



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 the child will **swallow**. You have to give these medicines **exactly** as prescribed, the student may have to take them at school.

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

These medicines can make anyone who takes them bleed more than usual. They don't need that! So before giving any **aspirin** or **Advil®** or **Motrin®**, ask. And, ask the 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 parent or nurse. The child's nurse is a special nurse that just takes care of people with bleeding disorders and is there to help you and the child understand von Willebrand disease.



The child also has a special doctor, social worker, physical therapist and other people who are a 'team', to help take care of them.

The school is also a part of the child's 'team'. We want to work with you.

Child's Name & Diagnosis:

Contact information-

Parent's name(s):

Telephone number(s):

Nurse's name(s):

Telephone number(s):

Treatment center name:

Doctor(s) and other team members:

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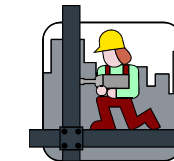
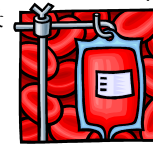
Von Willebrand Fact(or) Sheet

FOR SCHOOL PERSONNEL

BY SUSAN C. ZAPPA RN, CPN, CPON
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This fact sheet was created to help you understand von Willebrand disease (vWD), a bleeding disorder.

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).



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 student 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. The kids always think it would have been easier to remember a number like 8 or 9, but they need to remember the name- **von Willebrand disease (vWD)**. 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 and may also have decreased amounts of vWD factor and Type 3 are missing vWD factor altogether.

How do we know a person has von Willebrand disease?

The doctor tested the child's blood to see how much von Willebrand factor they have. Sometimes they have to be tested a couple of times because the von Willebrand factor levels in your blood can **briefly** (a day or two) go higher from things like exercise, surgery, certain medicines, illness, 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. **OR** there could also be a chance of a genetic mutation occurring. **The 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 disease.



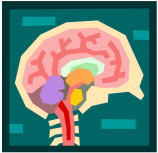
So, what does it mean to be missing, have non-functioning or decreased von Willebrand factor?

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 the 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. Girls may experience very heavy bleeding during their period. They may need to change their sanitary protection hourly and still may experience break through bleeding. Please keep this in mind and help us work out the best solutions to help the student.

We hope the school will be understanding of students who may have nosebleeds or other bleeding problems. Keeping the child in class and as normal as possible is the goal. Working together, we hope to achieve that goal. Contact the student's nurse (information on last page) for any questions or concerns.

Can the student 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 an adult if they get hurt or think they are hurt. Their parent or nurse should then be contacted for instructions.



We want the student to play non-contact sports. We can take care of accidents that may happen.

The student 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.



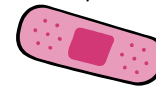
What would we do for bleeding?

That depends on a couple of things, like what type of von Willebrand disease the person has. The front page describes the 3 '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 or reduce 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, but it can stop the bleeding.

Stimate* is kept in the refrigerator and the parent has it at their house for them to give the child when they are bleeding. This medicine is usually not kept at school.

Only the special nasal spray form of DDAVP named Stimate* will stop the bleeding. It starts to work in about 1 hr.

Dosing of DDAVP is usually only every 48 hrs. and there are some side effects, ask the parent or nurse for details. DDAVP can also be given by injection.



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 the family has been taught to start an IV. It has to be given in a vein. **This is what is given if the child is really bleeding a lot or if the Stimate* spray doesn't work for the child.** This factor product can make the von Willebrand levels or numbers 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.

