



Adult Bleeding Disorder Program  
Spring 2020



### Know the facts about coronavirus disease (COVID-19)



We will be sending out weekly updates with information relevant to the Adult Bleeding Disorder Program. Our first email was sent March 16, 2020. In case you missed it [here is the link](#). If you have any questions or concerns please feel free to contact us via phone or email. The latest information from the BC Centre for Disease Control

can be found [here](#).

## Welcome a New Team Member



Dr. Hayley Merkeley is a hematologist who works with Dr. Jackson at Providence Hematology, as well as in the Provincial Hemoglobinopathy Program where she treats other genetic blood conditions. She completed her medical training at UBC and the University of Toronto. She also holds a Master's in Public Health from the London School of Hygiene and Tropical Medicine. Hayley is interested in health promotion and global health. She looks forward to working with all of you.

## Research Corner

**For the time being, we will be holding off on enrolling new patients until the hospitals and outpatient clinics are back to normal operation. However, please still feel free to contact Ming ([MYang@providencehealth.bc.ca](mailto:MYang@providencehealth.bc.ca)) if you are interested in being involved in the future.**

1. **DYNAMO study** (The dynamic interplay between bleeding phenotype and baseline factor level in moderate and mild hemophilia A and B)

You are being invited to take part in this research study if you have previously been diagnosed with a moderate or mild form of hemophilia A or B. The purpose of this study is to gain insight into the relationship between the coagulation factor levels and the bleeding episodes in Hemophilia A or B. This study is designed to find out if we can predict the amount and/or the severity of the bleeding by assessing the coagulation factor levels.

2. **PMCH study** (Personalized Medicine for Canadians with Hemophilia: a pragmatic evaluation of the Web-Accessible Population Pharmacokinetics Service- Hemophilia (WAPPS-Hemo) tailored dosing)

This is a study for severe to moderate hemophilia A or B who are on continuous factor prophylaxis. The purpose of this project is to generate a method of individualizing hemophilia treatment with the goal to improve patient quality of life and maximize benefits on patient important outcomes.

## World Hemophilia Day April 17<sup>th</sup>, 2020

***Watch as BC place lights up in red.***

The theme of World Hemophilia Day in 2020 is "Get+involved". It's a call to action for everyone to help drive the WFH vision of "Treatment for all" at the community and global level. Whether you are a patient, a family member or caregiver, a corporate partner, a volunteer, or a healthcare provider, we want to encourage you to help increase the awareness of inherited bleeding disorders and the need to make access to adequate care possible everywhere in the world.

To help bring awareness and celebrate World hemophilia Day on April the 17 BC place will be wearing a vibrant red crown.



## Uncertain Times and Uncomfortable Feelings

Anxiety is a spectrum of feelings that many people will have encountered along the course of hemophilia and other bleeding disorders. These feelings can range from feeling apprehensive with something and needing time to gather yourself before proceeding; to a true phobia with crippling terror, refusal or avoiding the situation entirely. People with bleeding disorders commonly worry about bleeding from injuries, worry about treatments and especially can worry about needles. Anxiety can impact health care experiences significantly so recognizing, addressing and strategizing how anxiety can be managed is important as it may make care quicker, less painful (mentally and physically) and lead to the optimal health outcomes.

Some useful strategies suggested on by experts at Harvard for the slightly worried or “almost” anxious [are here](#).

For more bleeding disorder specific discussion and resources there also is a nice (but long) video from the National Hemophilia Foundation on Skills for Coping with Anxiety and Depression in Bleeding Disorders led by Karen Boyd, an American social worker involved in bleeding disorder care. [Link to video](#)

## Are you Moving/Going off to school?

Not all factor/treatments for bleeding disorders are carried by all hospitals. If you are moving or have moved recently please let us know. In addition to updating your records we will ensure that the factor/treatments most appropriate for you are available at your nearest hospital.

## Prescription refills/Home Infusion Program

### Help us help you and review the following;

For now....please request refills of your Factor/Product/Medication at least 14 business days before required. This additional lead time will allow us to do our usual review (iCHIP records, inhibitor screens, recent bleeds...) but also ensure proper levels of product are available where and when they are needed. Average refills are 8 weeks of product. Sometimes more and sometimes less depending on your unique circumstance.

Ensure your iCHIP infusion records and inventory are up to date before requesting a refill. Records are to be submitted at least monthly as per standard national practices.

## Our Website

We are continuing to updating content regularly. Do you have a procedure coming up? Check out the procedure resource section [Here](#). We hope you will find it useful and welcome your feedback!

<http://hemophilia.providencehealthcare.org/>

## Hemophilia Today Magazine

Hemophilia Today Magazine from the Canadian Hemophilia Society released its last edition in December 2019..

[Click here to read it](#)

It will be replaced with an online information platform providing news stories and headlines on a more continuous basis. The details of this are yet to be released. Stay tuned....

Thanks for reading, and **Happy Spring (almost)** from all of us at the St. Paul's Adult Bleeding Disorder Program!



1081 Burrard Street, Rm 491 Burrard Building, Vancouver , BC. | Tel. 604-806-8855 |

[H&HClinics@providencehealth.bc.ca](mailto:H&HClinics@providencehealth.bc.ca)

<http://hemophilia.providencehealthcare.org/>