



# Bleeding & Clotting Disorders Institute

*Family-oriented care for persons with bleeding, clotting and other blood disorders*

**von Willebrand Disease (vWD)** is a lifelong bleeding disorder that affects a person's clotting process. Individuals with von Willebrand Disease have deficient, defective, or missing von Willebrand factor (vWF). There are three main types of vWD:

- Type 1: 70%-80% of diagnosed cases
  - Individual has decreased amounts of vWF
- Type 2: (subcategories of A, B, M, N):
  - Defect in vWF function
- Type 3: Rare, Severe
  - Missing vWF and low levels of FVIII (Factor 8)

\*Your Hemophilia Treatment Center staff will educate you on your type of von Willebrand Disease at the time of diagnosis.

✓ You have been diagnosed with     **Type 1**     von Willebrand Disease

✓ Your primary Provider here is     **Dr. Jonathan Roberts**    

## **Inheritance of von Willebrand Disease:**

- affects 1-2 % of the population
  - affects both men and women equally
  - is hereditary – not sex linked (meaning it occurs in males and females)
  - may occur rarely through spontaneous genetic mutation
- Inheritance example: if one parent (regardless of gender) has von Willebrand Disease, there is a 50 percent chance that each of their children will also be affected.

## **Common symptoms of vWD:**

- Easy bruising
- Frequent nosebleeds
- Bleeding gums
- Heavy menstrual periods
- Prolonged bleeding after injuries or surgery
- In severe cases (rare): bleeding in stomach, intestines, muscles or joints



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## **If you or a loved one has been diagnosed with vWD, it is important to know when you should contact your Hemophilia Treatment Center.**

### **Please call if the person with von Willebrand disease has:**

- been scheduled for **any** type of dental or surgical procedure
- prolonged (greater than 10 minutes) nose bleeding
- prolonged (greater than 20 minutes) gum or mouth bleeding
- blood in the urine or stool
- excessive or prolonged (more than 7 days) menstrual bleeding
- more frequent bruising or large, painful bruising with knots
- has suffered an injury to the head, neck, or stomach
  - **If loss of consciousness or significant bleeding – call 911 prior to making other calls.**

### **When in doubt, we ask that you call our office for recommendations.**

- **To reach a nurse, please call (309) 692-5337.**
- **After regular business hours, please call (309) 677-6085 to reach the provider on call.**

\*Any of the above situations **may** require a person with vWD to receive treatment. It is important to contact BCDI so that treatment recommendations can be discussed.

## **Available treatment options for symptoms of vWD:**

- **Aminocaproic Acid (Amicar™):**
  - Available in liquid and pill form
  - Used for mouth or nose bleeding
  - Will likely be necessary with dental procedures
- **DDAVP (Stimate™):**
  - Nasal Spray/IV solution
  - Only given after a “trial” or “Stimate Challenge” of this medication has been completed and patient has been found to “respond” to the medication, meaning that it works well for the patient
  - Used for minor bleeding (including minor injuries, nosebleeds, menstrual bleeding, surgical procedures, etc.)
  - If you use Stimate, please ask BCDI for a copy of our “Fluid Restriction Guidelines”
  - **Not** indicated for patients with Type 2B or Type 3 vWD
- **Tranexamic Acid (Lysteda™):**
  - Available in pill form
  - Used for heavy menstrual bleeding
- **von Willebrand Factor Concentrate (Humate-P™, Wilate™, Alphanate™, Vonvendi™):**
  - Given as intravenous infusion
  - Indicated with some surgical procedures and with major injuries/bleeding episodes



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**There are also certain medications that persons with von Willebrand Disease should avoid due to their ability to cause an increase in bleeding symptoms. Persons with vWD should avoid:**

- Aspirin™
- Ibuprofen (Motrin™, Advil™, etc.)
- All other NSAIDS – excluding Celebrex™ and Meloxicam™

## **Staying active and activities that should be avoided:**

- Although you have been diagnosed with vWD, it is still important for you to stay active and participate in the activities that you enjoy. Persons with vWD have few limitations when it comes to sports, but there are some select activities that are too dangerous and should be avoided.
  - **Activities to avoid:**
    - Contact sports
      - Tackle Football
      - Hockey
      - Boxing, or any other contact sports
    - Riding roller coasters
  - **Refer to “Playing it Safe” Manual for more details on activity safety**
  - **Please inform your or your child’s coach of the bleeding disorder diagnosis**
  - **An emergency treatment plan should be in place when playing organized sports**

\*If you are interested in a specific activity and are unsure if it is safe, please do not hesitate to contact BCDI for formal recommendations.

## **How to inform others about your diagnosis:**

- BCDI has outreach staff that is available to come to your child’s school, local emergency department, and/or other important areas to do education on vWD. These services are offered by our clinical staff.
- Once diagnosed, a piece of medical alert jewelry should be worn at all times. Your first medic alert tag can be provided by BCDI.
- BCDI can provide you with informational travel letters, wallet cards, and other important documentation that explain your diagnosis and emergency treatment options. These documents should be carried with you or in your vehicle at all times.