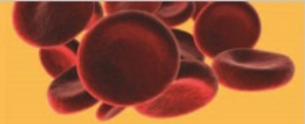




What is von Willebrand Disease?

Von Willebrand disease (VWD) is a bleeding disorder caused by a defect in or shortage of a blood clotting protein called von Willebrand factor (VWF). People who have VWD bruise easily and bleed longer than other people when they are injured.



Erik Adolf von Willebrand

von Willebrand (born February 1, 1870 – died December 12, 1949) was a Doctor of internal medicine from Finland. He was the first to describe the blood clotting disorder later named for him, von Willebrand disease (VWD). He first discovered the condition through a five-year-old girl whose

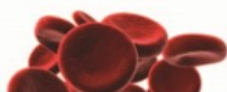
family had an extensive history of bleeding.

Symptoms

- Heavy menstrual bleeding
- Frequent and prolonged nosebleeds
- Easy bruising
- Bleeding gums
- Prolonged bleeding following dental work, surgery, childbirth, or trauma.

von Willebrand Factor

VWD is caused by a deficiency or lack VWF, a clotting protein produced in the endothelial cells that line blood vessels. VWF is the protein that causes platelets to adhere to the wall of an injured blood vessel and it serves as a carrier protein for factor VIII. About one third of the body's VWF is in the blood stream and the rest is stored in the endothelial cells that line the blood vessels.



Who has von Willebrand Disease?

It is estimated that 1 to 3 % of the population has VWD. It occurs in both men and women equally and since it is inherited, it runs in families.

Types of von Willebrand Disease



In Type 1 VWD, the mildest and most common form of VWD, patients do not have enough VWF to control bleeding. In Type 2, VWF is produced but does not work properly. Type 3 is the rarest form of VWD and can cause severe bleeding into muscles, joints, and other body parts. In this type of VWD, there is little or no VWF in the blood. Patients usually also have low levels of factor VIII.

Diagnosis and Testing

Diagnosing VWD can be quite difficult. According to the Centers for Disease Control and Prevention (CDC), it can take an average of 16 years from the onset of VWD symptoms until diagnosis. Patients who are suspected of having VWD or other bleeding disorders should be referred to a Hemophilia Treatment Center (HTC) for testing and diagnosis. A listing of HTC's in Georgia is available on www.hog.org.

To view a national listing visit www.hemophilia.org or www.cdc.gov.

Treatment

There is no cure for VWD, but good treatment is available. Most types of VWD can be treated with a synthetic hormone called Desmopressin Acetate (DDAVP), either by IV or Stimate® nasal spray. People who do not respond to DDAVP may be treated with a clotting factor concentrate rich in VWF.



Minor bleeds such as nosebleeds are usually managed by applying pressure to the bridge of the nose and applying ice packs to the back of the neck or forehead.

Any invasive procedure, such as stitches, dental work, or surgery requires a treatment plan from the HTC to prevent serious bleeding.

**Hemophilia
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It takes more than medicine...

Women's Health and von Willebrand Disease

Women with VWD can have heavy menstrual bleeding that lasts for several days or even weeks. This kind of bleeding can usually be managed with oral estrogens or Stimate® nasal spray. Some estimates say that VWD affects 1.4 to 2.8 million women in the United States and may be the cause of 1 in 6 cases of heavy periods.



Hemophilia of Georgia Can Help

Hemophilia of Georgia (HOG) provides services and support for people with all types of inherited bleeding disorders, including VWD.

1. VWD Community Outreach Nurse: The HOG full-time VWD Community Outreach Nurse is an expert in VWD treatment and diagnosis. In addition to visiting patients in their homes, she frequently makes presentations to medical professionals, community organizations, and women's groups to build awareness of the disease and its treatment options.

2. Pharmacy: HOG's nonprofit pharmacy provides convenient home delivery of VWD medications at competitive prices.

Hemophilia of Georgia exists
so that people in Georgia
affected by bleeding disorders
live as normally and
productively as possible.

Additional Resources

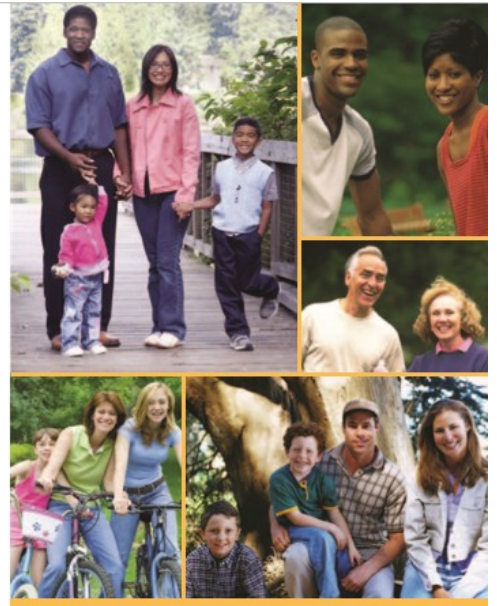
Extensive resources are available from Hemophilia of Georgia (HOG). Contact VWD Community Outreach Nurse at 770.518.8272 (phone) or 770.518.3310 (fax).

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www.hog.org



von Willebrand Disease

Affecting 1 in 100 people, it is the most common bleeding disorder.

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