Information about rare bleeding disorders is often hard to find. You may find yourself spending time looking through many resources to get what you need. This guide aims to provide help in your search for information.

Here, you can get an overview of rare bleeding disorders all in one place. You will learn about why these disorders occur and how they affect bleeding in the body. You will also learn about available resources and support that can help you start a plan of action.

Just because a disorder is rare does not mean it cannot be managed. It just means it is uncommon. That’s why this guide also offers ways to connect you with people and resources that can help you manage a bleeding disorder. After all, just because you are unique doesn’t mean you are alone.

Words in bold can be found in the Glossary section.

If you have one of the disorders in this guide, talk with your doctor. He or she can tell you about treatment options that are available for you.
Your body takes a series of complex steps to stop bleeding. It begins with small blood vessels called capillaries. When you are injured, such as from a cut or bruise, these capillaries break and you begin to bleed. The injured blood vessel then narrows to slow down the flow of blood.

Soon after that, cells called platelets stick to the walls of the injured blood vessel. They also stick to each other and form an initial plug. This triggers a process called clotting, in which a group of proteins work together to create a firm blood clot. This process involves a series of steps that result in a protein called fibrin. Fibrin then forms strands that link together, much like a net. This net makes the blood clot stable and stops the bleeding.

Take a look at the picture of the clotting process below. The clotting factors are named using Roman numerals: factor I (1), factor II (2), factor III (3), factor IV (4), factor V (5), factor VI (6), factor VII (7), factor VIII (8), factor IX (9), factor X (10), factor XI (11), factor XII (12), and factor XIII (13). You can also see that the reactions in the process are linked. For example, early reactions must happen before the later ones can occur.
You may have a clotting factor disorder if:
- Your body is missing clotting factors
- Your body does not make enough factors
- The factors don’t work as they should

For example, the bleeding disorder called hemophilia involves problems with factor VIII or factor IX.

Other times, you may have normal clotting factors, but there are not enough platelets or they do not work as they should. This is called platelet deficiency or a platelet disorder.

Rare bleeding disorders can be caused by either clotting factor disorders or platelet disorders. The disorders described in this guide do not happen often. Many affect both men and women of all ages. Most of the time, these disorders are hereditary. This means the disorder was genetically passed from one or both parents to their child.
What happens if I have a rare bleeding disorder?

If you have a rare bleeding disorder, it does not mean you have to worry about every single cut or bruise. However, it does mean your body will not be able to form a stable blood clot. The severity and location of the bleeding depends on which factor and how much of it you are missing. If you have a rare bleeding disorder, it does not mean you bleed faster than someone without the disorder; it means you will bleed longer.

How do I stop bleeding if I have one of these disorders?

Whether or not you need treatment depends on the type and severity of your disorder and type of bleed or procedure. This can vary widely. It can be as simple as applying pressure to the site of bleeding. Or, you may need to replace the missing or deficient factor or platelets as routine treatment to stop bleeding.

Depending on your condition, your doctor can help you select a treatment that’s right for you.
Q. What can I do to protect and help myself?

The most important thing you can do is to get educated. If you have a rare bleeding disorder, you should register with a hemophilia treatment center (HTC). HTCs have a team of experts that can explain your condition and provide the special care you need. An HTC may treat only children or adults, or it may treat both. HTCs can also help you find a center if you need an invasive procedure such as surgery or dental work.

Because many of these disorders are hereditary, you may want to ask your doctor or HTC about genetic counseling. This is especially important for newborns and women who are pregnant or who are planning to become pregnant.

Some other things you can do:

• Talk to your HTC about getting a medical ID bracelet or tag that is appropriate for your condition and age
• Fill out an emergency medical information card and give it to the people who need to know. Like a medical ID bracelet, it provides valuable information in case of an emergency
• Avoid, if possible, activities with a high risk of injury, such as contact sports. Your doctor can help you choose activities that are right for you
• Ask your doctor about any medicines (such as aspirin) and supplements you take because some can affect blood clotting
What is von Willebrand disease?

It may come as a surprise, but the most common inherited bleeding disorder is von Willebrand disease (vWD). As many as 1 in every 100 people have some form of the disease. vWD is inherited from one or both parents, depending on the type of the disease. vWD affects men and women equally. Although uncommon, vWD can also develop as a person gets older.

vWD affects a protein in the blood called von Willebrand factor (vWF). vWF does 2 important things that allow normal blood clotting. First, it helps platelets stick to each other and/or to injured blood vessels. Second, it helps protect factor VIII. Factor VIII helps make thrombin, a protein needed to form a stable blood clot.

A person with vWD can have any of the 3 types of the disease. These types are:

**Type 1 (classic)**
Describes vWD in a person with low levels of vWF and/or factor VIII. This is the most common type (around 70% to 75% of cases) and the mildest form of the disease.

**Type 2 (variant)**
Describes vWD in a person with low or normal levels of vWF, but the factor does not work as it should. This type affects around 20% to 25% of people with vWD. There are also 4 subtypes of type 2 vWD.

**Type 3 (severe)**
Describes vWD in a person with very low or almost no levels of vWF and low levels of factor VIII. This is the most serious and rarest type of the disease. Type 3 vWD affects 1 in every 1 million people.

It is also possible for people to acquire vWD. This can happen suddenly. It may also happen because of an underlying condition, such as an immune system problem or because of certain medicines.

It is important to know the type of vWD because that will affect the type of treatment your doctor will help you choose.

**Signs and symptoms of vWD**

Because people with vWD can have severe or mild forms of the disease, there is a wide range of signs and symptoms. The following signs and symptoms are common among all people with vWD:

- Easy bruising
- Bleeding from the nose, gums, or mouth
- Upset stomach
- Vomit that is black and syrupy or bright red
- Red- or black-colored stool
- Bleeding after surgery, such as dental work
- In women, heavy menstrual bleeding

People with moderate or severe forms of the disease often show signs in childhood or young adulthood.
What is **factor I (fibrinogen) deficiency**?

**Factor I** deficiency describes several conditions that involve problems with a **protein** called **fibrinogen**. Fibrinogen helps produce another protein called **fibrin**, which is needed to form a stable clot. Factor I deficiency includes the conditions afibrinogenemia (no fibrinogen), hypofibrinogenemia (low fibrinogen), and dysfibrinogenemia (faulty fibrinogen). These conditions are described on the next pages. Factor I deficiency occurs in about 1 in every 1 million people.
What is afibrinogenemia?

People with afibrinogenemia have no factor I (fibrinogen) in their blood. Without enough fibrinogen, the body cannot make fibrin and a stable blood clot will not form. Afibrinogenemia is inherited from both parents and can occur in men and women.

Signs and symptoms of afibrinogenemia

A wide range of bleeding is seen in people with afibrinogenemia. They may have severe or even life-threatening bleeding or go years during which no bleeding occurs. Afibrinogenemia is often diagnosed in newborns. Common signs and symptoms of afibrinogenemia include:

- Umbilical cord bleeding
- Swelling, pain, or warmth around a joint
- Inability to straighten or bend a joint normally
- Muscle, head, or neck ache
- Tight and shiny appearance of skin
- Bleeding into the skin
- Upset stomach
- Vomit that is black and syrupy or bright red
- Difficulty with urination or bowel movements
- Blood in the urine
- Red- or black-colored stool
- Drowsiness or loss of consciousness
- Sensitivity to light
- Weakness, tingling, or pain in the arms or legs
- In women, heavy menstrual bleeding or recurrent miscarriage
- Difficulty healing wounds
What is hypofibrinogenemia?

People who have hypofibrinogenemia have lower-than-normal levels of factor I (fibrinogen). Without enough fibrinogen, the body cannot make fibrin and a stable clot will not form. Hypofibrinogenemia is inherited from both parents and can occur equally in men and women. It can also develop as a person gets older.

Signs and symptoms of hypofibrinogenemia

Bleeding in people with hypofibrinogenemia is often mild. It may go undiagnosed until an episode of trauma or surgery. The most common signs and symptoms include:

- In women, heavy menstrual bleeding
- Muscle ache
- Tight and shiny appearance of skin
- Upset stomach
- Vomit that is black and syrupy or bright red
- Red- or black-colored stool
What is dysfibrinogenemia?

A person with dysfibrinogenemia has fibrinogen, but it does not work as it should. Dysfibrinogenemia is usually inherited from one parent. It can also develop as a person gets older. Dysfibrinogenemia can occur in men and women equally.

+ Signs and symptoms of dysfibrinogenemia

People with dysfibrinogenemia do not always have bleeding problems. A person is often diagnosed with dysfibrinogenemia after bleeding or having a blood clot, but the disease may go undiagnosed. Diagnosis often occurs in adulthood. There is a wide range of signs and symptoms. The most common signs and symptoms include:

- Delayed wound healing
- Rupture of surgical sutures
- Dead or dying skin (necrosis)
- In women, miscarriage, stillbirths, and excessive bleeding following childbirth
- Blood clots
What is factor II deficiency?

Factor II deficiency (also called prothrombin deficiency) means someone does not have enough factor II, also called prothrombin. When the protein, prothrombin, is activated to make thrombin, this helps change fibrinogen into fibrin, which is needed to form a stable clot. Factor II deficiency is inherited from both parents and can occur in men and women. It occurs in 1 in every 2 million people. Factor II deficiency is one of the rarest inherited bleeding disorders. Studies have shown a higher incidence of factor II deficiency among Latinos.

Signs and symptoms of factor II deficiency

- Swelling, pain, or warmth around a joint
- Inability to straighten or bend a joint normally
- Easy bruising
- Bleeding from the nose, gums, or uterus
- Bleeding after surgery
- Headache or neck ache
- Drowsiness or loss of consciousness
- Upset stomach
- Vomiting that is black and syrupy or bright red
- Sensitivity to light

In newborns:

- Hematomas
- Bleeding after circumcision
- Bleeding in the umbilical cord
What is factor V deficiency?

People with factor V deficiency have low levels of factor V. In the body, factor V helps produce a protein called thrombin. Without thrombin, the body cannot form a stable clot to stop the bleed. Factor V deficiency is inherited from both parents and can occur in men and women. It can also develop as a person gets older. Factor V deficiency occurs in 1 in every 1 million people.

Signs and symptoms of factor V deficiency

Factor V is often seen in childhood. Common signs and symptoms include:

- Bruises that appear easily
- Bleeding from the mouth or nose
- In women, heavy menstrual bleeding

Less common signs and symptoms include:

- Swelling, pain, or warmth around a joint
- Inability to straighten or bend a joint normally
- Headache or muscle or neck ache
- Tight and shiny appearance of skin
- Drowsiness or loss of consciousness
- Sensitivity to light
- Upset stomach
- Vomit that is black and syrupy or bright red
- Red- or black-colored stool
- Blood in the urine
- Bleeding after surgery or dental work
- Prolonged bleeding after childbirth
What is factor VII deficiency?

People with factor VII deficiency have low levels of factor VII in their blood. Factor VII plays an important role in starting the blood-clotting process. When there’s not enough factor VII, fibrin cannot be formed and blood clotting cannot start.

Factor VII deficiency is one of the most common among rare bleeding disorders. It occurs in 1 in every 300,000 to 500,000 people. Factor VII deficiency is inherited from both parents and occurs in men and women equally.

The level of factor VII in the blood does not always match the severity of bleeding.

Signs and symptoms of factor VII deficiency

There is a wide range of signs and symptoms of factor VII deficiency. People with severe factor VII deficiency may experience life-threatening bleeds in the head or the stomach.

People who have factor VII deficiency should watch for these signs and symptoms in the parts of the body listed below:

**Head**
- Drowsiness or loss of consciousness
- Headache or muscle or neck ache
- Nausea and vomiting
- Sensitivity to light

**Joint**
- Inability to straighten or bend a joint normally
- Swelling, pain, or warmth around a joint
- Tight and shiny appearance of skin
- Weakness, tingling, or pain in the arms or legs

**Muscle**
- Tight and shiny appearance of skin
- Weakness, tingling, or pain in the arms or legs

**Spinal cord**
- Difficulty with urination or bowel movements
- Weakness, tingling, or pain in the arms or legs

**Stomach**
- Red- or black-colored stool
- Upset stomach
- Vomit that is black and syrupy or bright red

**Other**
- Bleeding from the nose, gums, or mouth
- Bleeding after surgery
- Blood clots
- Easy bruising
- Heavy menstrual bleeding/iron deficiency in women

NIKI
NIKI has congenital factor VII deficiency
What is **factor VIII deficiency**?

People with factor VIII deficiency (hemophilia A, or “classic hemophilia”) have low levels of factor VIII in the blood. Without enough factor VIII, the body cannot form a stable **blood clot**. Hemophilia A affects mostly males who inherit the abnormal gene from their mothers. It occurs in 1 in 5000 live male births. However, as many as 30% of people with hemophilia A have no family history. When this happens, it is the result of a gene mutation.

**Signs and symptoms of factor VIII deficiency**

Factor VIII deficiency can be mild, moderate, or severe. It depends on how much factor VIII is missing. People with severe hemophilia A should watch for these signs and symptoms in the parts of the body listed below:

- **Head**
  - Drowsiness or loss of consciousness
  - Headache or muscle or neck ache
  - Nausea and vomiting
  - Sensitivity to light
- **Joint**
  - Bleeding from minor injury, such as easy bruising
  - Inability to straighten or bend a joint normally
  - Swelling, pain, or warmth around a joint
  - Tight and shiny appearance of skin
  - Weakness, tingling, or pain in the arms or legs
- **Muscle**
  - Bleeding from minor injury, such as easy bruising
  - Tight and shiny appearance of skin
  - Weakness, tingling, or pain in the arms or legs
- **Spinal cord**
  - Difficulty with urination or bowel movements
  - Weakness, tingling, or pain in the arms or legs
- **Stomach**
  - Upset stomach
  - Vomit that is black and syrupy or bright red
- **Other**
  - Bleeding from the nose
  - Spontaneous bleeding

People with moderate hemophilia A experience spontaneous bleeding less often. Usually, they bleed only after trauma or injury.

People with mild hemophilia A experience abnormal bleeding after major trauma or surgery.
What is factor IX deficiency?

People with factor IX deficiency (hemophilia B, or “Christmas disease”) have low levels of factor IX in the blood. Without enough factor IX, the body cannot form a stable blood clot. Hemophilia B is inherited and affects mostly males. It occurs in 1 in 30,000 live male births.

Signs and symptoms of factor IX deficiency

Factor IX deficiency can be mild, moderate, or severe. It depends on how much factor IX is missing. People with severe hemophilia B may experience these signs and symptoms in the parts of the body listed below:

**Head**
- Drowsiness or loss of consciousness
- Headache or muscle or neck ache
- Nausea and vomiting
- Sensitivity to light

**Joint**
- Bleeding from minor injury, such as easy bruising
- Inability to straighten or bend a joint normally
- Swelling, pain, or warmth around a joint
- Tight and shiny appearance of skin
- Weakness, tingling, or pain in the arms or legs

**Muscle**
- Bleeding from minor injury, such as easy bruising
- Tight and shiny appearance of skin
- Weakness, tingling, or pain in the arms or legs

**Spinal cord**
- Difficulty with urination or bowel movements
- Weakness, tingling, or pain in the arms or legs

**Stomach**
- Blood in the urine
- Upset stomach
- Vomit that is black and syrupy or bright red

**Other**
- Bleeding from the nose
- Spontaneous bleeding

People with moderate hemophilia B experience spontaneous bleeding less often. Usually, they bleed only after trauma or injury.

People with mild hemophilia B experience abnormal bleeding after major trauma or surgery.

Unlike factor VIII deficiency, people with factor IX deficiency can develop severe allergic reactions upon exposure to factor IX.
People with factor X deficiency (sometimes called Stuart-Prower deficiency) have low levels of factor X in their blood. Factor X helps activate a protein called prothrombin, which is needed to form a stable blood clot. Factor X deficiency is inherited from both parents. It can also develop as a person gets older. It is rare and occurs in 1 in every 500,000 to 1 million people.

What is factor X deficiency?

People with factor X deficiency (sometimes called Stuart-Prower deficiency) have low levels of factor X in their blood. Factor X helps activate a protein called prothrombin, which is needed to form a stable blood clot. Factor X deficiency is inherited from both parents. It can also develop as a person gets older. It is rare and occurs in 1 in every 500,000 to 1 million people.

Signs and symptoms of factor X deficiency

The level of factor X in the blood does not always match the severity of bleeding. Common signs and symptoms include:

- Umbilical stump bleeding at birth (for those severely affected)
- Bleeding from the nose

Other signs and symptoms include:

- Bleeding from the mouth
- Easy bruising
- Swelling, pain, or warmth around a joint
- Inability to straighten or bend a joint normally
- Headache or neck ache
- Drowsiness or loss of consciousness
- Upset stomach
- Vomit that is black and syrupy or bright red
- Sensitivity to light
- Weakness, tingling, or pain in the arms or legs
- Difficulty with urination or bowel movements
- Bleeding after surgery or trauma
- In women, heavy menstrual bleeding
People with factor XI deficiency, also called hemophilia C, have low levels of factor XI. Although factor XI is not as critical to clotting as other factors, a person with factor XI deficiency may still need treatment and attention. If either parent has factor XI deficiency, it will be passed on to their children. It can occur in both men and women. It is more common among Ashkenazi Jews (nearly 1 in every 8), but it affects non-Jewish people as well. Factor XI deficiency occurs in 1 in every 1 million people. Bleeding in people with factor XI deficiency is sometimes affected by other factors or may be apparent only with surgery. It is also possible for inhibitors to develop in people with severe factor XI deficiency.

### What is factor XI deficiency?

People with factor XI deficiency, also called hemophilia C, have low levels of factor XI. Although factor XI is not as critical to clotting as other factors, a person with factor XI deficiency may still need treatment and attention. If either parent has factor XI deficiency, it will be passed on to their children. It can occur in both men and women. It is more common among Ashkenazi Jews (nearly 1 in every 8), but it affects non-Jewish people as well. Factor XI deficiency occurs in 1 in every 1 million people. Bleeding in people with factor XI deficiency is sometimes affected by other factors or may be apparent only with surgery. It is also possible for inhibitors to develop in people with severe factor XI deficiency.

### Signs and symptoms of factor XI deficiency

Bleeding in people with factor XI deficiency is not predictable. Spontaneous bleeding is very rare. However, there are common signs and symptoms, such as:

- Bleeding after injury in the mouth or nose
- Blood in the urine
- Bleeding after surgery, especially tonsillectomy, sinus surgery, and dental work
- In women, heavy menstrual bleeding and bleeding related to childbirth
What is factor XIII deficiency?

People with factor XIII deficiency (sometimes called fibrin-stabilizing factor deficiency) have low levels of factor XIII in the blood. Factor XIII works toward the end of the blood-clotting process. It helps a protein called fibrin link together so that clots don’t break down after they are formed. So, if a person does not have enough factor XIII, a stable clot cannot be formed.

There are 2 types of factor XIII deficiency: factor XIII A subunit deficiency and factor XIII B subunit deficiency. Factor XIII A subunit deficiency is seen in roughly 95% of people with factor XIII deficiency.

Factor XIII deficiency is usually inherited from both parents. However, it can also develop as a person gets older. Factor XIII deficiency can occur in both men and women. It is rare and occurs in 1 in every 3-5 million people.

Signs and symptoms of factor XIII deficiency

Bleeding severity depends on the level of factor XIII in the blood. Those with very low levels may experience severe spontaneous bleeding. Other people with factor XIII deficiency may have no symptoms at all. Patients with severe factor XIII deficiency may develop life-threatening bleeds in the head without treatment. Some signs and symptoms of factor XIII deficiency include:

- Bleeding from the umbilical cord at birth (appears in 80% of cases)
- Headache or muscle or neck ache
- Drowsiness or loss of consciousness
- Upset stomach
- Vomit that is black and syrupy or bright red
- Sensitivity to light
- Easy bruising/skin discoloration
- Swelling, pain, or warmth around a joint
- Inability to straighten or bend a joint normally
- Tight and shiny appearance of skin
- Bleeding after surgery or trauma
- In women, miscarriages or excessive bleeding after childbirth

SKYLAR
Skylar has congenital factor XIII deficiency
Your blood contains small, sticky cells called platelets. When you cut or injure a blood vessel and begin to bleed, platelets rush to the site of injury. There, they stick to the blood vessel and try to block the leak. They also send out a chemical signal that attracts other platelets. Then, those platelets stick to the platelets at the injury site to form a plug that stops the bleed.

However, sometimes platelets do not work as they should.

- Platelets may not be able to stick to the blood vessel or to each other
- There may not be enough platelets
- Platelets are sometimes not able to send or receive the chemical signals

When any of these happen, a person has a platelet disorder.

The 3 platelet disorders discussed in this guide are Glanzmann thrombasthenia, Bernard-Soulier syndrome, and platelet storage pool deficiency.

However, there are many others.
What is **Glanzmann thrombasthenia**?

Numerous **proteins** help **platelets** work properly. One of these is called glycoprotein. Glycoproteins work together like a bridge to connect platelets with each other. This way, platelets stick together to form a plug to stop bleeding. However, someone with Glanzmann thrombasthenia has specific defective glycoprotein or no glycoprotein at all. This means platelets cannot form a plug to stop bleeding.

Glanzmann thrombasthenia is inherited from both parents. It can occur in both men and women. It is not well known how often Glanzmann thrombasthenia occurs.

**Signs and symptoms of Glanzmann thrombasthenia**

The most common signs and symptoms of Glanzmann thrombasthenia include:

- Excessive bleeding after surgery or injury
- Easy bruising
- Bleeding from the nose or gums
- In women, heavy menstruation

**Less common signs and symptoms include:**

- Swelling, pain, or warmth around a joint
- Inability to straighten or bend a joint normally
- Headache or neck ache
- Drowsiness or loss of consciousness
- Sensitivity to light
- Upset stomach
- Vomit that is black and syrupy or bright red
- Red- or black-colored stool
What is **Bernard-Soulier syndrome**?

Glycoprotein is one of the many **proteins** that help **platelets** work as they should. Glycoproteins serve as a bridge that connects platelets to each other. This way, platelets can stick together to form a plug to stop bleeding. However, someone with Bernard-Soulier syndrome (also called giant platelet syndrome) has defective glycoprotein. Platelets may be abnormally large, they may not stick to each other, or there may not be enough platelets. This means platelets cannot form a plug to stop bleeding.

Bernard-Soulier syndrome is inherited from both parents and can occur in both men and women. The prevalence of Bernard-Soulier syndrome is not well known.

**Signs and symptoms of Bernard-Soulier syndrome**

The most common signs and symptoms of Bernard-Soulier syndrome include:

- Easy bruising
- Bleeding from the nose or gums
- In women, heavy menstrual bleeding or bleeding related to childbirth
- Excessive bleeding after surgery or injury

**Less common signs and symptoms include:**

- Swelling, pain, or warmth around a joint
- Inability to straighten or bend a joint normally
- Headache or neck ache
- Drowsiness or loss of consciousness
- Sensitivity to light
- Upset stomach
- Vomit that is black and syrupy or bright red
- Red- or black-colored stool
What is **platelet storage pool deficiency**?

In order for **platelets** to work normally, they need the help of granules. Granules help carry signals from one end of a platelet to the other. When these granules do not work properly, a person may have a platelet storage pool deficiency. This means platelets cannot form a plug to stop bleeding.

There are different types of platelet storage pool deficiency. Sometimes, there are not enough granules to send the signal. Other times, there are enough granules, but they cannot be put together correctly. Depending on the type, platelet storage pool deficiency can occur in men or women and is inherited from one or both parents. The prevalence of platelet storage pool deficiency is not well known. This is because there is no single lab test that can predict the many disorders.

### Signs and symptoms of platelet storage pool deficiency

The most common signs and symptoms of platelet storage pool deficiency include:

- Easy bruising
- Bleeding from the nose or gums
- In women, heavy menstrual bleeding or bleeding related to childbirth
- Excessive bleeding after surgery or injury
Acquired: Not passed down through the genes; may develop over time.

Antibodies: Proteins in the blood that attack substances that the body thinks present a danger. Antibodies that attack replacement therapies for hemophilia are called inhibitors.

A

B

Bleed: A collection of blood in an area. It is a term people with bleeding disorders use to describe their bleeding episodes.

Blood clot: A thick clump or mass of blood.

Blood clotting: The process by which the blood forms clots to stop a bleed. See also Clotting.

C

Capillaries: Very small blood vessels.

Clotting: The series of events by which the blood forms clots to stop a bleed. See also Blood clotting.

Clotting factors: The proteins that circulate in the blood and are needed for normal coagulation.

Clotting factor disorder: A disorder in which there are missing or low levels of blood-clotting factors.

F

Factor: A protein in the blood that helps form blood clots.

Fibrin: A protein that helps form a stable clot.

Fibrinogen (factor I): A protein needed to make fibrin, which helps form a stable clot.

H

Hemophilia: A bleeding disorder that occurs mostly in males. The disorder makes bleeding hard to control.

Hemophilia A: A bleeding disorder caused by a lack of factor VIII. It is sometimes called “classic hemophilia.”

Hemophilia B: A bleeding disorder caused by a lack of factor IX. It is sometimes called “Christmas disease.”

Hemophilia treatment center (HTC): A place that provides specialty care for hemophilia. Doctors, nurses, social workers, physical therapists, and dentists are part of the healthcare team.

Hereditary: Passed from parents to children. Diseases and disorders can be hereditary.

I

Immune system: A bodily system that protects the body from foreign or harmful substances.

Inhibitors: With rare bleeding disorders, inhibitors are antibodies in the blood that react to infused factor and slow the clotting process. See also Antibodies.

N

Necrosis: Early death of cells or living tissue by damage or disease.

P

Platelet deficiency or platelet disorder: A defect in the number and/or function of platelets.

Platelets: Tiny cells in the blood that stick to an injured blood vessel, and to each other, to form a plug.

Proteins: Compounds that do vital tasks in the body.

Prothrombin (factor II): A protein needed to form a stable blood clot.

R

Rare bleeding disorders: Conditions in which defects and/or low levels of platelets or clotting factors lead to lifelong bleeding problems.

T

Thrombin: A protein needed to form a stable clot.
resources and support

**Rare bleeding disorder information:**

**Centers for Disease Control and Prevention (CDC)**
Hemophilia Treatment Centers
cdc.gov/ncbddd/hemophilia/HTC.html (Click on the Hemophilia Treatment Centers Directory link.)

**Factor VII Deficiency (HemAware: The Bleeding Disorders Magazine)**
hemaware.org/story/factor-vii-deficiency

**HemAware: The Bleeding Disorders Magazine (NHF sponsored)**
hemaware.org

**LA Kelley Communications, Inc.**
kelleycom.com

**National Heart, Lung, and Blood Institute (NHLBI)**
1-301-592-8573
www.nhlbi.nih.gov

**Rare Bleeding Disorders Database**
rbdd.org

**Organizations and foundations:**

**Canadian Hemophilia Society (CHS)**
hemophilia.ca

**Hemophilia Federation of America (HFA)**
1-800-230-9797
hemophiliafed.org

**National Hemophilia Foundation (NHF)**
1-800-42-HANDI (1-800-424-2634)
hemophilia.org

**National Hemophilia Foundation (NHF)—Inhibitor Education Summits**
1-877-560-5833
nhfinhibitorsummits.org

**National Institutes of Health, Genetic and Rare Diseases Information Center (GARD)**
rarediseases.info.nih.gov/GARD

**National Organization for Rare Disorders (NORD)**
rarediseases.org

**World Federation of Hemophilia (WFH)**
wfh.org

**Networking and support:**

**The Art of Lion Taming**
fourlittlelions.com

**Changing Possibilities in Hemophilia®**
ChangingPossibilities-US.com

**Madisons Foundation**
madisonsfoundation.org

**Platelet disorder information:**

**Glanzmann’s Research Foundation**
glanzmanns.org

**Platelet Disorder Support Association**
pdsa.org

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**STEPHANIE**
Stephanie has congenital factor XIII deficiency

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**Changing possibilities in hemophilia**

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**novo nordisk**
The challenges that come with having a bleeding disorder should not stand between you and your goals. That’s why Changing Possibilities in Hemophilia® was created. This community was formed so patients and families could connect. It is a place to share information, resources, experiences, and advice. It is an educated, close-knit community empowered to change possibilities.

ChangingPossibilities-US.com is your place to find out more about living with a rare bleeding disorder. The Web site has real stories of people living with rare bleeding disorders. Plus, it has a wealth of information and resources created by real people dealing with rare bleeding disorders. Join the community at ChangingPossibilities-US.com or Like Changing Possibilities in Hemophilia® on Facebook® and keep moving forward!