

Von Willebrand Disease (VWD) HubKit

"Read and research on your own about VWD, speak with others within the community, and seek out healthcare providers who have experience treating VWD."
~ Erica, diagnosed with VWD since 1981

Diagnostic Inequities

- VWD is the most common bleeding disorder, affecting 3.2 million (or ~ 1 in every 100) people in the United States.
- Globally, up to 1.3% of the general population is affected by VWD (or approximately 10 per 100,000 people).
- Typically takes an average of 16 years between the onset of a patient's bleeding symptoms and diagnosis of von Willebrand disease.
- Occurs equally in men and women. However, women are more likely to experience symptoms of VWD because of the increased bleeding it causes during their menstrual periods, pregnancy, and after childbirth.

[Source](#), [Source](#)



Tests and Diagnostic Tools

- **Physical exam:** done by your physician to check for unusual bruising or other signs of recent bleeding, as well as evidence of liver disease, or anemia.
- **Complete blood count (CBC):** measures the amount of hemoglobin (the red pigment inside red blood cells that carries oxygen), the size and number of red blood cells, and the numbers of different types of white blood cells and platelets found in blood. If a person with VWD has unusually heavy bleeding or bleeds for a long time, the hemoglobin and red blood cell counts can be low.
- **Platelet count (PLT) blood test:** measures the number of platelets you have in your blood.
- **Partial Thromboplastin Time (PPT) blood test and Prothrombin Time (PT) blood test:** these tests help evaluate a person's ability to form blood clots by how long it takes a clot to form. Assesses the amount and the function of certain proteins in the blood called coagulation or clotting factors that are an important part of blood clot formation.
- **Von Willebrand factor (vWF) test:** measures the amount of vWF in your blood and how well it works to determine which type of VWD you have.
- **Factor VIII test:** measures the activity of factor VIII in your blood. If you have very low levels of clotting factor VIII, you may have hemophilia A. The assay can also assess how serious your factor deficiency is, which may help determine what treatment you need.

[Source](#), [Source](#)

Access Barriers

- Uncertain diagnostic criteria.
- Poor clinical/scientific understanding and familiarity.
- Lack of routine use of standardized laboratory tools and access to comprehensive tests.
- High interpatient variability.
- Variations on von Willebrand Factor (VWF) concentration levels and gene mutations.
- Patient inability to be treated at hemophilia treatment center.

[Source](#), [Source](#)

Call to Action

Read up. Keep reading to increase your awareness and understanding of diagnostic testing.

Learn. If you have a disease or health problem, learn about the specific tests and how they may impact your health and treatment outcomes.

Understand. Know what's normal and abnormal for you.