

## Von Willebrand Disease

### Living with, Treating and Understanding Von Willebrand Disease

#### **Where does it come from?**

vWD is an inherited bleeding disorder that effects both male and female, and can be passed on to the children from either of their parents.

#### **What are the symptoms?**

Easy bruising is one of the typical symptoms, also frequent nosebleeds or heavy and prolonged menstrual cycle as well as excessive bleeding following dental work or child birth. People with mild vWD may experience few or mild symptoms while others with more severe forms can experience uncontrolled bleeding into muscles or joints.

#### **Are there different types of vWD?**

Yes. There are four different types. Each type ranges from mild to severe. Other contributing factors are blood type and hormone levels. Because of this, symptoms can change as you grow older.

#### **How do you treat?**

Because of the four different types and different levels of severity, each incident needs to be evaluated and handled appropriately.

Many minor symptoms may be treated without medication just by using appropriate first aid measures.

More serious bleeds may require the use of medications such as DDAVP or Stimate and in some cases the use of Factor that contains active von Willebrand factor( Humate-P) Mouth bleeds are usually treated with Amicar. Your physician will decide what therapy is best for you.

### Tips on living with vWD

- Monitor your health closely and check with your Doctor before you take any over the counter medications.
- Avoid any Anti-Inflammatory drugs that interfere with your bloods clotting ability. This includes: aspirin, ibuprofen, midol, and alka-seltzer. Check with your Doctor if you have any questions.
- Exercise regularly to strengthen joints and muscles.



- Avoid contact sports or any activity that has a risk for serious injury.
- Wear or carry medical information about your condition for emergency situations.
- Always carry your medication with you when you travel. Many hospitals may not keep it in stock, so it will not be readily available.
- If you are thinking about having children and you or your partner has vWD, please consult with your Hematologist, Obstetrician and a genetic counselor. They will be able to give you guidance and answer all your questions.
- If you or a loved one suspects they may have a bleeding disorder. Contact a Hematologist who specializes in bleeding disorders or your local HTC for testing.

### **How to find help:**

Von Willebrand is known to be the most common and also the most undiagnosed, inherited bleeding disorder. It is caused by the absence or deficiency of Von Willibrand factor in a person's blood.

Your local HTC and Hemophilia chapters/foundations can be great resources. The HTC has a comprehensive care team specifically for people with bleeding disorders. The Chapters or Foundations can provide you with support on education, advocacy and outreach.

Gaining knowledge and identifying resources will help you to make the best choice possible, when it comes to your health care.

When diagnosed and treated properly, there is nothing to keep a person with vWD from living a normal, active and healthy life.

