

What is Von Willebrand Disease?

Von Willebrand disease (vWD) is the most common inherited bleeding disorder. It was first described about 70 years ago and is named after the doctor who first discovered it: Dr. Erik A. von Willebrand.

With vWD, there is a shortage of von Willebrand factor (also known as ristocetin co-factor), one of the proteins in the blood that helps blood to clot (quantitative), or there is something wrong with the factor so that it does not work properly (qualitative). Whether there is a quantitative or qualitative deficiency, it takes longer for the blood to clot and for bleeding to stop. VWD is essentially the glue that holds platelets together to form the plug portion of a clot; low levels of von Willebrand factor can cause no plug to form or form a plug that cannot hold in place.

VWD is estimated to affect about 1% to 3% of the population, including men and women and all races equally. For many people, the condition is so mild that it is not diagnosed at all unless they have excessive bleeding after surgery or a major accident.

VWD is divided into types, according to whether someone has:

- a low amount of von Willebrand factor - **Type 1**
- von Willebrand factor that doesn't work properly - **Type 2**
- little or no functioning von Willebrand factor at all - **Type 3**

Symptoms:

- *Frequent, large bruises from minor bumps or injuries*
- *Frequent or hard-to-stop nosebleeds*
More than 1-2 nosebleeds a month is not normal!
- *Extended bleeding from the gums after a dental procedure*
- *Heavy or extended menstrual bleeding in women*
More than 7 to 8 days of bleeding or using both super tampons and pads is not normal!
- *Blood in your stools, from bleeding in intestines or stomach*
- *Blood in your urine, from bleeding in kidneys or bladder*
- *Heavy bleeding after a cut or other accident*
- *Heavy bleeding after surgery*

Treatment Options:

1. Do nothing. If you have major surgery or an accident, inform the doctor so he/she can monitor bleeding.
2. Use medication such as desmopressin acetate (also in nasal form as Stimate), which releases the stores of extra vWD (for Type 1s), or actually replace the poor functioning or non-existent vWD factor intravenously. **Your hematologist will determine your treatment/therapy if needed.**

Living with von Willebrand Disease can be challenging at times, especially upon diagnosis, but precautionary measures can be taken to prevent bleeding and maintain health.

- Visit your hematologist or hemophilia treatment center (HTC) for annual "comprehensive clinic" visits.
- When prescribed medication from another doctor or dentist (other than your hematologist), or prior to taking over-the-counter medications and herbal remedies, check with your hematologist to ensure that the medications do not cause bleeding. Some of the medications that cause bleeding and affect blood clotting are: aspirin, ibuprofen, and nonsteroidal anti-inflammatory drugs (NSAIDs).
- Inform all other healthcare providers of your diagnosis, including your primary care physician, gynecologist / obstetrician, dentist, pharmacist, and school/employer nurse.
- Inform anyone who is responsible for providing care for your child with vWD about his or her diagnosis (teachers, school nurse, daycare provider, coach, etc.).
- Prior to having surgery or any invasive medical procedure, inform your hematologist of the surgery/procedure, to ensure that the doctors can coordinate your care and have a treatment plan in place to prevent bleeding.
- Wear a medical alert ID bracelet so that emergency personnel will know of your diagnosis. **You may contact your BioRx representative to obtain a medical alert ID bracelet, Strap Wrap, or medical alert visor for your vehicle.**
- Eat healthful foods to maintain a healthy weight, and exercise to strengthen muscles. Safe exercise activities may include biking, hiking, golf, walking and swimming. Ask the physical therapist at your HTC for additional exercise ideas to promote muscle health. A healthy lifestyle helps prevent damage to bones, joints and muscles.
- Educate and advocate for yourself! Attend National Hemophilia Foundation chapter meetings (hemophilia has similar therapies and some common symptoms as vWD), and get involved in your community. Attend educational seminars within the bleeding disorders community.

Knowledge is power!

Contact your BioRx Representative or Patient Advocate for additional information or assistance.