

What is a Bleeding Disorder?

Bleeding disorders are a group of disorders in which the blood does not clot properly. They are characterized by spontaneous bleeding or prolonged bleeding after injury, surgery, trauma or during menstruation in women. Von Willebrand Disease (VWD) is the most common bleeding disorder in women, affecting more than 1.5 million American women. Hemophilia is another type of bleeding disorder that primarily affects men, but more than 1/3 of women carrying the hemophilia gene experience bleeding symptoms as well. Other rare bleeding disorders and common platelet function disorders may also cause bleeding in women. Bleeding disorders among women and girls may cause special challenges because of bleeding associated with menstruation and childbirth. Women and girls with untreated bleeding disorders are at risk for:

- Unnecessary medical procedures including hysterectomies and ablations
- Postpartum hemorrhage
- Recurring anemia
- Having to limit or change activities because of heavy or prolonged menstrual bleeding

Know the Signs & Symptoms

Signs of abnormally heavy or prolonged menstrual bleeding include:

- ✓ Periods with large amounts of blood loss, that last more than 7 days
- ✓ Soaking through an extra absorbency pad or tampon in 1 hour
- ✓ Needing to wear two or more pads or tampons at a time to control bleeding
- ✓ Passing blood clots the size of a quarter or larger
- ✓ Having a menstrual flow so heavy it keeps you from your usual activities
- ✓ Low iron levels

Other symptoms common to women with bleeding disorders include:

- ✓ Frequent nosebleeds – lasting longer than 10 minutes and having more than 5 per year
- ✓ Prolonged bleeding from minor cuts
- ✓ Easy/unexplained bruising
- ✓ Excessive bleeding after giving birth or after dental extractions/dental work or other surgery

Resources for Women About Bleeding Disorders

Knowing your bleeding disorder status is the first step to improving your quality of life. There are steps you can take and treatments are available to relieve symptoms and help you feel better. There are organizations that are here to support you. Remember, knowledge is the first step to improving your quality of life!

Bleeding disorder resources and education opportunities are available from:



The Foundation for Women and Girls with Blood Disorders (FWGBD).

The Foundation for Women & Girls with Blood Disorders educates healthcare providers across disciplines in order to ensure that all women and adolescent girls with blood disorders are correctly diagnosed and optimally treated and managed at every life stage.

Visit their website at: www.fwgbd.org



Hemophilia Federation of America (HFA). Hemophilia Federation of America is a national non-profit

organization that assists, educates and advocates for the bleeding disorders community. It specifically serves women through its Blood Sisterhood program which provides education and support that women need to reach a diagnosis and continue that support through the stages of their life with a bleeding disorder.

Visit their website at: www.hemophiliafed.org

Could I Have a Bleeding Disorder?

WHAT YOU NEED TO KNOW ABOUT

- ◆ Signs & Symptoms
- ◆ Where to Get Tested
- ◆ Preparing for Your Appointment



“I went 26 years without knowing I had a bleeding disorder.”

~ Vera, a woman with von Willebrand Disease

Have you had one or more of the following?

✓ Check all that apply:

- ☐ Periods with large amounts of blood loss, that last more than 7 days
- ☐ Soaking through an extra absorbency pad or tampon in 1 hour during your period
- ☐ Needing to wear double the feminine hygiene products during your period.
- ☐ Having to change your pad or tampon overnight during your period
- ☐ Excessive nosebleeds – lasting longer than 10 minutes and having more than 5 per year
- ☐ Easy bruising
- ☐ Frequent bleeding gums – gums that do not stop bleeding after a mouth injury or dental cleaning
- ☐ Treatment for low iron or for anemia
- ☐ Heavy bleeding following...
 - Dental work
 - Surgery
 - Injury
 - Childbirth
- ☐ Family history of bleeding disorders

✓ If you checked more than one of these signs or symptoms, you may want to consider talking to your healthcare provider about your risk of having a bleeding disorder.

Find Care

Talk to your primary care physician or Ob/Gyn about your risk of having a bleeding disorder. He/she can provide information and if a bleeding disorder is suspected, refer you to a specialist in the care of individuals with bleeding disorders. These specialists are called hematologists.

Many hematologists practice at federally funded clinics called hemophilia treatment centers (HTCs).

HEMOPHILIA TREATMENT CENTERS (HTCs)

Comprehensive HTCs specialize in care that brings together a team of physicians, nurses and other professionals experienced in treating people with bleeding disorders.

Today, several centers now offer clinics or services specifically devoted to the care of women and girls with bleeding disorders. To learn more about the services for women and girls at federally funded HTCs across the country, visit: www.fwgbd.org/clinics.

Screening for a bleeding disorder can be done at the hematologist's request at a lab that is equipped to perform the testing needed to diagnose a bleeding disorder. Your primary care provider and/or Ob/Gyn, should become partners in care with the hematologist and other practitioners at the HTC.

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Prepare for Your Appointment

Before you go to your healthcare provider, you should gather the following information:

♦ **CURRENT SYMPTOMS.** What are the symptoms that you are experiencing? When did you first notice your symptoms? Over what period of time have you experienced these symptoms? Have they changed over time? Does anything provide relief?

**SISTERHOOD**
An app from HFA for women with bleeding disorders!

HFA's Sisterhood App for mobile devices can assist you in tracking your bleeds and allows you to share this information directly with your provider.

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

- ♦ Symptom and treatment logs
- ♦ Track the number and type of feminine hygiene products used
- ♦ Reminders for upcoming period, to take medication, to add data, and more

Search **"Sisterhood"** in the iTunes and Google Play app stores.



♦ **MEDICAL HISTORY.** Include current medical problems, any past surgeries and whether you had any significant bleeding events from these.

♦ **FAMILY HISTORY.** Find out whether anyone in your family has a bleeding disorder.

♦ **LIST OF MEDICATIONS AND DOSAGE.** Include all medications, supplements, and vitamins that you take.