

OBTAIN A DETAILED HISTORY

An accurate patient assessment including a detailed patient and family history is critical to a bleeding disorder's diagnosis. Answers to the following questions will assist you and your patient in providing a well-rounded description of their experience.

Does your patient have one or more of the following*

(symptoms may vary with severity or may not be present at all):

- Heavy periods, especially those starting at time of menarche (i.e., periods that last longer than 7 days; changing pad or tampon every hour or more often)
- Experience a sensation of “flooding” or “gushing” during her period
- Easy bruising
- Frequent or prolonged nosebleeds (>10 minutes) that are difficult to stop
- Low in iron or treated for anemia
- Mouth and gum bleeding
- Joint bleeding
- Continual bleeding at immunization sites
- Prolonged bleeding following injury, childbirth or dental work
- Family history of bleeding disorders
- Several of the above symptoms (even without a diagnosis)

*Philipp C. Menorrhagia screening tool for bleeding disorders. AM J Obstet Gynecol 2011.

Additionally, the bleeding history should include inquiries about:

- When were the symptoms first noticed, and how long did the symptoms last?
- What were the locations and frequency of the symptoms?
- What treatment was required to make the bleeding stop (birth control pills, Amicar, plasma)?
- Did the bleeding require blood products?
- Are there any coexisting medical conditions and what is medication history?
- How were activities of daily life affected?

FIND OUT MORE

Menstruation, pregnancy, childbirth, and menopause present unique challenges in women and girls with bleeding disorders. However, **many women who experience excessive or unusual reproductive tract bleeding are unaware that they are living with a bleeding disorder.**

Undiagnosed bleeding disorders can cause significant bleeding after injury, minor surgery or outpatient procedures, childbirth, postpartum, or even dental work. Adverse outcomes of bleeding disorders can be prevented and/or controlled with treatment. This can, significantly enhancing the patient's health, safety, and her quality of life, but the bleeding disorder must first be recognized

Heavy menstrual bleeding (HMB) is one of the first and most common symptoms of a bleeding disorder. Heavy menstrual bleeding can have several causes, including hormonal imbalances, infection, and the use of certain medications. Additionally, a young woman may consider her heavy bleeding to be “normal” because her mother's bleeding patterns were similar.

We know that:

- 1 out of 5 women has heavy menstrual bleeding*
- 12-20 out of 100 women and girls with heavy menstrual bleeding may have an underlying bleeding disorder
- 1 in 6 girls who present to the Emergency Department ED with heavy menstrual bleeding (HMB) may have von Willebrand Disease (VWD)

*CDC Centers for Disease Control and Prevention, <http://www.cdc.gov/ncbddd/vwd/data.html>

MORE: Educating Providers. Changing Lives.

A RESOURCE ABOUT WOMEN
WITH BLEEDING DISORDERS FOR
YOU TO SHARE WITH YOUR
PROVIDER

Brought to you by the **Foundation for Women & Girls with Blood Disorders** and **Hemophilia Federation of America.**

Doing **MORE** together to help women & girls with blood disorders.



This publication was supported by the Grant or Cooperative Agreement Number, 1U27 00001151-01 funded by the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC or the Department of Health and Human Services.

RESOURCES

If your patient presents with one or more of these symptoms, finding effective, quality and comprehensive medical care is essential for correct diagnosis and treatment.

Women & Girls with Blood Disorders Clinic Directory

Several Hemophilia Treatment Centers (HTCs) now offer clinics specifically devoted to the care of women and/or girls with bleeding and clotting disorders (WGBD) and many others offer a range of services for these women and girls.

These multidisciplinary services often include access to Ob/Gyn or Adolescent Medicine care. Additionally, testing for a bleeding disorder should be carefully performed, with proper temperature and storage time considered. To learn more about the services and testing capabilities for women and girls at national HTCs, visit: www.fwgbd.org/clinics

Hemophilia Treatment Centers (HTCs) Directory

Comprehensive hemophilia treatment centers (HTCs) specialize in care that brings together a team of physicians, nurses and other professionals experienced in treating people with bleeding disorders. To access the HTC directory, visit: www.cdc.gov/ncbddd/hemophilia.treatment.html

Hemophilia Federation of America's Blood Sisterhood

HFA's Blood Sisterhood program was established to provide women with the information and support they need throughout life's stages. A main component of the program is a peer network where women support one another on their life's journey through diagnosis, treatment and day-to-day living with a bleeding disorder. For more information visit: www.hemophiliafed.org/programs/blood-sisterhood HFA's Sisterhood App for smart phones assists women in tracking their bleeds and allows them to share this information directly with their providers.

The app is free and easy to use, and features many helpful tools including:

- ◆ personalized calendars
- ◆ alarms for reminders
- ◆ symptom and treatment logs

For more information visit: www.sisterhoodapp.com



EDUCATION



Foundation for Women & Girls with Blood Disorders

www.fwgbd.org

At the Foundation for Women & Girls with Blood Disorders (FWGBD), we believe that every woman with a bleeding disorder deserves **MORE** – more information, more treatments, more support. That is why FWGBD is dedicated to ensuring that:

All women and adolescent girls with blood disorders are correctly diagnosed and optimally treated and managed at every life stage.

Since 2010, FWGBD has been inspired to offer medical education that enhances knowledge, ignites research, and builds expertise among healthcare providers who treat women and girls with bleeding and other blood disorders across the lifespan. Whether you are a hematologist, obstetrician or community healthcare provider, FWGBD is committed to providing you with **MORE** access to the most current, highest quality resources about bleeding disorders which can be found at fwgbd.org.



Hemophilia Federation of America

www.hemophiliafed.org

Hemophilia Federation of America (HFA) is a national nonprofit organization that assists and advocates for the bleeding disorders community. The vision of HFA is that the bleeding disorders community has removed all barriers to both choice of treatment and quality of life.

Together, FWGBD and the Hemophilia Federation of America (HFA) are doing **MORE** to increase awareness about bleeding disorders in women among physicians and patients alike.

Additionally, the two organizations encourage patients' awareness in knowing that their care has greater value and more dimensions than what a number might indicate.

As FWGBD and HFA work together in this effort, the two organizations hope that **MORE** can be done to enhance professional education to encourage and uplift patients on their pathways to the correct diagnosis, treatment and management of their daily lives.