

**CSL Behring**  
Biotherapies for Life™



## **A guide for children with von Willebrand disease**

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Staying well and having fun!



## Hey, good to see you!

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You are reading this booklet because your doctor has found that you have von Willebrand disease or 'VWD' for short. Up to 1 in every 100 people has VWD, so there are many millions of people with VWD all around the world.

This booklet has been written to help you learn more about VWD. Knowing what it is and how it affects you will help you to live an active life, full of fun and adventures, so get reading!

## So what exactly is VWD?

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If someone trips over in the playground and cuts the skin on their knee, they start to bleed. But the bleeding eventually stops. That is because cells in the blood stick together and plug the hole in the skin. This plug is called a blood clot.

The glue that holds the blood clot together is a substance called von Willebrand factor – shortened to 'VWF'. People with von Willebrand disease don't have enough VWF in their blood, or it doesn't work properly. This means that they bleed for longer because their blood takes longer to clot.

That is why VWD is called a 'bleeding disorder'.



## How did I get VWD?

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Von Willebrand disease is named after Erik von Willebrand, a doctor from Finland who first identified the condition around 100 years ago.

VWD usually runs in families, so it was probably passed to you by one or both of your parents, even if they didn't know they had it themselves.

VWD is not contagious, which means you can't pass it on to people around you, like a cold or the flu.

Adults can sometimes get VWD because of another medical problem, but this is very rare.



## How does VWD show itself?

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The ways that you might notice you have VWD are called 'symptoms'. These can vary a lot, so the symptoms you notice might not be the same as someone else with VWD.

The symptoms seen most include:

- Having lots of nose bleeds, or nose bleeds that are difficult to stop
- Getting large bruises from little bumps or injuries
- Bleeding for longer than usual after an injury
- Bleeding when you go to the dentist

Some people with VWD can get pain and swelling in joints such as their knees and ankles.

You can get help for all of these things, so be sure to let a doctor, parent or carer know about any symptoms you have noticed.



Girls may find VWD affects their periods. These are monthly bleeds that are a normal part of growing up for girls. VWD can make periods heavier or last for longer. If you have any questions about your periods and VWD, ask your doctor or nurse.



## Is there a cure for VWD?

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There's no cure for VWD, but there are a lots of ways that it can be controlled so you can get on with living a full, fun and active life. Your doctor will decide on the best plan for you, based on your type of VWD and any symptoms that you have.

Even people with the most severe type of VWD can live full and active lives once they have a plan in place to manage their symptoms.

People with VWD live just as long as other people.



## Can I still be active and play sports?

**Being active is really important for everyone, as it helps to keep us fit and healthy.**

The sports or activities that suit you best will depend on what you enjoy and your type of VWD, so talk to your nurse or doctor for advice.

Whatever fun things you do, always think about your safety too. For example, try to avoid getting into scrapes at playtime, and be sure to wear a helmet when you ride your bike. These are things that everyone should do, and they're even more important for kids with VWD.

**Try and be active for at least an hour a day!**



## Can I have my ears pierced?

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Ear piercing can cause bleeding, so check with your doctor or nurse first before having your ears or any other part of your body pierced.



## Where can I find out more?

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Your doctor or specialist nurse will be able to answer any questions that you may have.

The Haemophilia Society provides help and support to people with bleeding disorders, including VWD. Find out more by calling **020 7939 0780**.



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