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

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.

**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](http://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](http://www.sisterhoodapp.com)

**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](http://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](http://www.cdc.gov/ncbddd/hemophilia.treatment.html)

**Foundation for Women & Girls with Blood Disorders**

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.

**EDUCATION**

**Hemophilia Federation of America**

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