Hemophilia Handbook

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Chapter 1: Understanding Hemophilia

What is Hemophilia?
Hemophilia A and B are rare, lifelong, blood-clotting disorders resulting from defects in the production of one of the coagulation (clotting) factors. Because the body cannot make enough coagulation factor, it takes a longer amount of time to form a clot when bleeding occurs. The person with hemophilia does not bleed faster than others but takes longer to stop bleeding.

Hemophilia is an inherited disorder. It is carried on the X chromosome but occurs almost exclusively in males. On occasion, females who carry hemophilia may have bleeding problems themselves. Not every person with hemophilia has a family history of the disorder. Sometimes genetic changes called “mutations” lead to the new occurrence of hemophilia in a family.

Hemophilia is diagnosed by blood tests that measure the clotting time of blood and the level of coagulation factors. There are two basic types of hemophilia, defined by which clotting factor in the blood is deficient. In Hemophilia A (also known as factor VIII deficiency or Classical Hemophilia), there is an absence or lack of coagulation factor VIII. In Hemophilia B (also known as factor IX deficiency or Christmas Disease), coagulation factor IX is deficient.

When blood vessels are injured, bleeding may occur. Platelets, which are small blood cells, stick to the injured blood vessel and form a platelet plug. Also, the blood contains several coagulation factors that work together to form a clot, which seals the damaged vessel. In a person with hemophilia, either coagulation factor VIII or IX is missing or occurs in such small amounts that the blood has difficulty making an effective clot.

Normal Factor VIII and Factor IX levels are 50-150%. The severity of hemophilia varies from family to family, depending on clotting factor levels in the blood. These levels affect the pattern and frequency of bleeding and are usually consistent through life. Family members with hemophilia usually have similar levels. Based on the levels of the missing clotting factor, hemophilia may be divided into three classes.
Levels of Severity In Hemophilia

<table>
<thead>
<tr>
<th>MILD</th>
<th>MODERATE</th>
<th>SEVERE</th>
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<tbody>
<tr>
<td>Factor levels are 5-40%.</td>
<td>Factor levels are 1 – 5%.</td>
<td>Factor levels are less than 1%</td>
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<tr>
<td>Episodes of bleeding are usually related to surgery or dental extraction.</td>
<td>Bleeding episodes are usually related to injury, but can occur spontaneously.</td>
<td>Spontaneous bleeding can occur unrelated to injury.</td>
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<tr>
<td>Joint bleeding is uncommon, but can occur.</td>
<td>Joint bleeding can occur.</td>
<td>Joint bleeding is common.</td>
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Although there is no cure for hemophilia, medical treatment is designed to prevent complications related to bleeding and allow individuals to live full and active lives.
Chapter 2: Treatment for Hemophilia

Treatment for Hemophilia A or B
The goal of treatment is to prevent bleeding and to stop active bleeding. This is accomplished by replacing the missing coagulation factor VIII or IX, which normalizes the clotting process, allowing an effective clot to form. Purified coagulation factor VIII or IX is available in a powdered form called, “concentrate.” When factor is needed, the powder is dissolved in a sterile solution and administered into a vein.

Factor products are expensive. Although many private health insurance and Medicaid programs cover much of the expense, the cost can create additional concerns for the family. Our Hemophilia and Thrombosis Center can assist with these insurance and financial matters.

Types of Factor
There are two distinctions made between factor concentrate types. Plasma-derived factor concentrate, which is made from plasma collected from blood donors, and recombinant factor concentrate, which is not made from human blood products.

Plasma-derived concentrates have the possibility to have viruses and unwanted proteins left behind from the plasma. Drug companies have several ways to treat the plasma-derived concentrates to decrease the amount or eliminate the viruses and unwanted proteins. When possible, we recommend that recombinant products be used in patients with hemophilia.

In 2014, new long-acting recombinant factor VIII and a factor IX products came on the market. The two new products work similarly in how they allow clotting factor VIII and IX last longer in the blood stream. The half-life (the time it takes the factor level to fall by 50% after infusion) of the new factor VIII product is about 20 hours, compared to 12 hours for regular factor VIII. The half-life of the new factor IX product is about 80 hours, nearly three times that of regular factor IX. A patient who first receives a long-acting factor will need to get lab draws to see how long the drug
will last in their system. Other long-acting factors from different companies may also come on the market in the coming years. These new factors allow persons with severe hemophilia to dose their factor less frequently and still remain protected from bleeds. This may translate to a better quality of life.

**Other Treatment Medications**

**DDAVP**

Desmopressin acetate, also referred to as DDAVP, is a synthetic antidiuretic hormone that can be used in a few patients with mild hemophilia A. It causes the body to release stored factor VIII and its carrier protein von Willebrand factor. Von Willebrand factor protects Factor VIII in the blood stream and allows it to remain in the blood stream longer. To determine if an individual with mild Hemophilia A will respond to DDAVP during a bleeding episode, a test dose is administered in clinic when the person is not bleeding. If the lab results reveal that clotting levels had a sufficient rise, it is likely that DDAVP is an effective treatment option for minor bleeds. Side effects of DDAVP can include flushing, headache, change in blood pressure and nausea. DDAVP also causes the body to hold onto water, and people who have taken DDAVP should **not** drink excessive amounts of fluids over the following 24 hours. DDAVP should not be used more than once every 24 hours and cannot be used for more than three days in a row, as it can be less effective at increasing factor VIII levels. DDAVP is a synthetic product that carries no risk of infectious disease.

**Stimate**

Stimate is a nasal form of DDAVP and it used to treat individuals with mild hemophilia A. Bleeding is controlled by using this nasal spray to boost a person’s own factor VIII. DDAVP may be given to increase the amount of factor VIII long enough for surgery or dental procedures to be performed.

**Amicar®**

Amicar® is an oral medication that prevents our body from breaking down blood clots as quickly as normal. Amicar® can be used after dental procedures or with mouth bleeding, but is used only after administering clotting factor replacement.

**Inhibitors**

Some people with hemophilia may develop inhibitors. Inhibitors are antibodies against factor VIII or factor IX produced by the body’s protective system (immune
The inhibitors cancel out the infused coagulation factor, making the medicine not work to prevent or treat bleeds. Anyone with hemophilia can get an inhibitor, but inhibitors are much more common in individuals with severe hemophilia. The cause of inhibitors is unclear, but persons with a family history of inhibitors may be more likely to develop them. Persons with hemophilia and inhibitors often require special medications to treat bleeding episodes, since the coagulation factor concentrate often does not work.

Inhibitors tend to develop during early childhood. Routine screening for an inhibitor is part of the comprehensive hemophilia examination.

Inhibitors can be classified into two types:

**Low-Responding Inhibitor**: The level of antibody remains low despite repeated exposure to coagulation factor.

**High-Responding Inhibitor**: The amount of antibody can rise to very high levels after exposure to factor. These levels of inhibitor may decrease if the person receives no further coagulation factor, but upon re-exposure, the inhibitor levels rise again.

In some persons, usually low responders, inhibitors can disappear without special treatment. For persons with a persistent inhibitor, immune tolerance induction may be helpful. This refers to the frequent administration of large doses of coagulation factor in order to reduce and eliminate the inhibitor. Treatment of bleeding in persons with inhibitors must be individualized.

**Managing Bleeding Episodes:**

**Early Treatment is Key to Success**

Correctly treating bleeding episodes is key to successful hemophilia care. The person with hemophilia should receive treatment as soon as possible after bleeding occurs. Prompt treatment of a bleeding episode will:
- Reduce the chances of permanent damage.
- Prevent further pain and discomfort.
- Reduce the number of treatments needed.

Early symptoms of bleeding may include feelings of pain, tingling or warmth. Many serious bleeding episodes are not easily visible. If in doubt as to whether symptoms are related to a bleed, treat first and then observe. If pain or swelling continue after treatment, contact the Hemophilia Treatment Center.

**Pain Medications**

For the treatment of pain, avoid aspirin and nonsteroidal anti-inflammatory drugs (such as Advil, Motrin or Naproxen), which can affect blood platelets and increase bleeding. Acetaminophen products (such as Tylenol) are safe alternatives. Discuss other pain medications with the Hemophilia Treatment Center staff.

**Serious Bleeds Require Immediate Action**

Significant injury or suspected bleeding in any of the following areas requires immediate medical attention: head, eye, throat or neck, lower back, abdomen, hip or groin.

**Home Therapy**

Treatment for a bleeding episode can be administered in the outpatient clinic, in the emergency room or at home. Home therapy can help to normalize the lifestyle of the family and person with a bleeding disorder by providing early treatment and decreasing trips to the hospital. As you become familiar with your child’s bleeding disorder, you may want to discuss with the Center staff whether home therapy is right for you.

**Learning to Self-Infuse**

An important part of managing home therapy is learning how to self-infuse factor treatments. Patients and family members can learn how to infuse factor concentrate through peripheral veins and central lines. Learning to self-infuse requires understanding when and where to infuse; gathering supplies and sanitizing work surface; identifying and cleaning appropriate infusion site; calculating medication dose; and appropriate disposal of supplies. Family members will work with the infusion nurse at the Hemophilia Treatment Center to learn and demonstrate skills and complete a written skills test. The family will then meet with their physician for a final review of skills and comfort level of performing independent infusions at home. The amount of time it takes to become independent at home depends on each family.
Our Hemophilia Treatment Center aims for all patients with severe hemophilia to learn to self-infuse at a young age.

Patients also have the opportunity to attend the annual hemophilia summer camp where they will learn self-infusion techniques along with other kids who have bleeding disorders. This experience has proven to be a fun-filled week where the kids find support from their peers at becoming independent with their infusions. Please speak to your care manager about how to sign up for the camp, which is usually in July.

**Prophylactic Treatment**

Prophylactic treatment is given to help prevent bleeding episodes. Bleeding episodes can be spontaneous, meaning there was no injury to cause the bleed. Bleeding can also occur after sustaining an injury. Prophylactic treatment in patients with severe hemophilia is usually started when the child is about 1 year old or after the first major joint bleed, whichever comes first. When treatment begins, the child is usually started on once-a-week factor treatment. As the child gets older, the frequency of factor will increase. Your hematologist will help decide what dose of factor and the frequency your child should receive. Studies have shown that children with severe hemophilia will have better outcomes if they are on prophylactic treatment.

When receiving the prophylactic treatment, it is important to come to all scheduled appointments. If your child has a bleeding episode, call the Treatment Center immediately.

**The Benefits of Prophylactic Treatment**

The benefits of prophylactic treatment include a decrease in pain, joint dysfunction and long-term disability, along with a decrease in hospital admissions from bleeding episodes.

**Prophylactic Treatment’s Impact on Joint Health**

In 2007, the *New England Journal of Medicine* published the results of a study by The Centers for Disease Control and the National Institute of Health that showed evidence that prophylactic treatment in children ages six months to six years old is effective at preventing joint bleeds and maintaining joint function.

In the study, 93% of the children receiving prophylactic infusions regularly showed normal joint function, compared to 55% of the group who received factor as needed.
for bleeds. Overall, the study showed that there was an 83% reduction in the risk for joint damage in the children who received prophylactic treatment.

**Infusion Logs**
Maintaining an infusion log is required while on prophylactic treatment. Infusion logs should include date, time, infusion site, reason for infusion, and the amount of factor concentrate given. This allows the care team to monitor how your child is doing while on prophylactic treatment. The Hemophilia Treatment Center staff will help your family find the best way to maintain an infusion log.

**Bleeding Symptoms**
**Urinary Tract Bleeding**
The urinary tract includes the kidneys, ureters, bladder and urethra. When urinary tract bleeding occurs, a medical evaluation is necessary. Blood in the urine can result from an injury, infection or unknown cause (spontaneously).

**Signs and Symptoms of a Urinary Tract Bleed:**
- urine that is a bright red or deep brown color
- lower back pain or groin pain
- painful or frequent urination

**Treatment**
Treatment can include the use of clotting factor replacement, increased fluid intake either through an IV or by mouth, steroids (Prednisone), and bed rest. Sometimes, unwanted clots can form that are difficult to pass. For this reason, Amicar should never be used in this setting. Always contact the Center if your child has urinary tract bleeding.

**Follow-Up**
Your physician will advise you about physical activity limitations and the need for additional treatment.
Intracranial (Head) Bleeding

Intracranial bleeding includes bleeding in and around the brain. Bleeding into this area can occur suddenly with the rapid onset of symptoms or can develop slowly over several days. Head bleeding can occur as a result of an injury or without a known cause (spontaneously). Intracranial bleeding can lead to death or significant disability.

Signs and Symptoms of a Head Bleed:

- unexplained irritability or sleepiness in infants
- severe or prolonged headache
- confusion
- unusual drowsiness or difficulty arousing
- slurred speech
- vomiting
- onset of poor coordination
- stiff neck or back
- numbness, tingling or loss of feeling
- unequal pupil size or discomfort in bright light
- seizures
- loss of consciousness

Treatment

Seek medical care immediately. If your child is on home infusion therapy, he should receive a dose of factor immediately, even before leaving for the hospital. All suspected intracranial bleeds require immediate clotting factor replacement. Confirmed bleeds require hospitalization.

Follow-Up

Your physician will advise you about physical activity limitations and the need for additional treatment.

Other Information

- Significant head injuries should be treated with clotting factor replacement first and then evaluated.
- Any injury leading to loss of consciousness needs immediate medical treatment and evaluation.
- The decision about which head bumps require treatment is a difficult one. Toddlers receive frequent bumps to the head that usually do not require
treatment.
- Some families of younger children find comfort in the use of a soft helmet to reduce the risk of head injury.
- Many intracranial bleeds occur with no known history of head injury.
- Speak with the Treatment Center for any questions regarding head injury.

**Throat or Neck Bleeding**
Bleeding into the throat or neck can lead to blockage of the airway and be a life-threatening situation. Immediate medical attention is required. Throat or neck bleeds can be caused by:
- an injury
- tonsillitis
- dental work without factor treatment beforehand
- no apparent injury (spontaneous)

**Signs and Symptoms of a Throat or Neck Bleed:**
- swelling of the neck
- choking feeling
- trouble swallowing
- difficulty in breathing
- unexplained, sudden onset of hoarseness

**Treatment**
Bleeding into the throat or neck requires immediate medical attention and clotting factor replacement.

**Follow-Up**
Continued clotting factor replacement is required until the bleeding episode has resolved.

**Other Information**
All injuries of the throat and neck are potentially serious and should be treated promptly and evaluated.

**Gastrointestinal Bleeding**
The gastrointestinal (GI) tract includes the stomach, and small and large intestines. Gastrointestinal bleeding can be caused by:
- an injury to the abdomen
- prolonged, forceful vomiting
ulcer disease
no apparent illness or injury (spontaneous)

Signs and Symptoms of a GI Bleed:
vomiting blood that may resemble coffee grounds
black, tar-like stools
pain in the abdomen
headache, weakness and dizziness on standing, which can be a sign of significant blood loss

Treatment
Gastrointestinal bleeding must be treated immediately with clotting factor replacement. Contact the Treatment Center immediately.

Follow-Up
Contact the Treatment Center if signs or symptoms recur.

Other Information
Abdominal pain should be treated with factor replacement until the cause is found.
Constipation can be associated with small amounts of rectal bleeding. If bleeding continues, contact the Treatment Center.
Continued blood loss, even in small amounts, can lead to anemia.

Joint Bleeding “Hemarthrosis”
Bleeding can occur in any joint of the body, but the joints most often affected include the elbows, knees and ankles. The shoulders, hips and the joints in the fingers and toes can also be affected.

Signs and Symptoms of a Joint Bleed:
stiffness and pain
a feeling of bubbling, tingling or warmth
swelling
inability to bear weight and refusal to use the limb
in a baby, unusual fussiness or crying that cannot be relieved
**Treatment**
Bleeding into joints always requires clotting factor replacement. Pain and swelling may be partly relieved by using ice and acetaminophen (Tylenol®). Avoid weight bearing until pain and swelling resolve.

**Follow-Up**
After treatment with clotting factor replacement, contact the Treatment Center if:
- there is no improvement
- movement continues to be painful
- full movement has not been restored within 24 hours.

Contact the Treatment Center immediately for pain in the hip or groin area, as bleeding into these areas can result in life-threatening blood loss.

**Other Information**
- Bleeding into joints can occur with no visible bruising.
- Untreated or repeated joint bleeding can lead to permanent damage.
- Regular exercise strengthens muscles and can protect joints.
- Special treatment may be needed for hip bleeding episodes associated with pain in the lower abdomen, groin or thigh. Contact the Treatment Center for an immediate evaluation.

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**Synovectomy As Treatment for Chronic Joint Problems in Hemophilia**

**What is a Synovectomy?**
A synovectomy is a surgical procedure that removes the damaged lining of the joint, or synovium. This can benefit individuals with hemophilia who have chronic joint problems. People with hemophilia may experience bleeding into joints. Frequent bleeds into the same joint, often called a “target joint,” can cause the joint tissue, or synovium, to become inflamed. This inflammation can cause pain, swelling, and a loss of range of motion of the joint. The term for this type of inflammation is synovitis and it can lead to changes within the joint that causes erosion of the cartilage, eventual bone damage, and cyst formation.
Ligament and muscle damage may also occur which can lead to loss or motion and contractures in the affected joint.

**Benefits of a Synovectomy**

After the damaged synovial tissue is removed, healthy tissue will grow back. Although a synovectomy can decrease target joint symptoms, it will not necessarily improve the joint’s range of motion. **Other benefits include:**

- Can slow down the progression of joint damage
- May decrease the amount of pain and swelling in the joint
- Can prevent continued joint damage and loss of range of motion

Ideally, a synovectomy is performed early in the development of a target joint, before significant damage occurs to joint cartilage. Once joint cartilage damage occurs it is not reversible. Once joint damage occurs, progressive joint damage (arthritis) may develop despite a synovectomy.

A synovectomy is considered an “elective surgery,” meaning it may be beneficial to you and may improve your quality of life, but does not need to be done at a particular time. Synovectomy surgery is done by an orthopedic surgeon, a physician specializes in surgery of the joints and bones.

**Is a Synovectomy Right for You?**

Your hematologist and orthopedic surgeon can help determine if you are a candidate for a synovectomy. They will consider several factors including whether or not you are having recurrent pain and swelling in the joint, your range of motion in the joint, how your target joint is impacting your daily life and whether or not you may have other complications, such as an inhibitor.

A special radiology test called a Magnetic Resonance Imaging (MRI) of the joint will be done which helps the hematologist and orthopedic surgeon evaluate the extent of synovitis, cartilage or ligament damage. Other considerations include the status of your health and your willingness and ability to complete the post-operative care that is required after a synovectomy.

**Points about the Procedure**

Most synovectomies are done arthroscopically. An arthroscopic synovectomy involves the surgeon making small incisions around the joint and removing the
damaged tissue with a special device through the small incisions. You will be put to sleep (general anesthesia) for the procedure. Advantages of this type of surgery include decreased recovery time and less post operative pain than with an open synovectomy, in which a larger incision is made into the joint to allow the surgeon to remove the damaged tissue.

Factor is given before and after the surgery to prevent bleeding.

The goal of factor replacement therapy after surgery is to keep a person's factor level in the normal range for several days after surgery. This prevents bleeding at the surgical site. Most people will require factor once or twice daily during this period after surgery. Due to the frequency of factor, a special catheter, called a PICC (peripherally inserted central catheter) may need to be placed before or after surgery for intravenous access.

A 2-to 3-day hospital stay is usually required so that clotting factor levels can be carefully monitored. Physical therapy plays a key role in synovectomy success. Physical therapy will usually start within a week of the surgery and usually continues for up to 6 to 8 weeks after surgery.

Your Comprehensive Care team at the Hemophilia Treatment Center can help you further explore these questions. It is important to carefully consider all aspects of the procedure when making a decision as to whether or not a synovectomy may be the right choice for you.

**Iliopsoas Bleeding**

The iliopsoas muscle group is located in the pelvis and connects the lower spine and upper thigh, allowing for leg movement and rotation. With iliopsoas bleeding, significant blood loss can occur before the onset of symptoms.

**Signs and Symptoms of an Iliopsoas Bleed:**

- pain in the hip, groin, abdomen, buttocks, lower back or thigh
- pain when the hip is straightened
- numbness or tingling along the outside of the upper thigh
**Treatment**
Bleeding into iliopsoas muscle group always requires clotting factor replacement. Iliopsoas muscle bleeds are usually confirmed by an ultrasound or CT scan. Hospitalization may be required.

**Follow-Up**
After treatment with clotting factor replacement, contact the Treatment Center if:
- pain recurs
- mobility is limited.

**Other Information**
- Untreated iliopsoas bleeds can lead to significant blood loss and permanent damage.
- Iliopsoas bleeding can be mistaken for a hip bleed, appendicitis or a pulled groin muscle and must be properly identified.

**Nosebleeds**
Nosebleeds are a nuisance but rarely require treatment. Nosebleeds may occur spontaneously or result from injury or nose-picking. Dry air, allergies and respiratory illnesses also can aggravate the problem.

**Treatment**
Standard first aid procedures to control nosebleeds include:
- gently blowing out any loose clots
- pinching the soft part of the nose just above the nostrils with the thumb and forefinger for 10 minutes. Pinching the hard bone or cartilage on the bridge of the nose is not helpful.

**Follow-Up**
If bleeding persists for longer than 30 minutes, contact the Treatment Center.
Other Information
- Tilting the head forward may reduce swallowing blood, which can upset the stomach.
- To reduce the risk of nosebleeds during dry, winter months, keep nasal membranes moist with saline nose drops, nasal saline gel and use a vaporizer or humidifier to keep the air moist.

Muscle Bleeding
Bleeding most commonly occurs in the muscle groups of the shoulder, upper arm, forearm, thigh and calf. In these areas, bleeding is usually associated with swelling or pain.

Signs and Symptoms of a Muscle Bleed:
- difficulty or pain with movement; small children may refuse to use the limb
- a feeling of warmth or tightness in the muscle
- numbness or tingling, which may be described as feeling “asleep.”

Treatment
Bleeding into muscles requires clotting factor replacement. Pain and swelling may be relieved by elevating the injured limb and by using ice and acetaminophen (Tylenol®).

Follow-Up
After treatment with clotting factor replacement, contact the Treatment Center if:
- movement continues to be painful
- full movement has not been restored within 24 hours.

Other Information
- Bleeding into muscles can occur with no visible bruising.
- Untreated muscle bleeds can lead to long-term nerve or tissue damage.
- Regular exercise strengthens muscles and can decrease bleeding episodes.
- Contact the Treatment Center immediately for bleeding into the forearm or calf. Untreated bleeding into these areas can cause damage by compressing vital nerves and blood vessels.

Mouth Bleeding
Mouth bleeding can occur from an injury to the gums, tongue or cheek. Mouth bleeds that persist for longer than 30 minutes, or stop and start again, require treatment.
Treatment
Clotting factor replacement and Amicar®, an oral medication that prevents the breakdown of clots in the mouth, are necessary for persistent mouth bleeding. Amicar® is used only after administering clotting factor replacement.

Follow-Up
- A cool, soft diet is suggested.
- To prevent dislodging clots, the use of straws is discouraged.
- Tooth brushing may irritate the injured area.
- Using a swab to clean the teeth may be helpful.
- Contact the Center if mouth bleeding continues or recurs.

Other Information
- Consult the Center for dental work that requires an anesthetic injection, because clotting factor replacement may be necessary.
- Swallowing blood can upset the stomach.
- The loss of baby teeth rarely requires treatment. To reduce the risk of mouth bleeds, maintain good dental care and hygiene and avoid placing hard objects like pencils or paper clips in the mouth.

Bruising
Bruising refers to a small amount of bleeding under the skin and can be associated with a small “knot” that can be felt in the center of the bruise. Bruising is common in persons with hemophilia.

Treatment
Clotting factor replacement is not needed for most bruises. Contact the Center if pain or swelling increases or persists.

Follow-Up
As a bruise disappears, the bluish color may fade to a green or yellow appearance.

Other Information
Bruises commonly occur on the head, trunk and extremities of children with hemophilia.
Cuts and Scrapes
Minor cuts and scrapes are usually associated with only a small amount of bleeding, and clotting factor replacement is usually not necessary. Cuts (lacerations) that require stitches (sutures) always require replacement therapy.

Treatment
Standard first aid procedures may be followed for cuts that do not require stitches:

- Clean the injured area with soap and water.
- If bleeding occurs, apply firm pressure for several minutes.
- Apply a bandage with an antibiotic ointment and change daily or more often as necessary.
- Clotting factor replacement is necessary before suturing a laceration. Contact the Center.

Follow-Up
To promote healing, keep the area clean and dry. Clotting factor replacement is necessary for three to five days after stitches to prevent recurrence of bleeding into the wound.

Other Information
Contact the Center if bleeding persists or signs of infection develop, such as redness and swelling.
Chapter 3: Hemophilia in the First Year of Life

There are several issues that are unique to caring for a child with hemophilia. Parents may encounter certain challenges related to having an infant with a bleeding disorder. However, being prepared for possible difficulties related to your child’s developmental stage will help to reduce stress.

Teething
Infants usually start teething between three and seven months of age. Teething can occasionally cause mouth bleeds. Mouth bleeds can occur from a small cut on the gums or tongue or a tear in the frenulum (the skin that attaches the upper lip to the gums). Mouth bleeds can also be cause from babies teething on hard or sharp objects or from the eruption of new teeth.

If a mouth bleed occurs, your child may have red drool. It is important to check your child’s mouth to see where the bleeding is coming from. If your child is bleeding more or the bleeding does not stop for several hours, you should contact the Hemophilia Treatment Center for an evaluation. Amicar®, an oral medicine that prevents breakdown of clots in the mouth, may be ordered by your child’s doctor to treat a minor mouth bleed. If your child has a tongue bleed, you should call the hematologist right away. Because the tongue is used for drinking, eating and sucking, the tongue can continue to bleed. Tongue bleeds or bleeding of the floor of the mouth will require factor replacement.

You should start taking your child to a dentist at the time that the baby teeth start to erupt.

Immunizations
The Centers for Disease Control (CDC) guidelines on immunizations are followed by our treatment center. You can have your child’s immunizations done at the hematology clinic or the primary care doctor. Vaccines should be administered under the skin rather than between the layers of the skin or in the muscle unless a dose of factor is given before the vaccine is given. It is helpful to have an icepack applied to the injection area for five minutes before the immunization is given and pressure...
should be applied to the vaccination site for five minutes afterward. Treatment for immunizations can vary. Please check with your child’s hematologist before he or she receives immunizations.

**Safety and Injury Prevention**

Babies and toddlers learn to interact from their environment and this is very important to their growth. As they learn to crawl, stand and walk, they are going to fall down and potentially get bruised. You can take a few steps to prevent serious injuries while also allowing your child to continue to play and explore.

**Protective Gear and Childproofing**

The Hemophilia and Thrombosis Center can provide your child with knee and elbow pads to prevent your child from getting injured as he or she learns how to crawl and walk. We also offer a soft helmet for children who are at risk of a head injury or bleed as they are learning to balance themselves.

There are various forms of childproofing that can be useful for reducing injuries for your child. Padding can be taped or glued to sharp table and counter edges. The railings of cribs can also be padded to prevent injuries. Baby gates should also be used around stairs to prevent falls. Several different childproofing items are sold at a discounted price at the CCHMC gift shop.

**Medic Alert System**

The Tri-State Bleeding Disorder Foundation, the local bleeding disorder chapter, offers medic alert bracelets to all children with a bleeding disorder who are patients of Cincinnati Children’s. A medic alert bracelet has information about your child’s medical condition and a 24-hour number that an emergency medical professional can contact for more information. Please contact your child’s nurse coordinator if you are interested in getting a medic alert bracelet for your child.

**Yellow Cards**

Your child’s nurse coordinator will provide you with a yellow card with information about your child’s type of bleeding disorder, contact information for the hematologist at Cincinnati Children’s and information about the type of factor of medication your child is treated with for bleeding.
Travel
Traveling with young children can be a challenge, but with some planning and preparation, it can be made easier. Below are some tips to prepare for traveling and make the experience of traveling easier.

- Always remember to bring your child’s yellow card and travel letter with you while traveling. Please see Chapter 7 and speak to your child’s care team for instruction on how to obtain a travel letter.
- Remember to bring all your child’s medications, including factor, and to bring any medical supplies your child will need throughout the trip.
- Travel with your child’s car seat for plane rides and car trips. Bring any childproofing supplies, such as table padding and outlet covers, to give your child a safe environment to explore while on a trip.
- Visit the World Federation of Hemophilia’s website (www.wfh.org) for a listing of hemophilia treatment centers in the United States and around the world before you travel. Bring the contact information for the treatment center that is closest to your destination(s).

Childcare
It is important to educate the person that will be providing childcare for your child with hemophilia, whether it is a babysitter, childcare center or teachers. Below are some suggestions on educating your child’s caregivers or teachers about hemophilia.

- Provide your child’s caregiver with information about the signs of a bleed and basic first aid. Please refer to NHF’s First Aid for School Personnel pamphlet included with this handbook for more information on these topics.
- Develop a plan for emergencies and share this with your child’s caregiver. Let him or her know that all head injuries are considered an emergency and 911 must be called when a head injury occurs. An emergency plan can be written or typed out and can include information about your child’s diagnosis and emergency contact information for parents and family members.
- The hemophilia team can assist with educating your child’s caregiver or teachers with information about his or her diagnosis by doing a school or childcare visit. Please contact your child’s nurse coordinator if you are interested in scheduling a school visit.
Helping Your Child Cope
Here are four ways you can help your child with encouraging self-control during their healthcare journey.

1. **Rituals**: behaviors that are always performed in the same way for the same event. Rituals need to be consistent and caregivers should always be honest.

2. **Direct Participation**: letting your child participate in his or her healthcare needs at a level that is safe to his or her age or developmental level. This helps your child gain independence in his or her care and helps him or her feel less dependent on the caregiver. Just remember to offer a choice to help with a choice really exists.

3. **Medical Play** allows your child to use his or her imagination and provides the opportunity for mastering a skill. Allowing your child to manipulate the equipment that is part of their medical play allows for a sense of control. Medical play teaches concepts and explores feelings around having a health condition.

4. **Rewards** are small gifts or awards given to recognize an achievement. Small gifts can help challenge a child to strengthen his or her self-control. Once your child has started to show more self-control, it is time to start weaning your child from expecting rewards. Using a chart to mark the milestones for rewards is a good visual tool. Once you start weaning the rewards, try to space out the time between rewards. Ideas for rewards include a special treat, an extra activity, going out somewhere like the part or an inexpensive toy.

Just remember that children mirror the behavior and attitude of their caregiver. You are your child’s mirror and he or she will gain self-esteem and self-control from watching and interacting with you.

If you have any questions or need support, please feel free to contact a Karen Martin, Child Life Specialist, at 513-636-3791.
Chapter 4: Exercise and Fitness

Being physically active is encouraged for children and teens with hemophilia. Getting regular exercise helps to maintain a healthy body, increases self-esteem and provides the opportunity for kids to socialize and set goals. Being physically active can build strong muscles, which can reduce stress on joints. Exercise improves balance and coordination and improves flexibility. In addition, it can improve sleep, increase energy and help people feel better emotionally.

People with hemophilia may experience a decrease in bone density. With this in mind, weight-bearing activities like walking, hiking and weightlifting (for teens and young adults) that promote the development and maintenance of good bone density should be encouraged to the extent that joint health permits.

Choosing an Activity or Sport

There are a great variety of sports to choose from, so choosing the right sport to reduce any possible risk is very important for someone with hemophilia. Swimming, for example, is a great sport for people with hemophilia. It makes muscles strong, is aerobic activity, and it does not put stress on the joints. Having a variety of interests is beneficial in case one sport or activity becomes unsafe because of injuries.

Before participating in any activity, you and your child should meet with his or her hematologist and physical therapist to choose the best sport or activities for your child to participate in.

- A sport should be chosen based on several factors, including any target joint or muscle problems that your child has, where your child has had bleeds and how often and intensely your child will participate in the activity.

- High collision and high contact sports, such as football, lacrosse, rugby, ice hockey or wrestling are not recommended for children and teens with hemophilia.
For more information on the risks and safety of specific activities, please read the National Hemophilia Foundation’s *Playing it Safe* manual. For an online version of this manual, visit the National Hemophilia Foundation's website at [www.hemophilia.org](http://www.hemophilia.org). Click on the “Learn About Coagulation Disorders” tab, pull down and click on “Resources” and then click on the link for a list of NHF Publications. Please contact the Hemophilia Treatment Center for a copy of the manual.

**Prophylaxis and Protection**
- If your child is on prophylactic factor infusions, you should speak to your hematologist about scheduling your child’s infusions around sports activities to ensure safe coverage.
- If your child has any target joints, they can be protected by braces or splints during activities.

**Treating Sports Injuries**
- Children and parents must know how to recognize and treat a bleed that may occur from physical activity. For a child with hemophilia, playing through an injury could lead to permanent joint damage. Children should be encouraged to let parents, teachers or coaches know immediately if they think they might be injured.
- It is very important that the coaches are aware of your child’s bleeding disorder. Parents should also be present at sporting events.
- When an injury occurs, factor replacement may be needed. Use the RICE plan (Rest, Ice, Compress, Elevate) and contact the Hemophilia Treatment Center.
- If a head injury is suspected, seek medical care immediately. All suspected intracranial bleeds require immediate clotting factor replacement. Confirmed bleeds require hospitalization.

**Exercising After A Bleed**
Injuries need time to heal. Your child should not participate in any vigorous activity while the injured joint or muscle is healing. Major injuries can occur in children who return to sports too soon after a minor injury. Your child’s hematologist and physical therapists can help determine when it is safe for your child to return to full activities.
Chapter 5: Hemophilia Research at Cincinnati Children’s

The Hemophilia Treatment Center at Cincinnati Children’s Hospital Medical Center conducts many clinical trials nationally and internationally, helping to improve effective treatment for people with hemophilia. A clinical trial, sometimes referred to as a research study, is a carefully designed test of the effects of medication, medical treatment or a device in a specific group of volunteers. By becoming involved in clinical trials, your Hemophilia Treatment Center is able to better understand diseases as well as develop new ways to prevent or treat health problems in patients with hemophilia. Without clinical trials, doctors cannot know how to best treat patients safely and effectively.

What are the benefits of participating in a clinical trial?
A clinical trial may benefit patients with a particular illness. Clinical trials may prove whether a treatment is effective or not, what doses are needed and what negative side effects can happen when a new drug or treatment is given.

- Trial participants may learn new information about their conditions.
- Clinical trials offer new treatment opportunities to patients who have explored all other avenues.
- Participating may mean an opportunity for access to a drug that has not yet been approved by the Food and Drug Administration.

How can a patient participate in a clinical trial?
Deciding whether to participate in a clinical research trial is an important decision.

- Participation is always voluntary and a choice which must be made through informed consent by the patient or by the parent(s)/guardian(s) is the patient is a child.
- Patients and parents are encouraged to ask questions and feel comfortable and informed about the process.
- Trial participants may withdraw from a trial at any time.
- Patients under 18 years old need parental consent.
- Not all patients can be eligible for research studies.
What else do I need to know about clinical trials?
During a clinical trial, your treatment center must comply with strict local, hospital and federal guidelines. These guidelines are designed to be sure you understand your or your child’s role in the study and that the possible benefits of participation are greater than the risks. Each trial has different requirements for time involved, clinic visits, test and hospital stays, Patients receive personal expert attention and individualized care.

Where can I find out more information about clinical trials?
To learn more about Cincinnati Children’s clinical trials, visit www.cincinnatichildrens.org/clinical-studies, email clinicalstudies@cchmc.org or call 513-636-0098.
# Chapter 6: Telephone Directory

**Hemophilia and Thrombosis Center**  
Ralph A. Gruppo, MD  
Eric Mullins, MD  
Cristina Tarango, MD  
Anne Blackmore, Nurse Care Manager  
Kim Davis, Nurse Care Manager  
Nancy Dodson, Clinic Nurse  
Carrie Moore, Nurse Care Manager  
Erin Weigel, Hemophilia Nurse Care Manager  
Amy Grant, Hemophilia Nurse Care Manager  
Marina Bischoff, Social Worker  
Lisa Littner, Social Worker  
Karen Martin, Child Life Specialist  

**Hospital Operator**  
513-636-4200

**Toll Free Hospital Operator**  
1-800-344-2462

**Outpatient Clinic**  
513-636-8790

**Division of Pediatric Dentistry**  
513-636-4641

**Division of Physical Therapy**  
Molly Mays, Physical Therapist  
513-636-4651

**Billing/Credit Department**  
Outpatient Services  
513-636-4427

Inpatient Services  
513-636-4734

Physician Services  
513-636-4772

**Financial Counseling**  
513-636-0201

**Insurance Authorization Specialist**  
513-803-6170

**Factor Program**  
Dennis Eling, Pharmacist  
Tracy Matheny, Factor Program Rep.  
513-803-5296

**Human Genetics**  
Martha Walker, Genetic Counselor  
513-636-4351
Chapter 7: Visiting the Clinic

Visits to the Hemophilia Clinic: The Importance in Hemophilia Care

Your hemophilia clinic visit is an important part of comprehensive care. The following questions and answers help to show why “clinic” is so important.

What is the comprehensive care visit?

Comprehensive care for the person with hemophilia is defined as continuing supervision of all medical and psychosocial aspects affecting your child and your family. Care is provided by a team of professionals, including a hematologist, physical therapist, nurse coordinator, clinic nurse and nurse practitioner, social worker, educator, psychologist, geneticist and dentist. Other specialists such as orthopedic surgeons are available as needed. Comprehensive care serves various needs of persons with hemophilia including:

- an accurate diagnosis
- ongoing general and holistic preventative medical care
- physical fitness
- prevention and treatment of muscle and joint problems
- dental care
- education about hemophilia, health and child development
- genetic counseling
- solving individual and family problems
- financial counseling
- school conferences
- vocational counseling
- home visits

Why is the hemophilia clinic visit so important?

The comprehensive care model, which was developed more than 30 years ago, has significantly improved the lives of people with a bleeding disorder. People who receive treatment at a hemophilia comprehensive care center have a lower rate for bleeding complications. A comprehensive care program offers cost effective care long term. This program is also very convenient for patients and families.
The hemophilia clinic is a time when your child will see a hematologist. Your clinic visit will help make us aware of your child’s current hemophilia status and needs. A summary of your child’s medical visit is sent to your private pediatrician or family physician.

Since the goal of comprehensive care is to treat the whole person—not just the hemophilia—the team members at the Hemophilia and Thrombosis Center have experience and are trained to assist you with the many questions you may have. The clinic visit may be a time to address these concerns.

**What blood work is usually done at the routine clinic visit?**
In order to help us evaluate your child, we conduct periodic blood studies. These include a blood count, liver and hepatitis tests, and clotting studies with inhibitor screen.

The liver tests and hepatitis studies are important because hepatitis (an inflammation of the liver) is potentially transmitted through blood and blood products. Persons with hemophilia who have received treatment with these products in the past may be at risk. The development of an inhibitor is a complication of hemophilia in which an antibody in the blood neutralizes the clotting factor that is infused.

**What is a joint survey?**
Starting at the age of five, your child will begin to receive an x-ray during a comprehensive clinic visit. This x-ray is done every five years is used to assess the health of the patient’s joints.

**Education about Hemophilia**
When your child comes to comprehensive clinic, the nurse coordinator will ask questions related to you and your child’s knowledge of hemophilia. The comprehensive clinic visit helps guide the Treatment Center Staff toward creating educational goals to better help your child and you learn about their bleeding disorder, promote health maintenance and plan for the future. The goal of hemophilia care is transition to independent self-care. As a parent or patient, these discussions can be an opportunity to give input on planning for the future as it relates to you and/or your child’s bleeding disorder.

**What if my child must miss school to come to clinic?**
The hemophilia team is sensitive to the importance of regular school attendance for all children, particularly the child with hemophilia, who may miss more school than average due to bleeding episodes.
In general, clinic appointments are scheduled every 6 to 12 months for most children. Those under the age of 2 are seen in the comprehensive care clinic more often. Those with particular problems, such as frequent joint bleeds may need to be seen more frequently. We will try to avoid unnecessary visits.

**In Summary**
The routine clinic visit allows us to evaluate your child and for you as a parent to voice any concerns you may have. It is important to keep these scheduled visits to ensure that your child is receiving the best treatment available. Please use this time to ask any questions you might have about your child's treatment.

**Campus Map**
A map and the address of Cincinnati Children’s Campus follows. A more detailed map is available at [www.cincinnatichildrens.org/patients/visit/directions/burnet/default](http://www.cincinnatichildrens.org/patients/visit/directions/burnet/default) or at the Family Resource Center.

**Main campus (Burnet Avenue) location and phone number:**
3333 Burnet Avenue
Cincinnati, OH  45229-3039
Phone: 513-636-4200
Hemophilia and Thrombosis Center
Staff and Service Team Members

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hematologist</td>
<td>The pediatric hematologist is an expert in the care of children and young adults with blood disorders. The hematologist will oversee your comprehensive hemophilia care.</td>
</tr>
<tr>
<td>Nurse Coordinator</td>
<td>The nurse coordinator is the link between the person with hemophilia and other members of the Treatment Center team. The nurse will help you arrange routine tests, visits and medical referrals. The nurse coordinator is always available to discuss your concerns about your child.</td>
</tr>
<tr>
<td>Hemophilia Clinic Nurse</td>
<td>The clinic nurse is a registered nurse specially trained to evaluate bleeding episodes, administer treatments and instruct families on home therapy.</td>
</tr>
<tr>
<td>Social Worker</td>
<td>The social worker is knowledgeable about community services as well as financial related resources. With special training in individual, family and group counseling, the social worker can offer support to children and families dealing with a chronic illness across the lifespan.</td>
</tr>
<tr>
<td>Genetic Counselor</td>
<td>The genetic counselor provides information to families about inherited conditions and counsels families about hemophilia carrier testing and availability of prenatal diagnosis of hemophilia.</td>
</tr>
<tr>
<td>Nutritionist</td>
<td>The nutritionist assists with nutritional assessments, dietary counseling and meal planning. The nutritionist is available to consult with the patients and families during the comprehensive clinic visit.</td>
</tr>
</tbody>
</table>
Physical Therapist  At the comprehensive clinic, the physical therapist assesses physical conditioning as well as assesses joint and muscle health. The physical therapist plans individual programs for maintaining healthy muscles and joints. An annual physical therapy assessment will evaluate joint health.

Orthopedic Surgeon  The comprehensive clinic uses the services of an orthopedic surgeon, familiar with the effects of hemophilia on the bones, muscles and joints. The orthopedist prescribes physical therapy or may suggest surgery to correct muscular or joint complication from bleeds.

Dentist  A dentist from the Division of Pediatric Dentistry is available during the comprehensive care visit to coordinate each child’s dental care.

Psychologist  The psychologist is available to support patient and parents regarding diagnosis, treatments, or hospitalizations. The psychologist also works with families on pain management, medication and treatment adherence and behavioral concerns. Families can schedule time with the psychologist on the same day as their medical clinic appointments or the families can schedule an appointment with the psychologist in clinic.
Personalized Services

Home Visits  The nurse coordinator works closely with families and offers home visits. Home visits can be particularly helpful to the family of a child newly diagnosed with hemophilia. Home visits are arranged around the family’s schedule and may include friends and relatives. The home visit allows an informal opportunity to ask questions about hemophilia.

School Visits  As a part of comprehensive care, the hemophilia team assists families by providing schools with information about hemophilia. Personalized visits by the nurse coordinator and social worker are also available to help the school learn more about hemophilia.

School Intervention Services  The hemophilia team assists children with special school needs such as tutoring, transportation and development of individual education plans. Career and vocational planning resources and scholarship information are also provided.

Travel Letter  Before traveling, we suggest that you call the nurse coordinator to ask for a travel letter. This letter verifies your child’s hemophilia type and treatment. If you must visit a hospital or emergency room while out of town, medical information in the letter can help facilitate your child’s care. We can also provide a list of the hospitals nearest your travel route that offer hemophilia treatment. (Please provide two weeks’ notice before traveling to request this letter.)

Emergency Identification  You will receive an individual identification card stating your child’s type of bleeding disorder, severity, appropriate treatment and factor dosage, allergies and other specialized medical information. This card will be updated at clinic visits. We suggest providing this card to medical staff if your child needs to visit the hospital or emergency room. We can also assist with ordering a medical alert ID for your child.
Additional Medical Services

Dental care
All children need good dental care to prevent problems later in life. We recommend that your child's first dental check-up occurs between ages 2 and 3. By encouraging good eating habits, daily brushing routines and regular check-ups, you can prevent many problems. Options for your child’s dental care include:

- your family dentist
- Cincinnati Children's Division of Pediatric Dentistry, located on the 5th floor of Location C. Phone: 513-636-4641

Whatever your choice, it is important to let your dentist know about your child’s hemophilia so that dental care can be coordinated with your child’s individual hemophilia needs.

Physical therapy
As a result of hemophilia, bleeding may occur into joints and muscles. Physical therapy can help develop and maintain well-conditioned muscles and joints to protect against bleeding. An individualized physical therapy program will help maintain healthy joints and muscles by:

- Strengthening muscles to support and protect the joints
- Targeting weaknesses in muscles and joints and developing exercises to improve the fitness level
- Improving flexibility and a sense of balance to help physical coordination and avoid injury.

Rehabilitation is the process that restores flexibility or rebuilds an injured joint or muscle. Physical therapy plays an important part in the rehabilitation process by:

- Reducing pain and discomfort.
- Reducing the time of immobility.
- Utilizing and monitoring assistive devices such as braces and splints.

A physical therapist knowledgeable about hemophilia care attends comprehensive clinic. The physical therapist is also available to evaluate your child if special needs arise. The physical therapist is specially trained to assist with planning for sports and other physical activities. Physical therapists are also skilled in teaching pain control and exercise methods. The therapist designs a program for the whole person—to meet individual needs and lifestyle choices—and can assist in motivating and encouraging the continuation of therapy and the selection of sports or extracurricular activities.
The Physical Therapy Department of Cincinnati Children’s is located on the 4th floor of 3430 Burnet Avenue. They can be reached at 513-636-4651.

**Home Factor Infusion Care**
A variety of home care services are available, including:

- delivery of coagulation factor and home factor infusion supplies for families on the home infusion program
- home delivery of coagulation factor (concentrate) for use in the emergency department or while traveling
- nursing services for the administration of coagulation factor service and other specialized needs

**The CCHMC Factor Program**
Cincinnati Children's Home Care Pharmacy Factor Program is committed to making hemophilia care a small part of your life. The Factor Program provides low cost, high quality health care services to patients with bleeding and clotting disorders. You will receive personalized services from our experienced, professional staff to help you manage hemophilia using factor replacement therapy at home.

The Factor Program staff consists of pharmacists, family financial advocates, insurance authorization specialists, home care nurses specialized in hemophilia care, and the factor program representative to provide support and services to you and your family. The Factor Program staff has a close working relationship with your Cincinnati Children’s Hemophilia Treatment Center team to ensure continuity of care, consistency in service and easy access for patients and families.

The CCHMC Factor Program includes:

- home delivery of infusion-related supplies and factor concentrates
- same day delivery
- 24/7 service and support
- supervisory expertise of a registered pharmacist
- regular contact with patients and families.
- a full range of factor concentrates and vial sizes
- pick-up and disposal of infectious waste, including needles, syringes and empty vials
- financial counseling
- assistance with insurance claims
- nurses specializing in hemophilia care who can assist with in-home infusions
The Factor Program Benefits the Hemophilia Community
The CCHMC factor fund is a non-profit organization and purchases factor at a discounted rate through the Public Health Service Act (340B Program). As a result, the cost of purchasing factor is lower, allowing the factor program to pass savings along to patients, their families and to their insurance providers. Proceeds from the CCHMC factor program directly support a wide range of comprehensive services.

These services include:
- Providing funds that support the Hemophilia Treatment Center care team providers, including physical therapy, dental exams and social work.
- Supporting Hemophilia summer camp.
- Partnering with and supporting state and local hemophilia chapters to provide patient and family education and outreach services.

Hours
Monday-Friday
8:30 a.m. - 5:00 p.m.

After hours
Please call (513) 636-4200 and ask for the Home Care Factor Pharmacist on call.
Chapter 9: Emergency Treatment

How to get treatment when your child has a bleeding problem:

**Weekdays:**
The outpatient clinic is open to care for your child Monday through Friday from 8:30 a.m. to 4:00 p.m.

Please call one of the hemophilia nurse care managers before you come to the clinic so arrangements can be made for your child's treatment while you are on your way.

**Evenings, Weekends and Holidays:**
Treatment is available through the hospital emergency department. Call the hospital operator at 513-636-4200 and ask for the hematologist on call before coming to the emergency room.

Bring your emergency identification card when visiting the emergency department. This will provide information for the emergency department staff about your child’s bleeding disorder and the treatment. If possible, bring your child’s home factor supply with you. This can expedite treatment.
Chapter 10: While at the Hospital

Places to eat
The hospital cafeteria is located on the first floor of Location D. Various food options are available 24 hours a day, 7 days a week.

Helpful things to know
Automatic teller machines (ATM) are located on the first floor of Location C. Postage stamps may be purchased through some of the ATMs.

The gift shop is located on the first floor of Location C near the cafeteria. The hours are Monday through Friday, 9:00 a.m. to 6:00 p.m.; Saturday and Sunday, 12:30 to 3:30 p.m. Stamps may be purchased by the book at the gift shop.

The outpatient pharmacy is located on the first floor of Location B. Hours are Monday through Friday, 9:00 a.m. to 8:00 p.m.; Saturday and Sunday, 10:00 a.m. to 2:00 p.m. The pharmacy is closed on all major holidays. Phone: 513-636-8808.

The Cincinnati Children’s chapel is available for use. It is located on the first floor of Location A near the end of the hallway.

There is a US Postal Mailbox located just outside of the Location B Welcome Center.

No smoking is permitted anywhere on the medical center grounds. No cigarette machines are available.
If your child is admitted to the hospital
Visiting hours are 8:30 a.m. to 8:30 p.m. on most floors. Parents have unlimited visitation and siblings may have special visits arranged. Please check with your child's nurse on the unit for specific visitor guide.

The Ronald McDonald House is available for families who need to find lodging near the hospital. Check with Guest Services for specific information at 513-636-5009. There are also several other hotels nearby that offer discounts for families being treated at Cincinnati Children's Hospital.

Meal bags for parents are available on many inpatient units for a small fee. Ask your nurse for ordering information.

Cincinnati Children's has an outstanding Child Life Activity Program. The division provides activities for patients to ease the stresses of being away from home, while recognizing the fears and concerns that come from being hospitalized. Ask your nurse or call the Child Life Division at 513-636-8855.

A teacher from the Cincinnati Public Schools is available to help your child with class assignments, if medical treatments permit. Ask your nurse for more information.
Chapter 11: Patient Rights and Responsibilities

Patients and parents / guardians have the right:

• To have a family member or representative of your choice and the patient’s physician notified promptly of the patient’s admission to the hospital;
• To be treated considerately and respectfully regardless of the patient and/or family’s race, religion, sex, sexual orientation, gender identity/expression, cultural background, economic status, education or illness;
• To know the names of your child’s physicians and nurses and the role they play in your child’s care;
• To be told by the physician, in words you can understand, about your child’s illness, treatment and prospects for recovery;
• To receive as much information as you need in order to give or refuse consent for any proposed treatment;
• To have an active role in decisions about your child’s medical care, including the development and implementation of the care plan, which shall include the management of pain as appropriate;
• To make an informed decision regarding care including, to the extent allowed by law, the refusal of care;
• To privacy in medical care and treatment; this includes the right to be informed why individuals who are not directly involved in your child’s care are present when your child is being treated or discussed and personal privacy in general;
• To receive care in a safe setting, free from all forms of abuse or harassment;
• To confidential treatment of all communications and records regarding care received at Cincinnati Children’s; to access information in the medical record in a reasonable time frame pursuant to Cincinnati Children’s policy and procedure;
• To be aware and informed if Cincinnati Children’s feels that legal action is necessary to provide treatment for your child;
• To receive a clear explanation of the outcome of any treatments or procedures where the outcomes differ significantly from the anticipated outcomes;
• To expect a response to any reasonable request for help in meeting special needs;
• To remove your child from the hospital even when the physicians advise you not to, to the extent permitted by law; if you choose to remove your child from the hospital, you will be required to sign a form that relieves Cincinnati Children’s of responsibility for your child’s welfare;
• To know about any connections between Cincinnati Children’s and other institutions, as far as your child’s care is concerned;
• To consent or refuse to participate in any research project;
• To know your child’s continuing healthcare needs after discharge from the hospital or outpatient service;
• To know the charges for services provided, to examine your medical care bills and to receive an explanation of charges.

Patients and parents / guardians have the responsibility:
• To provide, to the best of your knowledge, accurate and complete information about all matters relating to your child’s health;
• To the extent allowed by law, to both formulate advance directives and expect the hospital staff and practitioners who provide care will comply with these directives;
• To be considerate of other patients and staff and to encourage your child’s visitors to be considerate as well;
• To pay for services provided, and/or to provide necessary information to process insurance claims related to your child’s hospital and outpatient service bills, and to plan for payment of your child’s healthcare bills as soon as possible;
• To discuss with a financial counselor the possibility of financial aid to help in the payment of your child’s hospital and outpatient bills in cases of financial hardship (contact our financial counselor at 513-636-0201);
• To follow the treatment plan recommended by the practitioner and agreed upon for your child’s care;
• To follow Cincinnati Children’s policies and procedures concerning patient care and conduct;
• To seek information, to the extent possible, from healthcare providers by asking any questions necessary to reach an understanding of your child’s health problem(s) and the treatment plan developed by you and the practitioner.
Chapter 12: Additional Resources

The Tri-State Bleeding Disorder Foundation
The Tri-State Bleeding Disorder Foundation is a nonprofit organization with an almost 40 year history of providing support, programs, and services to the bleeding disorder community of Greater Cincinnati, Northern Kentucky, and Southeast Indiana. They aspire to improve the quality of life for children and families living with bleeding disorders. Currently, the Tri-State Bleeding Disorder Foundation serves 16 counties, assisting more than 500 patients and their families. Visit their website at www.tsbdf.com for more information. They can be reached at 513-961-4366 or hemophilia@fuse.net.

National Hemophilia Foundation
The National Hemophilia Foundation (NHF) is the coordinating agency of all state and local chapters. NHF funds major hemophilia research, advocates for governmental reforms, organizes support networks, and develops hemophilia-related literature. NHF also sponsors an annual meeting that incorporates both families and professionals. Most topics of interest are discussed at this meeting and new treatments and procedures are reviewed. Visit their website at www.hemophilia.org or call them at 1-800-42HANDI for more information.

HANDI
HANDI is the 24-hour information center of the National Hemophilia Foundation. The center collects and makes available information on hemophilia, von Willebrand Disease, and other bleed disorders. The HANDI staff members are available to answer live requests Monday through Friday, 9:00 AM to 5:00 PM Eastern time, toll free by dialing 1-800-42HANDI. Requests for information can also be sent by fax (212-328-3799), or email at handi@hemophilia.org. HANDI provides wide range of educational materials to consumers in both English and Spanish and many of them can be accessed online by visiting the National Hemophilia Foundation's website at www.hemophilia.org.
World Federation of Hemophilia
The World Federation of Hemophilia (WFH) is an international, not for profit organization with a global network of patient organization in 122 countries. Their website contains a database of hemophilia treatment centers throughout the United States and around the world. WFH’s website also has medical information about the various bleeding disorders and information about different programs available to improve the care of hemophilia around the world. For more information visit their website at www.wfh.org.

Hemophilia Federation of America
Hemophilia Federation of America (HFA) is a non-profit organization focused on consumer advocacy within the hemophilia community. HFA offers resources and support for individuals with a bleeding disorder and their families. HFA offers programs to improve awareness and education of bleeding disorders. Visit their website at www.hemophiliafed.org for more information. They can be reached by calling 1-800-230-9797 or info@hemophiliafed.org.