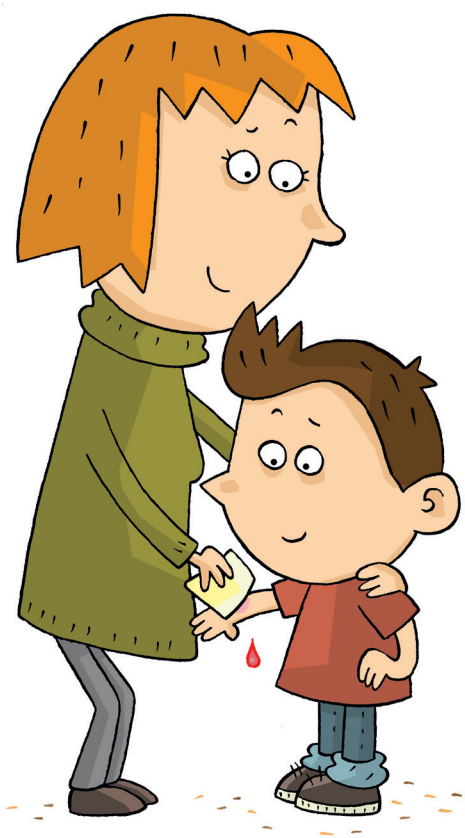
Everything You Want to Know about von Willebrand Disease



Facts & Advice for Children & Teens

Everything You Want to Know about von Willebrand Disease

Informational material about von Willebrand disease published by the Swedish Hemophilia Society and CSL Behring.

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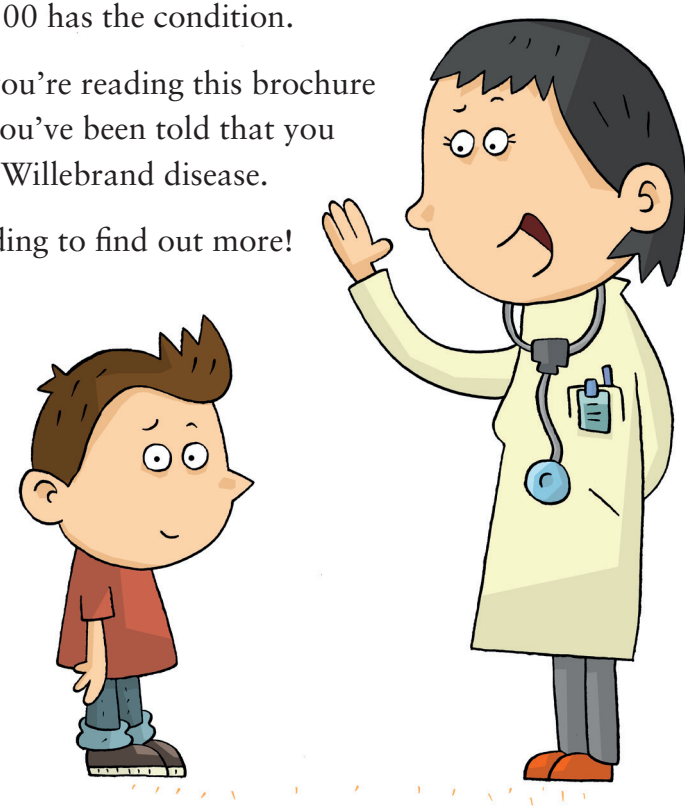
This brochure is about von Willebrand disease

The disease is one of a group of illnesses known as bleeding disorders. Although most people have never heard of von Willebrand disease, it is quite common. Around one person in every 100 has the condition.

Perhaps you're reading this brochure because you've been told that you have von Willebrand disease.

Keep reading to find out more!



What is von Willebrand disease?

Imagine that you're playing basketball with your friend when she suddenly falls and hurts her knee.

Ouch! Her knee is grazed!

It starts to bleed a bit, but after a while the bleeding stops.

This is thanks to different factors and platelets in the blood. Von Willebrand factor is something like glue, making the blood platelets stick together. This glue plugs up the hole in the wall of the blood vessel and a clot (scab) forms.

A person with von Willebrand disease either has too little von Willebrand factor in their blood or the factor doesn't work as well as it should, so their blood doesn't clot and they keep bleeding instead. That's why von Willebrand disease is called a bleeding disorder.

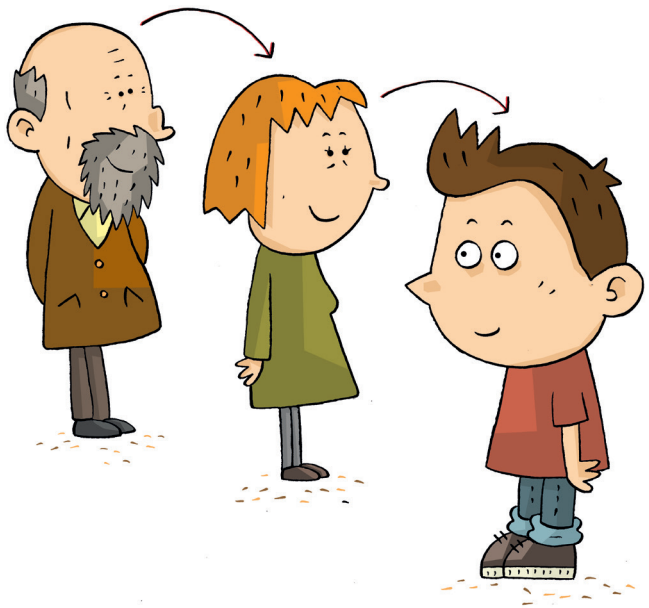
Your blood is made up of platelets, white blood cells, red blood cells and plasma. Your blood vessels are the tubes through which your blood is transported around your body. When you injure yourself, holes are torn in the vessel walls and blood leaks out. This blood can be seen, but you can also bleed inside your body, such as when you get a bruise, for example.

There are three different levels of von Willebrand disease: mild, moderate and severe. "Moderate" is another word for medium. Which type you have depends on your symptoms and the level of von Willebrand factor in your blood. Different medicines are needed depending on how severe the disease is.

Why do you get von Willebrand disease?

Von Willebrand disease is hereditary. That means you get it from either your mum or your dad, or from both. Both boys and girls can get the disease.

A person can never catch von Willebrand disease the way you catch a cold or a tummy bug, so you can't infect anyone else either, which is nice to know.



How the disease got its name

Von Willebrand disease was discovered by a Finnish doctor almost 100 years ago. His name was *Erik von Willebrand*.

He discovered the disease in several members of a large family living in Åland, a group of islands in the sea between Sweden and Finland.

Finding out which children, parents, uncles and aunts had the disease was like detective work. In this large family of 66 people, he found 23 who had the disease.

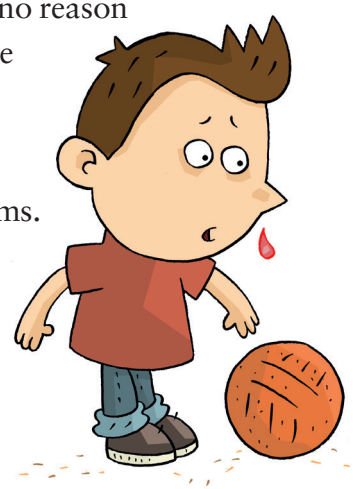
Von Willebrand described the disease in detail, which is why it was named after him.

Living with a bleeding disorder

A person's body reacts in different ways when they have a disease. These reactions are called symptoms. The symptoms of von Willebrand disease can vary. Here are some of the most common symptoms:

- You often get nosebleeds that are hard to stop
- You bruise more easily than other people
- Your gums might bleed more easily at the dentist
- You bleed longer when you hurt yourself
- If you're a girl and have begun menstruating, you have heavier and longer periods.

If you have the more severe form of the disease, you might also get bleeds in your muscles and joints for no reason at all, but this is unusual. These bleeds can be seen as a swollen knee or ankle that hurts.

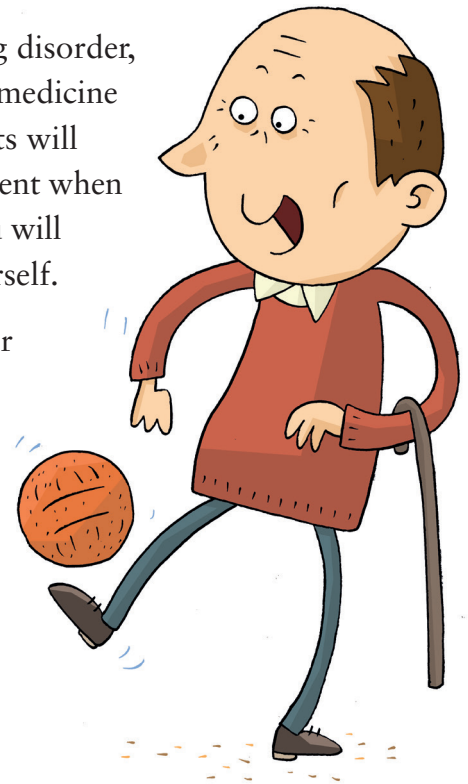


The best thing you can do is to tell your parents, doctor and nurse about your problems. That way, you can get the right treatment. The medicine you take when you have a bleeding disorder reduces the risk of bleeding.

Is there a cure?

There is no cure for von Willebrand disease, but there are medicines that can help. The treatment can vary depending on how severe the disease is. You will usually be given pills and a nasal spray when you hurt yourself, but a few people need to have medicine injected into their veins. Your doctor will recommend the best treatment for you.

If you have a severe bleeding disorder, it is important to take your medicine as a precaution. Your parents will usually give you your treatment when you are a child, but later you will need to learn to do this yourself.



Although a bleeding disorder can seem scary, you can live a completely normal life with the right treatment.

Safety tips when playing & doing sports

Do you like going to playgrounds and water parks and climbing on climbing frames? Even with von Willebrand disease, you can often do most things that your friends do. Exercise is good for the body and helps keep your muscles and joints healthy.

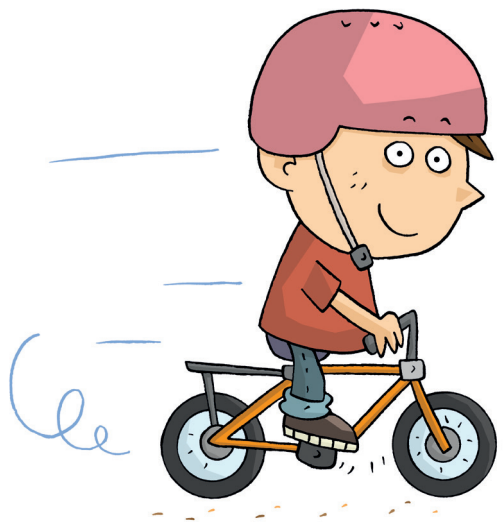
Ask your doctor which activities you can do and what you need to keep in mind.

It might also be a good idea to tell your friends about your condition. That way, they can tell your teacher or another adult if you hurt yourself. Then you can quickly get the help you need.

Smart kids wear helmets

Everyone should use a helmet when riding a bike, skating, or skiing. This is especially important when you have von Willebrand disease, because you don't always see the bleeding on the outside when you hit your head. Your head might be bleeding on the inside instead. That's why a helmet is such a clever way to protect yourself.

Always remember to put it on before you set off on an adventure.



Would you like to know more about von Willebrand disease, or do you have questions about your treatment? Feel free to talk to your doctor or nurse.

This brochure is about what it means to be a young person with von Willebrand disease. It contains facts, advice and answers to some common questions about the disease.

Förbundet Blödarsjuka i Sverige
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