

# MASAC for You



NATIONAL BLEEDING DISORDERS FOUNDATION

## RECOMMENDATIONS FOR WOMEN, GIRLS, AND PEOPLE WHO HAVE THE POTENTIAL TO MENSTRUATE WITH INHERITED BLEEDING DISORDERS

### PART 1: BEFORE AND DURING PREGNANCY

Women, girls, and people who have the potential to menstruate (WGPPM) who live with a bleeding disorder are at risk for bleeding during and following pregnancy.

- If you have, or are a carrier of an inheritable bleeding disorder and are considering pregnancy, it is important to know what may be different leading up to pregnancy and during pregnancy.
- WGPPM who carry the genes for a bleeding disorder may have babies that are at risk for bleeding at birth or as a newborn.

#### BEFORE PREGNANCY

WGPPM that have a bleeding disorder, or those who have a family history could pass down the bleeding disorder to future children.



Genetic testing should be done to find out if you could pass the gene to future children.



It is important to meet with your doctor to determine your base factor level before becoming pregnant.



There are different tests and procedures to diagnose an unborn child which all have different risks. Talk to your doctor about these tests and the risks if you are planning a pregnancy in the future.

#### BEGINNING OF PREGNANCY

When pregnant, there are many specialists that can manage your pregnancy including:



A hematologist (bleeding disorder specialist),



An obstetrician/gynecologist (OB/GYN): (reproductive health)



An anesthesiologist (anesthesia or pain management)



A social worker (social, emotional, and mental health)

Those pregnant with a bleeding disorder do not have an increased risk of early pregnancy loss unless they have fibrinogen or factor XIII (13) deficiency.

- Those with fibrinogen deficiency that have bleeds have a high risk of early pregnancy loss when fibrinogen levels are below 100 mg/dL.
- Those with severe factor XIII (13) deficiency are at a high risk of early pregnancy loss.
- Both conditions should be managed with factor replacement therapy during pregnancy.

MASAC Guideline 265 (see below in the Additional Resources section) is a great resource for your doctor with details on the recommended treatments to prevent or limit bleeding for the following tests and procedures.:

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## PART 1: BEFORE AND DURING PREGNANCY

### TESTING

Any procedures during pregnancy should be performed in a setting where bleeding issues can quickly be managed. These procedures may include ones that help find any genetic problems with the fetus, including chorionic villous sampling (CVS) or amniocentesis, and usually do not cause extra bleeding.

### PROCEDURES

- There are more involved procedures during pregnancy, such as cerclage which is putting stitches in the cervix to stop or slow down early birth. Some procedures are done with anesthesia in a hospital. These procedures take more planning and may need longer care.
- Procedures for early pregnancy loss or abortion are called uterine evacuations and can be done in an office. These have low risk for extra bleeding. If you have a bleeding disorder, it is important to find offices that have equipment and supplies to treat heavy bleeding for these procedures.



**Medication, as opposed to a procedure to manage early pregnancy loss or abortion, is not recommended due to the high risk of bleeding away from medical care.**

**Abortion restrictions in many states may impact access to early pregnancy care for WGPPM with bleeding disorders. Providers in all states are currently required to provide care for people with life-threatening bleeding during pregnancy. It is important that you know and understand abortion laws in your state.**

### ADDITIONAL RESOURCES & INFORMATION

#### WGPPM Health Resources

<https://www.hemophilia.org/educational-programs/education/women>

#### 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 265

<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/>

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