If you ride a skateboard or play a sport, you probably know about bruises and banged-up knees and elbows.

But for people with a rare bleeding disorder called hemophilia (pronounced: hee-muh-FIL-ee-uh), what might seem like minor cuts and bruises can be a big deal.

What Is Hemophilia?

Hemophilia is a disease that prevents blood from clotting properly, so a person who has it bleeds more than someone without hemophilia does. It's a genetic disorder, which means it's the result of a change in genes that was either inherited (passed on from parent to child) or occurred during development in the womb.

A person who has hemophilia has a tendency to bleed excessively. Hemophilia affects mostly guys, although it's not common: Only about 1 in every 5,000-10,000 boys is born with it. In rare cases, girls can have the disease and get bleeding problems similar to the ones boys have. The disease can affect people of any race or nationality.

When most people get a cut, the body naturally protects itself. Sticky cells in the blood called platelets go to where the bleeding is and plug up the hole. This is the first step in the clotting process. When the platelets plug the hole, they release chemicals that attract more sticky platelets and also activate various proteins in the blood known as clotting factors. These proteins mix with the platelets to form fibers, and these fibers make the clot stronger and stop the bleeding.

Our bodies have 12 clotting factors that work together in this process (numbered using Roman numerals from I through XII). Having too little of factors VIII (8) or IX (9) is what causes hemophilia. A person with hemophilia will only lack one factor, either factor VIII or factor IX, but not both.

There are two major kinds of hemophilia. About 80% of cases are hemophilia A, which is a factor VIII deficiency. Hemophilia B is when factor IX is lacking.

Hemophilia is classified as mild, moderate, or severe, based on the amount of the clotting factor in the person's blood. If someone produces only 1% or less of the affected factor, the case is called severe. Someone that produces 2% to 5% has a moderate case, and someone that produces 6% to 50% of the affected factor level is considered to have a mild case of hemophilia.

In general, a person with milder hemophilia may only bleed excessively once in a while, whereas severe hemophilia puts someone at risk for having bleeding problems much more often.

Most people with hemophilia discover they have the condition when they are babies or young kids. Sometimes the disease is so mild that a guy doesn't even know he has it until he has minor surgery — like getting his tonsils or appendix out — and it's found in blood tests that doctors perform before surgery.

What Causes Hemophilia?

Men and women each have 23 pairs of chromosomes. Women have two X chromosomes; men have one X and one Y chromosome. Hemophilia is an X-linked genetic disorder, which means that it's passed from mother to son on the X chromosome. If the mother carries the gene for hemophilia on one of her X chromosomes, each of her sons will have a 50% chance of having hemophilia.

Although girls rarely develop the symptoms of hemophilia itself, they can be carriers of the disease. In some cases, girls who are carriers can have mild bleeding symptoms. For a girl to get hemophilia, she would have to receive affected X chromosomes from both of her parents. Although this is not impossible, it is highly unlikely.

What Are the Signs and Symptoms?

If you've just found out you have hemophilia, you probably have a milder form of the disease.

Symptoms of hemophilia include:

- bruises that are unusual in location or number
- nosebleeds that won't stop
- excessive bleeding from biting a lip, having a tooth pulled, or losing a tooth
- painful or swollen joints
- blood in the urine

What to do Doctors Do?

Doctors diagnose hemophilia by performing blood tests. Although the disease can't be cured (except by a liver transplant — which sometimes can cause health problems worse than hemophilia itself), it can be managed.

A cut or minor wound is usually no big deal for a person with hemophilia, just as it isn't for someone without the disease. However, internal bleeding can be serious. When bleeding occurs in the joints, muscles, or internal body organs, treatment is necessary.

Patients with more serious cases of hemophilia often get regular shots of the factor that they're missing — known as clotting factor replacement therapy — to prevent bleeding episodes. The clotting factors are transfused through an IV into a vein, and can be given in the hospital, at the doctor's office, or at home. People with moderate or mild cases of hemophilia usually don't need these shots unless they have a serious injury or require surgery.

If you have hemophilia, you are probably used to working with a medical team of hematologists (doctors who specialize in blood disorders), nurses, and social workers. Your medical team can help you learn to recognize how it feels when you bleed internally (the place where the bleeding is happening will probably feel warm and tingly or bubbly). This is important to know because when you begin to bleed internally you need to infuse (replace) the missing clotting factor right away to make the bleeding stop. Putting off doing so can cause damage to the joints.

If you will be injecting the clotting factors at home, your treatment team will probably teach you and your parents how to mix the clotting factor and inject it into a vein.

If you have bleeds fairly often, though, your doctor might consider having you infuse clotting factor regularly to prevent bleeds from happening in the first place. If that's the case, you might get a small tube called a portacath, or port, implanted in your chest. That way, you never have to worry about finding a vein and there's no pain when the infusion is done.

Scientists are working on something called gene therapy for people with hemophilia. Gene therapy is an experimental technique that tries to provide the body with the genetic information it doesn't have. Hemophilia is considered a good test for gene therapy because it is caused by only one defective gene. Scientists hope that they will be able to provide people with hemophilia with the genetic information they need to produce their own missing clotting factors.

Living With Hemophilia

If you have hemophilia, your day-to-day life is probably pretty normal. Exercise is important for teens with hemophilia because it makes muscles stronger, which protects the joints and decreases bleeds. Swimming and cycling are great because they don't put pressure on the joints.

- In fact, you can participate in many sports, although team sports, such as soccer, basketball, or baseball, present a higher risk and all contact sports (like football, boxing, lacrosse, and hockey) are off-limits because there's a high risk of injury.
- It's also important to maintain a healthy weight because extra pounds can strain the body. And don't take any product that contains aspirin, ibuprofen, or naproxen sodium. All of these can keep blood from clotting.
- If you have hemophilia and want to hang out with other people who have the disease, think about going to a camp for teens with hemophilia. You do all the fun stuff they have at any camp, but you also learn how to take the very best control of your condition.
- At times you might feel really overwhelmed. Try to remember that you're not alone. Talk to your mom or dad, your doctor, a nurse, or anyone on your treatment team. They can help you deal with the emotional aspects of having hemophilia.
- Having hemophilia doesn't mean you can't work out, go on dates, or do most of the things that guys like to do. You just have to be smart about your condition. Learn everything you can so you can take care of yourself and make choices that are right for you.
- Evan couldn't wait for school to begin. All summer long, he'd looked forward to trying out for the basketball team. He'd be a natural, everyone told him. At 14, he pretty much towered over his classmates.

But when the time came for his sports physical, the doctor noticed some things about Evan that warranted a closer look. It wasn't just that Evan was really tall for his age and compared with other people in his family. In addition to being 6'1", his arms, legs, and fingers were very long and thin and his breastbone curved inward, giving his chest a caved-in look.