



Information for people and families

living with hemophilia B



Living With Hemophilia B

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Living With Hemophilia B

An important part of managing any health condition is having a clear awareness of the condition—this comes with education. In the case of hemophilia B, sorting through the specifics of treatment and life stages can be challenging without knowledge of the disorder itself. With this in mind, Pfizer has prepared this book as an informational resource for people and families living with hemophilia B.

Note: *The information in this book should in no way replace the advice of a health care professional (HCP). Be sure to talk to your HCP, nurse, or hemophilia treatment center (HTC) staff regarding any form of medical advice and treatment.*

Section 1 Background on Hemophilia

Living With Hemophilia B

Section 1

Background on Hemophilia

What Is Hemophilia?

Hemophilia is one of several types of bleeding disorders. It is caused by an inherited deficiency (shortage) or lack of a protein in the blood called clotting factor (often referred to simply as factor). Without enough clotting factor, the blood cannot clot properly and a person may bleed longer. This can also occur after an injury. The main types of hemophilia are hemophilia A and hemophilia B. Hemophilia B is less common than hemophilia A.^{1,2}

Did You Know?

- Approximately 1 in 5,000 males has hemophilia³
- Hemophilia A occurs in about 80% to 85% of all hemophilia cases³
- Hemophilia B occurs in approximately 1 in 25,000 male births²

All ethnic and racial groups appear to be equally affected.²



What Are the Types of Hemophilia?

The type of hemophilia depends on which clotting factor is missing or lacking in the blood. Hemophilia A is caused by a lack of clotting factor VIII. Hemophilia B is caused by a lack of clotting factor IX. Patients with hemophilia A or hemophilia B can present with similar signs and symptoms; however, each type is caused by a different clotting factor deficiency.⁴ Because of this difference, people with hemophilia A and people with hemophilia B are treated with different medications.

What Are the Types of Bleeds?

Hemorrhages or “bleeds” may be caused by injury or may occur spontaneously (without any apparent cause).⁵ Hemophilia can range from mild to moderate to severe.² Bleeds can begin in infancy, childhood, adolescence, or adulthood.⁴ For more information, see the section “Types of Bleeds” on page 35.



Living With Hemophilia B

How Is Hemophilia Classified?

Hemophilia A and hemophilia B are clinically similar, although type A is four to six times more common than type B.⁴ Hemophilia can be classified by the amount or level of clotting factor a person has. This determines the disorder severity.³

Disorder severity is classified by factor levels^{2,4}:

- **Severe hemophilia (factor levels less than 1% of normal):** frequent spontaneous bleeding and continued bleeding after trauma or surgery
- **Moderate hemophilia (factor levels between 1% and 5% of normal):** occasional spontaneous bleeding and excessive bleeding after trauma or surgery
- **Mild hemophilia (factor levels greater than 5% of normal):** rare spontaneous bleeds; however, there may be excessive bleeding after trauma or surgery

About 50% to 60% of people with hemophilia A have severe disorder. Twenty percent to 45% of people with hemophilia B have severe disorder.^{4,6}

For a person without hemophilia, the normal range of factor VIII and factor IX in the blood is 50% to 150%.⁴ As with any average, for a biologic measurement, some people have higher levels, and others have lower levels.



Hemophilia History: A Timeline

100 AD	First mention of bleeding signs and symptoms —In the Talmud it says Jewish male infants were exempt from circumcision if older brothers had died as a result. ⁷
1803	An inherited bleeding disorder —Doctor John Conrad Otto studied families and showed that bleeding signs and symptoms are passed along from mothers to sons. ⁷
1800s-1900s	Hemophilia gets the “royal treatment” —Cases of hemophilia were reported in royal families of Europe. ⁷
1930s	Discovery of clotting factor —Two Harvard doctors discovered that blood from people without hemophilia has something in it that can be used to help clotting in patients with hemophilia. ⁷
1940s	Clotting factor tested —A doctor in Argentina performed a lab test showing that blood from one hemophilia patient could correct the clotting problem in another patient. It was unknown to the doctor that each patient had a different type of hemophilia. ⁷
1952	Two types of hemophilia —Factor IX was identified as being decreased in hemophilia B, so two types of hemophilia were now known. ^{3,7}
1950s-1960s	Early hemophilia treatments —Plasma was first used to replace missing clotting factor and treat hemophilia bleeds. ⁷
1984	First approval of plasma-derived coagulation factor IX⁸
1997	First recombinant factor IX product became available⁹

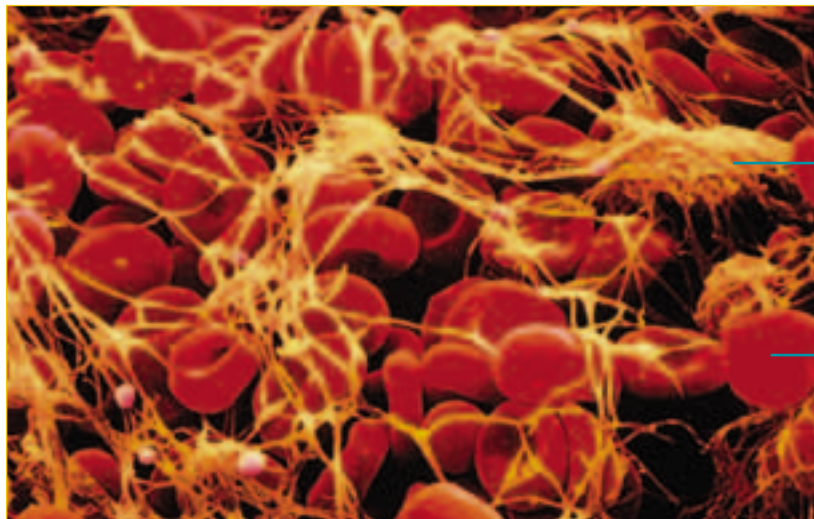
For more information about a recombinant factor IX product, please see page 18.

Living With Hemophilia B

Understanding the Blood-Clotting Process

Blood is a vital part of life. It carries oxygen and important nutrients to all of the tissues in the body. This process provides the body's cells with sources of energy so they can function. Blood moves throughout the body in vessels within a network of tubes. The tubes are found throughout the body in joints, muscles, organs, and tissues. There are three varieties of blood vessels. Arteries carry blood away from the heart, capillaries connect arteries to veins, and veins carry blood back to the heart.

If someone without hemophilia injures a blood vessel through a bump, a bruise, or everyday wear and tear, the body will form a clot to stop the bleeding. This process is called coagulation—it keeps the blood inside the vessels. To form a clot, clotting factors act together with platelets in a series of reactions. The clotting factors make strong threads of fibrin that hold the clot together. This helps to close the injury and stop the bleeding.¹⁰



Fibrin

Platelets

This is what a clot looks like in the body. The yellow threads of fibrin gather around the platelets. This forms a net to make the clot strong.



If any clotting factors are missing or low, the body will have trouble stopping a bleed. This is what happens when someone has hemophilia. The clot does not form properly and bleeding continues.⁵

Hemophilia Is a Genetic Disorder

With hemophilia, the deficiency of clotting factor is caused by an abnormal gene. This is the reason why hemophilia is called a genetic disorder. Certain genes help the body make clotting factor. When the gene for making clotting factor is abnormal, the body does not make enough factor. The genes for both factor VIII and factor IX are located on the X chromosome. Both hemophilia A and B are inherited as X-linked traits.³

Hemophilia runs in families. In most cases, people are born with it. The abnormal gene responsible for clotting factor is inherited.¹

Chromosomes come in pairs—females have two X chromosomes, males have one X chromosome and one Y chromosome. The X chromosome carries the genes related to clotting factors. The Y chromosome does not.¹

A male with the abnormal gene on his X chromosome will have hemophilia. For a female to have hemophilia, she must have an abnormal gene on both of her X chromosomes, which is very rare.¹

A female is the “carrier” of hemophilia if she has the abnormal gene on one of her X chromosomes. Even though she does not have hemophilia, she can pass the gene on to her children. Females who are carriers usually have enough clotting factors from their one normal X chromosome to prevent serious bleeding problems.¹ Known carriers should have their levels of clotting factor measured at least once to determine whether they are at increased risk for clinical bleeding episodes.³

What Is a Gene?

Genes carry information (DNA) that determines the traits a person will have, such as brown eyes or red hair. DNA makes every person different. Genes are located on chromosomes, which are found inside almost every cell of the body. Genes are the “blueprints” that tell the cells what to do, such as how to digest food or how tall a person will be. Genes can also control whether a person has a disorder or disease.^{5,11}

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Because it is inherited as a gene defect on the X chromosome, the majority of people with hemophilia are males, but in rare cases, a girl can be born with hemophilia.⁴ This can happen if the father has hemophilia and the mother is a carrier.¹

Some males with hemophilia are born to mothers who are not carriers. In these cases, a mutation (random change) occurs in the gene as it is passed to the child.¹

Patterns of Inheritance

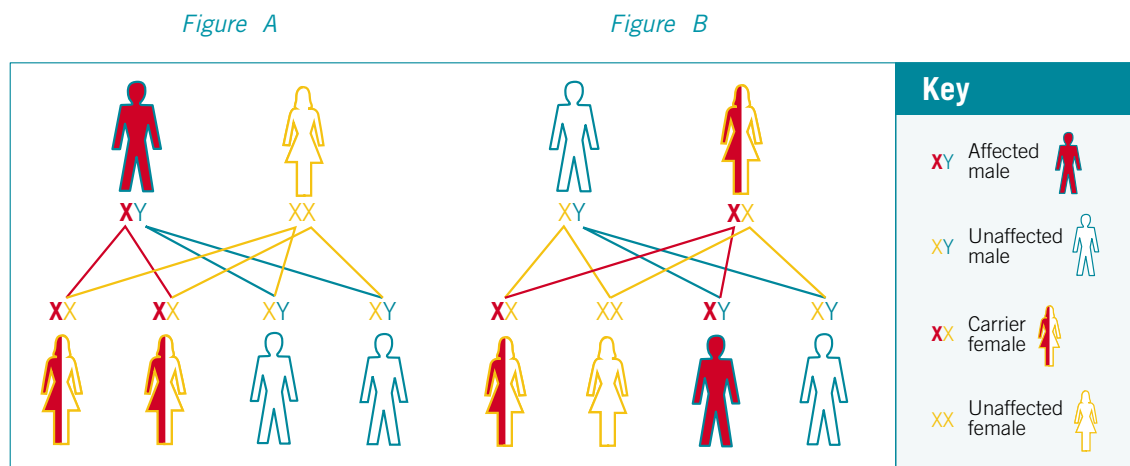


Fig. A A father with hemophilia will pass the defective gene to his daughters, making them carriers. His sons, however, will not be affected because they get their X chromosome from their unaffected mother.¹

Fig. B In a mother who is a carrier, there is a 50% chance her daughter will be a carrier also. If she has a son, there is a 50% chance he will have hemophilia because she has one “affected” X chromosome.¹



Spontaneous Occurrence

Hemophilia B is caused by a variety of genetic defects. However, about one third of all people with hemophilia B have no family history of the disorder.¹² This type of hemophilia B is referred to as acquired hemophilia.¹ It can develop if the body forms antibodies (protein substances produced in the blood or tissues in response to a specific antigen¹¹) to the clotting factors in the bloodstream. The antibodies can block the clotting factors from working.¹ Researchers believe this spontaneous occurrence is caused by a new mutation (or change) to the gene that produces clotting factor.¹²

Some carriers may show no signs or symptoms of hemophilia. They are called asymptomatic. They may not be tested until they decide to have children. However, women with low enough factor levels may have signs or symptoms. This puts them at a higher risk for excessive bleeding from trauma, surgery, or menstrual cycles. Early testing can help avoid serious complications.^{13,14}

Factor levels alone may not be enough to determine carrier status. Because levels of clotting factor can vary greatly among carriers, health care professionals (HCPs) use additional tools to determine carrier status.¹⁴ Carrier testing involves a detailed family history taken by an HCP or genetic counselor.¹⁵ This information is then used to construct a family tree, or pedigree, to help identify potential carriers. See the section “Hemophilia Is a Genetic Disorder” on page 11.

Direct mutational analysis is a blood test to identify the abnormal gene in a male family member with hemophilia B. Scientists may then check to see if this abnormality appears in the potential carrier (mother or father).¹⁵

Check with your local hemophilia treatment center (HTC) for details about carrier testing and genetic counseling. Many hemophilia organizations are also available for more support and information.



Living With Hemophilia B

By now you have gained a general understanding of what hemophilia, specifically hemophilia B, is and how people acquire the disorder. In Section 2, we will discuss some of the treatment options currently available to people living with hemophilia B.

Treatment with any factor product should be managed under the supervision of an HCP who is experienced in the treatment of hemophilia B.

Section 2

Treatment of Hemophilia B

Living With Hemophilia B

Section 2

Treatment of Hemophilia B

Hemophilia Treatment: A Timeline

1911	Factor VIII was identified. ⁶
1930s	Patients were treated with transfusions of whole blood plasma. ³ Researchers discovered that plasma precipitates given through intravenous (IV) infusions shortened clotting time. ¹⁶
1944	An American researcher developed fractionation, the process of separating plasma into its different parts. ¹⁶
1952	Factor IX was identified. ¹²
1955	The first effective therapy for hemophilia was developed using intravenous (IV) infusion of factor VIII. ¹⁶
1964	Cryoprecipitate (the solid material, rich in clotting factor, that forms when plasma is frozen and then thawed) was discovered. ¹⁶
1968	Factor VIII concentrate became available. ¹⁶
1980s	Plasma-derived factor products were improved, purified, and treated to remove viruses. Genes for factor VIII and factor IX were cloned. ³
1989	The first clinical use of recombinant factor VIII occurred. ³
1992	Recombinant factor VIII products became available. ¹⁶
1997	The first recombinant factor IX product, BeneFix [®] Coagulation Factor IX (Recombinant), became available. ⁹
2007	Reformulated BeneFix [®] was introduced.

Please see Important Safety Information on page 18 and accompanying full Prescribing Information.



How Is Hemophilia B Treated?

The main goal of hemophilia B care is to treat bleeds as soon as they begin.³ As we previously learned, hemophilia B is caused by a low level of clotting factor IX in the blood. To correct this problem, treatment should begin with replacement of the missing clotting factor IX. Factor IX replacement products, also called “factor,” help raise the level of clotting factor IX in the blood, allowing blood to clot properly.

There are two types of factor IX replacement products used to treat hemophilia B. Both products work in the same way to help replace the missing clotting factor IX, and both have proven to be effective. The choices include⁴:

- Plasma derived factor IX concentrate
- Recombinant factor IX concentrate

Important

Factor replacement is a treatment, not a cure. After receiving factor, the body uses it up and will eventually need more. People with hemophilia B need to use factor replacement for the remainder of their lives to help control bleeding.

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What Is BeneFix® Coagulation Factor IX (Recombinant)?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

Important Safety Information for BeneFix

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash or hives.
- Your body can make antibodies, called “inhibitors,” which may interfere with the effectiveness of BeneFix.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

If you do not have prescription drug insurance and need help paying for BeneFix, Pfizer may be able to help. Visit us at www.PfizerHelpfulAnswers.com, or call us at 888-999-2349 for more information.



You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 800-FDA-1088.

How Is BeneFix Made?

BeneFix is manufactured through the use of a recombinant DNA process. Scientists find and make a copy of the factor IX gene in the lab.⁹

Recombination is when scientists take the gene, modify it, and transplant it into special cells.^{17*} These cells are called host cells. They grow and multiply, and then produce the factor IX protein used to make BeneFix. All this takes place in specialized manufacturing facilities using the most advanced methods.¹⁷

BeneFix Convenience Features

BeneFix Rapid Reconstitution (R2) Kit provides a short and simple preparation process and offers added convenience for busy lives:

- > **2000 IU** vial for few vials, less packaging waste, and fast cleanup—less packaging may reduce the amount of waste with the R2 Kit⁹
- > **Low 5 mL** diluent volume for all vial sizes
- > **Prefilled diluent syringe** means few components and fast preparation⁹
- > **Needle-less** rapid reconstitution without risk of needlestick
- > **Clear vial adapter** to easily confirm a good connection
- > **Color-coded vials** for quick identification

*Chinese hamster ovary cells.

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 **BeneFix[®]**
Coagulation Factor IX
(Recombinant)

Living With Hemophilia B

Reconstitution Steps¹⁰



1. Let the vial of BeneFix and the prefilled diluent syringe reach room temperature.
2. Remove the plastic flip-top cap from the BeneFix vial to show the center part of the rubber stopper.
3. Wipe the top of the vial with the alcohol swab provided, or use another antiseptic solution, and allow to dry. After cleaning, do not touch the rubber stopper with your hand or allow it to touch any surface.



4. Peel back the cover from the clear plastic vial adapter package. **Do not remove the adapter from the package.**
5. Place the vial on a flat surface. While holding the adapter in the package, place the vial adapter over the vial. Press down firmly on the package until the adapter snaps into place on top of the vial, with the adapter spike penetrating the vial stopper.



6. Grasp the plunger rod as shown in the picture on the left. Do not touch the shaft of the plunger rod. Attach the threaded end of the plunger rod to the diluent syringe plunger by pushing and turning firmly.



7. Break off the tamper-resistant, plastic-tip cap from the diluent syringe by snapping the perforation of the cap. Do not touch the inside of the cap or the syringe tip. The diluent syringe may need to be recapped (if reconstituted BeneFix is not used immediately), so place the cap on its tip on a clean surface in a spot where it will stay clean.
8. Lift the package away from the adapter and discard the package.

Please see Important Safety Information on page 18 and accompanying full Prescribing Information.

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Coagulation Factor IX
(Recombinant)

Living With Hemophilia B

Reconstitution Steps (continued)



9. Place the vial on a flat surface. Connect the diluent syringe to the vial adapter by inserting the tip of the syringe into the adapter opening while firmly pushing and turning the syringe clockwise until the connection is secured.



10. Slowly push the plunger rod to inject all the diluent into the BeneFix vial.



11. With the syringe still connected to the adapter, **gently** swirl the contents of the vial until the powder is dissolved.

Look at the final solution before infusing it. The solution should be clear to colorless. If it is not, throw away the solution and use a new kit.



12. Make sure the syringe plunger rod is still fully pressed down, then turn over the vial. Slowly pull the solution into the syringe. Turn the syringe upward again and remove any air bubbles by gently tapping the syringe with your finger and slowly pushing air out of the syringe.

If you reconstituted more than one vial of BeneFix, remove the diluent syringe from the vial adapter and leave the vial adapter attached to the vial. Quickly attach a separate large luer lock syringe and pull the reconstituted solution as instructed above. Repeat this procedure with each vial in turn. Do not detach the diluent syringes or the large luer lock syringe until you are ready to attach the large luer lock syringe to the next vial adapter.

13. Remove the syringe from the vial adapter by gently pulling and turning the syringe counter-clockwise. Throw away the vial with the adapter attached.

If you are not using the solution right away, you should carefully replace the syringe cap. Do not touch the syringe tip or the inside of the cap.

BeneFix should be infused within 3 hours after reconstitution. The reconstituted solution may be stored at room temperature prior to infusion.

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The reconstituted solution may be stored at room temperature prior to administration, but should be administered within 3 hours after reconstitution.⁹ BeneFix vials should not be reconstituted and used after the expiration date on the BeneFix vial label.⁹ Patients should follow the specific reconstitution and administration procedures provided by their HPCs.⁹



People with hemophilia B often require frequent factor IX infusions. Those who have difficulty receiving the infusions may need to have a port or central venous line (CVL) surgically inserted through the skin into a large vein to make it easier to receive infusions.¹⁸ A port is often used throughout childhood. One of the risks of having a port is a potential for the port site to become infected.¹⁸ It is advisable to watch this area for any sign of infection.

How Much to Infuse—Factor Dosing

Only your doctor can decide on the proper dose of BeneFix that will work best for you. He or she will base the recommended dosage for you on the following information:

- The seriousness of the bleed and its location⁹
- The severity of the factor IX deficiency⁹
- Your weight and age¹⁹
- Recovery of factor IX⁹

Factor therapy works right away to help stop a bleed. At some point the body will use up the entire factor. The time it takes for half the amount of factor in the blood to be used is called the half-life. The half-life of BeneFix is 18.8 hours.⁹



The goal of factor IX therapy is to replace the missing factor so that there is enough factor IX in the blood to stop the bleed. Some bleeds may stop after one dose, while others may need several infusions to stop the bleeding. Severe bleeds may even need therapy once or twice a day for several days.⁹

The amount of factor IX needed is based on the severity of the bleed.⁹

Type of Bleed	Circulating Factor IX Activity Required ⁹
Minor	20% to 30% of normal
Moderate	25% to 50% of normal
Major	50% to 100% of normal

How Often to Infuse—Dosing Schedule

In general, there are several dosing schedules for the treatment of hemophilia B with factor therapy:

- On-demand therapy involves giving factor infusions when a bleed begins
- Preventive infusions are those given prior to an event that may cause bleeding
- HCPs prescribe dosing schedules to meet the needs of their patients

Selected Important Safety Information

- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

Please see Important Safety Information on page 18 and accompanying full Prescribing Information.

How Is Hemophilia Classified?^{2,4}

Severe hemophilia
(factor levels less than 1% of normal)

Moderate hemophilia
(factor levels between 1% and 5% of normal)

Mild hemophilia
(factor levels greater than 5% of normal)

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Coagulation Factor IX
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Important Information About Factor Replacement

After an infusion, your HCP may measure or keep track of the amount of factor IX in your blood. This is called recovery. Recovery time is important to know because it helps your HCP figure out the proper dose of factor your own body needs. Recovery is measured by taking a blood test, also called an assay.¹⁹

Recovery is different for every person. It can be influenced by age and weight, and it also differs based on the type of factor product used—recombinant or plasma derived.¹⁹

Using an Infusion Log

To remember the details about when and how to infuse, you will need a place to write down the information. An infusion log is a book used to record factor treatments given at home. This log can help you record how you treat your hemophilia B between HCP visits. Using an infusion log similar to this one can help you keep track of important medical information such as:

- How much factor was given
- Products used and when
- How often factor was given
- Side effects or problems

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 800-FDA-1088.

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 **Benefix[®]**
Coagulation Factor IX
(Recombinant)



Sample Daily Infusion Log

Be sure to write the date and time for each infusion.

Date _____ **Time** _____

Product _____

Place the vial stickers here so you have a record of the lot number, expiration date, and the number of units per vial.

Place stickers here



Write down the units in each vial and the number of units used. This tracks how much factor was needed for each bleed.

Total # units _____

Reason for infusion

___ Prevention Activity/Event _____

___ Bleed/Injury Location _____

___ Bleeding Symptom(s) _____

___ Follow-up Scheduled _____

Check the reason for your infusion.

NOTES _____

Describe how long after the bleed your treatment began. You can also note if you had any reaction to the factor.

There is a larger version of this infusion log for you to cut out on page 61.

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Inhibitors

Some people on factor replacement therapy may develop inhibitors. Inhibitors are proteins in the blood called antibodies that are made by the immune system.

Although antibodies help protect the body from infections or other “invaders,” the body may make antibodies in response to factor therapy because they see the infused factor IX as an invader and attack it. Activity-neutralizing antibodies that act this way are referred to as inhibitors because they inhibit (hinder), or stop, the factor from working the correct way. Despite a lot of research and many ongoing studies, HCPs do not yet fully understand all the reasons that may influence the development of inhibitors.²⁰

- About 2% to 3% of people with hemophilia B develop inhibitors²¹
- About 5% to 10% of all people with hemophilia A and 20% to 30% of people with severe hemophilia A develop inhibitors²¹

When learning about hemophilia B and inhibitors, it is important to know the difference between previously treated patients (PTPs) and previously untreated patients (PUPs). These two patient types may respond differently to treatment.

PTPs—patients who have been treated before with factor IX and may have developed inhibitors while using another product

- Clinical studies have shown that 1.5% of PTPs (1 of 65) developed inhibitors while using BeneFix⁹

PUPs—patients who have never been treated with any antihemophilic product

- Clinical studies have shown that 3.2% of pediatric PUPs (2 of 63) developed inhibitors while using BeneFix⁹

Inhibitor levels are measured in Bethesda Units (BUs).



Selected Important Safety Information

- Your body can make antibodies, called “inhibitors,” which may interfere with the effectiveness of BeneFix.

Where to Go for Treatment

Hemophilia treatment centers (HTCs) provide comprehensive care for people with bleeding disorders. Comprehensive care means that a person’s medical, social, and emotional needs are all addressed. Care at an HTC is in addition to the care you receive from family and HCPs (primary care physicians).

HTCs are located all over the United States. See the section “To Locate an HTC Near You” on page 32 for more information. Some HTCs are located internationally. HTCs provide many services, including supply and delivery of factor, home infusion education, dental care, home visits by social workers, and insurance counseling. Many types of specialists work together to meet challenges a person with a bleeding disorder may encounter.

Who’s Who at Your HTC

Here is a list of people who may be involved in caring for you when you visit an HTC²²:

- **Hematologists**—doctors who specialize in bleeding disorders and oversee patient care
- **Pediatricians**—doctors who specialize in the care of children
- **Hemophilia nurses**—specialists in hemophilia care who work closely with patients to give treatment
- **Orthopedists**—doctors who work closely with the HTC in managing skeletal disease resulting from repeated bleeding episodes
- **Physical therapists**—specialists in activity, exercise, and rehabilitation

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Who's Who at Your HTC (continued)

- **Social workers**—counseling specialists who help you with issues of daily living and with locating resources
- **Genetic counselors**—professionals who counsel families about carrier testing and prenatal diagnosis of genetic disorders such as hemophilia
- **Dentists**—some HTCs have dentists who are specially trained to treat people with bleeding disorders

To Locate an HTC Near You

1. Use the HTC locator at www.hemophiliavillage.com

Or

2. Contact HANDI, the informational branch of the National Hemophilia Foundation (NHF), at

800-42-HANDI
(800-424-2634)

by e-mail at

handi@hemophilia.org

or visit their Web site at

www.hemophilia.org

Or

3. Visit the Centers for Disease Control and Prevention Web site for a complete list of treatment centers at www.cdc.gov/ncbddd/hbd/htc_list.htm

hemophilia **village**

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Activities and Exercise: Tips on staying active and fit

HEMOPHILIA
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YOUR
COMMUNITY



RESOURCES
& SUPPORT
FOR YOU



PHONE
ON/OFF

1

ABC 2

GHI 4

JKL 5

PRS 7

TUV 8

*
TONE
PAUSE

OPEN

AUTO

LOC



Living With Hemophilia B

We have now discussed hemophilia B—how people acquire the disorder and how it is treated. There is still much to talk about, including the different types of bleeds a person with hemophilia B can experience and how to determine their severity. The level of severity depends on the **location** of the bleed in the body and the **cause** of the occurrence.

We will also talk a little about lifestyle and how hemophilia B impacts life stages from infancy into the teenage years. Hopefully, we can shed some light on what might be expected when living with hemophilia B.

Section 3

Hemophilia B: What to Expect

Living With Hemophilia B

Section 3

Hemophilia B: What to Expect

What Are the Signs and Symptoms of Hemophilia B?

An accurate diagnosis of hemophilia B is the first essential step to hemophilia B care.

Bleeding is the most common symptom of hemophilia B. When people with hemophilia B are injured, they do not bleed faster than a person without hemophilia B, just longer. They may also start bleeding again several days after an injury or surgery. For a person with hemophilia B, small cuts or surface bruises are usually not a problem, but deeper injuries may result in bleeding episodes that could cause serious problems and lead to permanent disability unless treated promptly.²³

The signs and symptoms of hemophilia B bleeding depend on where the bleeding is occurring. The signs and symptoms of these types of bleeds include:

- Pain
- Swelling
- Loss of range of motion
- Inability to move or use the affected arm or leg²³

There is usually no bruising or discoloration of the skin to indicate that the swelling and pain are due to bleeding.²³

Other signs and symptoms of hemophilia B include:

- Easy bruising; people may have many bruises of different sizes all over their bodies
- Prolonged nosebleed
- Vomiting of blood²³



In the majority of patients, hemophilia B is diagnosed at birth because of a family history. In approximately one third of patients, the occurrence of hemophilia B represents a new genetic event or mutation.²³

The usual initial signs and symptoms include easy bruising; oral bleeding, especially from a torn frenulum; hemarthrosis; and intramuscular hemorrhage. When hemophilia B is suspected on the basis of either clinical findings or a positive family history, initial diagnostic studies may be done to confirm the diagnosis.³

Hemorrhages or “bleeds” may be caused by injury or may occur spontaneously (without any apparent cause).⁵ Bleeds can begin in infancy, childhood, adolescence, or adulthood.⁴ Depending on the severity of the underlying bleeding disorder, bleeding episodes may be frequent to rare or only occur with surgery or other procedures.²⁴

It’s important that you learn to recognize the signs and symptoms of a bleed at the earliest possible time and treat appropriately.

Types of Bleeds

Bleeding episodes in hemophilia B that threaten life, limb, or function are:

Intracranial or Head Bleeds²⁵

A bleed into the brain is very serious. The signs and symptoms include headache, blurred vision, nausea or vomiting, mood or personality changes, drowsiness, loss of balance or coordination, weakness or clumsiness, stiffness of the neck, loss of consciousness, and seizures.

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R.I.C.E.

Bleeds in the muscles or soft tissues can be treated by using a form of first aid called **R.I.C.E.**

(**R**est [**R** can also mean **R**eplacement of clotting factor], **I**ce, **C**ompression, **E**levation).

During a bleed, the affected area should be **rested**—no walking if the bleed is in the knee, no lifting if the bleed is in the elbow. To lessen pain or swelling, apply **ice** to the affected area—10 to 15 minutes every 2 hours is recommended.

Applying pressure (**compression**) to the area can also help to slow the bleeding—such as using an elastic bandage. Always check with your local HTC for the proper way to apply the bandage. **Elevating** or raising the injured limb (arm or leg) above the heart will help to slow the bleeding.²⁵

It is always a good idea to check with an HCP if there are any questions about how to control a bleed.

For more details about appropriate activities, see the section “Complete List of NHF-Rated Sports and Activities” on page 51.

Nose, Mouth, and Throat Injuries²⁵

Injury or infection in the nose, mouth, or throat causes blood to fill the tissues. As the tissues swell with blood, they can press on the airway, making it smaller or closing it completely. It is important to watch out for pain in the neck or throat, swelling, difficulty swallowing, and difficulty breathing.

Joint Bleeds

Joint bleeds, also called hemarthroses, are one of the most common kinds of bleeding for a person with hemophilia.³ A joint bleed may begin with a warm, tingling,^{3,4,5} and/or bubbling feeling that is usually followed by pain, decreased movement, and swelling of the joint.^{3,4} Recurring bleeds in a joint can cause permanent damage by destroying the synovial membrane and the cartilage at the end of bones.³

Chest Injuries²⁵

Injury to the chest may cause bleeding in the lungs, heart, and major blood vessels. Bleeding in the lung tissues forces blood into the spaces that normally contain air, making it difficult to breathe. Signs and symptoms are pain in the chest and difficulty breathing.

Abdomen²⁵

Injury to the belly area, including the stomach, spleen, and intestines, could result in massive bleeding from an organ or major blood vessel. Pain in the abdomen or lower back, nausea, and/or vomiting are signs and symptoms to watch out for.

All of these bleeds require a call to your doctor, immediate intervention, or a trip to your local emergency room.



Additional Types of Bleeds

Please speak with a medical professional to learn when to seek medical care.

Urinary Tract Bleeds^{4,25}

About 66% to 90% of people with hemophilia B have bleeding in the urinary tract, also called hematuria, at least once in their lives. A symptom to watch for includes dark red urine.

Iliopsoas Bleeds⁴

Iliopsoas bleeds occur in the muscle of the pelvic area, near the hip. This type of bleed can damage the nerves of the thigh muscle, thereby limiting a person's movement. If an iliopsoas bleed is left untreated, it can cause heavy blood loss and permanent damage.

Compartment Bleeds

Compartments are closed-in spaces, such as in the forearm muscles. When a person bleeds deep inside these closed spaces, the blood settles in this area and puts pressure on the nerves and blood vessels within the muscle. If left untreated, compartment bleeds can cause permanent nerve damage and sometimes a loss of limb.⁴ Signs and symptoms to watch for include pain and tingling in the fingers or toes.²⁵

Bruising²⁵

Bruises are another common bleeding symptom in people with hemophilia B. Some bruises can be mild and heal on their own with ice, and others may not. Please seek medical attention for bruises that are very painful, grow larger over time, limit movement, or affect sensitive critical areas.

Mouth Bleeds

Mouth bleeds, such as those caused by biting the lip or tongue, a torn frenulum, new teeth coming in, or a dental procedure, are very common in people with hemophilia B.³ They can be very serious because persistent mouth bleeding can cause severe anemia.²⁵

Living With Hemophilia B

Preparing for Emergencies

It can be difficult for patients with hemophilia B to achieve and maintain a normal level of factor IX to prevent all potential hemorrhages. People with hemophilia B are at risk for severe bleeding that may lead to serious or life-threatening circumstances requiring emergency care.²⁶

People with hemophilia B, or parents of children with hemophilia B, are in the best position to manage their health or their child's health.

- Learn as much as possible about hemophilia B
- Learn what to do if a bleeding situation may be happening

Health care professionals in the emergency room (ER) will ask to be provided with information on the hemophilia B patient's past and current medical history. Be prepared to answer their questions.





Recognizing an Emergency Situation

There may be no visible signs or symptoms of bleeding in a person with hemophilia B, but bleeding issues, such as head injuries, muscle bleeds, and trauma can be serious. Emergency bleeding events require recognition and immediate intervention with factor replacement products to replace the missing factor IX in the blood and restore normal blood clotting.²⁷

The following situations typically require factor replacement therapy:

- **Any signs or symptoms of bleeding in the brain. Such bleeding is life threatening and requires immediate emergency care¹**
- Suspected bleeding into a muscle²⁸
- Significant injury to the head, neck, mouth, or eyes, or evidence of bleeding in those areas²⁸
- New or unusual headache, particularly one following trauma²⁸
- Severe pain or swelling at any site²⁸
- Open wounds requiring surgical closure, wound adhesive, or steri-strips²⁸
- History of an accident or a trauma that might result in internal bleeding²⁸
- Invasive procedure or surgery²⁸
- Heavy or persistent bleeding from any site²⁸
- Gastrointestinal bleeding²⁸
- Acute fractures, dislocations, and sprains²⁸
- Limited motion, pain, or swelling of any area¹

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Infusion Log

It's a good idea to keep a log of all previous treatments. Be sure to take this log to all medical appointments and to the hospital or ER.

See "Sample Daily Infusion Log" on page 27.

Important Points to Remember When Emergency Care Is Needed

- **Factor IX replacement therapy is used in patients with hemophilia B for acute bleeding episodes or presumed acute bleeding episodes**
- **Have an emergency dose of clotting factor concentrate in your home at all times**
 - Clotting factor concentrates might not be kept on hand at all hospitals. If you do not have factor with you, the ER personnel may have to identify another hospital to best deal with the emergency. This will increase the time it takes until treatment is provided
- **Take your factor IX with you when you travel and/or if you go to the ER**
 - The ER personnel may ask you if you have your own factor IX with you, and they may ask you to infuse the dose



What to Take When You Go to the Emergency Room

- Clotting factor IX and infusion supplies
- HCP's phone number in case the ER personnel need to speak to him or her
- Information about hemophilia B—the ER staff may have little experience with hemophilia B and may ask you about your or your child's treatment
- Your infusion log (if readily available)

You may also want to carry a letter from your or your child's HCP describing your or your child's hemophilia B and your or your child's treatment. It's also a good idea to find out in advance where to go for care when you're out of town.

Living With Hemophilia B

When Surgery Is Needed

The following issues should be considered²⁹:

- Surgical procedures should be performed in coordination with a team experienced in the management of hemophilia B
- Procedures should take place in a center with adequate laboratory support for reliable monitoring of clotting factor level
- Preoperative assessment should include inhibitor screening
- About 10% to 15% of hemophilia A patients and 1% to 3% of hemophilia B patients may develop persistent inhibitors rendering treatments with factor concentrates difficult
- Availability of sufficient quantities of clotting factor concentrates should be ensured before undertaking major surgery for hemophilia B
- The dosage and duration of clotting factor concentrate coverage depends on the type of surgery performed
- Surgery should be scheduled early in the week and early in the day for optimal laboratory and blood bank support, if needed

Clotting factor replacement is often given before, during, and after surgery to help prevent excessive bleeding. Please speak with your medical team before you undergo surgery and ask any questions you might have. It is important that your surgeon has experience in operating on people with bleeding disorders and that he or she understands your individual needs. Check with your local HTC for additional information.

Hemophilia B in Infants and Toddlers

Dental Hygiene

As a child ages, dental hygiene is very important. Mouth bleeds are still possible as children lose their baby teeth and adult teeth appear. Maintaining a clean, healthy mouth



is important to help prevent infection. It is also important to help prevent gum disease, which can also cause bleeding in the mouth.

All children should see the dentist for regular visits, especially those children with hemophilia B.³⁰ It is important for the dentist to be aware of a child's hemophilia B. The dentist should always check with the hemophilia team when planning any dental work. Prior treatment with factor may be needed.

Learning to Walk

Bleeding often becomes an issue when toddlers begin to stand and walk, putting weight on their legs for the very first time.^{4,31} During the time when children are learning to walk, they get plenty of bumps and bruises. However, a child with hemophilia B should be watched carefully to make sure these bumps and bruises are not serious. The following list offers some steps you can take to make sure your home is safe for a child.

- Place safety gates at the top and the bottom of all stairs³⁰
- Place padding on the corners of coffee tables, fireplaces, or other furniture³⁰
- Keep all sharp objects, such as knives and scissors, out of a child's reach³⁰
- Remove loose floor rugs that can cause a child to slip or trip³⁰
- Do not use a baby walker³⁰
- Cover all electrical outlets³²
- Keep guns, choking hazards, and toxic, hot, and sharp items out of reach³²
- Never leave young children unattended in a bath³²
- Install smoke detectors³²
- Install knob covers on doors to nonchild-proofed areas³²
- Don't put soft bedding or toys in cribs³²

Living With Hemophilia B

Talk to Your HCP About Pain or Anti-Inflammatory Medicines^{28,30}

When a child with hemophilia B has pain, it is important to follow the HCP's instructions for which medicines you can give to treat the pain. People with hemophilia B should not take Aspirin® (ASA or acetylsalicylic acid) or products that contain aspirin. These products cause the blood to thin and make it difficult for a clot to form—this promotes bleeding. Be sure to read all prescription and nonprescription labels before giving the child medicine. Some anti-inflammatory medicines such as ibuprofen, (Advil®, Motrin®), and naproxen (Aleve®) can also interfere with the clotting process. Make sure to check with your HCP to find out which products are safe for the child to take.

Babysitters

When you leave a child with hemophilia B with another person, or when the child plays with other children, make sure that the person in charge is aware of the child's bleeding disorder. More importantly, make sure that the person in charge knows what to do if the child should become injured. Ensure that this person has a general understanding of what hemophilia B is and the type(s) of bleeds the child may have. Write down all instructions you believe are important, and **advise the person NOT to give the child any prescription or nonprescription medications without your approval.** The instructions you leave may include:

- The signs and symptoms of a bleed
- The child's limitations—what the child can and cannot do
- Number(s) where you can be reached in case of an emergency
- Emergency contact names and phone numbers—your HCP and the local HTC



Hemophilia B in School-Age Children

As most parents know, sending a child off to school for the first time can be an emotional experience. This can be especially true for a parent of a child with hemophilia B. After carefully watching a child's every move for the first few years of life, you must now entrust this care to someone else.

Helping School Staff to Understand

To ease this transition, you should speak with people who will be caring for the child at school.³³ Introduce yourself to the school principal, the teachers, and the school nurse. Provide them with all the facts about the child's hemophilia B.³³ Because many people are not familiar with hemophilia B, you may find yourself having to educate them. Reassure them that hemophilia B is not contagious. It may be helpful to arrange a meeting between the school staff and a member from the local HTC.



Things to Make the School Aware of³³:

- Any physical restrictions or limitations a child may have
- A child's medications and how they are used
- Signs and symptoms of a bleed and how to treat it
- Names and phone numbers for emergency contacts, such as your HCP and local HTC
- Where you can be reached during the day

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Social Reassurance

No child wants to stand out as different or needy among his peers. To help the school understand the child's bleeding disorder and his or her potential needs, explain to staff that being overprotective is not necessary. Let the school know the activities the child may take part in and if there are special needs, discuss how to handle them in a less-noticeable manner.

Need More Info?

The National Hemophilia Foundation (NHF) has information to educate school staff members about hemophilia B. To obtain free HANDI publications, contact the NHF at 800-42-HANDI or go online to www.hemophilia.org. You can also look for educational publications at your local HTC.

If a child should have a bleed while at school, advise the staff ahead of time that the bleed will need to be treated immediately. A child with hemophilia B who is injured should always be given prompt attention, and the staff must contact you right away. You may have to go to the school to give your child an infusion.

If you are still feeling uneasy about your child attending school, it may help you to speak with other parents in your area who have children with hemophilia B. Discussing your feelings and these issues with other people in a similar situation might help you to feel more confident. Support groups with parents of children with hemophilia B can be found at your HTC.



Hemophilia B in the Preteen Years

As children move from childhood to preadolescence they face new challenges, including heightened peer acceptance. Preteens with hemophilia B need to be reminded that having hemophilia B does not determine who they are or what they will become. Instead of focusing on what they cannot do, they need to learn to focus on their strengths and abilities. It is important for them to become involved with hobbies and activities, such as art or music.

By the time children become preteens, they are generally capable of thinking logically and seeing the cause and effect of situations. They will be able to report when they have a bleed. They will begin to understand that certain activities are more likely to cause bleeds than others, and they can be encouraged to be cautious about those activities.

During this age, children are aware of adult feelings. If you react to their bleeds with anger, fear, and frustration, they may try to “protect” you by not telling you about a bleed until the pain becomes hard to bear.

Parents should respond to bleeds in a matter-of-fact, reassuring way. For example, you may say, “I’m sorry you’re hurt, and I’m glad you told me you had a bleed. Let’s get your treatment started so you can feel better soon.”

Parents of preteens often find it difficult to set limits for the child’s activities. Permissive parents may feel sorry for their child and try to “make it up to him” by not setting appropriate boundaries. Overprotective parents may set too many limits and monitor their child’s every move in an effort to keep him safe.

Preteens need both clear and consistent rules and the freedom to develop their own interests and abilities. For example, by establishing the rule “no hitting” between your child and his playmates, difficulties may be avoided later. As long as no one is hitting, try to avoid jumping in to settle every argument that arises. Let the child learn different ways to resolve conflict.³⁴

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Hemophilia B in the Teenage Years

The transition from preteen to teenager can be a challenging time for parents and for their children. A teenage child may want more freedom and independence, more privacy, and may not talk as openly as they once did. It may be harder to keep the lines of communication open.

By the time preteens become teenagers, they may know as much about hemophilia B as the parent. If the teen is self-infusing, he is already beginning to manage his own treatment. He may ask to visit his HCP on his own and speak privately with his medical team.

The teenage years represent transitional times for adolescents; they are trying to figure out who they are and what they want to do with their lives. A teenager may have friends that think his factor treatment is different and poke fun at him because he doesn't participate in all of their activities.

During this time, it's important for parents to be sympathetic and become sensitive listeners. If a parent notices a serious emotional problem, professional counseling may be necessary. Parents may find it helpful to speak to friends, social workers at an HTC, or the teen's physician about a referral to an appropriate counselor.

Most adolescents go through a stage where they want to experience risky behavior because they feel nothing can happen to them. When parents notice this type of behavior with teens, it can be a good opportunity to discuss future goals and how current choices may interfere with reaching those goals. Challenges arise during the teenage years, and parents should take this opportunity to try and work together with the teen to arrive at alternative solutions and compromises. If this does not work, parents may have to set clear limits and consequences that they can enforce with their teenager.³⁴

Transitioning From Adolescence to Adulthood

Health Costs

The economic issues of the high costs of managing hemophilia B over a lifetime necessitate that every young adult with hemophilia B learn certain financial basics—budgeting, applying for medical insurance, and handling insurance claims and coverage. At what age will they no longer be covered under your insurance? What type of insurance will they be able to obtain when they must look for coverage on their own? Before accepting a job, they must review the insurance offered to make sure that their hemophilia B treatment will be covered.

Good Nutrition

Young adults on their own must learn how to cook healthy foods for themselves. People with hemophilia B need to maintain a healthy diet to ensure total wellness.



Living With Hemophilia B

Mental and Physical Health

Helping Your Child's Confidence

Many children have self-esteem issues at some point in their lives. These feelings can stem from not liking things about themselves, such as their body or their personality. They may lack confidence in their own ability to do anything. Self-esteem issues can be caused by a feeling of not fitting in with their peers. These types of feelings become magnified when children have hemophilia B because they may feel that the hemophilia B makes them very different from other children. They may even blame themselves for having hemophilia B, causing additional negative feelings to develop.

You can help your child with these self-esteem issues by speaking with him on a regular basis and becoming a source of support and comfort. When children feel good about themselves, they have an easier time handling pressure and conflicts in their lives.

Staying Fit

Maintaining physical activity is important for all children. It is especially important for children with hemophilia B because building strong muscles can help protect joints from bleeds.³⁵ Exercise helps to build strength and flexibility, both of which aid in preventing injuries. It is also good for the mind and assists in building a child's confidence. Taking part in sports can teach teamwork and develop self-esteem. Exercise develops healthy lifestyle habits that can be carried through a person's life. There are limitations, however, because some activities might be risky to a person with hemophilia B.³⁶ **It's important to consult an HCP before participating in any sports activity.**





Complete List of NHF-Rated Sports and Activities

Activities have been divided into five ratings based on a scale from 1 to 3³⁶:

Safe (1)

aquatics	hiking
archery	snorkeling
elliptical machine	stationary bike
fishing	swimming
Frisbee® disc tossing	tai chi
golf	walking

Safe – Moderate (1.5)

biking	ski machine
body sculpting	spinning
circuit training	treadmill
Frisbee® disc golf	weight lifting/ resistance training
pilates	
rowing machine	

Moderate (2)

aerobics	rowing/crew
bowling	running/jogging
cardio kickboxing	skiing (cross-country)
dance	stepper
diving (recreational)	T-ball
jumping rope	tennis
rock climbing (indoor)	ultimate Frisbee®
roller skating	yoga

Moderate – Dangerous (2.5)

baseball	scooter (nonmotorized)
basketball	scuba diving
canoeing	skateboarding
cheerleading	skiing (downhill)
gymnastics	skiing (telemark)
horseback riding	snowboarding
ice skating	soccer
in-line skating	softball
jet skiing	surfing
karate	tae kwon do
kayaking	track and field
kung fu	volleyball
mountain biking	waterskiing
racquetball	
river rafting	

Dangerous (3)

BMX racing	rodeo
boxing	rugby
diving (competitive)	scooter (motorized)
football	snowmobiling
hockey (field, ice, street)	trampoline
lacrosse	weight lifting/ power lifting
motor cross racing	wrestling
motorcycling	
rock climbing (outdoor)	

The National Hemophilia Foundation does not recommend any sports activities rated 3 for people with bleeding disorders.

Activities rated 1 to 2 indicate the benefits outweigh the associated risks.

Frisbee is a registered trademark of Wham-O, Inc.

Living With Hemophilia B

Exercising Is Important at Any Age

Exercising is important for anyone with hemophilia B. It can help increase muscle strength, joint mobility, balance, coordination, and flexibility—all important to help protect the body from injuries.³⁵ Any exercise routine should always begin with stretching. This will help prepare the muscles and prevent them from being injured during the workout.³⁵

In addition to the physical benefits, there are psychological and social benefits from exercise, such as increased relaxation, improved self-esteem, self-image, and mood, and an increase in feelings of acceptance and belonging to a group of peers.³⁵

Talk with the physical therapist at your local HTC about an exercise program that meets your or the child's needs. With a graduated exercise program, most of the chronic postural changes that occur in people with hemophilia B can be avoided. By maintaining mobile joints and strong, flexible muscles, all people with hemophilia B should be able to continue with regular daily activities at home, school, and work.³⁷

Take it Easy

The most important thing you can do for a child when he or she plays sports or exercises is to teach them to be aware of their limitations. Teach them to listen to their bodies and stop if they get tired or do not feel right.

Eating Right

Part of staying fit includes eating right—eating a well-balanced diet that includes plenty of fresh fruits and vegetables. Check with your local HTC for more information about nutrition. Maintaining a healthy weight is important for anyone with hemophilia B, not just children. Being overweight can put additional pressure and stress on joints, such as knees and ankles. The additional pressure and stress can cause damage to the padding between the joints, or cartilage. Over time, a person can develop a painful, mobility-limiting joint condition called arthritis.



Eating right can also help prevent diabetes and heart disease—health problems that can put added stress on the body and complicate a person’s overall condition.

For additional information about nutrition, visit www.health.gov/dietaryguidelines.

Conclusion

People living with hemophilia B can have a bright and promising future. Science and technology have made great strides over the years in improving hemophilia B treatment. The combinations of factor therapy, comprehensive care, and support resources like HTC, allow many families with hemophilia B to lead active lives.

We hope you were able to benefit from the information and advice provided in this book. Understandably, you may have many more questions about hemophilia B and other topics discussed in this book. There are numerous resources and support services available that can help you sort through the details. You should take advantage of every opportunity to become more knowledgeable about hemophilia B.

Living With Hemophilia B

Pfizer Programs and Services

Pfizer Hemophilia Hotline

This hotline answers questions about Pfizer’s products and services: 888-999-2349.

Pfizer RSVP Program

RSVP—the Reimbursement Solutions, Verification, and Payment HELPLine—is a reimbursement support service and patient assistance program designed to help patients gain access to the Pfizer medicines they need: 888-327-RSVP (7787).

Summer Camp Support

Pfizer sponsors camp information conferences, provides financial assistance for scholarships to camp, and donates emergency factor for campers. We know how important it is for children with hemophilia to make new friends and enjoy themselves with people who understand their disorder.

Soozie Courter “Sharing a Brighter Tomorrow” Hemophilia Scholarship Program

Pfizer provides scholarships to students with hemophilia A or hemophilia B who are high school seniors, have a graduate equivalency diploma (GED), or are currently enrolled in an accredited junior college, college (undergraduate or graduate), or vocational school. Awards are based on academics, recommendations, and a personal statement from the student. Visit www.hemophiliavillage.com to download an application.

Hemophiliavillage.com

The Pfizer-sponsored Web site, www.hemophiliavillage.com, provides information for the hemophilia community. Consumers and professionals alike can find product information and learn about programs and services.

World Federation of Hemophilia (WFH) Twinning Program

Pfizer Inc is an exclusive sponsor of this program, which links hemophilia treatment centers (HTCs) in developed countries, such as the United States, with countries that have limited medical resources. The goal of the program is to help improve hemophilia care worldwide. For more information about this program, call 514-875-7944, or visit the Web site at www.wfh.org.



Resources

Arizona Hemophilia Association
North American Camping Conference
of Hemophilia Organizations (NACCHO)
Phone: 888-754-7017
Web site: www.naccho.com

Canadian Hemophilia Society
Phone: 800-668-2686
Web site: www.hemophilia.ca

Centers for Disease Control
and Prevention (CDC)
Hemophilia Treatment Centers
Web site:
www.cdc.gov/ncbddd/hemophilia/HTC.html

The Coalition for Hemophilia B, Inc.
Phone: 212-520-8272
Web site: www.coalitionforhemophiliab.org

Hemophilia Federation of America (HFA)
Phone: 800-230-9797
Web site: www.hemophiliafed.org

National Heart Lung and Blood
Institute (NHLBI)
Phone: 301-592-8573
Web site: www.nhlbi.nih.gov

National Hemophilia Foundation (NHF)
Phone: 800-424-2634 (42-HANDI)
Web site: www.hemophilia.org

Patient Services Inc. (PSI)
Phone: 800-366-7741
Web site: www.patientservicesinc.org

World Federation of Hemophilia (WFH)
Phone: 514-875-7944
Web site: www.wfh.org

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NOTES:

Cut along the dotted lines to remove this wallet HTC information card.

HTC Information	
Name	_____
Address	_____
Phone #	_____
HCP/Nurse Contact	_____
Hours	_____



Cut along the dotted lines to remove this Daily Infusion Log.

Daily Infusion Log

Date _____

Time _____

Product _____

Place stickers here



Total # units _____

Reason for Infusion

_____ Prevention Activity/Event _____

_____ Bleed/Injury Location _____

_____ Bleeding Symptom(s) _____

_____ Follow-up Scheduled _____

NOTES _____

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