

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

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 final 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.

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Are you a female between the ages of 11-18 with a bleeding disorder, or do you have one in your family? If so, have you or your teenage loved one experienced any of the following:

Heavy Menstrual Bleeding Symptoms

- Period lasting longer than 7 days
- Soaking through a pad or tampon in 1-2 hours
- Passing clots larger than the size of a quarter
- Iron deficiency, anemia, or need for blood transfusion
- Missing days of school or work due to bleeding

Other Bleeding Symptoms

- Excessive bleeding after surgery, dental work or childbirth
- Frequent and prolonged nosebleeds
- Prolonged bleeding from cuts or wounds
- Easy bruising
- Family history of a bleeding or clotting disorder

IHTC's Girls Only (GO) Clinic is committed to providing expert care for teenage females ages 11-18 years with bleeding disorders who have experienced any of the above symptoms. Our one-of-a-kind clinic focuses on individuals with either heavy menstrual bleeding (HMB) requiring safe hormonal therapy.

The GO Clinic is the only specialty clinic of its kind in the state of Indiana, and the IHTC is staffed with an integrated on-site multidisciplinary team to help with issues that arise during your appointment. A visit to the IHTC's GO Clinic will include a laboratory work up, and if a bleeding disorder is diagnosed, comprehensive care is provided at the IHTC with regular follow-up. Hormonal therapy might also be discussed.

GO Clinic hours are 8:00 a.m. - 12 p.m. (noon) on the second and fourth Friday of every month at IHTC— 8326 Naab Road, Indianapolis, IN 46260. Call the IHTC to make an appointment (1.877.CLOTTER).

Family Planning

There are many planning options currently available for women who are carriers of hemophilia



Does my unborn child have hemophilia?

Prenatal Diagnosis: Chorionic Villus Sampling (CVS) or Amniocentesis (amnio)

Both CVS and amniocentesis can help couples learn if they are carrying a boy with or without hemophilia. A small sample of the placenta (chorionic villi for CVS) or the fluid surrounding the baby (amniotic fluid for amniocentesis) is taken and tested to see if the pregnancy has the hemophilia-causing genetic alteration in the family. Fetal gender can also be determined. CVS is performed between weeks 10-12 of pregnancy and has a less than 1% risk of miscarriage. Amniocentesis has a less than 0.5% risk of miscarriage and is performed after 15 weeks of pregnancy

Does my newborn child have hemophilia?

Cord Blood Testing

If the newborn baby is a boy, blood from his umbilical cord is collected in a special way and sent to the laboratory. The lab looks at his factor VIII and/or IX activity level to determine if he has hemophilia.

Are there other family planning options?

In-vitro fertilization (IVF) with

Preimplantation Genetic Diagnosis (PGD)

PGD can significantly raise the chance that a couple's children will be of a certain gender or will not have hemophilia. With PGD, a woman's eggs are collected and fertilized with sperm from her partner (IVF). When the fertilized eggs have developed for 3 to 5 days, testing (PGD) is performed to look for the genetic alteration causing hemophilia and/or whether the fertilized eggs are male or female.

Using an Egg Donor

A couple may conceive a pregnancy through in-vitro fertilization using the egg of a donor (anonymous or a family member) who is not a carrier of hemophilia

Adoption

Some couples are not comfortable with having a child with hemophilia, but are also not comfortable with choosing IVF or prenatal testing. For these couples, adoption may be a choice

Getting More Information

Because we are all different, there is no single choice that is right for everyone. If you are interested, genetic counselors can give you detailed information about all of your options in a judgement-free environment to help you make the decision that is right for you. If you would like more information, please contact the IHTC's Genetic Counselors.

We're here to help 

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The IHTC now offers Virtual Appointments, allowing our patients to speak with our multidisciplinary (MDT) team from the comfort of their home. These appointments are completed through a safe and secure internet connection. Just contact Jennifer Maahs at jmaahs@ihtc.org to schedule.

HEMOPHILIA OF INDIANA

2019 Annual Meeting: August 10 & 11

The 2019 Hemophilia of Indiana Annual Meeting will be held August 10th & 11th at the Crowne Plaza Hotel Indianapolis-Airport. The objective of the Annual Meeting is to provide patients and families with educational and advocacy programs as well as a strong sense of community. Program content is still in the planning process but will include a variety of educational and informative programs. In addition to the educational sessions, the event will include an exhibit hall in which families will be able to interact with various vendors. There will also be on-site daycare, a children's program, and a teen program. Additional information and registration coming soon!

<https://hoii.org/educationalprograms/annual-meeting/>



IHTC Virtual Appointments

What is required?

A phone or computer with internet connection.

Who can I talk to?

As an IHTC patient, you can speak to any of IHTC's MDT staff. For example:

- Speak 1-on-1 with a genetic counselor
- Discuss weight loss with the IHTC dietician
- Express concerns about issues that impact your healthcare with an IHTC social worker

How do I schedule a virtual appointment?

It's easy to schedule an IHTC Virtual Appointment. Just contact Jennifer Maahs at jmaahs@ihtc.org.

Take action today

Please contact the IHTC at 317.871.0000 or 877.CLOTTER if you have any questions—but especially if any of the following are true:

- You know you are a carrier but do not know your factor level
- You are having bleeding symptoms
- You are pregnant or considering becoming pregnant
- You have family members who need to be contacted by IHTC

We hope you found the information in the *Guide for Women Carriers & Women with Hemophilia* newsletters helpful. This is the final issue of our three-part newsletter series.

Now is the time to take action!



Did you miss our other newsletters? Read our complete series of Carrier news: ihtc.org/carriers