

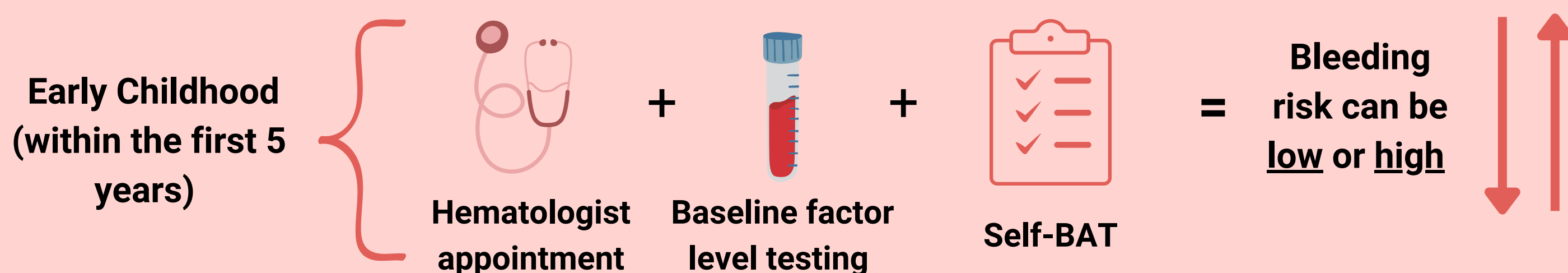
GIRLS AFFECTED BY HEMOPHILIA

Hemophilia is an X-linked inherited bleeding disorder that is passed from parent to child. It is more common in boys but girls can also be affected with low factor levels and/or bleeding symptoms.

There are **TWO** important things that every girl potentially affected by hemophilia should know...

01 KNOW YOUR BLEEDING RISK

- Current guidelines recommend having a bleeding risk assessment by a hematologist with baseline factor level testing **in early childhood** (within the first 5 years). Repeat assessment and testing should be done before **menstruation begins** and prior to any **major dental/surgical procedures**
- Additionally, a Bleeding Assessment Tool (BAT) such as the **Self-BAT** can help you understand whether bleeding is considered normal or abnormal. The Self-BAT is available at www.letstalkperiod.ca



02 KNOW YOUR CARRIER STATUS

- **Obligate carrier** = Ex. a girl whose father has hemophilia. The girl is **100%** a carrier of hemophilia. Genetic testing is usually done at some point to confirm carrier status
- **Potential carrier** = Ex. a girl whose mother has hemophilia. The girl has a **50%** chance of being a carrier of hemophilia. Genetic testing is needed to confirm carrier status and is usually done when a girl is old enough to understand the results, but may be done earlier if needed

Disclaimer: We recognize the language used may not be inclusive to all those who identify as a female or girl and their experiences with hemophilia

FREQUENTLY ASKED QUESTIONS



Q

Where can I get more information on hemophilia?

Let's Talk Period has resources for women and girls affected by hemophilia that can help you identify abnormal bleeding symptoms. The Canadian Hemophilia Society (hemophilia.ca) and Heroixx (heroixx.ca) are other great options for learning about bleeding disorders.



Q

What factor levels are being measured in the blood test? What if the levels are normal?

Factor level testing is a blood test that measures the level of **Factor VIII (8) or Factor IX (9)** in the blood. Low levels are a sign that someone has Hemophilia A (Factor VIII) or Hemophilia B (Factor IX). Female carriers of Hemophilia A or B may have low factor levels. Knowing your factor level is an important step in determining your bleeding risk, but even **carriers with normal factor levels can have abnormal bleeding symptoms!**



Q

Can factor levels change throughout life?

Yes, **factor levels (both FVIII and FIX) can change throughout a person's lifetime.** There are changes in these levels during infancy, pregnancy, as someone ages, and during times of stress. It is important to understand that the results of one blood test may not reflect a person's levels in the future.



Q

When should a girl get genetic testing for being a hemophilia carrier?

Decisions around genetic testing will depend on the **medical situation of the child** (ex. if they are having abnormal bleeding symptoms) as well as **patient/family preferences.** Genetic testing of potential carriers can be done around the age of consent and should always be done prior to pregnancy. Earlier genetic testing can be done in consultation with your healthcare provider.