

# MASAC for You



NATIONAL BLEEDING DISORDERS FOUNDATION



## RECOMMENDATIONS FOR WOMEN, GIRLS, AND PEOPLE WHO HAVE OR HAD THE POTENTIAL TO MENSTRUATE PART I: GETTING A DIAGNOSIS

### FACTS ABOUT BLEEDING DISORDERS

Inherited bleeding disorders are a group of disorders that prevent the body from forming a clot due to low levels of specific clotting factors.

**While past research, treatment, and care focused mostly on men and boys, updated research shows that women, girls, and people who have or had the potential to menstruate (WGPPM) also need care:**

- 50% of WGPPM who are carriers, have mild hemophilia A or B, and have an increased risk for bleeding issues
- Those who are carriers that have normal levels may have an increased risk of bleeding and bruising
- 1% of all WGPPM may have von Willebrand Disease, with heavy periods and bleeding after surgery or childbirth

### MOST COMMON INHERITED BLEEDING DISORDERS ARE:

- |                          |                      |
|--------------------------|----------------------|
| • Hemophilia A           | • Hemophilia B       |
| • Von Willebrand Disease | • Platelet Disorders |

### SIGNS OF A BLEEDING DISORDER IN WGPPM

**WGPPM who are experiencing the following may have a bleeding disorder:**



Heavy periods: Those that last more than 7 days, soak through a pad or tampon in 1 to 2 hours, and pass clots larger than a quarter



Heavy bleeding after pregnancy

**All individuals with a bleeding disorder may experience the following as well:**



Bruising easily, often for no reason, and may include raised bruises larger than a quarter



Frequent nosebleeds that last longer than 10 minutes



Bleeding from cuts or scrapes for longer than 5 to 10 minutes



Heavy bleeding after surgery or medical procedures (dental work, colonoscopy, biopsy, etc.).



Low iron or anemia

# RECOMMENDATIONS FOR WOMEN, GIRLS, AND PEOPLE WHO HAVE OR HAD THE POTENTIAL TO MENSTRUATE

## PART 1: GETTING A DIAGNOSIS

### 💧 THE IMPORTANCE OF ACCESS TO CARE

**WGPPM with inherited bleeding disorders should have access to:**

- Care within a clinical program with experience in bleeding disorders, such as a Hemophilia Treatment center (HTC) - see HTC directory in additional resources section
- Comprehensive care provided by hematologists and gynecologist/adolescent medicine specialists to manage heavy periods and other gynecologic conditions
- Genetic counseling and genetic testing for diagnostic purposes and family testing and planning
- Treatment to decrease or stop bleeding – see current treatment link in additional resources section



### 💧 ADDITIONAL RESOURCES & INFORMATION

#### **Better You Know Screening Tools**

<https://www.betteryouknow.org/healthcare-providers-educators/resources-on-bleeding-disorders>

#### **Current Treatment Options: NBDF Website**

<https://www.hemophilia.org/bleeding-disorders-a-z/treatment/current-treatments>

#### **HTC Search Directory (cdc.gov)**

<https://dbdgateway.cdc.gov/HTCDirSearch.aspx>

#### **MASAC Document 264**

<https://www.hemophilia.org/healthcare-professionals/guidelines-on-care/masac-documents/masac-document-264-masac-recommendations-regarding-diagnosis-and-management-of-inherited-bleeding-disorders-in-girls-and-women-with-personal-and-family-history-of-bleeding>

#### **Victory for Women**

<https://www.victoryforwomen.org/>

**NBDF'S BETTER YOU  
KNOW RESOURCES:**



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