

VON WILLEBRAND DISEASE


The case of the missing von Willebrand factor



Featuring:

Detective Von Willebrand and
her trusty sidekick, Factor 8

GRIFOLS



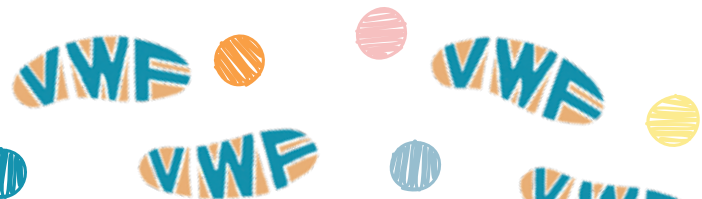
THIS BOOK BELONGS TO:





Diagnosed with von Willebrand disease?

Detective Von Willebrand and her trusty sidekick, Factor 8, are on the case to help you uncover the mysteries of your condition.



What is von Willebrand disease?

You may have heard your mom and dad referring to von Willebrand disease as VWD, but let's investigate what that really means.

Having von Willebrand disease means that your blood does not clot the way it should when you have a cut or injury. This happens because people with VWD are missing a glue-like protein called **von Willebrand factor**, or **VWF** for short. Without VWF, platelets (the sticky cells in your blood) are unable to clump together and form a plug to stop the bleeding.

Detective Von Willebrand set out to show people with VWD how they can stop bleeding when they are missing VWF.





During her investigation, she discovered that there are 4 facts about blood clotting when you have VWD and get a wound:

1

Blood vessels (tubes that carry blood through your body) shrink, reducing blood flow to the wounded area

2

Since someone with VWD does not produce enough VWF, platelets don't stick together and cannot form a plug to stop the bleeding

3

People with VWD also may not have enough clotting factor VIII. Factor VIII is important when forming the plug that stops bleeding. Without enough factor VIII, the plug cannot stay in place the way it should

4

There are a few treatment options for people with VWD that can temporarily add enough VWF and factor VIII to their blood and stop their bleeding!

What are the types of VWD?

There are 3 different types of VWD. It is important to know which type you have because each type is treated differently.

Detective Von Willebrand and her trusty sidekick, Factor 8, are tracking down what makes each type different:

TYPE 1

Most people with VWD have type 1. It is the mildest form of VWD. People with type 1 have less VWF in their blood than normal. If you have type 1 VWD, you may have a lot of bleeding if you get hurt or need to have surgery, and you may bleed for no reason.



TYPE 2

Having type 2 means your body makes VWF that doesn't work right. Having VWF that is not normal will make you have bleeding problems. There are a lot of different forms of type 2 VWD and they all have a problem with the way VWF works. If you have type 2 VWD, you have VWF, but it doesn't work right.



TYPE 3

Type 3 is the most serious type of VWD. People with it have major bleeding problems. Having type 3 VWD means your body only makes a little or no VWF and has very little factor VIII. This is the rarest type of VWD, and only a few people have it.

How do I know if I have von Willebrand disease?

VWD leaves behind many clues that VWF might be missing.

Detective Von Willebrand has followed the trail of the missing VWF, and has found some of the clues:

- Bruise easily
- Bleed a lot from a cut
- Have nosebleeds a lot
- Have bleeding from the gums at the dentist
- Heavy menstrual periods (for girls)



Detective Von Willebrand found that no matter what type of VWD you have, you may have all these symptoms. However, if you have type 3, the most serious type, you may show signs of one more clue: bleeding in your muscles and joints (which will probably hurt a lot, too).

How does my doctor know if I have von Willebrand disease?

After uncovering the first set of VWD clues, Detective Von Willebrand knew she needed to speak with an expert to confirm her suspicions.

After speaking with the doctor, Detective Von Willebrand learned that diagnosing VWD can be hard. That is why it is so important to tell your doctor and parents when you discover symptoms.

After finding the first set of VWD clues, doctors will check your body and will ask you and your parents some questions to help them learn more about you and your health.

Some of these questions could be:

- Do you have a lot of nosebleeds?
- Have you been told that you are anemic (low iron in your blood)?
- Do your gums bleed a lot?
- Does anyone in your family have other health problems?
- Are you taking any medications?
- Do you have any allergies?



Next, doctors will take some blood and do some tests to be completely sure. These tests will also let you know what type of VWD you have.

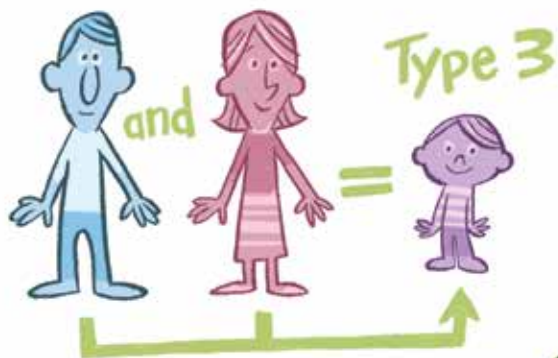
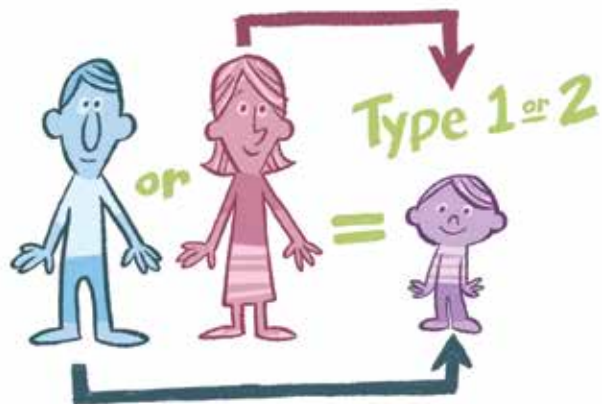
What causes von Willebrand disease?

Even after interviewing the doctor, Detective Von Willebrand was still not sure why some people are missing VWF while others are not. She needed to continue her investigation.

So Detective Von Willebrand hit the books. She found that von Willebrand disease is a genetic disorder: when you were born, VWD was passed to you from your mom or dad through their genes.

The type and how serious your VWD is can depend on which parent you inherit the VWD gene from.





TYPE 1&2 VWD

happens when either mom or dad passes along the gene.

TYPE 3 VWD

happens when both mom and dad pass the gene along.

Most importantly, Detective Von Willebrand realized that VWD is no one's fault—there is nothing you can do to prevent getting VWD.

Will I always have von Willebrand disease?

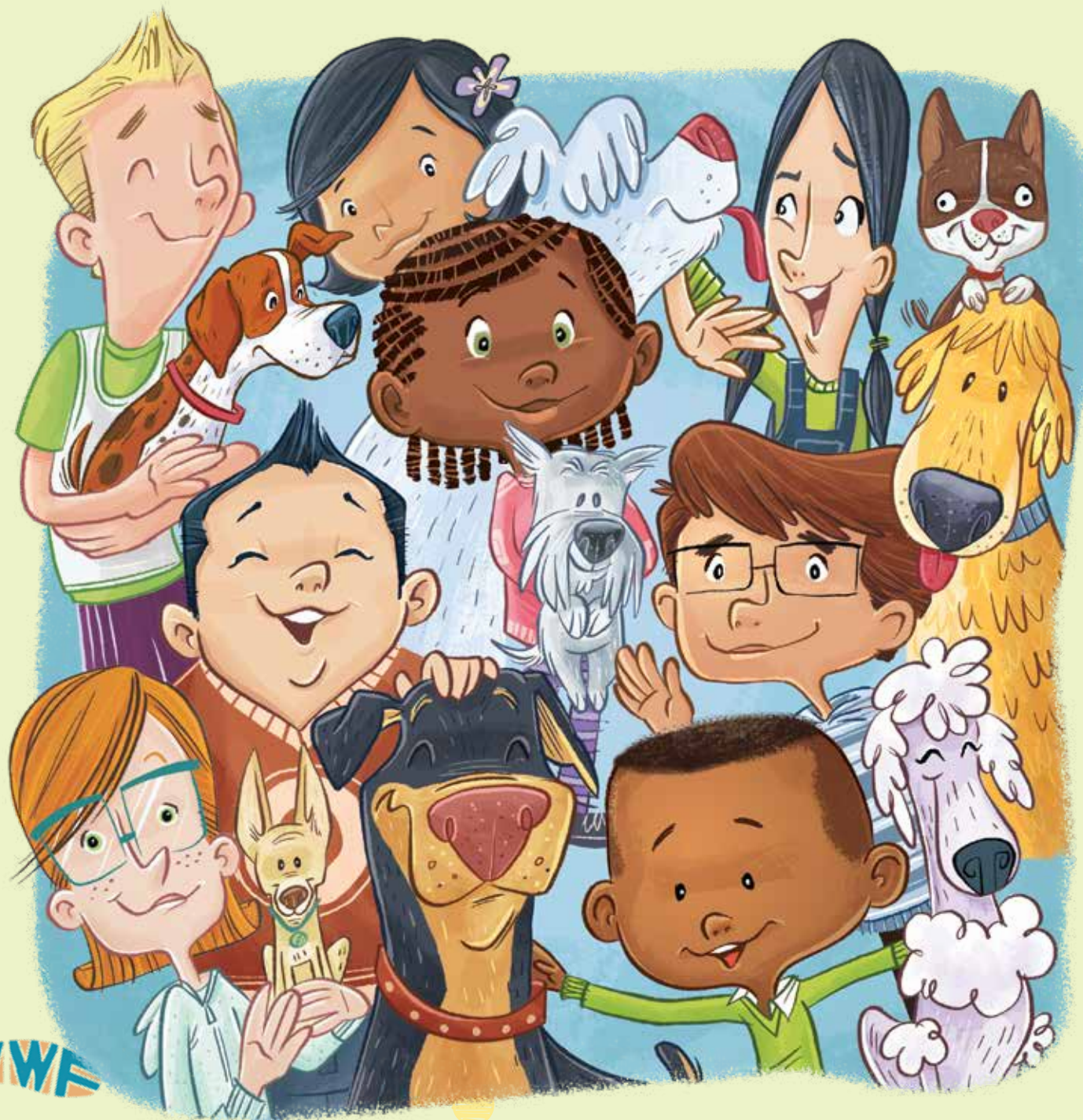
Detective Von Willebrand had her trusty sidekick, Factor 8, follow the scent of VWD to help confirm the rumor that if someone is missing VWF, they will always have VWD.

Since VWD is a genetic condition, this is something you will have for your entire life. It is important to remember that many kids just like you have VWD and do just fine. You will, too, if you do what your doctors say and take good care of yourself.

Did you know?

Dogs can have VWD too! It is the most common inherited blood disorder found among dogs.





VWF

VWF

VWF

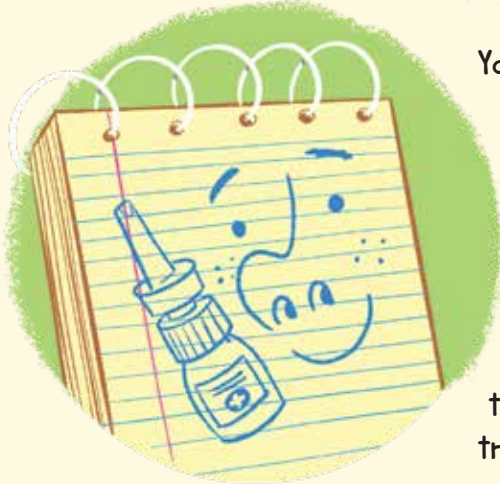
How is von Willebrand disease treated?

Earlier in her investigation, Detective Von Willebrand learned that the type of VWD can determine how the disease is treated. Here are the VWD treatment options she discovered.

Many kids with VWD only need to see the doctor if they get hurt, are having surgery, or need to see the dentist. However, other kids need to see the doctor more often to keep their bleeding under control.



IF YOU HAVE TYPE 1 OR 2



You will most likely need a medicine called desmopressin. You may hear your parents or doctor call it "DDAVP." Desmopressin helps boost how much VWF you have in your blood. It pulls the VWF out of your tissues and cells and puts it to work making a clot. Your doctor may give you DDAVP by injecting it into your vein or with a nose spray. Some forms of type 2 VWD may not be able to be treated with DDAVP because it does not help with bleeding. This can occasionally happen with type 1 VWD as well. If this is the case, there is a different treatment option.

IF YOU HAVE TYPE 2 OR 3



If you have type 3 VWD, or your type 2 VWD does not respond to DDAVP, you will need a different kind of medicine to stop and treat your bleeding. Your doctor will give you a medicine that replaces the missing factor proteins in your body that are needed to stop you from bleeding. This 'factor' is given as a shot into your vein, called an infusion. You can infuse factor at home and your parents may do it for you a few times each week. It depends on how often you bleed. Some kids even learn to infuse it on their own!

What can I do?

Going to school and having fun with family and friends is important kid stuff that you don't want to miss. If you do your part, you can continue to do most things you normally do, and feel better.

Detective Von Willebrand knows that sometimes your disease may make you feel different from your friends. The good news is that her investigation has found a lot of things you can do to help make you feel better.



Visit the hemophilia treatment center

While looking into VWD treatments, Detective Von Willebrand discovered that many patients need to visit a hemophilia treatment center at least once a year.

A hemophilia treatment center (or HTC) is a special place where people who take care of adults and kids with bleeding disorders all work together. At the HTC, your family will learn all about how to take care of you. You will also learn the best way to deal with your bleeding, and meet other kids who have VWD, too. One of the coolest things some kids learn at the HTC is how to infuse their own factor.

Doctors say if you go to the HTC once a year for a check-up you can learn ways to help stay healthy.





Take care of your bleeding

When you get hurt and bleed, press down hard on the spot. If you get a nosebleed don't lie down. Sit up, pinch the end of your nose, and lean forward a little. Stay like that for about 10 minutes and put an icepack on your nose to help stop the bleeding. If your nose is still bleeding after 15 minutes, ask an adult to take you to a doctor.



Get moving

By playing games and exercising, you can stay fit and build strong bones and muscles that protect your joints. With strong muscles and joints you may have less bleeding.

Just be careful when picking what sports you play—you don't want to choose something that can hurt you easily! Some sports considered safe are swimming, Frisbee, golf, fishing, and hiking.



Ask the grown-ups

Remember that your mom, dad, doctor, and nurse all want you to be as healthy as you can be. If you have any questions or worries, talk to them about how you feel. Your mom and dad have learned a lot about VWD, so ask away!



Detective Von Willebrand has closed her investigation into VWD,

Use this space to start your own investigation into your condition. Write down any questions or concerns you have about VWD here, so you will remember when you speak with your doctor.



A large white notepad area with horizontal dotted lines for writing, occupying the lower two-thirds of the page.



but that doesn't mean you have to!



Don't forget to bring your investigation notes with you to your next appointment!



This educational leaflet has been developed by Grifols.
Consult your healthcare professional for further information.

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