

# Guide for Women Carriers & Women with Hemophilia



A publication by the Indiana Hemophilia & Thrombosis Center, Inc.  
8326 Naab Road • Indianapolis, IN 46260 • 317.871.0000 • 877.256.8837 • [ihtc.org](http://ihtc.org)

## Dear families with hemophilia:

The Indiana Hemophilia and Thrombosis Center, Inc. (IHTC), cares about your health. One of the initiatives at the IHTC is to focus on women with bleeding disorders.

This is the second of three educational newsletters designed specifically for **women with hemophilia and hemophilia carriers**. These newsletters highlight important issues related to your healthcare; topics covered include how to stay connected with the IHTC, what to tell your family, current treatments for females with bleeding symptoms, inheritance information, and more!

Share the information with your family. If you have family members who are experiencing bleeding symptoms, please put them in contact with us so that they can receive the very best care.

Please feel free to reach out to the IHTC if you have any questions or concerns. Call Meadow Heiman or Kristen Dieter, IHTC's Genetic Counselors, at 317.871.0000.

Amy Shapiro, MD  
CEO, Co-Medical Director  
Indiana Hemophilia & Thrombosis Center, Inc.

Anne Greist, MD  
Co-Founder, Co-Medical Director  
Indiana Hemophilia & Thrombosis Center, Inc.

## Frequently Asked Questions

### How do I know if I have more bleeding than the average woman?

There are questionnaires (*called bleeding assessment tools*) to determine if your bleeding is heavier or lasts longer than average. These questionnaires ask about your bleeding history, including: menstrual cycles, bruising, bleeding after surgery or childbirth, and how long you bleed when you have a cut or a nosebleed. The Indiana Hemophilia and Thrombosis Center (IHTC) can mail you a questionnaire to fill out, or you may visit [www.letstalkperiod.ca](http://www.letstalkperiod.ca) for a quick online version. You can also call the IHTC and talk to our nursing staff about your bleeding symptoms, and they will guide you in the right direction.

### Are there ways to prevent or treat my bleeding?

Yes! Women have many options available to treat a wide range of bleeding symptoms. Please contact the IHTC to discuss your symptoms and treatment options.

### My factor level is low, but I've never had bleeding issues. Do I need to worry?

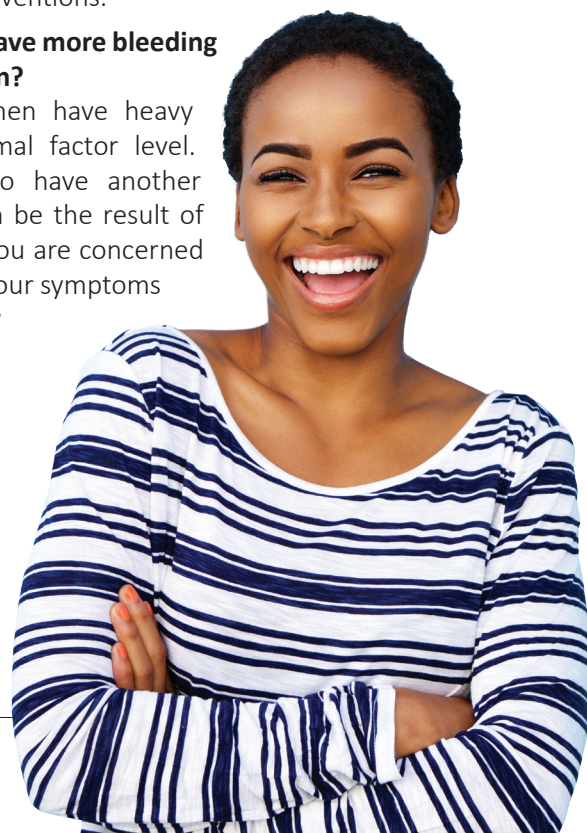
If you are in a situation where your body has to work harder to clot, you might have abnormal bleeding. This may happen with surgery, serious injury, an invasive medical or dental procedure, or during childbirth. We recommend contacting the IHTC to discuss whether treatment is needed to prevent or treat any heavy or prolonged bleeding. It is best to have a treatment plan in place in case of emergencies or prior to planned interventions.

### My factor level is normal, but I still have more bleeding than expected. What does that mean?

There are many reasons why women have heavy or prolonged bleeding with a normal factor level. Occasionally, a woman is found to have another bleeding disorder. Heavy periods can be the result of other gynecological (GYN) issues. If you are concerned about your bleeding, please discuss your symptoms with your physician at the IHTC so they can evaluate other potential causes for your bleeding. In some cases, IHTC will repeat your factor level.

### When should I contact the IHTC?

We recommend contacting the IHTC for concerning bleeding symptoms, prior to any invasive procedure, as well as during pregnancy to discuss your specific case. Please contact the IHTC with any questions and/or concerns.





# Meet Sheila

## ***Sheila's son has severe (<1%) factor VIII (8) hemophilia***

Her factor VIII is low at 30% (normal 50-150%).

She had heavy periods, but has not had bleeding issues since starting birth control pills.

In general, she is not having problems with abnormal bleeding.

Her son is followed by the Indiana Hemophilia & Thrombosis Center (IHTC). She has not established care with an adult hematologist due to lack of bleeding symptoms.

**One evening, Sheila injured her knee when she fell walking on an icy sidewalk.** The next day she was unable to walk because of pain, bruising and swelling, so she contacted her son's IHTC hematologist to discuss her symptoms and was referred to the local ER.

In the emergency room, she had an x-ray and fortunately did not have a broken bone. The ER contacted the IHTC for recommendations as she had a right knee bleed. Sheila was then infused with factor VIII, advised RICE (**R**est, **I**ce, **C**ompression, **E**levation), and sent home with a follow-up appointment to see an adult hematologist at the IHTC. Her pain, bruising, and swelling eventually got better.

### **Follow-up**

After this event, Sheila received the following:

- ✓ Evaluation by an IHTC adult hematologist and a treatment plan
- ✓ Education on her personal bleeding risks & importance of early treatment
- ✓ Medical alert bracelet and travel letter
- ✓ Stimate nasal spray could now be used instead of factor concentrate for bleeding

*She is prepared for the next emergency*





# Included in the next and final issue of: Guide for Women Carriers & Women with Hemophilia

- Family Planning
- Girls Only (GO) Clinic
- Meet the IHTC Genetic Counseling Team
- ... and more!



## Prevent or treat bleeding with the right medications

It is recommended that if you have a low factor level you are seen at the Indiana Hemophilia and Thrombosis Center (IHTC) for a medical visit. Your treatment will be personalized based on your specific needs. The IHTC will also provide education related to your treatment.

### Is there a way to prevent or treat my bleeding?

Yes—there are a wide range of medications available: oral tablets, nasal sprays, topical products, as well as factor infusions. Your care team will help you decide which products are best based on your specific factor deficiency and the type of bleeding. Amicar®, Lysteda®, Stimate®, and factor VIII or factor IX-containing concentrates are the most commonly used medications. Below is a general description of the products used.

### What medications would be used to treat bleeding?

#### **Low factor VIII (8) level** (normal level ~50-150%)

##### Desmopressin Acetate (Stimate® or DDAVP)

This is a medication that helps your body release your own stored factor VIII into your blood. It can be used before a procedure or if you are bleeding. It is available both as a nasal spray (Stimate®) and is commonly used at home, as well as an injectable solution (DDAVP), which may be given under the skin (subcutaneous) or through a needle inserted in your vein (venipuncture). You need to receive a test dose of this medication in clinic to determine if it is effective. There might be side effects that prevent some patients from using it for treatment.

##### Factor VIII concentrate

It is used to increase factor VIII level prior to a procedure or if you are bleeding. This medication is only given through venipuncture and requires training for home use.

##### Antifibrinolytic therapy (aminocaproic acid or Amicar, tranexamic acid or Lysteda)

Medications used to strengthen a blood clot or prevent a clot from being dissolved too quickly are usually given as a pill or liquid, but may also be given through venipuncture. Mostly used for bleeding from mucous membranes (mouth, nose, gastrointestinal tract, or menstrual bleeding), but not recommended for urinary tract bleeding. Often used in addition to DDAVP or factor concentrate.

#### **Low Factor IX (9) level** (normal level ~50-150%)

Desmopressin Acetate is not effective, as it does not increase your factor IX level.

##### Factor IX concentrate

It is used to increase factor IX level prior to a procedure or if you are bleeding and is only given through venipuncture.

##### Antifibrinolytic therapy (Aminocaproic acid or Amicar, tranexamic acid or Lysteda)

Medications used to strengthen a blood clot or prevent it from being dissolved too quickly are usually given as a pill or liquid, but may also be given through venipuncture. These are mostly used for bleeding from mucous membranes (mouth, nose, GI tract, or menstrual bleeding) and are often used in addition to DDAVP or factor concentrate.

