you through it is time, and finding another passion."

For Quinn, that other passion was coaching. Returning to BU, he assisted the staff of the junior varsity men's team. "The impact my coaches had on me was powerful," he says. "I thought it would be cool to have that same impact on other people. To go from not being a player, it softened the blow a little bit."

"The impact my coaches had on me was powerful," Quinn says. "I thought it would be cool to have that same impact on other people. To go from not being a player, coaching softened the blow a little bit. Ben wanted me to quit playing hockey, and he helped me through my difficult times." With Smith's help Quinn jumped into coaching full time.

Quinn also leaned on one of his old coaches, Ben Smith, for advice. Smith was key to Quinn's recovery and transition from player to coach. "He wanted me to quit playing hockey, and he helped me through my difficult times," Quinn says of Smith. Today, Quinn says he and Smith still speak five days a week.

After graduation, Quinn worked in a Boston law firm, then with Smith's help he jumped into coaching full time. He put in long hours building a team at the University of Nebraska Omaha, worked as a developmental coach for USA Hockey, coached the minor league Lake Erie Monsters in Cleveland and worked as an assistant for the NHL's Colorado Avalanche.

In 2013, Quinn made a full circle of sorts when his alma mater, BU, hired him as head coach of the men's hockey team. Faced with big expectations, Quinn delivered, leading the Terriers to the NCAA national championship game in 2015 (a tough loss to Providence) and two conference titles. After five years in charge at BU, Quinn's achievements led to the offer from the Rangers.

Over the years, as Quinn grew as a coach, his management of his hemophilia evolved as well. His factor levels are sufficient that the only regular infusions he needs are before and after surgery or dental work, he says. "I don't live with it daily," he says of his hemophilia. "I live a very normal life." Outside of work, Quinn's set to make another big change when he marries Kerry O'Brien, a woman he dated while they were undergraduates at BU.

Today he gets in his exercise at the gym and plays golf. He still has to be careful, though. A normal day working means lacing up his skates during practice and getting up close with his players. His hemophilia isn't something he's disclosed to them. "This is not about me," he explains. "It's about them."

Not that Quinn's hiding anything. He's happy to share his experiences with people in the bleeding disorders community. "I think my story can be very helpful and give people hope," he says. "The hemophilia world can be a world of 'no' and extra cautiousness. Every person with hemophilia has their own limitations, but with the proper medical guidance, we can figure out what we can do."

Everything Quinn's gone through has prepared him for his next steps. He knows that consistent hard work, mental toughness and focus—the kind it took him, at 20 years old, to re-envision his life after his hemophilia diagnosis—gets teams to the Stanley Cup. "It's a psychological game," he says. "It's all mental!"

Article from Hemaware: <https://hemaware.org/community-pulse/new-york-rangers-head-coach-david-quinn-hockey-and-hemophilia>

We Need Your Help!

Dear Members,

Hemlibra (Emicizumab) is not available to Canadian patients even though it was approved by Health Canada in August 2018. At this rate, it will not be available until 2020 – unless you speak up!

It takes Canadian Blood Services (CBS) up to 24 months and 30 different steps to add a new therapy to their formulary after it has been approved by Health Canada. We think this is too long. Inhibitor patients' lives and limbs cannot afford to wait 2 years for approval. Hemlibra has been shown to be safe, effective, and game-changing for patients with inhibitors, and they need it now.

What can you do to Help?

Within the next two weeks, draft a letter/email to your Minister of Health and Long-Term Care at christine.elliott@pc.ola.org. Please use this link to view Minister Christine Elliott's ministry and constituency office contact information. If you want to go the extra mile, you can also email/mail your local MPP. To find out who your local representative is, you can follow this link to Elections Ontario, and to find out your MPP's contact information you can follow this link to the legislative directory.

When you send an email, please cc info@hemophilia.on.ca unless there is confidential information in the letter, so we can track community support for this initiative. Go to our post on the Hemophilia Ontario Facebook page, "like it" and add a comment once you have sent your letter indicating you have done so. This is to create awareness and boost the post.

Who Should Speak Up?

All those affected by Hemophilia and their family members, not just those affected by inhibitors. Hemlibra has already had positive life-changing effects for many and there are many patients in Ontario that could benefit from having this drug now!

We need to put pressure on our Government to act now and we can't do that without your help! Inhibitor patients need your support to make this happen!

Please contact us at director@hemophilia.on.ca to obtain a sample letter.

Thank You,
Hemophilia Ontario

How to Get Involved ...

Hemophilia Ontario welcomes the interest of individuals in our organization. The Board of Directors is elected at our Annual General meetings for a one year term. Each region elects a Regional Council at their Regional General Meeting.

For further information please contact:

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How You Can Help ...

Want to continue receiving a hard copy of **Blood Matters** by mail?

Please contact Jenna at 888-838-8846 ext 17 or jfoley@hemophilia.on.ca

Your generosity is the key to providing programs and services to individuals with inherited bleeding disorders. No other organization in Ontario offers these supports to those living with and / or affected by inherited bleeding disorders. With your passion, commitment and dedication we know we can make a difference.

HERE ARE SOME OF THE WAYS YOU CAN HELP:



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To make a donation, please visit:

<http://events.hemophilia.on.ca/payments.php>

Donate monthly through direct debit or on your credit card

If your employer has a charitable donation program, have an amount taken off each pay cheque

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FUNDRAISE

Volunteer at a fundraising event, such as Bingo

Join an event, such as the Polar Bear Dip, and obtain sponsors

Nominate Hemophilia Ontario as your company's charity of the year



CAMPAIGN

Become a Hemophilia Ontario campaigner. Tell your family, friends and colleagues about our work



VOLUNTEER

Become a Hemophilia Ontario volunteer. Each and every one of our six regions across Ontario are always looking for volunteers to become active and involved. Give a little bit of time, or give a lot. Whatever time you can give will be greatly appreciated.



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