
B2B
Speaking From Experience
NAVIGATING
THE PRETEEN
YEARS

Foreword

People with bleeding disorders often develop special bonds with each other through their disease. This may be especially true in the hemophilia B community because it includes a small population as disease states go. The hemophilia B community is a family and, as such, the members support each other through shared experiences—happy and not so happy. In spite of this closeness, however, many people in the community feel there is a need for more information and support for those with hemophilia B.

The B2B (hemophilia B patient to hemophilia B patient) program began in 2005 as a way to empower individuals with hemophilia B through peer support and education. The objective of the program remains to address the challenges of having hemophilia B, especially those found when transitioning from one life stage to another. Another goal of the B2B program is to help strengthen the internal support system and educational network within the hemophilia B community. The B2B program is a sharing of firsthand accounts about everyday life from those living with hemophilia B.

The two previous B2B books, *Young Adults and Hemophilia B* and *Learn From Experience: A Guide for Mature Adults,* presented peer-to-peer life experiences from young adults with hemophilia B and from mature adults with hemophilia B respectively. This third book, *Navigating the Preteen Years*, provides parents and caregivers of preteens with hemophilia B a heads-up about the future from parents and caregivers who have raised preteens with hemophilia B.

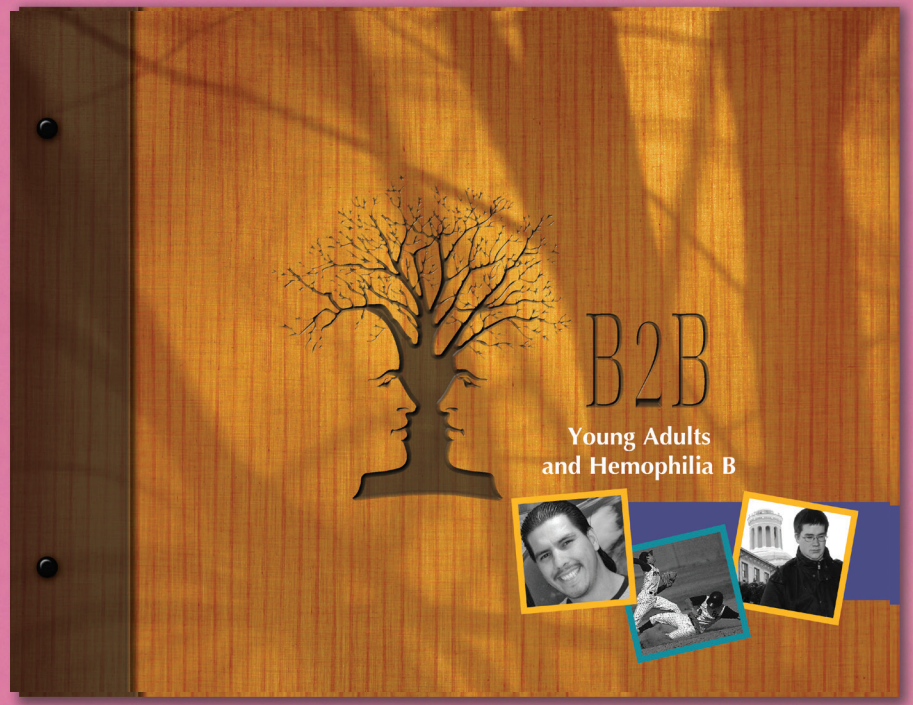
On behalf of Pfizer Inc, The Coalition for Hemophilia B, Inc., and the B2B Advisory Board, we would like to extend our gratitude to the members of the hemophilia B community who contributed to this book. Your time, knowledge, and personal stories about life with hemophilia B are greatly appreciated: Chris Blair, Nina Duggan, Ron Ricchiuto, and Maria Vetter.

We would also like to thank the professionals involved with hemophilia care who shared their insights about hemophilia B:
Alcuin Johnson, PhD, and Thomas Truncale, DO, MPH.

The narratives and statements from health care professionals in this book were provided prior to its initial publication in 2010.

The views and opinions expressed in this book are those of patients, parents, and hemophilia care specialists who are members of an advisory board within the hemophilia B community and not of Pfizer.

The information in this booklet should in no way replace the advice of your health care professional. Be sure to talk with your doctor, nurse, or hemophilia treatment center (HTC) staff regarding any form of medical advice or treatment.


B2B
Young Adults
and Hemophilia B


B2B
Learn From
Experience
A Guide for Mature Adults

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Introduction

The preteen years are an in-between time of life often called the "tweens." These can be the years sometimes overlooked by parents and experts alike because they fall between two very busy and exciting stages of life—early childhood and the teenage years. However, the preteen years are very important developmental years when changes that affect sense of self, family, and peer relationships are taking place. It is a time of extremes, emotional fluctuations, and anticipation. It is a time when support and understanding from parents are desperately needed as preadolescent children work to find their way through a maze of questions and uncertainty. The good news is that preteens will emerge on the other side as full-fledged adolescents on the edge of adulthood. How children manage the maze of the tween years often predicts how they will handle themselves emotionally and academically in the future.

Added to the normal stress of preteen life for parents, as well as the preteen child, is the difficulty of living with a chronic condition such as hemophilia B. Parents of a tween with hemophilia B may find it tricky to manage their child's new behavioral challenges and self-image issues. For the family of a child with hemophilia B and the child himself, the added challenges of disease acceptance and management can create anxiety. Thankfully, guidance and support are available from medical professionals and other families with like situations.

The objectives of this book are to:

- Provide an overview of hemophilia B, including treatment issues and parenting situations that may arise during the preteen years
- Offer recommendations from B2B Advisory Board members and medical experts for meeting the challenges of everyday living
- Suggest resources for parents of preteens with hemophilia B to help them manage specific psychosocial and/or treatment issues that may arise during this time

Section One

What Is Hemophilia?

Hemophilia is a congenital bleeding disorder. About 20,000 people in the United States have hemophilia. Each year, another 400 babies are born with the disorder.[1] Hemophilia usually manifests only in males; however, there are exceptions.[2]

The term bleeding disorder refers to a wide range of medical conditions that lead to poor blood clotting and continuous bleeding. You may hear them referred to as coagulopathies or clotting disorders. A person with a bleeding disorder tends to bleed for a longer period of time following an injury to a blood vessel than someone who does not have a bleeding disorder.

People with hemophilia do not have enough clotting factor VIII or IX in their blood; sometimes, they do not have any. Clotting factor works together with other proteins and platelets to help blood clot. Platelets are small blood cells that are formed in the bone marrow. When blood vessels are injured, clotting factors help the platelets stick together to plug cuts and breaks at the site of the injury to stop the bleeding. Without clotting factors, normal blood clotting cannot take place.

There are two main varieties of hemophilia:

- Hemophilia A—the most common type of hemophilia
  - The body has little or no clotting factor VIII[2]
  - Hemophilia A affects 1 in 5,000 to 10,000 males[2]
- Hemophilia B—the second most common type of hemophilia, is also known as factor IX deficiency, or Christmas disease[1]
  - The body has little or no clotting factor IX[2]
  - Hemophilia B occurs in about 1 in 25,000 male births[2]

Hemophilia can range from mild to severe.

- People with mild hemophilia (5% to 40% factor level), about 25% of the hemophilia B population, usually have problems with bleeding only after serious injury, trauma, or surgery. In many cases, mild hemophilia is not discovered until an injury, surgery, or tooth extraction results in unusual bleeding. The first episode may not occur until adulthood[3]
- People with moderate hemophilia (1% to 5% factor level[4]), about 15% of the hemophilia B population, tend to have bleeding episodes after injuries. They may also experience occasional bleeding episodes without obvious cause. These are called "spontaneous bleeding episodes"[3]
- People with severe hemophilia (less than 1% factor level[3]), about 60% of the hemophilia B population, have bleeding following an injury and may have frequent spontaneous bleeding episodes, often into the joints and muscles[4]

People with normal blood have factor IX levels between 50% and 150%.[3]

Table 1. Levels of Factor IX in the Blood of Normal People and People with Hemophilia of Different Severities[5]

Severity	Levels of Factor IX in the blood
Normal (person who does not have hemophilia)	50% to 100%
Mild hemophilia	5% to 40%
Moderate hemophilia	1% to 5%
Severe hemophilia	Less than 1%

Severe hemophilia causes severe bleeding throughout life, usually beginning soon after birth. In some babies, hemophilia is suspected with the appearance of a scalp hematoma after delivery or when a routine circumcision (removal of the foreskin of the penis) results in excessive bleeding.[6] Toddlers are at particular risk because they fall frequently and may bleed into the soft tissue of their arms and legs. These small bleeds result in bruising and noticeable lumps, but do not usually require treatment. As a child becomes more active, bleeding may occur into the muscles, a much more painful and debilitating situation.[7]

The age when hemophilia B is first diagnosed in a child who does not have a family history of the disorder, as well as the frequency of bleeding episodes the child experiences, are generally related to the factor IX clotting activity. In any affected individual, bleeding episodes may be more frequent in childhood and adolescence than in adulthood. This greater frequency is a function of both physical activity levels and vulnerability during periods of more rapid growth.[4]

There are several important considerations when caring for a person who has hemophilia B. Prevention of bleeding episodes should be a primary goal. The second goal involves treating bleeding episodes early and aggressively. Additionally, supportive and adjunctive measures for each bleeding episode in the context of a multidisciplinary team approach should be used.[8]

Standard treatment is infusion of factor IX concentrates to replace the defective clotting factor. The amount infused depends upon the severity of bleeding, the site of the bleeding, and the weight and height of the patient.[9]

Following an infusion, the doctor may perform a blood test to measure the level of circulating factor IX activity in a patient's blood, also called recovery. Knowing this important recovery value helps the doctor figure out the proper dose of factor needed.

Factor IX recovery varies for each individual.[10]

What Are the Symptoms of Hemophilia B?

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

Bleeding is the most common symptom of hemophilia B, especially into the joints and muscles. For a child 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.[11]

The symptoms of hemophilia B bleeding depend on where the bleeding is occurring. Young infants may have bleeding from their mouth when they are cutting teeth or if they bite their tongue or tear tissue in their mouth.[11]

Toddlers and older children commonly have bleeding into their muscles and joints. The symptoms of these types of bleeds include[11]:

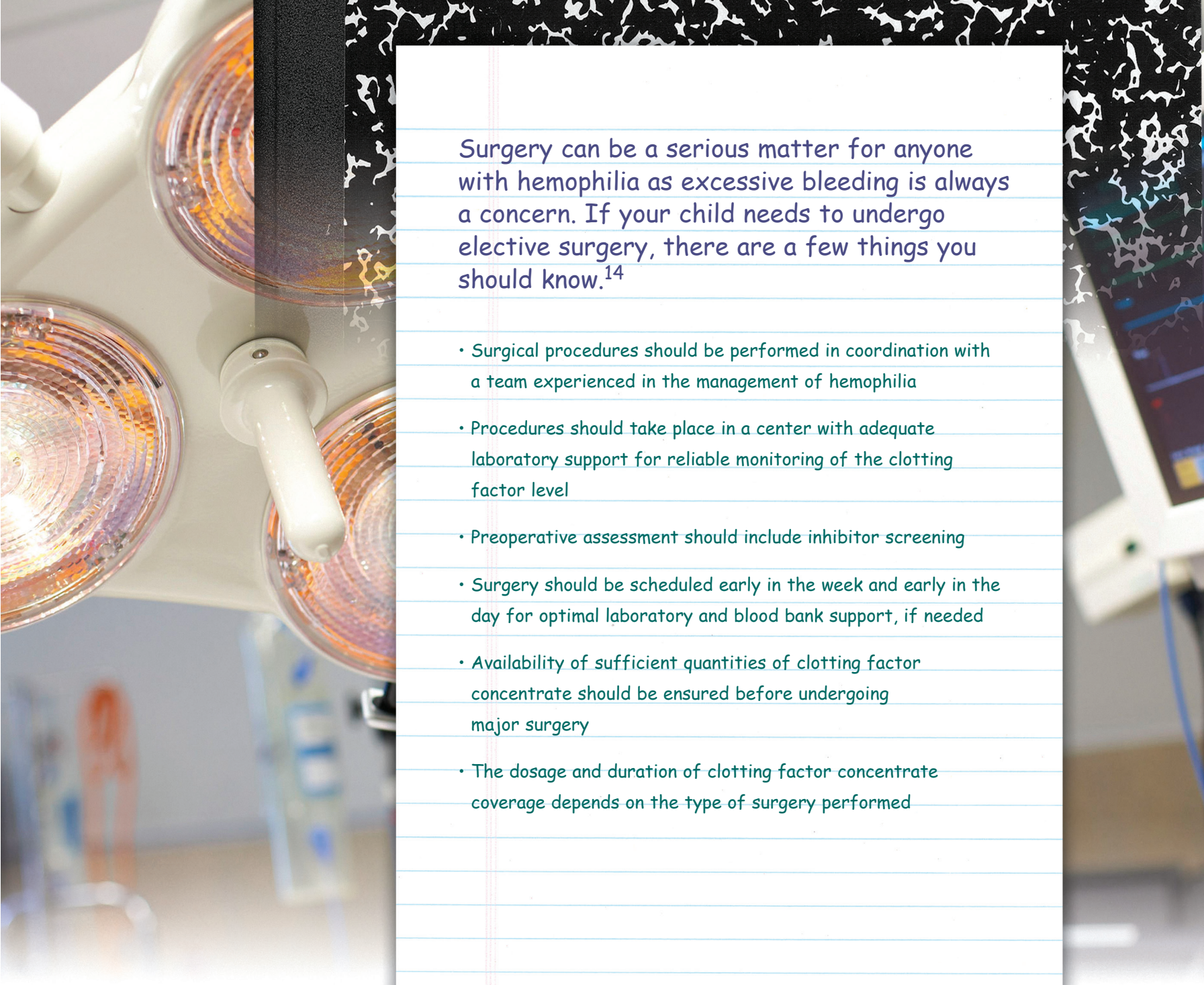
- Pain
- Swelling
- Loss of range of motion
- Inability to move or use the affected arm or leg

In joint bleeds, there is usually no bruising or discoloration of the skin to indicate that the swelling and pain are due to bleeding.[11]

Repeated bleeding into joints is a cause of disability in people with hemophilia. About 90% of all bleeding in individuals with severe hemophilia B occurs in the joints. Repeated bleeding into the same joint results in progressive damage and development of a condition called hemophilic arthropathy that can eventually lead to arthritis.[12]

When there is bleeding into a joint, the blood is gradually resorbed and significant permanent damage is unlikely. If this occurs repeatedly, materials contained in red blood cells (iron and other substances) begin to accumulate in the joint. These materials cause long-lasting inflammation and changes in the structure of the joint, such as loss of cartilage. Repeated bleeding into a joint may also decrease the activity of cells that form new bone, a process that normally occurs throughout life and keeps joints healthy.[12]

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 represents a new genetic event or mutation.[11] When hemophilia B is suspected on the basis of either clinical findings or a positive family history, diagnostic studies may be done to confirm the diagnosis.[13]



Surgery can be a serious matter for anyone with hemophilia as excessive bleeding is always a concern. If your child needs to undergo elective surgery, there are a few things you should know.[14]

- Surgical procedures should be performed in coordination with a team experienced in the management of hemophilia
- Procedures should take place in a center with adequate laboratory support for reliable monitoring of the clotting factor level
- Preoperative assessment should include inhibitor screening
- Surgery should be scheduled early in the week and early in the day for optimal laboratory and blood bank support, if needed
- Availability of sufficient quantities of clotting factor concentrate should be ensured before undergoing major surgery
- The dosage and duration of clotting factor concentrate coverage depends on the type of surgery performed

Inhibitors - A Special Problem in Hemophilia

It is possible that after a few treatments, the factor IX concentrate used to control bleeding may no longer be effective. This occurs in about 3% of all patients with hemophilia B and is due to the development of molecules called inhibitors. In a small number of people with hemophilia B, the immune system mistakenly identifies replacement factor IX as a molecule against which it should make antibodies.[16] In some instances, these antibodies block the activity of factor IX concentrate, and it loses its effectiveness for stopping bleeds.[17]

MASAC RECOMMENDATIONS[15]

In 1954, the National Hemophilia Foundation (NHF) formed a medical advisory council comprising scientists, physicians, and other treatment professionals who are regarded as experts in the field of bleeding disorders to advance clinical care and promote hemophilia research. This group is now known as the Medical and Scientific Advisory Council (MASAC), and it establishes the quality-of-care guidelines for the treatment of hemophilia. The recommendations issued by MASAC are guidelines that are intended to set the standard of care and are referred to by physicians, medical schools, pharmacists, emergency room personnel, insurance companies, and others.

Building a Glossary

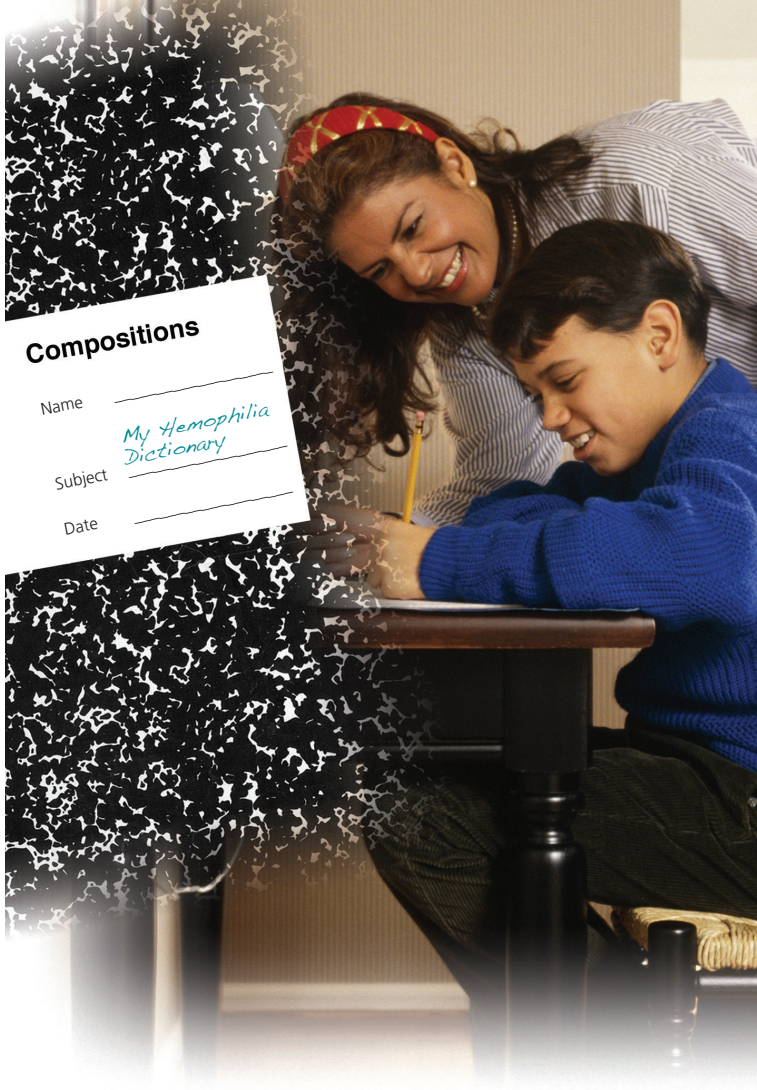
There are many terms that your doctor or other medical professionals will use when they discuss hemophilia B with you and your child. To help you and your child communicate about hemophilia B and understand and use the words that relate to the disorder, consider developing a glossary together. This is a project that will take time and can easily become a weekly event for your family and your child.

Purchase a notebook and give it to your child with the title, "My Hemophilia Dictionary." (If your child uses a computer, open a new file with this name.)

Pick a day during the week when the family is usually together, such as Monday evening before dinner, and add one new word on this same day each week. Begin by asking your child what new word he heard when talking about hemophilia during the week. You may want to suggest the first word: hemophilia.

If you look up this word (hemophilia) in the dictionary, you will find the following: "Any of several X-linked genetic disorders, symptomatic chiefly in males, in which excessive bleeding occurs from minor injuries owing to the absence or abnormality of a clotting factor in the blood."[18] You will probably want to simplify this definition with phrasing such as, "Hemophilia is a bleeding disorder in which the blood is missing something that helps a person stop bleeding when a cut or an injury happens." You may come up with something better, but this is the idea.

Shore up this activity by reviewing the words in the book each month—almost like a test, but not a test. There may be times you will find a picture to put next to the word to help your child better understand the meaning.



Section Two

How Did My Child Get Hemophilia B?

Why Me?

It is often difficult to understand how your child can have hemophilia B when you, the parent, do not have hemophilia B. However, you have probably been told that you are the carrier of the disorder.

Hemophilia B is a sex-linked disease passed on from a female to her male offspring. As previously discussed, hemophilia B is caused by a deficiency in factor IX, resulting from a genetic defect in the FIX gene, which is carried on the X chromosome.

We each have two chromosomes determining our sex: females have two X chromosomes, and males have an X chromosome and a Y chromosome. A female child always receives two X chromosomes; if she receives one abnormal X chromosome (that is to say, an X chromosome that has an abnormal FIX gene), she will usually still be capable of producing a sufficient quantity of factor IX. A person who has one abnormal chromosome but does not have any bleeding manifestations is called an asymptomatic carrier. If, however, she has a son who receives her abnormal X chromosome, he will be unable to produce the right quantity of factor IX, and he will suffer some degree of hemophilia. In rare cases, a father with hemophilia and a carrier mother can pass on the right combination of chromosomes that result in a female child with hemophilia.[19] Carrier females with factor IX clotting activity lower than 30% are at risk for bleeding that is usually comparable to that seen in males with mild hemophilia. However, subtler abnormal bleeding may occur with baseline factor IX clotting activities between 30% and 60%.[4] Please see Figures 1 and 2 on page 15.

Figure 1 Figure 2

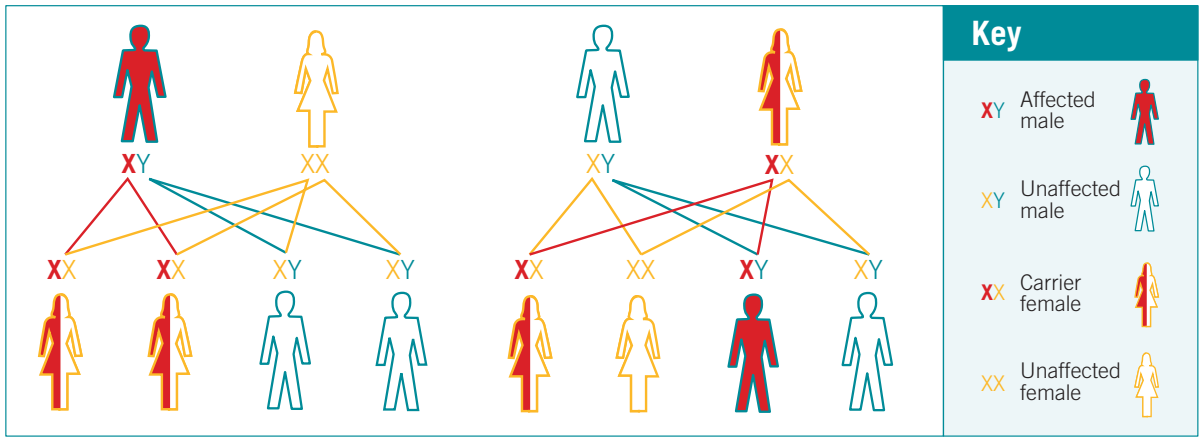


Figure 1 A father with hemophilia will pass the defective gene to his daughters, making them carriers. His sons, however, will not be affected because they get their X chromosome from their unaffected mother.[19]

Figure 2 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.[19]

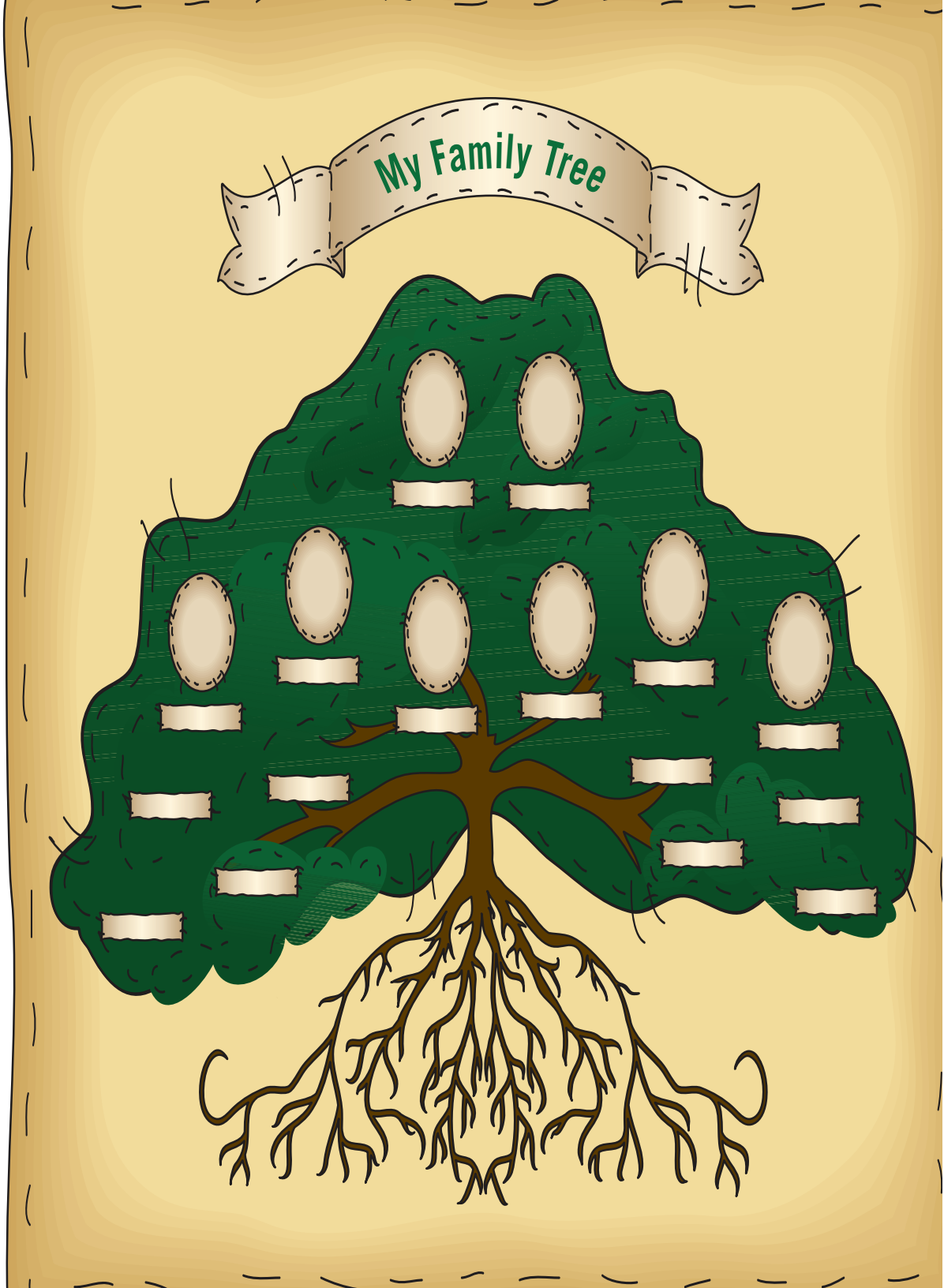
About one-third of all people with hemophilia B are the first member of their family in whom the disease has been detected, resulting from a spontaneous change in the FIX gene that occurs for unknown reasons.[20] Once such a spontaneous change takes place, children of the affected person can inherit the abnormal gene.

Creating a Family Tree

Prepare a family tree poster that you and your child can continually update together. Refer to the figure to the right to see an example of a chart you may want to use on the poster. When you create the family tree poster, help your child add names to the figures, as well as family photographs. This activity can provide an opportunity for you to speak with your child about how creating a family tree can help us to understand where we come from and how genes determine our traits. The chart can offer a way for you to explain how males and females differ in their ability to pass on or get hemophilia B. It may be interesting to see how far back you can trace your family on both sides.

Purchase a large piece of foam board and add the title "My Family Tree" before you give it to your child to begin the activity. (This can be done as a wall chart for younger children and as a computer chart for older children).

Once finished, the family tree can make a wonderful gift for your child to present to other family members.



Section Three

Family Issues in the Preteen Years

This section summarizes the interviews and meetings with members of the B2B Advisory Board about their experiences parenting a preteen with hemophilia B.

As parents of a preteen with hemophilia B, you understandably have many concerns as you prepare your child for a life with hemophilia. The preteen years are a rite of passage as he or she now spends many hours a day away from the family attending school and experiencing additional social influences. Your preteen may be exposed to increased peer pressure to engage in risky behavior and/or forego treatment because of not wanting to appear different from his peers. This phase signifies the time of life when your child begins to separate from your ideas and opinions in order to form his own ideas and opinions. Open communications between you and your child are essential during the preteen stage.

The passage from childhood to the preteen years may raise important psychological and social issues that should be addressed. During this period, young people experience a great transformation, and understanding who they are can be very challenging.[21] During adolescence, the young person's focus shifts away from the family and toward peers. Acceptance by peers who are not affected by hemophilia becomes very important.[22]

Self-perception is very important and preteens with hemophilia B may feel different and alone. These feelings may be exacerbated by missing school, sports, and travel as a result of bleeding or medical appointments.[21]

All of these factors may result in disengagement from the disorder and development of a "don't care" attitude. It's also important to remember that young boys may feel invulnerable, and they may not want to discuss their disorder.[21]

Be a great listener. Be all ears when your child wants to talk about things he enjoys. These probably represent things he excels in or for which he has a great love. He may also talk about issues that are arising that are not so enjoyable. During the preteen stage, peer identity—fitting in with peers and not appearing different from others or being excluded from social groups—becomes very important.

Ask questions. Whenever possible, ask open-ended questions that stimulate conversation. Questions that cannot be answered with a "yes" or a "no" can help to foster good communication between you and your child, and you may pick up on problems or difficulties your child is having. Disappointment and self-consciousness begin to show up during this time. Try creating opportunities for family and social interactions to help build your child's self-confidence and create a sense of belonging.

Physical or functional limitations can make young children feel shy and embarrassed or cause them to be teased by others. Children cannot always avoid meeting people who tease or bully, but they can be taught how to respond to provocation and not be afraid or intimidated by the bully. However, it is important that they learn how to be firm about not getting into physical fights. It is critical that children with hemophilia B learn how to take care of themselves and not put themselves at risk for bleeds.[23] Help your child learn to take responsibility for his health and avoid dangerous situations and risks.

When Dealing With Family Issues

- Be aware that your child's response to a situation may reflect your response. Keep in mind that coaches, teachers, and other caretakers will also be watching your reaction

- Offer age-appropriate information about bleeding disorders to members of your family. Ongoing communication about a child's disorder can help others to understand hemophilia B

- Listen to your children and encourage them to express their feelings about hemophilia B, even if the feelings are negative

- Reassure your nonaffected children that they are not at fault for their sibling's medical condition

- Explain to your children that hemophilia B is not contagious. This is a good time to discuss the genetic component of the disorder

- Consider involving all siblings in the medical process when a child with hemophilia B is being treated

- Ensure that a support system is in place so that plans for siblings are not often disrupted by the needs of the child with hemophilia B

- Schedule one-on-one time with each child. Let all of your children know that you love and appreciate them and value their opinions. Discuss with each of them why a bleeding disorder must sometimes receive more attention

- Join a support group to discuss your own feelings

- Locate peer support groups for your children

- Encourage all of the siblings to attend hemophilia camp if siblings are allowed

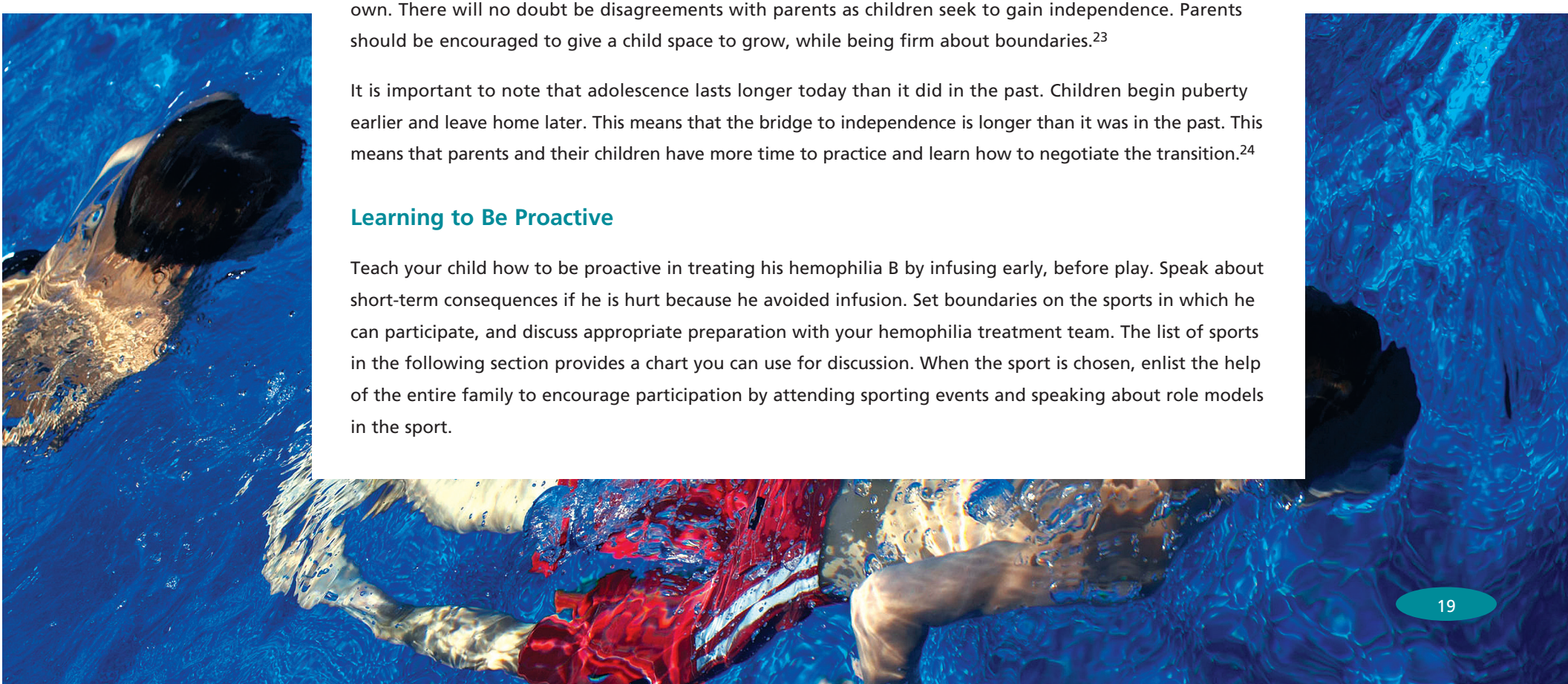
- Empower your family members to be self-sufficient and self-reliant

Adolescents have the job of crossing the bridge from childhood to adulthood and parents have the role to decide when limits or boundaries are necessary. Many new experiences must occur for the adolescent to cross that bridge.[24] The preteen stage is the time for your child to begin becoming an independent person. However, although preteens are becoming more self-aware, they need more guidance from their parents. How a child moves through the tweens often predicts how he handles himself academically and emotionally in the future. Preteens do not yet have a lot of life experience, and although they begin trying to negotiate and stand on their own, it is important that parents set limits. Preadolescents do not yet handle their impulses and desires maturely.[23] They are still learning how to make responsible decisions, such as proactively treating their hemophilia B before playing sports, or even choosing the correct sport for that matter. Although your child may want very much to participate in a sport with his friend, as the parent, you may have to tell him "no" because it is too dangerous for a person with hemophilia B. Guiding your child through these decisions can help to prepare him for the future and the many decisions he will have to make on his own. There will no doubt be disagreements with parents as children seek to gain independence. Parents should be encouraged to give a child space to grow, while being firm about boundaries.[23]

It is important to note that adolescence lasts longer today than it did in the past. Children begin puberty earlier and leave home later. This means that the bridge to independence is longer than it was in the past. This means that parents and their children have more time to practice and learn how to negotiate the transition.[24]

Learning to Be Proactive

Teach your child how to be proactive in treating his hemophilia B by infusing early, before play. Speak about short-term consequences if he is hurt because he avoided infusion. Set boundaries on the sports in which he can participate, and discuss appropriate preparation with your hemophilia treatment team. The list of sports in the following section provides a chart you can use for discussion. When the sport is chosen, enlist the help of the entire family to encourage participation by attending sporting events and speaking about role models in the sport.



Sports and Their Risks[25]

The following list, adapted from one compiled by the NHF, provides ratings for people with hemophilia regarding their participation in various sports activities. This is intended for informational purposes only.

No matter how well conditioned you are and your level of instruction or proficiency, different activities have different benefits, risks, and safety considerations. Understanding all of these factors can help you make good choices about physical activity.

The risk of participation in a specific activity will vary, depending on how you choose to play. The list is divided into five ratings:

- Low risk (1)
- Low risk to moderate risk (1.5)
- Moderate risk (2)
- Moderate risk to high risk (2.5)
- High risk (3)

Level 1

Even though an activity may be rated a "1," or low risk, there is still no guarantee that you'll be injury free or that a particular "1" activity may be the best one for you to try. For example, a person with a target shoulder may have difficulty swimming. Work with your health care provider to make the best choice on an activity that is right for you.

Level 2

Even though activities rated as "2" or "2.5" have more risks, this does not mean that you need to avoid all of them. For example, if you wear appropriate safety gear and choose not to slide into bases, the injury risk when playing baseball may be in the "1.5-2" range. In contrast, if you choose to routinely slide into bases or play catcher, the risk level could be in the "2-2.5" range. Work with your health care provider to make the best choices and maximize the benefits of the activity while minimizing the risk.

Level 3

These activities contain aspects that can be dangerous for ANYONE who participates, regardless of a bleeding disorder. The risks of these activities are due to the physical contact with other players, equipment or hard surfaces that may result in serious traumatic injury. These activities result in the highest percentage of injury in the general population. The risk to a person with a bleeding disorder may be even greater due to bleeding.

Partial List of NHF-Rated Sports and Activities

Activities have been divided into five ratings based on a scale from 1 to 3[25]:

1
Low risk

1.5
Low to moderate risk

2
Moderate risk

2.5
Moderate to high risk

3
High risk

Choices that are rated "1-2" generally indicate that the benefits of these exercises or sports MAY outweigh the associated risks. If you are considering in participating in an activity with a rating of "2.5" or "3," keep in mind that the activity is higher risk. Speak with your health care provider before participating.

Activity	Category
Aquatics	1
Archery	1
Baseball/Softball	1.5-2.5
Basketball	1.5-2.5
Bicycling	1.5-3
BMX Racing	3
Body Sculpting Class	1.5
Boot Camp Workout Class	2
Bounce Houses	2.5-3
Bowling	2
Boxing	3
Canoeing	1.5-2.5
Cardio Kickboxing Class	2
Cheerleading	1.5-2.5
Circuit Training	1.5
Dance	1-3
Diving, Competitive	2-3
Diving, Recreational	2
Elliptical Machine (Training Equipment)	1
Fishing	1-2
Football, Flag or Touch	2
Football, Tackle	3
Frisbee®	1-1.5
Frisbee®, Golf	1.5-2
Frisbee®, Ultimate	2-2.5
Golf	1
Gymnastics	2-3
High-Intensity Functional Training (Incl. CrossFit®) Class	2-3
Hiking	1-1.5
Hockey, Field/Ice/Street	2.5-3
Horseback Riding	1.5-2.5
Indoor Cycling Class	1.5-2
Jet-Ski® (Personal Watercraft, PWC)	2-3
Jumping Rope	2
Kayaking	1.5-2.5
Lacrosse	3
Martial Arts, Tai Chi	1
Martial Arts, Traditional and Mixed	2-3
Motorcycle/Motocross (ATV, Dirt Bikes)	3

Activity	Category
Mountain Biking	2.5
Power Lifting	3
Racquetball	2.5
River Rafting	2
Rock Climbing, Indoor or Challenge/Ropes Course	1.5-2
Rock Climbing, Outdoor	2-3
Rodeo	3
Rowing/Rowing Machine (Training Equipment)	1.5
Rugby	3
Running/Jogging	2
Scooters, Motorized	2-2.5
Scooters, Nonmotorized	1.5-2.5
Scuba Diving	2-2.5
Skateboarding	1.5-2.5
Skating, Ice/Inline/Roller	1.5-2.5
Skiing, Cross-Country	2
Skiing, Downhill	2.5
Skiing, Water	2-2.5
Ski Machine (Training Equipment)	1.5
Snorkeling	1
Snowboarding	2.5
Snowmobiling	3
Soccer	2-3
Stationary Bike (Training Equipment)	1
Stepper (Training Equipment)	1-1.5
Strength Training/Resistance Training/Weight Lifting	1.5
Surfing	2-2.5
Swimming	1
T-Ball	1.5
Tennis	2
Track and Field	2-2.5
Trampoline	2.5-3
Treadmill (Training Equipment)	1.5
Volleyball	2-2.5
Walking	1
Water Polo	2.5
Wrestling	3
Yoga/Pilates	1.5-2
Zumba® Class	1.5-2

Sibling Concerns

Sibling rivalry, a concern for many parents of two or more kids, usually begins shortly after the birth of the second child and can continue throughout childhood. Sibling rivalry can be frustrating and cause stress for parents and the entire family.

Family dynamics play a role in contributing to sibling rivalry. A child with hemophilia B naturally requires more time and attention from parents. This is especially true for the preteen with hemophilia B who not only has psychosocial issues to deal with outside of the home but also needs special attention for treatment, physician visits, treatment center visits, camp attendance, and many other situations. Family vacations are sometimes cancelled or delayed because of a medical need for the child with hemophilia B. Stress in the parents' lives can decrease the amount of attention they give the children and increase sibling rivalry.

Try to manage your family schedule so that your child's hemophilia treatments do not conflict with the schedules of your other children. Although this may seem inconvenient to you sometimes, it can allow you to manage activities for all members of the family instead of for only one. You can also make sure that each child has enough time and space of his or her own. Kids need to do their own thing, play with their own friends without a sibling, and have their space and property protected. Set aside some alone time with each child on a regular basis. Listen to how your children feel about what is going on in the family.

Sibling Rivalry-A Mother's View

Maria V, from Illinois, has four children: Anna, Tony, John, and Danny. Tony and Danny have severe hemophilia. Anna was 5½ when Tony was born, and the sibling rivalry problem was very mild. Hemophilia was just another part of the family's busy life, and Maria did her best to give attention to all four kids. When one needed more attention, she tried to include the others by making them the "medical team." Their job was to make their brother laugh during the infusion and to make Ninja headbands out of the Coban™ wraps that were used.

Trips to the emergency room, referred to as "adventures," often included everyone, but these trips, when happening on holidays, were not popular with the family. "Those times were most frustrating to the kids, and I would gently remind them that the one with the bleed was not only inconvenienced, but also felt bad for his siblings and was in pain."

"As Anna approached her teens, she did attempt to guilt me into allowing her more privileges. Whenever she rode her bike or was on rollerblades, I insisted that she wear a helmet. She reasoned that this was a rule only because the boys could get hurt if they did not wear one. I have assured her that my concern over her well-being has little to do with anyone's hemophilia. When she finally realized that playing the hemophilia 'card' was not quite working, she changed her strategy. Now she uses the card that reads, 'It's no fair! Why am I the only girl?'"

"My oldest son with hemophilia is very troubled when his younger brother is having a bleed. He says that he can 'feel his pain' and does all he can to comfort him. His younger brother without hemophilia is most often eager to help. He sometimes tries to act as if he is the older brother protecting the other two. The others tolerate that for only as long as it benefits them."

Maria shared her thoughts about emotions a sibling may feel or experience:

Envy – Siblings may have feelings of envy toward the child with the bleeding disorder because of the amount of attention that he receives.

Resentment – Siblings may be assigned extra chores or responsibilities when a child has a bleed, and they may feel they are being penalized for being "healthy."

Guilt – Siblings may feel guilty for not having a bleeding disorder. They may also feel guilty if they believe that they are responsible for causing a bleed. Often a sibling may feel anger toward the child with the bleeding disorder and then feel guilty for being angry.

Worry – Siblings may worry about the child with the bleeding disorder, and confusion and misconceptions about hemophilia may cause anxiety about the future.

Anger – Anger may arise when plans or activities have to be changed or cancelled because of a bleed.

Overprotectiveness – Siblings may take it upon themselves to "guard" their brother. Although they mean well, this can be irritating to the one with the bleeding disorder and to the rest of the family.

Embarrassment –The use of crutches or a wheelchair by the child with the bleeding disorder may cause a sibling to feel embarrassed. This emotion may occur in the preadolescent years when everything about the family seems to cause embarrassment.

Powerlessness – Siblings may feel overwhelmed at not being able to help their brother.

Compassion – Siblings may feel kindness and consideration toward their brother with the bleeding disorder.

Our Family Outings

Try to plan a weekly family outing, even if it is only a trip to the ice cream store or pizza parlor. Let each child take a turn planning an outing. If a sport is chosen, it should only be one in which your child with hemophilia B can participate. After the outing, encourage each child to say what they liked about the day. Take pictures and put them into a scrapbook each week. Perhaps title the book "Our Family." This type of activity can help to solidify the family unit and encourage more support and cohesiveness.

Section Four
Treatment of Hemophilia

One of the goals parents should have during the tween years is to begin to teach the child with hemophilia B how to manage his bleeding disorder. During this stage of life, children slowly gain confidence in their treatment, their bodies, and their own ability to manage their condition.[23] The child should now be encouraged to take an active role in the treatment and management of his health. The treatment team at the hemophilia treatment center (HTC) may be helpful in determining if your child is ready to begin taking control of his own health.

Treating bleeds early is crucial for preventing problems later in life. It is important that you teach your child how necessary it is to notify you or the school nurse immediately if he thinks he is having a bleed. This is often easier said than done. Children may not want to appear different from their peers, and as such may not want to interrupt their activities to let an adult know about the bleed. They also may not recognize the signs of a bleed.

The good news is that advances in treatment have enabled children to lead healthy, active lives while self-infusing on a regular schedule in the comfort of their own homes.

Keeping a Treatment Log

It is a good idea to keep a journal of your child's treatments, including dates and times of infusions, as well as emergency visits to the hospital. Make sure to include the site of the bleed, the date and time of infusion, how much factor was infused, and any side effects. Bring this journal to the doctor when you and your child visit the HTC, as it can help to speed up care and also may be needed by your insurance company.

HemMobile® is a free app that lets you keep track of your child's infusions and bleeds. This information may be helpful to share with the doctor at your child's next appointment.

Emergencies[26]

Emergencies happen. It is a good idea to speak with your child about the importance of letting an adult know immediately if an emergency occurs. In addition, learn how to examine your child to recognize signs of bleeding. Contact your child's physician immediately or call 911 if any of the following occur:

- Suspected bleeding into a joint or muscle
- Any significant injury to the head, neck, mouth, or eyes, or evidence of bleeding in those areas
- Any new or unusual headache, particularly one following trauma
- Severe pain or swelling at any site
- All open wounds requiring surgical closure, wound adhesive, or Steri-Strips™
- History of an accident or trauma that might result in internal bleeding
- Any invasive procedure or surgery
- Heavy or persistent bleeding from any site
- Gastrointestinal bleeding
- Acute fractures, dislocations, and sprains

Proactivity Is the Key!

Dr. Thomas Truncale ranks proactivity number 1 in managing hemophilia in treatment, in education, and in parenting. Preventive treatment has improved outcomes in hemophilia by helping patients take better care of themselves. Most children now experience fewer emergency bleeds and thereby enjoy a better quality of life.

Proactively encouraging children's education about this bleeding disorder can also improve their ability to begin to manage their own medical care. Although it is sometimes difficult for a parent to give up the responsibility for a child's medical care, it is important for children to become involved early in their own care. At a young age, children can begin to gather their own supplies for infusion or even decide the site where the infusion should take place. This involvement can help to prepare them for eventually managing their own self-infusion. Dr. Truncale recommends that families try to attend a summer camp, where older children mentor younger children to take responsibility for their own health. "Encourage your child to focus on what he or she can do, not what they can't do." Education can help them learn to make the right decisions. If a bleed should occur, the child will be able to identify it as soon as possible so it can be treated early.

Dr. Truncale also stresses that proactivity should extend beyond the home into the school, church, and community. Put together a package of educational materials for the school nurse, teachers, church personnel, babysitters, and other families. Most HTCs have educational materials available for this purpose. Do not forget to add your own contact information to this package.

Prepare an emergency kit for your home so you are prepared if your child should need prompt care if your hemophilia treatment team has recommended it. Be sure to always have an emergency supply of factor on hand, just to be safe. You should also know how to access an emergency rush order from your home care company. Otherwise, normal shipping generally takes 2 to 3 days. Include crutches and an elastic bandage in the kit, as well as physician and HTC phone numbers.

Be sure that any adult who is responsible for your child knows that the child has hemophilia B. Consider talking with your child's babysitter, day-care providers, teachers, other school staff, and coach leaders of after-school activities about when to contact you or when to call 911 for emergency care. Consider distributing a personal business card that includes your emergency phone numbers, physician's number, and a close friend's number to everyone in your family's social network.

YOUR PERSONAL BUSINESS CARD

Prepare a personal business card and consider distributing it to any people your child may come in contact with, such as parents of friends, relatives, teachers, church staff, sports staff, day care staff, sitters, and HTC personnel. Make sure to include your phone numbers (all of them) and other family phone numbers, as well as your child's doctors' numbers and HTC personnel numbers.

EMERGENCY CONTACT CARD

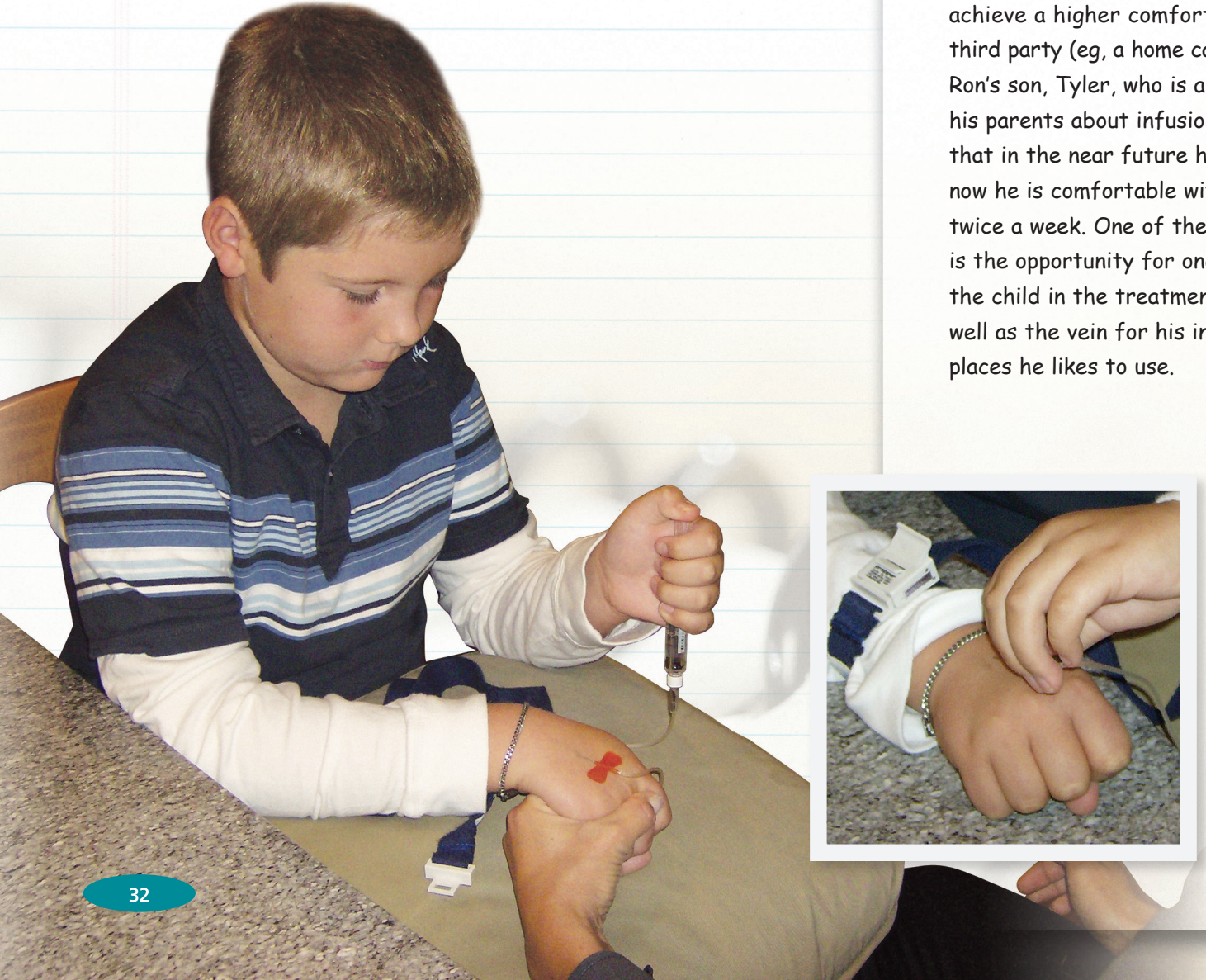
Jane Mother	732.272.1234 (cell) 732.272.1234 (home) 732.272.1234 (office)
Joe Father	732.272.1234 (cell) 732.272.1234 (home) 732.272.1234 (office)
Relative	732.272.1234 (cell) 732.272.1234 (home) 732.272.1234 (office)

Dr. Sam Physician
732.272.1234

HTC PERSONNEL
Sam Nurse
732.272.1234 ext. 413
Joe Nurse
732.272.1234 ext. 415
Susan Nurse
732.272.1234 ext. 411

Making Infusion a Team Effort

Ron R, from Maine, strongly believes that parents need to be able to infuse their child who has hemophilia B. He recommends that all parents attend an infusion training class that includes help in identifying veins and rolling veins. Children seem to achieve a higher comfort level when parents, rather than a third party (eg, a home care company), are involved in treatment. Ron's son, Tyler, who is almost 9 years old, speaks openly with his parents about infusion for his severe hemophilia. He knows that in the near future he will be learning self-infusion, but for now he is comfortable with his parents managing his infusions twice a week. One of the positives for parents learning to infuse is the opportunity for one-on-one communication while involving the child in the treatment. Sometimes Tyler selects the site as well as the vein for his infusion. He has three or four different places he likes to use.



Learning to Self-infuse

Until a child can self-infuse, he is dependent on someone else to deliver his factor IX. This can greatly limit the activities in which the child or adolescent can participate. He or she may be unable to go on school trips or outings or one of his parents may need to go with him. This can lead to a lack of self-confidence or even frustration, as he wants to participate in activities with his friends.[27]

Self-infusion is an important transition in the child or adolescent taking control of their hemophilia B. He can now take care of himself, and this creates a feeling of independence and confidence. Starting self-infusion can be daunting for parents and children, especially when things are going as well as they are. Children may begin to infuse between 7 and 9 years of age, and the best advice in relation to self-infusing is to do it as soon possible, when the child is ready.[27] Sticking yourself with a needle is a very scary thing to do. To help your child learn to infuse and to lessen the fear, provide a partner in the form of a friendly bear or doll.

Section Five

Staying Healthy

Making sure your child stays active and eats right are important steps in maintaining proper health and are good things for him to learn for the rest of his life. It is never too early to start eating right and getting proper exercise!

Nutrition

Following a good nutritious diet contributes to overall health and helps your child maintain a healthy weight. Being overweight has become one of the greatest health challenges for young people in this country. When it begins in childhood, obesity can continue into adulthood if it is not controlled.

Exercise

You have probably begun to explain to your child that strong muscles can help to protect joints from bleeds and to prevent injuries. Depending on the advice of the treatment team, participating in sports may be a great way to stay physically fit and a good opportunity for your child to socialize and meet new friends. Playing on a team is an excellent way for him to learn about teamwork and cooperation, which are skills that he will always need. Research has shown that children with strong musculoskeletal systems have fewer spontaneous episodes of bleeding.[25]

Young people with hemophilia need help understanding that they can prevent complications. Exercising is a good way to do this.[28]

Managing Weight

Keeping your child's weight under control is important for protecting his joints.[29] It has been noted that obesity is now more prevalent in the hemophilia population than in previous generations, with rates as high or higher than those in the general population. Increased body weight can result in decreased joint range of motion that is more pronounced in patients with hemophilia than in the general population.[30]

For tips on healthy eating, check out www.health.gov/dietaryguidelines

NHF has put together some guidance on sports and their potential benefits and risks. You may wish to review it with your child so he can choose an appropriate sport, but be sure to check with your treatment team before beginning any sports activity or exercise program.

The list is divided into five ratings based on a child's risk level: low risk (1), low to moderate risk (1.5), moderate risk (2), moderate to high risk (2.5), and high risk (3). Choices that are rated 1-2 generally indicate that the benefits MAY outweigh the associated risks. If you are considering participating in an activity with a rating of 2.5, keep in mind that the activity is higher risk. Speak with a health care provider before deciding about participation in any sport. (See pages 22-23 for a listing of sports in each category).

R.I.C.E.[31]

Bleeds in the joints, muscles, or soft tissues can be treated by using a form of first aid called R.I.C.E. (Rest ["R" can also mean Replacement of clotting factor], Ice, Compression, Elevation).

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, such as using an elastic bandage) to the area can also help to slow the bleeding. 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.

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

For more details about appropriate activities, see the section "Partial List of NHF-Rated Sports and Activities" on pages 22-23.

Choosing the Right Sport

Chris B, from Alabama, is very busy these days attending all the baseball games his 8-year-old son Tyler is playing in, including the all-star game. Tyler has severe hemophilia B and has had a port for infusion since he was 2 years old, but this has not held him back from playing the sport he loves.

Tyler's family has talked to him about the bleeding disorder and why he has needed to take medicine since he was 2 years old. By the time he was 5, he was playing T-ball with his friends, always under the watchful eyes of his parents. Even at that young age he understood about his bleeding disorder and that he had to take medicine to keep well. When he wanted to play more with his buddies, there were discussions about contact sports, such as football, and why he could not participate in them.

Chris believes strongly that open, daily communication with his son from very early on helped to establish the boundaries for what Tyler could do and what he could not do. Daily discussions centering on "What did you do today?" helped Tyler to openly discuss and question activities. Open communication also encouraged Tyler to let his parents know whenever he banged his leg or another part of his body without fear of discipline. Tyler infuses preventively, especially before ball games. He wears a face mask (attached to his batting helmet), a chest protector (to protect the port), and knee pads (under his uniform).

Chris or his wife attend every game to support Tyler and the team. They believe that parents set the example by getting involved. Their involvement helps to ease any apprehension that the coaches, team members, or parents may have about hemophilia B.

Chris has some advice for families of young children with hemophilia B when it comes to sports:

- Begin early to talk to your children
- Get involved—set a good example
- Make yourself available to the child's coaches, teammates, and other parents to answer questions about hemophilia B
- Work with your coach to set limits and boundaries in sports
- Be proactive with treatment—make a plan to infuse ahead of time

Sports Calendar

Purchase a very large calendar with blank areas for each day on which your child can keep track of his favorite sporting events. Let him choose which events he wants to note on the calendar—local, regional, or national. Sit together once a week as a family and discuss the different events that occurred during the week. Consider purchasing tickets to a ball game or watching something on television together. Try to steer him toward sports in which he can potentially take part, not ones in which he cannot take part, and be sure to check with his treatment team about any sports activities. Also encourage your child to add one nutritional item to his menu on this calendar each day. You can provide a list of items from which he can choose.

Section Six

Going to the Hemophilia Treatment Center (HTC)

A network of approximately 141 federally funded HTCs across the country offers excellent treatment, education, and support services to individuals with hemophilia and their families. Many of the HTCs are located at major university medical and research centers and offer hemophilia treatment teams consisting of[32]:

- Nurse coordinators
- Adult and pediatric hematologists (doctors who specialize in bleeding disorders)
- Social workers (people who can help with financial, transportation, mental health, and other issues)
- Physical therapists (specialists in activity, exercise, and rehabilitation)
- Pediatricians (doctors who specialize in caring for infants, young children, and teenagers)

The HTC may also be able to refer to orthopedists (doctors who specialize in disorders of the bones and joints) and dentists. The staff of the HTC needs your input to develop a plan of care that will help keep your child healthy, active, and able to live successfully with the challenge of hemophilia.[32]

The HTC is a valuable resource that enables your child to obtain a comprehensive evaluation, as well as many other types of services and opportunities. Sometimes, it is a place where your child can meet other children with hemophilia and you can meet other parents of children with hemophilia. Taking part in social activities may help your child see a fun side to the HTC in addition to the clinical side. You may also meet another family who lives close to you, allowing you to continue socialization outside of the HTC.

Finding an HTC

To take advantage of the services at an HTC, register at one near you. To find an HTC near you, contact handi@hemophilia.org.

The HTC can also help your child learn to self-infuse and begin to manage his own treatment. In many cases, the infusion clinic is located at the HTC.

The network of federally funded HTCs across the country offers excellent treatment, education, and support services to individuals with hemophilia and their families.

The Centers for Disease Control and Prevention (CDC) supports and funds the national network of HTCs, and they have provided an interactive directory that can be found at the following site:

Hemophilia Treatment Center (HTC) Directory
https://www2a.cdc.gov/ncbddd/htcweb/dir_report/dir_search.asp

Hemophilia Treatment Centers Make a Difference in Many Ways

A CDC study of approximately 3,000 people with hemophilia A or hemophilia B showed that those who used an HTC were 30% less likely to die of a hemophilia-related complication compared to those who did not receive care at an HTC.[33]

NHF "Top 10 Reasons to Get an Annual Comprehensive Checkup at an HTC"[34]*:

1. [Help live] longer, healthier lives
2. Early detection of complications
3. Fewer hospitalizations
4. Home infusion instruction
5. Physical therapy and an exercise plan designed for the patient
6. Participation in research studies
7. The latest product information, treatment, and specialized lab tests
8. Coordinated care and advocacy for added services
9. Counseling and support
10. Blood safety testing and monitoring

HTCs not only provide comprehensive care through a treatment team, they also emphasize prevention services to help reduce or eliminate complications. Some of these services include using preventive medicine and connecting patients with community groups that provide education and support to families.

*Data are from 2001.

Travel Assistance

The HTC is prepared to help with travel preparations as well. They contact the HTC in your travel destination and make sure all necessary information about your care is available to the center staff through a "travel letter." People with hemophilia carry this letter on trips and show it to any other HTC that they may need to visit while away.

Travel can be challenging for anyone today, but especially for those needing to travel with medications and supplies. The following tips can help to prepare for security screening at an airport:

- Pack your child's medications in a separate pouch/bag to simplify the inspection process
- Make sure that all your child's medications are clearly identified. Do not pack factor in your checked baggage
- If you are planning an extended stay and a large amount of factor will be needed, have your home care company send factor to your destination ahead of your visit

To learn more about security measures specific to travelers with disabilities and medical conditions, contact the Transportation Security Administration by visiting www.tsa.gov or calling 1.866.289.9673. You can also visit https://www.hemophilia.org/Travel-and-Vacation-Planning for air travel recommendations specific to the bleeding disorder community.

Section Seven

Off to School

When your child is adjusting to a new school environment, it is important to involve the school personnel as much as possible. Try setting up an appointment immediately with the school to introduce your child. At this meeting, you can provide a set of emergency telephone numbers and guidelines for your child's care. This is an opportunity for you to do some educating about hemophilia.

Make sure your child knows whom he can contact at the school should the need arise. School personnel who may be of help to you and your child include school counselors, the clinic staff, the school nurse, the physical education teacher, the special education teacher, the playground supervisors, the principal, and the security personnel.

It may be helpful to ask the teachers for an extra set of books to keep at home in case it becomes necessary for your child to remain at home for a period of time or if the books are too heavy for him to carry back and forth.

The tween years are also the time when your child begins to develop self-advocacy skills, including learning to speak up when necessary or when he cannot take part in activities specified by school personnel. He will learn little by little to manage his own care when you are not around. As part of self-advocacy, your child will also learn to develop healthy friendships and discourage risky ones.

This is not an easy time for your child, and you may want to continue your involvement whenever possible by volunteering to be a chaperone on school trips or at other activities.

Things Teachers Need to Know - Creating an Information Packet

There are a large number of things that teachers need to know and do when they have a child with hemophilia in their class, and it is important that parents and children with hemophilia provide them with information that they need.

Facts for Teachers

- Hemophilia is a blood disorder in which blood does not clot properly
- Listen to the child if he has any complaints that are worrisome
- Honor a parent's request for protective devices, such as helmets, to be worn during periods of physical activity
- Maintain open lines of communication with the child and the family
- Permit physical activity as defined by the child's family and their hemophilia treatment center personnel
- Recognize the importance of treating the child in most respects as you would any other[35]

Things Teachers Need to Do[36]

Contact parents immediately or call 911 in any emergency situation, or if the child suffers a blow to the head, neck, or abdomen.

- Small surface cuts, such as paper cuts, generally respond to first aid
- Wash the cut, apply pressure, and then bandage
- Contact the school nurse for additional information pertinent to the student

Teachers Should Also Be Aware That[37]:

- Regular exercise is very important for most students with hemophilia
- A student with hemophilia should be permitted to partake in physical activities as allowed by his doctor
- Participation in sports and recreational activities can enhance a student's self-esteem
- After a student with hemophilia has suffered an injury or a bleed, he usually should not resume vigorous activity/sports until the injury has completely recovered. This may mean missing recess or gym class

Create a Family Website

Involve your child in the creation of a family website on which all members of the family can post items or communicate with each other. Ask your child to name and design the site with your help and perhaps the help of a friend who can instruct you on the correct way to post the site to the Internet. This type of family activity may be ongoing for many years and can encourage communication among family members, as well as provide an outlet for expression of feelings. The website can be password-protected so that it is accessible only to family members.

Section Eight

Going Away to Camp

Many families arrange for their children with hemophilia B to attend hemophilia camp every summer. The families report wonderful experiences for their children as well as for themselves. This may be something you want to look into for your child.

If you do locate a camp you are interested in, try to check it out before you send your child. Talk to families of other campers in advance and get some reassurance that this is the right place for your child. Become familiar with the camp, meet the staff if possible, and see the clinic. Find out if you or any other family members will be permitted to accompany your child to camp.

Finding the Right Camp

The following websites may be of help to you in locating a hemophilia summer camp for your child:

- Hemophilia Federation of America
  www.hemophiliafed.org
- National Hemophilia Foundation
  www.hemophilia.org
- NACCHO (North American Camping Conference of Hemophilia Organizations)
  www.arizonahemophilia.org/naccho

These websites are neither owned or controlled by Pfizer. Pfizer does not endorse and is not responsible for the content or services of these sites.

When inquiring about cost, look into possible financial assistance from the HTC. Also, check on transportation options for getting to camp. Find out if self-infusion training or support is available at the camp. You may want to inquire if it is possible for your child to have a friend or a sibling attend camp with him.

The first time your child goes away to camp can be difficult for both of you. Your child will probably feel a little lost being away from you, and you will probably feel a little anxious not being close by. Camps are helpful in fostering independence, especially related to managing a child's own medical care. Taking responsibility for medical supplies is one thing your child will probably learn at camp.

Try to find an activity for yourself while your child is away at camp. Use this time to indulge in something you have wanted to do but never had time to do before.

What to Take to Camp

The first time you pack for your child to go to camp will probably be the hardest because you will not really know what he will need or want. The camp you select will probably suggest a list of things to bring that might include a few of the following items:

- Your child's favorite toy or stuffed animal
- A family picture
- Postcards, stamped and addressed to you so he can keep in touch
- A list of important phone numbers (child's physician, HTC, your numbers, a close friend's numbers, and any other contact information)
- A letter from your child's doctor outlining his normal treatment regimen
- Extra factor and ancillary supplies
- A journal for writing what he wants to remember
- A camera for taking photos of his new friends

How to Plan for Emergency Bleeds When Away at Camp

Make sure that you are familiar with the procedures followed at the camp with respect to emergency bleeding episodes. Because this is a hemophilia camp, procedures will probably be in place for this type of care. You may feel more at ease if you speak with the clinic staff at the camp and find out what information they will need from you. Also ask your child's doctor what supplies to bring for your child.

Section Nine
Personal Empowerment

Learning the Ropes

For your preteen who is already experiencing change and uncertainty, the additional burden of coping with a bleeding disorder can be discouraging at times. Coping with setbacks caused by the disorder, risks and consequences of certain sports, and new social situations can be challenging.

The importance of validating, openly discussing with, and encouraging your preteen cannot be stressed enough. This is the time for you to focus on personal empowerment for your preteen. Encourage him to use resources with you to aid him in understanding and preparing for living with hemophilia B now and in the future. This is a time for listening, encouraging with hope, and assuring him. Teach him how to make smart choices, not risky ones. Recognize the value of compromise in your discussions with him and focus on his strengths.

Provide him with educational materials to encourage self-infusion, and show him the importance of wearing a form of MedicAlert® identification and carrying emergency contact information. Through all of this, you should try to remain a solid listener to everything he wants and needs to talk about.

Creating Opportunities for Praise

For a child with hemophilia B, praise is a powerful motivator because it reinforces the positive and encourages repetition. The positive attention also makes him feel better about himself, cared for, and loved.

Gaining Independence

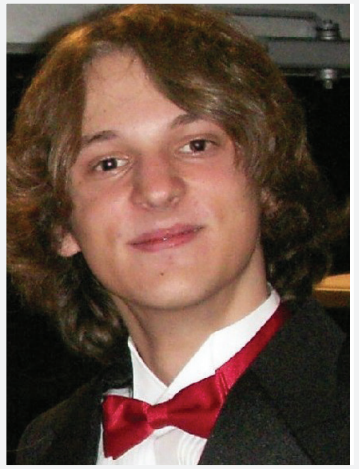
Nina D, from Virginia, believes that helping your children find their niche from an early age is a major step in their gaining independence. Beginning this process at the age of 7 or 8, when social interaction with friends becomes so important, is the best way for your child to achieve personal empowerment in his own life. For the child with a bleeding disorder, setting boundaries on activities is essential, as most parents are aware. However, the limited choices of sports may not be enough to fulfill the child's needs.

Nina's two children have hemophilia B. Spencer is 18 years old and has severe hemophilia B, and Kirstin is 25 and has mild hemophilia B. They both lead very active lives. At an early age, Spencer's interest turned to the arts, where he has been involved in singing, playing musical instruments, and composing. Spencer attends the Shenandoah Conservatory and traveled to Italy as a member of the chorus that performed for the Pope in March 2009.

Spencer learned to self-infuse at age 9, when his parents told him it was a prerequisite for attending camp. Nina suggests that this is a good age to begin encouraging a child to learn self-infusion, but adds that forcing a child who is not ready is not the answer. She does suggest that self-infusion brings independence in managing one's own bleeding disorder.

Nina offers a few pearls of wisdom that may help you lead your children into personal empowerment before they reach the adolescent years:

- Teach them to recognize a bleed
  - Teach them to treat early, as soon as they feel a bleed coming on
  - Let them know they can go back to what they were doing after treatment
  - Do not be critical; encourage them to deal with a bleed immediately
- Talk to them about the importance of preventative treatment before strenuous activities
  - The severity of their hemophilia will play a role in the need for preventative treatment
- When your children are 8 or 9 years of age, begin to address importance of learning self-infusion
  - Encourage them to become a participant in their own treatment, including making decisions about where to infuse
- Help them to find their area of interest
- Get involved with an HTC right away and network with other families; you and your child may just make some lifelong friends. Volunteer for chapter activities, and teach your children the importance of volunteerism and giving back to the community



WORKING TOWARD COMPETENCE AND INDEPENDENCE

Dr. Alcuin Johnson believes that parents should accentuate the positive when parenting young children. Parental guidance in the tween years involves the introduction of academic and physical independence. This is a time when all children are working at doing well in school to achieve a level of competence and mastery of their own care wherever possible. They are looking to parents for guidance to help them achieve these goals.

"Children at this age need to learn how to recognize a problem and know where to go for help." As they move from the "single-teacher" environment to the "multiteacher" environment, this may be a little more confusing for them to sort out. Dr. Johnson suggests that parents discuss these issues with teachers early and even suggests giving a pass to leave the room ahead of time so the child does not have to announce he has a bleeding issue in front of the class. This can be accomplished in a nonobtrusive way. It may even be wise to provide your child with a "cheat sheet" that has specific details about the bleeding disorder and emergency treatment that would allow the child to speak for himself.

Dr. Johnson suggests that the tween age is an "opportunity for guided, supervised practice." In addition, he enthusiastically recommends participation in an HTC as a way to interact with other families and take advantage of the extensive treatment teams.

Section Ten

Conclusion

We all probably realize that parenting preteens is a challenge. Their desire for independence versus their need for boundaries presents challenges for any parent. How much will you accept? What cannot be ignored? How do you decide? Answers to these questions do not come easily. There is one fact that remains clear—the more involvement you have in your child's life, the easier your communication will be. Communication is the key. This is especially true for parents of children with hemophilia, who have additional challenges to cope with when parenting and teaching new responsibilities for the management of a bleeding disorder.

Parents of a preadolescent child with hemophilia B can cope with this challenge by reaching out to others for guidance and support during this life stage. Whether it is through the HTC or the child's physician, ask for help. Medical professionals can help to steer you in the direction in which you and your family will find support.

Remember, no one knows your child like you do, and no one loves your child as much as you do. The best protection and guidance we can offer our children is our complete involvement in their well-being.

Resources

Pfizer Hemophilia Connect

We're committed to helping the hemophilia community.

For the past two decades, Pfizer has been a part of the hemophilia community. We recognize it can be difficult to understand what support is available to help families with bleeding disorders, and to help address this challenge, we created Pfizer Hemophilia Connect.

Pfizer Hemophilia Connect is a one-stop destination to access all of our resources for eligible patients.

Soozie Courter 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 website, www.HemophiliaVillage.com, provides information for the hemophilia community. Consumers and professionals alike can find product information and learn about programs and services.

B2Byourvoice.com

The Pfizer B2B Consumer Advisory Board was developed to directly connect Pfizer to hemophilia B patients and caregivers in order to gain firsthand feedback from the hemophilia B community. As a result, the B2B program has created tools and resources to support the community and continues to evolve to address needs as they change.

Visit www.b2byourvoice.com for more and to check out a series of books, videos, patient stories, and other resources for people living with hemophilia B.

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