



Other medicines we can give you to help mouth or nose bleeding are **Amicar®** or **Cyclokapron®**. **These medicines do not make you stop bleeding, but when you do form a clot, they will help keep that clot from breaking down.** They come as a pill or a liquid that you swallow. You have to take these medicines just like your doctor tells you.

There are a few medicines that you should **not** take without talking to your doctor or nurse first.

These medicines can make anyone who takes them bleed more than usual. You don't need that! So before taking any **aspirin** or **Advil®** or **Motrin®**, ask. And, ask your doctor or nurse if there are other medicines that they don't want you to take.

You can take Tylenol for a fever or for pain.



Any questions?



Ask your nurse. Your nurse is a special nurse that just takes care of people with bleeding disorders and is there to help you understand von Willebrand's. You also have a special doctor, social worker, physical therapist and other people who are a 'TEAM', working together to help you.



Isn't it great to have your own team?

Your Bleeding Disorder:

Your nurse's name(s):

Telephone number:

Your doctor's name(s):

Your treatment center:

Other team members:

Edited & printed by the Nursing/Psychosocial Group of Hemophilia Region VI. Special thanks to Lisa Logan, RN, BSN, CPON

Copyright 2003 May be reproduced with the author's permission for educational use only.

Von Willebrand Fact(or) Sheet

FOR: MIDDLE SCHOOL AGE AND UP

BY SUSAN C. ZAPPA RN, CPN, CPON
Cook Children's Medical Center, Fort Worth Texas 2003

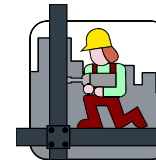
Your blood does a lot of different things as it goes around inside your veins. The veins are like a pipeline carrying your blood cells filled with oxygen to your heart and lungs. Blood is also made up of many different cells, like red blood cells (where iron is stored), white blood cells (these fight infection), and platelets (one of the parts of the blood that help you to stop bleeding).



Sorry, there are no **blue** blood cells! So what color is your blood?? Take a look at your hands. Some people think blood is blue because the veins the color of our veins (the pipelines) are blue or greenish, but the is **red**, just like it looks when you cut yourself and bleed.



veins on the tops of look blue. Actually, blood **INSIDE** the veins



Blood is **also** made up of '**factors**' that all work together to help you stop bleeding. Some factors have a number name, like Factor 8 or Factor 9. If you are missing one of these factors, you have the blood disorder called hemophilia.

You are missing or have only a small amount of a factor called **von Willebrand factor**. A doctor named Eric von Willebrand discovered this factor, so they named it after him. It's kind of a hard name to remember. You might think it would have been easier to remember a number like 8 or 9. Sorry, you need to remember the name- **von Willebrand**. It is a bleeding disorder.

How did we know you have von Willebrand disease?

Your doctor tested your blood to see how much von Willebrand factor you have. Sometimes you have to be tested a couple of times because the von Willebrand factor levels in your blood can **briefly** go higher from things like exercise, surgery, certain medicines, if you are sick, or if you are upset or stressed -like when someone is sticking you with a needle!

How did you get von Willebrand disease?

You got it from your mother or father. You **inherited** the gene from your family. Just like you got brown hair or blue eyes, you got the gene that gave you von Willebrand disease. **You will always have von Willebrand disease, it does not go away. And you can pass it on, in your genes, to your children (there's a 50/50 chance with each child).**



Both boys and girls can have von Willebrand's.

So, what does it mean to be missing or have small amounts of von Willebrand factor?

It means that you have everything else to help you stop bleeding, you have all the other factors (there are twelve) that work together to make a clot or scab. You are just missing or have small amounts of **one** of the factors. But, people need **all** of the factors to stop bleeding right away.

You do not bleed **more** than other people; instead, you bleed

LONGER

We call it **oozing**, because it happens slowly. Like ketchup oozing from your hamburger bun. Can you picture it? You can **ooze on the outside**, where you see the blood (like a nosebleed). You can **ooze just under the skin** (like in a bruise). Or, you can **ooze deep inside your body** (internally). If you are bleeding internally, you will have pain and you may (or may not) see swelling. This is the most serious type of bleeding, especially if it happens inside your head (lots of damage can be done in there).



What does this mean for you?

It just means that you will get **bigger bruises** than other people who don't have von Willebrand disease. You may get **nosebleeds** that take a long time to stop, or when you go to the dentist your **gums may ooze blood** for a long time. If you have to have surgery or if you were hurt, doctors would need to know that you have von Willebrand's so they could take care of you and stop the bleeding. All of your doctors, your dentist, plus your teachers need to know that you have von Willebrand disease.

There are cool medic alert bracelets, ankle bracelets, chains, etc. you can wear. If for some reason you were hurt and couldn't talk, wearing a medical alert would let the doctors know about your von Willebrand's.

Can I play sports?

Really **you can do almost anything** ...play basketball, baseball, soccer, and track. You **can** be on a swim team and you **can** do gymnastics. It doesn't mean you might not accidentally get hurt. You should **always wear protective gear**, like helmets and pads to try and prevent injuries. And you should know to tell your mom or dad or an adult if you get hurt. You are responsible.



We want you to play in non-contact sports and be normal. We can take care of accidents that may happen.

You should **NOT** play contact sports, like tackle football, hockey and boxing, though. That's because someone is out to hurt you in those sports. If you get badly hurt, we know you will have more bleeding than the person who doesn't have a bleeding disorder. That is too big of a risk to take.



What would we do for bleeding?

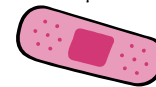
That depends on a couple of things like what **type** of von Willebrand disease that you have.

There are 3 'types': Type 1, Type 2 (a, b, m or n) and Type 3. **What type are you???** _____



For a lot of problems, you can just clean the cut and **put pressure on the bleeding** with a band-aid or clean cloth.

You can also **put ice on an injury**, not use or **rest the injured area** and also raise or **elevate the injury**. These simple things will often stop the bleeding.



Remember **RICE**

Rest

Ice

Compression

Elevation

What medicines are used to stop bleeding?

For some 'types' of von Willebrand disease, levels of the missing factor will go higher if you get a medicine called **DDAVP**. For other types, you get the **actual von Willebrand factor in your vein (IV)**. When von Willebrand levels are higher, the bleeding should stop.

DDAVP treatment is usually given as a spray in the nose with a special medicine called **Stimate®**. This medicine helps boost the amount of von Willebrand factor, so that you are like normal. It only lasts for 1 or 2 days, but it can stop the bleeding.



Stimate® is kept in the refrigerator and you can have it at your house for you to use when you are bleeding. Only the special nasal spray form of DDAVP is called Stimate®. It starts to work in about 1 hour.

You can also get DDAVP in a shot in your arm or leg or in an IV (in your vein) at the hospital. It's lots easier to spray something in your nose, though.



A special **factor product**, given IV, that actually **has von Willebrand factor (and factor 8)** in it can also be used to stop bleeding. This is given at the hospital or at home, if you or your mom or dad can start an IV. It has to be given in a vein. **This is what you would get if you were really bleeding a lot or if the Stimate® spray doesn't work for you.** This factor product can make your von Willebrand levels or numbers go up and be normal. A dose only lasts for awhile, though (12-24 hours, sometimes longer). It comes as a powder in a little bottle. You mix the powder with the special water that also comes in a little bottle. Then you draw up the medicine in a **syringe** (a shot) and using an IV needle, give it into a vein over just a few minutes. It starts to work in about 15 minutes.

