

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. People who have vWD bruise easily and bleed longer than other people when they are injured.

Symptoms

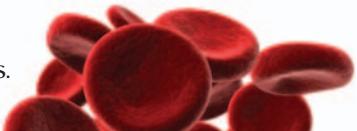
- Heavy menstrual bleeding
- Frequent and prolonged nosebleeds
- Easy bruising
- Bleeding gums
- Prolonged bleeding following dental work, surgery, childbirth or trauma.

Who has von Willebrand Disease?

It is estimated that one to three percent of the population has von Willebrand Disease. It occurs in both men and women equally and since it is inherited, it runs in families. Some estimates say that vWD affects 1.4 to 2.8 million women in the United States.

von Willebrand Factor

Von Willebrand Disease is caused by a deficiency or lack of von Willebrand factor, a clotting protein produced in the endothelial cells that line blood vessels. Von Willebrand factor 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.



Types of von Willebrand Disease



In Type 1 vWD, the mildest and most common form of vWD, patients do not have enough von Willebrand factor to control bleeding. In Type 2, von Willebrand factor

is produced but does not work properly. Type 3 is the rarest form of von Willebrand Disease and can cause severe bleeding into muscles, joints, and other body parts. In this type of vWD, there is little or no von Willebrand factor 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, it can take an average of sixteen 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 for testing and diagnosis. A listing of Hemophilia Treatment Centers 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 von Willebrand Disease 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 von Willebrand factor.



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.

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

**Hemophilia
of Georgia**



It takes more than medicine...



Hemophilia of Georgia Can Help

Hemophilia of Georgia provides services and support for people with all types of inherited bleeding disorders, including von Willebrand Disease.

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.

Pharmacy: HoG's nonprofit pharmacy provides convenient home delivery of vWD medications at competitive prices.



Resources: The vWD Community Outreach Nurse can provide brochures and other materials about vWD and its treatment.

Social Work: HoG's social workers provide many services such as counseling and community resource planning to help people with vWD or other bleeding disorders.

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

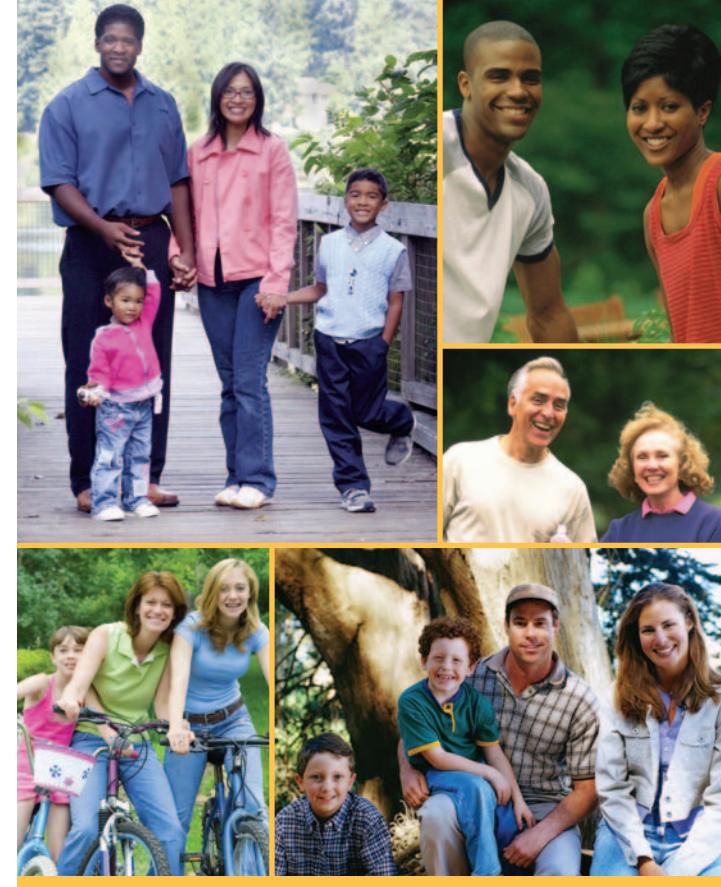
Additional Resources

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

**Hemophilia
of Georgia** 

It takes more than medicine...

8800 Roswell Road, Suite 170
Atlanta, Georgia 30350-1844
770.518.8272 • 770.518.3310 fax
www.hog.org



von Willebrand Disease

Affecting 1 in 100 people, it is the most common bleeding disorder and may cause 1 in 6 cases of heavy periods.

**Hemophilia
of Georgia** 

It takes more than medicine...