Von Willebrand Disease, FAQ's

IS THERE A CURE FOR VON WILLEBRAND DISEASE?

No. Von Willebrand disease is a lifelong disorder. Most people have a mild form of the disorder that causes little or no change in their lives.

WHO SHOULD KNOW THAT I HAVE VON WILLEBRAND DISEASE?

Adults should be sure that persons such as their doctor, dentist, employee health nurse, gym trainer, and sports coach are aware of their disorder. You should wear a medical ID bracelet stating that you have von Willebrand disease. In case of an accident or emergency, this will be very helpful to the caregivers treating you.

WHO SHOULD KNOW THAT MY CHILD HAS VON WILLEBRAND DISEASE?

It is important that anyone who will be responsible for your child know about his or her disorder. For example, the school nurse, teacher, daycare provider, coach, or any leader of any after-school activity should know that your son or daughter has von Willebrand disease.

WHY IS THIS CONDITION CALLED VON WILLEBRAND DISEASE?

A man named Erik von Willebrand discovered the disease in 1925. The disease was named after him.

IS VON WILLEBRAND DISEASE LIFE THREATENING?

Most people with von Willebrand disease have a mild form that usually does not cause bleeding that is life threatening. Any bleeding that cannot be controlled can be life threatening. People with severe forms of von Willebrand disease will rarely need to seek immediate emergency treatment to stop life threatening bleeding.

DO ALL PEOPLE WHO HAVE THE GENE FOR VON WILLEBRAND DISEASE HAVE BLEEDING PROBLEMS?

No. Many people carry the genes for the disease but do not have bleeding symptoms. Even though they do not have symptoms, they can still pass the disease on to their children.

HOW WILL I KNOW IF I HAVE VON WILLEBRAND DISEASE?

If you or anyone in your family has a history of bleeding, your doctor will use a number of blood tests to find out whether or not you have the disease. These tests will check how quickly your blood clots and the levels of clotting factors in your blood. Your caregiver will use these test results to diagnose your bleeding disorder.

This information is courtesy of the National Heart, Lung, and Blood institute.

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