

St. Paul's Hemophilia Program
Summer 2020



Women Matter

For every male affected by hemophilia it is estimated that 2-5 females are affected. This this means there are a lots of women out there with mild hemophilia as well as those with other bleeding disorders. At the World Federation of Hemophilia Virtual conference there were no less than FIVE sessions about women and bleeding disorders.

We wanted to pass on information regarding the Cinderella study. This is an exploration of the lived experience of women who bleed that aims to identify unmet medical need by means of social media-based surveys and regional focus groups. Please share this study link with any women affected by a bleeding disorder.

https://haemnet.typeform.com/to/uWufTl



Sharps Disposal for Home Infusion Programs

Dear Home Infusers,

There have been some issues in the past several years regarding acceptance of sharps generated from Home Infusion. We've done some research and can confirm the following process applies to St. Paul's hospital, and all hospital locations within Fraser Health, Interior Health, and Northern health:

- Sharps collected in a proper sharps container can be accepted at Hospital TML/Blood Banks ONLY IF you have no other means of safe disposal.
- The container **must NOT be overfilled** (observe maximum fill line on container) and must be fully closed – the technologist accepting the container may request that you finish securing the lid if it appears open
- Sharps collected in any and all alternate containers MUST NOT be brought to the lab (no Tupperware containers please)
- If you do not have a proper sharps container, please contact the Adult Bleeding Disorder Program we will provide you with instructions

COVID-The norm for now but not forever

Aside from sharpening our cleaning skills and wearing masks, we have returned to most of our original practices. We will see you in person when we need to do a physical exam, blood work or manage a complicated issue. We will continue to offer virtual visits when it makes sense for your care. Like all of you, we have small personal bubbles and are doing our best to keep ourselves, our team and all of you safe, healthy and happy.

We have standards (you know!)

In case you missed it, the new 2020 Canadian Integrated and Comprehensive Care Standards for Inherited Bleeding Disorders they are posted on the CHS website and can be accessed <u>here</u>

The document may seem long but the standards start on page 8 and it is only 5 pages

long. As a team we will be reviewing how we measure up this fall. We welcome any feedback you may have regarding how we are meeting the standards in the document,

Planning a Procedure? Upcoming Dental work?

Help us help you and review the following;

Please let us know at least 7 business days before any procedures or dental work. request prescription refills at least 7 business days before required. Do not assume that your dentist or surgeon will let us know. You know what they say about assumptions !

We will then connect with your specialist to gather more information about the procedure details and the associated bleeding risk. Once a date is confirmed we will send your specialist our formal recommendations. We will also share the recommendations with you and organise any factor and or other prescriptions required.

More helpful tips on our website

World Hepatitis Day was July 28th, 2020

Globally, more than 250 million people are living with chronic Hepatitis B Virus (HBV) infection. Have you been vaccinated. <u>Vaccine information</u>

Free vaccination for hepatitis B is provided by your local health unit if you:

- Have hemophilia or other bleeding disorder and receive factor infusions
- are a sexual partner of someone who has hepatitis B
- are a sexually active homosexual or bisexual male
- inject drugs or are a sexual partner of a needle drug user
- have many sexual partners or a recent history of a sexually transmitted disease
- have hepatitis C
- See all conditions here

If you would like to be vaccinated but are not included in the groups eligible for free vaccine, you can buy the vaccine through a travel clinic, your doctor or pharmacy.

Hemophilia Today Magazine Has Gone Virtual

The CHS is proud to launch its online news platform, <u>CHS CONTACT</u>, replacing its longstanding newsmagazine, Hemophilia Today. On <u>CHS CONTACT</u>, you will have access to the same quality information you always had with Hemophilia Today, but in a more timely manner. Should you want to contribute in any way, we welcome stories, letters and suggestions for articles. <u>Click here to read it</u>

Thanks for reading, and Happy Summer from all of us at the St. Paul's Adult Bleeding Disorder Program!

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