



Adult Bleeding Disorders Program of British Columbia

St. Paul's Hospital

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<http://hemophilia.providencehealthcare.org>

WELCOME TO THE ADULT BLEEDING DISORDERS PROGRAM of BC/Yukon

WHO WE ARE

The Adult Bleeding Disorders Program of BC/Yukon provides specialist interdisciplinary care to people with inherited bleeding disorders such as Hemophilia and von Willebrand Disease. Outpatients clinics are held at St. Paul's Hospital and at out-reach locations including Kelowna, Nanaimo, Prince George and Victoria.

We offer the following services:

- Comprehensive care for patients and families with hemophilia A and B of all severities
- Diagnosis and ongoing care of all inherited bleeding disorders
- Procedure/trauma/surgical hemostatic management recommendations
- Home coagulation factor infusion program
- Care of women with bleeding disorders
- Inpatient care when admitted to St Paul's Hospital
- Inpatient remote support and consultation when admitted to other hospitals

We promote independence, self-care and practice within a patient centre value based care model.

We assist you and your family and other health care providers to become more informed about your bleeding disorder so that you can receive optimal care as close to home as possible.

OUR TEAM

Read more about our team on our website: <http://hemophilia.providencehealthcare.org/>

Physicians:

Dr Shannon Jackson (Medical Director)
Dr Paul Yenson
Dr. Hayley Merkeley

Nurse Practitioners:

Karen Sims NP (A)
Michelle Bech Clark NP (A)

Physiotherapist: Monday-Wednesday-Friday

Stacey Cave B.A.Sc MPT

Social Workers:

Mireille LeClaire MSW RSW
Claude Bartholomew MSW RSW

Booking Secretary:

Alexia Caneloro

Clinic Coordinator:

Barbara Sheridan

WHAT BLEEDING DISORDERS DO WE CARE FOR?

Hemophilia A (Factor VIII) and B (Factor IX)

Hemophilia is a **lifelong, hereditary** disorder. In 1 out of 3 cases, there is no history in the family; the cause is a new genetic mutation, thus hemophilia can affect any family. The two types of hemophilia, A and B, affect “at least 3,700 Canadians”. Some cases go unrecognized until well into adulthood. The most severe forms of hemophilia affect almost only males. Women who are **carriers**, can have abnormal bleeding symptoms that affects their quality of life.

Von Willebrand Disease (VWD)

Von Willebrand disease (VWD) is the most common bleeding disorder. Symptoms affect an estimated 1/10,000 Canadians, both male and female. Many of these people have yet to be properly diagnosed and this can be a challenging disorder with only about 4,300 being followed in bleeding disorder centers. Life-threatening hemorrhaging can occur after childbirth, surgery or trauma. A woman’s quality of life can be more seriously affected (heavy menstrual bleeding can lead to hysterectomies, these can be avoided if the woman is properly diagnosed and treated). There are effective treatments that exist for von Willebrand disease.

Rare Factor Deficiencies

A small number of Canadians, fewer than 1,000, suffer from rare factor deficiencies. These people have low or absent levels of a specific blood protein, either factor fibrinogen i, II, V, VII, X, XI, or XIII. Like hemophilia and VWD, these are genetic conditions for which there are **treatments**.

Platelet Function Disorders

There are many different kinds of platelet function disorders. In these disorders, blood platelets do not function normally, resulting in blood not clotting properly. In some individuals, bleeding can be severe. Some people have no symptoms at all until they have a serious injury or surgery. As with von Willebrand disease and some platelet disorders, **many cases go undiagnosed for decades**.

Undefined Bleeding Disorders

There are a group of disorders with bonafide bleeding symptoms that resemble the conditions above but do not have a measureable defect in the coagulation laboratory. We presume there is an abnormality that cannot be measured using our currently available tests. Some of these patients have collagen disorders such as Ehler-Danlos syndrome.

WHEN TO CONTACT US

- You are bleeding
 - If you have a bleed that has required treatment
 - If you have a procedure or surgery planned (your current treatment may not be sufficient) please give us at least 2 weeks’ notice of the procedure so we can prepare recommendations for you and the care provider treating you.
 - If you are ordering Factor for home infusion 2 weeks’ notice is needed for CBS and the transfusion medicine system to supply factor.
 - You have a question
 - If we are closed please call SPH Hematology on-call
-

HOW TO CONTACT US:

We make contacting anyone of us easy with one number and one email

Phone: 604-806-8855 extension 1 (M-F 8:00-4:00, closed stats)

Toll free: 1-877-806-8855

After Hours call St. Paul's Hospital Hematology on-call 604-682-2344

E-mail: H&HClinics@providencehealth.bc.ca

HOW TO FIND US:

The Adult Bleeding Disorders Program offices are on the 4th floor West Burrard Building. Take the elevator across from gift shop to the 4th Floor, turn left off the elevator and follow signs to the Diabetes Clinic. Take the ramp up through the waiting area and turn right, walk down the hall to Room 491 which is on the left (Hemophilia/Hemoglobinopathy sign on door). Please check in with the booking secretary.

WHEN ARE CLINICS

St. Paul's clinics are generally set up weekly on Monday afternoons between 1300-1600 and Wednesday mornings 0800-1200. Monday clinic is generally for women with bleeding disorders, assessments for whether you have a bleeding disorders, undefined bleeding disorder and Von Willebrand Disease. Wednesday Clinic is generally for patients with Hemophilia. We also offer urgent drop in appointments as needed.

WHERE ARE CLINICS

There are two locations for the clinics and one treatment room for drop-in appointments at St. Paul's Hospital. The booking secretary will advise you of which location you will be seen at.

1. **Rapid Access Clinic** – 5th floor Burrard Building, Go in through Main Entrance, take the elevator across from the gift shop to 5th Floor, turn right outside of the elevator. Check in at the registration desk
2. **UBC Faculty of Medicine - Clinical Skills Teaching Room** – 5th floor Burrard Building, Room 541A. Same as above except turn left outside of elevator on the 5th floor and walk down to Room 541A, right side of hallway and check in with program secretary
3. **Treatment Room** – 4th Floor, Burrard Building (see directions for how to find us above)

EMERGENCY CARE PROCEDURE

If you are injured or are headed to the emergency department please call us first so we may assist with the triage and treatment recommendations. Call the Adult Bleeding Disorders Program at 604-806-8855 extension 1 during office hours, Monday to Friday 8:00 a.m. to 4:00 pm (no stats). After hours call the St. Paul's Hospital switchboard at 604-682-2344 press 0 and ask for the hematologist on-call to be paged before proceeding to the Emergency Department. In general, the guidelines in Factor First Card for triage of bleeding in patients with inherited disorders is urgently or ≤ 30 minutes and product infused if possible.

FACTOR FIRST CARD

In the event of an emergency, we encourage you to get the care that you need from the nearest hospital emergency department. The clinic will provide you with a Factor First Card. It is very important that you keep the Factor First Card with you at all times as this contains information about your prescribed therapies. You will need to show this to card to healthcare providers when accessing care. Consider storing a picture image on your smart phone.

MEDIC ALERT

We recommend you get a medic alert with your bleeding disorder listed on it. For more information visit our program website:

<http://hemophilia.providencehealthcare.org/patient-resources/useful-links/medic-alert>





NEW PATIENT CHECKLIST:

The basics:

- Do you know how to get a hold of us at the clinic?
- Are you interested in participating in Research?
- Have you signed up in Cambian Navigator?

Next steps:

- When is your next visit with us?
- Have you completed all baseline laboratory work?
- Have you had an inhibitor screen?
- Do you need genetic testing?
- Do you need Pharmacokinetic testing (PK) on your current factor dose?
- If you had PK testing did you ask about the WAPPS program?
- Do you need DDAVP testing?
- If you are on plasma derived factor do you have a current blood consent on file (to be signed yearly)?

Home infusion program (HIP): (not all patients)

- Have you signed the ICHIP Patient Consent form?
- Have you signed the HIP Patient Agreement?
- Have you downloaded the free ICHIP app?
- Do you know how to use ICHIP?
- Have you had your infusion skills assessed?
- Do you know how to order factor and supplies?

Do you have any questions?