BETTER YOU KNOW

betteryouknow.org

Please refer to NHF's resources below for more information.

References

HANDI, NHF's Information Resource Center
www.hemophilia.org/Community-Resources/HANDI-NHFs-Information-Resource-Center

NHF Health Care Provider Education
Women with Bleeding Disorders
www.hemophilia.org/Researchers-Healthcare-Providers/Health-Care-Provider-Education

Other Resources

Centers for Disease Control and Prevention (CDC), Information on Bleeding Disorders in Women
www.cdc.gov/ncbddd/blooddisorders/women/index.html

Centers for Disease Control and Prevention (CDC), Hemophilia Treatment Center Directory
www2a.cdc.gov/ncbddd/htcweb/Dir_Report/Dir_Search.asp

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Local Bleeding Disorders Resources

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betteryouknow.org

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

www.hemophilia.org

CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

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DON'T MISS THE SIGNS.
Bleeding Disorders in Women & Girls: Screening, Testing, & Coordinating Care

Primary care physicians, pediatricians, dentists, and ENTs are often the first to see signs of a bleeding disorder in their patients. Know the signs and the steps to take toward diagnosis.

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NATIONAL HEMOPHILIA FOUNDATION

BLEEDING DISORDERS IN WOMEN & GIRLS

Up to 1% of women have a bleeding disorder and many don't know it.

Von Willebrand disease (VWD) is the most common bleeding disorder in women.

- The overall prevalence among men and women is 0.6% to 1.3%
- 5% to 24% of women with heavy menstrual bleeding (HMB) are diagnosed with VWD
- VWD often goes undiagnosed despite a positive history of excessive bleeding, due to the large range in disorder severity

Factor Deficiencies

- Women can have deficiencies of factor VIII (hemophilia A) or factor IX (hemophilia B)
- Other rare factor deficiencies (II, V, VII, X, XI, XIII)

Qualitative platelet disorders

- Alpha and delta storage pool deficiencies

Other rare bleeding disorders

- Glanzmann thrombasthenia
- Bernard-Soulier syndrome

It's Better You Know: Steps for Screening, Testing & Coordinating Care

betteryouknow.org

Step 1. Assess Symptoms

Examine your patient for **ANY** of the following symptoms:

Nosebleeds that occur for no apparent reason and last longer than 10 minutes or need medical attention

Easy bruising with little or no apparent physical trauma

Excessive bleeding in the mouth or after a medical procedure/dental extraction that either continues for more than 20 to 30 minutes despite first aid measures (pressure, ice, etc.) **OR** that results in large clots.

Heavy menstrual bleeding (HMB)

- Experiencing menstrual bleeding that lasts more than 7 days
- Changing a pad or tampon every hour or more on heaviest day(s)
- Using more than one pad and/or tampon at a time or changing pads/tampons during the night
- Having an iron deficiency
- Experiencing menstrual blood clots larger than a grape

A history of muscle or joint bleeding without physical trauma

A family member has a bleeding disorder or similar symptoms

Abnormal uterine bleeding

Any one of these symptoms could be a sign of a bleeding disorder.

Step 2. Determine Risk

Determine your patient's risk for a bleeding disorder.

Refer the patient to **www.betteryouknow.org/i-want-to-know-for-women** to take the Phillip Screening Tool during the appointment. If a patient has an "At Risk" result from the screening tool, laboratory testing is needed to determine if the patient has a bleeding disorder.

Step 3. Coordinate Care for Diagnostic Tests

Coordination of care between the patient's medical providers and hematologist is critical for accurate diagnosis. To find a hematologist at a Hemophilia Treatment Center near you, go to **www.hemophilia.org**.

Coordinate Care

Work with a hematologist to identify a specialized lab in your region and request lab testing for the patient.

Due to the complex nature of diagnosis, it is standard practice to run lab screening tests more than once. Keep in mind that the lab testing results can vary based upon several factors, such as the patient's current health status, hormone levels, use of other medications, and handling of the blood sample. In addition, the following can influence clotting factor levels: stress, recent exercise, pregnancy, recent surgery, blood type, menstrual cycle and age.

Common tests to perform include the following:

- Complete blood count (CBC)
- Activated partial thromboplastin time (aPTT)
- Prothrombin time (PT)
- Fibrinogen activity
- Thyroid-stimulating hormone (TSH)
- Thyroxine (T4)
- Thrombin time
- Von Willebrand disease (VWD) profile
  - Von Willebrand factor (VWF) antigen test (VWF:Ag)
  - Ristocetin cofactor test (VWF:Rco) also known as VWF activity test
  - Factor VIII activity
- Platelet function testing: PFA-100 closure time

Next Steps

If tests indicate a bleeding disorder:

Coordinate care with a hematologist for management of bleeding disorder symptoms. For more information on diagnosis and treatment, refer to the National Hemophilia Foundation's (NHF) free and accredited provider webinar series on Women with Bleeding Disorders:
www.hemophilia.org/Researchers-Healthcare-Providers/Health-Care-Provider-Education

If tests indicate symptoms are not due to a bleeding disorder:

Remember, diagnosing a bleeding disorder is complex. Repeat laboratory testing should be considered if suspicion of a bleeding disorder remains high. If you have additional questions, consult with a hematologist at your nearest hemophilia treatment center.