



Other medicines we can prescribe to help mouth, nose, or menstrual 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 your child will **swallow**. You have to give these medicines **exactly** as the doctor or nurse tells you.

There are a few medicines that your child should **not** take without asking your doctor or nurse first.

These medicines can make anyone who takes them bleed more than usual. You don't need that! So before giving 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 give.

You **can** give Tylenol for a fever or for pain.



Any questions?



Ask the nurse. Your child's nurse is a special nurse that just takes care of people with bleeding disorders and is there to help you and your child 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 Child's Diagnosis:

Your doctor's name(s):

Your nurse's name(s):

Telephone number(s):

Emergency number(s):

Your treatment center name:

Other team members:

Telephone number(s):

Edited and printed by the Nursing/Psychosocial Group of Hemophilia Region VI. Special thanks to: LISA LOGAN RN, BSN, CPON

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

Von Willebrand Fact(or) Sheet

FOR PARENTS AND CAREGIVERS

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

This fact sheet was created to help you understand von Willebrand disease (vWD), a bleeding disorder.

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 (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!



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 a person is missing one of these factors, they have the blood disorder called hemophilia.

Your child is missing, has non-functioning or has 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. There are 3 sub-categories or 'Types': Type 1 patients have decreased amounts of vWD factor, Type 2 have non-functioning & also may have decreased amounts of vWD factor and Type 3 are missing vWD factor altogether. You need to learn what type of vWD your child has, this is important.

How did we know your child has von Willebrand disease?

Your doctor tested your child's blood to see how much von Willebrand factor they have. **Sometimes people have to be tested a couple of times because the von Willebrand factor levels in your blood can briefly (for a day or two) 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 do you get von Willebrand disease?

You **inherit** the gene from your family (like eye or hair color). **OR** there could also be a chance of a genetic mutation occurring. **Your child will always have von Willebrand disease, it does not go away and it can be passed on, in their genes, to their 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, have non-functioning or decreased 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. For people with vWD:

They do not bleed **more** than other people; instead, they bleed

LONGER

We call it **oozing**, because it happens slowly. 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 someone is bleeding internally, the person will have pain and you may (or may not) see swelling. This is the most serious type of bleeding, especially if it happens inside the head (lots of damage can be done in there), joints or muscles.



What does this mean for your child?

It just means that they will get **bigger bruises** than other people who don't have von Willebrand disease. They may get **nosebleeds** that take a long time to stop, or when they go to the dentist their **gums may ooze blood** for a long time. For girls, they may experience very heavy bleeding with their periods. If your child has to have surgery or if they were hurt, doctors would need to know that they have von Willebrand's so bleeding could be taken care of with medicine. All of your child's doctors, the dentist, plus teachers need to know that your child has a bleeding disorder.

There are cool medic alert bracelets, ankle bracelets, chains, etc. you can buy for your child to wear to let medical personnel know they have von Willebrand's.

Can my child play sports?

Really he or she **can do almost anything** ...play basketball, baseball, soccer, and track. They **can** be on a ski team, swim team and they **can** do gymnastics. It doesn't mean they might not accidentally get hurt. They should **always wear protective gear**, like helmets (essential in any sport that puts the child on wheels) and pads to try and prevent injuries. And they should know to tell you or an adult if they get hurt.



We want your child to play in non-contact sports and be normal.

We can take care of accidents that may happen.

Your child should **NOT** play contact sports, like tackle football, hockey and boxing, though. That's because someone is out to hurt them in those sports. If they get badly hurt, we know they 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 the person has. The front page describes the three 'types': Type 1, Type 2 (a, b, m or n) and Type 3.



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 vWD factor will go higher if the person gets a medicine called DDAVP. For other types, the actual von Willebrand factor is given in a 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 can  clot. It only lasts for 1-2 days, it is usually given every 48 hrs.

Stimate* is kept in the refrigerator and you can have it at your house to give your child when they are bleeding (per your doctors orders). Only the nasal spray form of DDAVP named Stimate* will stop the bleeding. It starts to work in about 1 hr.

Ask your nurse about side effects.

DDAVP can also be given by injection in an arm or leg. Or it can be given IV at the hospital. It may be given by injection or IV for testing purposes.



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, if you have been taught to start an IV, at home. Your doctor or nurse will tell you when to give this factor. **This is what is given if your child is really bleeding a lot or if the Stimate* spray doesn't work for your child.** This factor product can make von Willebrand levels go up or 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 and using an IV needle, give it into a vein over just a few minutes. It starts to work in about 15 minutes. If old enough, your child can learn to give this factor to themselves.

