

What is VWD?

- VWD is the most common hereditary bleeding disorder in the United States¹
- VWD is classified by types, ranging from Type 1 (the most common and usually mild) to Type 3 (the most severe)²

Causes

- In some cases, VWD is caused by low or nonexistent levels of von Willebrand factor (VWF), a protein in the blood that is necessary for normal blood clotting
- In other cases, VWD presents with normal levels of VWF, but the factor does not work properly

The 5 Signs & Symptoms of VWD

- Easy bruising
- Frequent or prolonged nosebleeds
- Women with VWD are more likely to experience heavy, prolonged menstruation
- Prolonged bleeding following injury, childbirth, or surgery
- Prolonged bleeding during dental procedures

Incidence and Prevalence

- According to the US Centers for Disease Control and Prevention (CDC), VWD may affect 1% to 2% of the US population (3 to 6 million people)¹
- The incidence of VWD is equal between males and females³
- A man or woman with the disease has a 50% chance of passing the gene to a child
- Parents who carry the disease but do not have symptoms can pass the gene to their children
- A family history of a bleeding disorder is the primary risk factor⁴

Living with VWD

- Patients with VWD typically have a normal life span
- Bleeding can be mild or serious, and can occur as a result of injury or without an obvious cause
- Those with more severe VWD should avoid unnecessary sources of trauma, including contact sports
- Women affected by VWD who experience heavy and prolonged menstrual bleeding are often misdiagnosed with a gynecological problem⁵
- Special care may be required during childbirth, surgery, and dental procedures
- Although VWF and factor VIII (FVIII) levels initially rise in pregnancy, after delivery they may drop much lower than even the woman's baseline, resulting in a higher rate of postpartum hemorrhage

Diagnosis

- Because VWD is usually mild, many people are asymptomatic or fail to report symptoms, leaving the condition undiagnosed in most cases
- The diagnosis of VWD can be complex, and no single blood test can diagnose VWD in all patients⁵
- Establishing a comprehensive family medical history is also essential but not always adequate to identify VWD⁶
- The 2008 National Heart, Lung, and Blood Institute (NHLBI) clinical guidelines provide evidence-based recommendations on screening and diagnosis⁵

Treatment

- The 2008 NHLBI clinical guidelines also provide evidence-based recommendations on disease management, treatments, and directions for future research⁵
- Treatment is aimed at raising the levels of VWF circulating in the bloodstream
- Nonreplacement therapy (desmopressin acetate [for patients with Type 1 and some Type 2a]): This therapy is available as a nasal spray or injection to help the body release stored VWF into the bloodstream
- Replacement therapy (for patients with Type 1, Type 2, or Type 3): Factor concentrates replace the missing VWF proteins.⁷ Factor concentrates are approved by the US Food and Drug Administration for use in treating adult and pediatric patients who experience spontaneous and trauma-induced bleeding episodes in severe VWD, and in mild or moderate VWD where the use of desmopressin acetate is known or suspected to be inadequate
- Other therapies (oral contraceptives, antifibrinolytics, topical agents [for patients with mild VWD]): These therapies may be used to control bleeding

References: **1.** US Centers for Disease Control and Prevention. Bleeding disorders. Available at <http://www.cdc.gov/ncbddd/hbd/hemophilia.htm>. Accessed November 17, 2009. **2.** National Heart, Lung, and Blood Institute. What is von Willebrand disease? Available at http://www.nhlbi.nih.gov/health/dci/Diseases/vWD/vWD_WhatIs.html. Accessed November 17, 2009. **3.** National Hemophilia Foundation. What is von Willebrand disease? Available at <http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=182&contentid=47&rptname=bleeding>. Accessed November 17, 2009. **4.** National Heart, Lung, and Blood Institute. What causes von Willebrand disease? Available at http://www.nhlbi.nih.gov/health/dci/Diseases/vWD/vWD_Causes.html. Accessed November 17, 2009. **5.** National Heart, Lung, and Blood Institute. *The Diagnosis, Evaluation, and Management of von Willebrand Disease*. Bethesda, MD: US Department of Health and Human Services; 2008. **6.** National Heart, Lung, and Blood Institute. How is von Willebrand disease diagnosed? Available at http://www.nhlbi.nih.gov/health/dci/Diseases/vWD/vWD_Diagnosis.html. Accessed November 17, 2009. **7.** National Heart, Lung, and Blood Institute. How is von Willebrand disease treated? Available at http://www.nhlbi.nih.gov/health/dci/Diseases/vWD/vWD_Treatments.html. Accessed November 17, 2009.