

— HF Healthcare presents —

BACK 2 SCHOOL GUIDE

{ What you need to know }



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504 Plan & Your Child

— *What is a 504 Plan?* —

Section 504 is a part of the Rehabilitation Act of 1973 that prohibits discrimination based upon disability. Section 504 is an anti-discrimination, civil rights statute that requires the needs of students with disabilities to be met as adequately as the needs of the non-disabled are met. For more information on section 504, please call our office at (805) 981-1171.

*The keys to successfully requesting a 504 Plan for your child mean that you stand **FIRM** in the following:*

Facts about your child

How does your child's bleeding disorder impact their schooling?

What will your child need to be successful?

- How to get missed school work?
- In-home tutoring?
- Modified Physical Education?

Immediately ask for formal meeting with school and district staff

Request a meeting in writing to make a 504 plan

- Include school officials: principal, teacher(s), school nurse
- Check with the district office or website for their policy on other people to be included

• INCLUDE THE DATE

The district office or website can give you the legal details of how long they have to respond (typically 30 thirty days) and the time frame they have to give you a date for a meeting (typically within 45 days)

Records and reports from professionals is essential

For the meeting, bring all your doctor/HTC paperwork regarding treatment

- An idea of the child's typical infusion schedule
- Include number of missed school days in previous years

Use this paperwork to prove why accommodations need to be made, and what they should be

This is also a good time to offer to educate others about bleeding disorders

- In the student's class(es), a school assembly, or district-wide

Make detailed documentation of *everything* for Legal Actions (just in case)

Take notes at the meeting

- Who said what, who promised what, who denied what
- Get as much from others **IN WRITING**
- Save any emails or letters
- Save **EVERYTHING** and keep it organized
- Be ready to take legal action, if you have to

The Responsibilities of the School Team Members

STUDENT

- Wear a Medic Alert bracelet
- Communicate any concerns
- Report any bleeding episodes
- Discuss your physical limitations
- Avoid risk-taking behaviors
- Complete your school assignments
- Make the same effort as all other students

PARENTS OR GUARDIANS

- Make sure the school has the correct contact and insurance information
- Make sure your child goes to school and completes all assignments
- Communicate your child's condition, activities, and treatments to the school
- Discuss problems with appropriate personnel
- Advise school of any appointments
- Obtain make-up work or arrange tutoring, if needed
- Have an intermittent homebound school form signed and in place, if appropriate and necessary for the school district
- Arrange for your child to do school work at home following an injury or bleed
- Provide infusion equipment and proper disposal of equipment when used at school

TEACHERS

- Encourage early reporting of bleeds
- Inform parents of bleeding or injury, as appropriate
- Permit treatment of bleeds while the student is at school
- While there is increased public awareness regarding child abuse issues, the student with hemophilia often has bruises due to his bleeding condition. Be aware of this issue
- Monitor school performance and note changes
- Question absences that are not documented
- Consider physical limitations when determining appropriate activities for PE class. Keep in mind that older students can determine their own limitations
- Provide an alternative activity so the student can stay involved (example: get the student involved in tennis rather than football)
- Respect privacy and confidentiality
- Develop academic expectations based upon the student's abilities, not his limitations

SCHOOL NURSE

- Provide first aid to the student using standard precautions to prevent blood contamination
- Inform parents of any healthcare concerns
- Respect the privacy and confidentiality of the student and family
- Do not give NSAIDs (non-steroidal anti-inflammatory drugs) or any product containing aspirin to the student unless it is specifically prescribed by the student's physician
- Share information and answer questions about hemophilia, not the student, with the staff and students, as issues come up

It's all about **Communication**

The people in the student's school life are a team. Each person in the team has responsibilities that can add to the success of a student with hemophilia.

The Basics of Hemophilia

WHAT IS HEMOPHILIA?

- Hemophilia is a condition someone is born with. It is passed down through the family like blue eyes or brown hair. With hemophilia, a part of the person's blood that helps stop bleeding is missing or not working the way it's supposed to work. When the person is injured, the blood does not clot as quickly as it does in a person without hemophilia
- Students with hemophilia do not bleed faster than others, but bleeding may last longer

TYPES OF BLEEDS

- Mouth bleed
- Nose bleed
- Minor cuts and scrapes
- Internal muscle and joint bleeds—these can be very serious
- Head, eye, throat, neck, chest, back, abdominal, groin, or hip injuries—these can be very serious
- Broken bones and severe cuts requiring stitches can be limb-threatening. These also can be very serious

INFUSION OF FACTOR

- Factor concentrate is a liquid that is injected with a needle and syringe into a vein. Giving the shot is called infusion

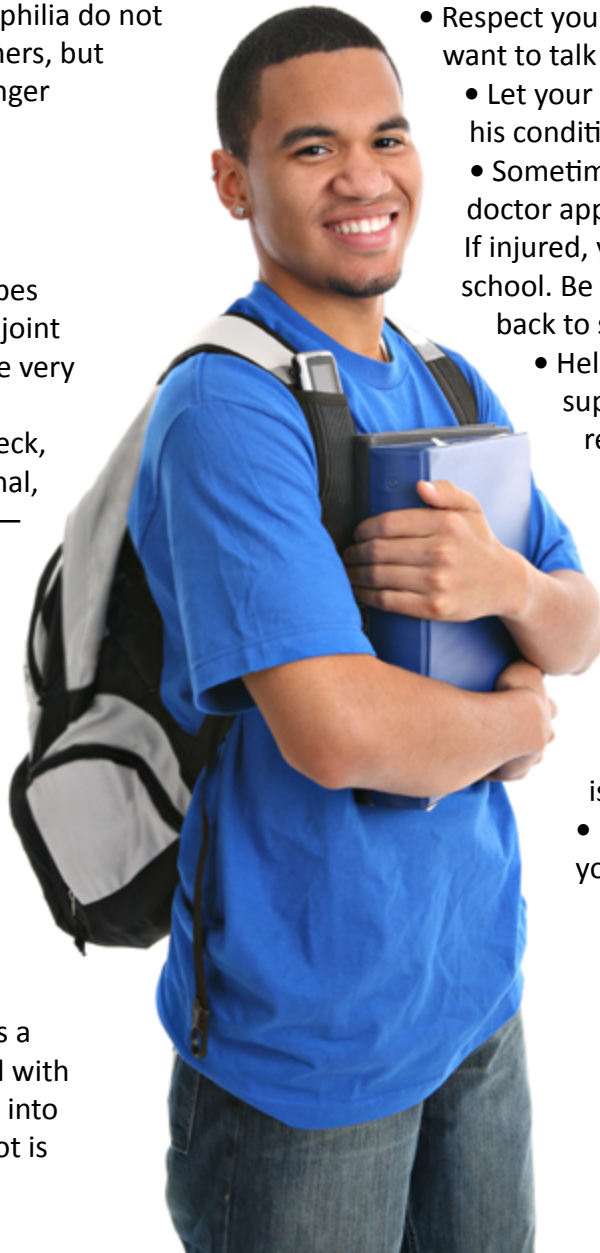
- Factor (the missing blood protein) helps blood clot when your friend is injured
- A person may give the factor to himself, or his parent/guardian may help him with the infusion

HOW CAN A FRIEND HELP?

- Listen to your friend when he wants to talk with you
- Respect your friend's privacy if he doesn't want to talk about hemophilia
 - Let your friend tell other people about his condition if and when he is ready
 - Sometimes, your friend will have doctor appointments he has to go to. If injured, your friend may miss some school. Be there for him when he comes back to school
- Help carry books or school supplies if your friend has had a recent injury
- Include your friend in conversations with other students, or in activities with others

FRIENDSHIP

- A wonderful thing that can help a person feel much better is to just be there for him!
- Remember, to have a friend, you have to be a friend



For School Faculty

REMEMBER: THESE ARE NORMAL KIDS WHO JUST HAPPEN TO HAVE A BLEEDING DISORDER

- Informed and responsive school personnel play a major role in the growth and development of the student with hemophilia
- Good education as well as vocational guidance and career planning is essential for the future success of any student
- Things you can do to help the student be successful in school:
 - Provide extra set of books at home to decrease the amount of weight carried to and from school
 - Allow additional time to walk to/from class if bleeding episodes have occurred
 - Obtain hall passes to increase ease of moving throughout the building at less busy times if bleeding episodes have occurred
 - Issue student's locker on lower level and at the end of a row

IMPORTANCE OF EDUCATIONAL PLANNING FOR THE STUDENT

- Completion of school requirements and graduation build self-esteem in student
- School counselor can be important guide in exploring possibilities of college or advanced education

IMPORTANCE OF VOCATIONAL OPTIONS FOR THE STUDENT

- Professional and technical jobs are encouraged due to lack of physical stress and the increased likelihood that these jobs will have good medical insurance benefits
- Ability to choose vocation is empowering
- With good basic education and exposure to the world of work and specialized training,

student can become a productive and vocationally successful adult

ABSENTEEISM

- May occur for some students if bleeding episode is severe
- Some students find it difficult to return to school after an absence
- Help school personnel realize challenges of student with injury and chronic condition
- Help student realize importance of follow-through with completion of assignments and participation in school activities
- Assist student and family in obtaining tutors, if appropriate

RESOURCES

- Hemophilia Treatment Center social worker
- Visit hfhealthcare.com for more information on Hemophilia Treatment Centers, NHF Chapters, and other important information
- www.hemosocal.org
- www.hemophilia.org
- www.hemophiliamed.org
- www.hemophiliaca.org



For School Nurses

NEVER KEEP THE STUDENT WAITING IF INJURY IS SUSPECTED.

A student can generally detect a bleed before there are any visible signs.

Also, keep in mind that a student with hemophilia has bruises due to his bleeding condition. With the public's increased awareness regarding child abuse issues, bruising can become a significant concern. Balance this concern with the student's condition before taking action.

CONTACT THE PARENTS IMMEDIATELY IF:

- There is a blow to the head, eye, throat, neck, chest, back, abdomen, hip, or groin —this can be life threatening
- There is a broken bone —this can be limb-threatening
- There are joint or muscle bleeds —these can be limb-threatening
- There is a cut requiring stitches —this can be limb-threatening
- Common bleeds (mouth, nose, superficial cuts and scrapes) don't stop bleeding after 20 minutes

SIGNS AND SYMPTOMS OF BLEED

- The student may complain of pain, tingling, bubbling, stiffness, or decreased range of motion in limb
- There may be a swollen body part, usually a joint or area that is warm to touch
- The student may favor an arm or leg more than usual
- The student may limp or refuse to use a limb

USE FIRST AID GUIDELINES AND UNIVERSAL PRECAUTIONS WITH ANY OPEN WOUND

- Wash hands, wear gloves
- Keep wound as clean as possible
- If factor is infused, follow specific guidelines regarding needle usage and disposal
- Do not give aspirin or aspirin-containing products to a student with hemophilia

INJURY CARE PLANS

- **Remember:**
Students with hemophilia do not bleed faster than others, just longer
Students will not bleed to death from a small cut
- **Mouth Bleeds**
Apply continuous pressure to the site of bleed
If possible, use ice chips or a popsicle in the mouth

- **Nose bleeds**

With the student sitting upright, pinch the soft part of nose

- **Superficial Cuts and Scrapes**

Wash the area with antiseptic soap

Apply firm pressure to the wound with gauze for 20 minutes

Apply dressing

- **Joint and muscle bleeds**—can be serious

Trust the student's judgement; outward signs may not be visible

Contact parents immediately

Use R.I.C.E. (see below)

- **Life-threatening and limb-threatening bleeds**

Contact parents/guardians immediately

If parents/guardians unavailable, contact Hemophilia Treatment Center or physician

Follow school's policies for emergency notification

ADJUNCTIVE THERAPY: R.I.C.E.

- **Rest:** keep student as still as possible
- **Ice:** use wrapped ice or a bag of frozen vegetables on the injured area. Do not leave this on more than 20 minutes
- **Compression:** wrap the injured area with an elastic bandage. Make it tight enough to provide pressure, but still comfortable for student
- **Elevation:** keep the injured area elevated above the heart, if possible



Physical Education & Team Sport Activities

IMPORTANCE OF REGULAR EXERCISE AND PHYSICAL ACTIVITY

- Participation in group activities builds self-esteem and a sense of belonging, and teaches teamwork
- It keeps muscles and joints strong and healthy, which decreases bleeding problems

BE AWARE OF EMOTIONAL NEEDS

- Feelings of being “different” due to his condition
- Possible increased anxiety and frustration due to limitations with his condition
- Feeling part of the “team” is very important

PHYSICAL EDUCATION ACTIVITIES: WHAT'S ACCEPTABLE & WHAT'S NOT?

- See “Physical Education Activity Worksheet”
- Non-contact sports such as swimming, biking, golf, and tennis are recommended. They help build strong muscles and increase flexibility without putting unnecessary stress on the joints
- Contact sports such as football and wrestling are discouraged due to the potential for injury
- If one type of sport is not acceptable, be prepared to offer the student another type of sports activity
- Recommend the student use protective devices if appropriate: helmet, knee pads, etc.
- Evaluate activity following an injury with the parents and medical team: when to return to activity, and what intensity is acceptable

BASIC FIRST AID

- Wash hands, wear gloves
- Keep wound as clean as possible
- Use pressure to stop or slow bleeding

- Use R.I.C.E. (rest, ice, compression, and elevation) as appropriate
- Do not give aspirin or aspirin-containing products to a student with hemophilia

CONTACT INFORMATION

- See “Emergency Contact List for School”
- Contact parents/guardians immediately with life threatening injuries (injury to head, eye, throat, neck, chest, back, abdomen, groin, or hip), limb-threatening injuries (broken bones or cut requiring stitches), or with a joint or muscle bleed
- Contact parents/guardians if minor injuries (mouth or nose bleed, superficial cuts and scrapes) do not stop bleeding after 20 minutes
- If parents/guardian unavailable, contact Hemophilia Treatment Center or physician
- Follow school's policies for emergency notification

ABSENTEEISM

- The student may miss class or sports practices following a bleed
- Contact the Hemophilia Treatment Center for guidance about participation after a bleed has occurred



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facebook en Español: [Hemofilia - Actualizate](https://www.facebook.com/Hemofilia-Actualizate)

Injury Care

REMEMBER

- Students with hemophilia do not bleed faster than others, just longer
- Students will not bleed to death from a small cut
- Do not give aspirin or aspirin-containing products to a student with hemophilia

MOUTH BLEEDS

- Put on protective gloves
- If possible, apply firm continuous pressure to the site of bleeding with a cold cloth for 20 minutes
- If bleeding does not stop in 20 minutes, contact the parents

NOSE BLEEDS

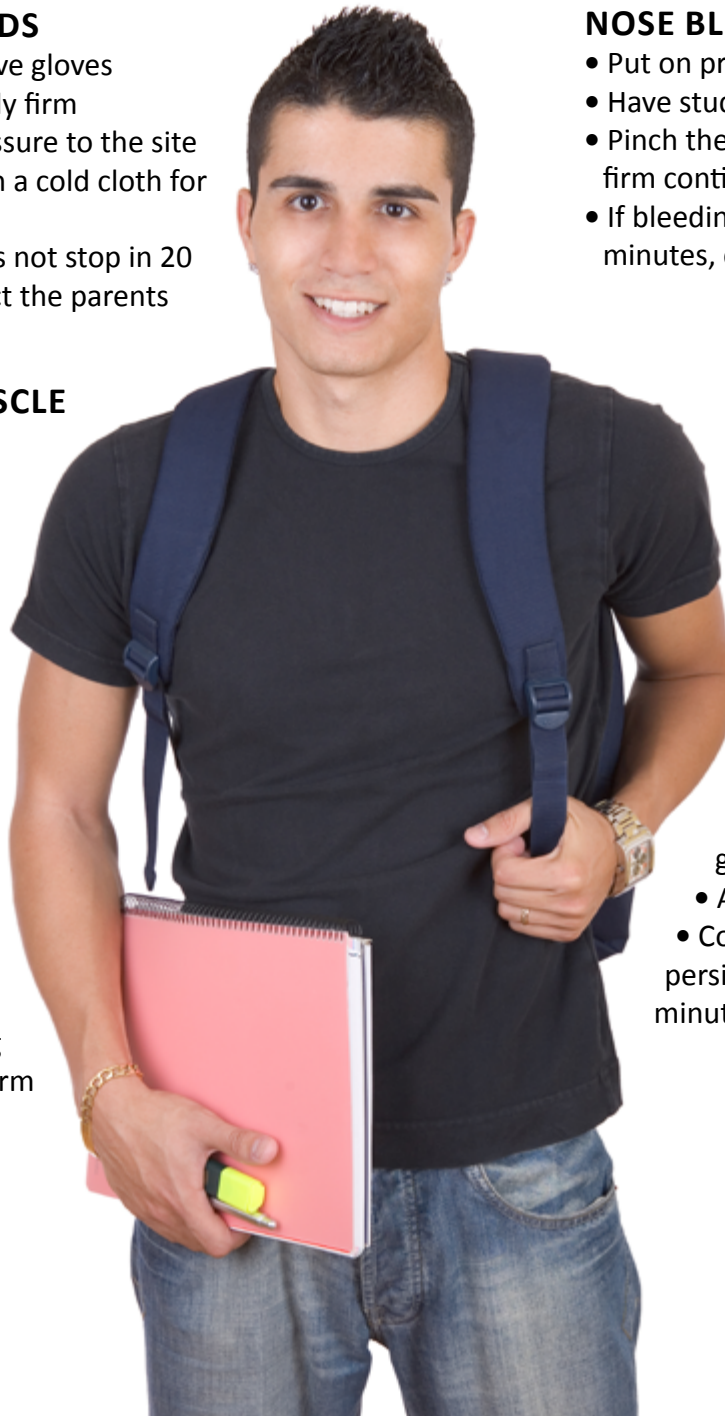
- Put on protective gloves
- Have student sit upright
- Pinch the soft part of the nose with firm continuous pressure
- If bleeding does not stop in 20 minutes, contact the parents

JOINT OR MUSCLE BLEEDS BROKEN BONES OR CUTS

- **NOTE: can be limb- or life-threatening**
- Always believe the student if he says he is bleeding, as there may be no outward signs
- May be seen as a student limping or not using his arm
- Use R.I.C.E.: rest, ice, compression, elevation
- Contact parents immediately

SUPERFICIAL CUTS AND SCRAPES

- Put on protective gloves
- Wash the area with an antiseptic soap
- Apply firm pressure to cut or scrape with gauze
- Apply a dressing
- Contact parents if bleeding persists for more than 20 minutes



Emergency Care Plan for the Student with Hemophilia

CONDITIONS FOR EMERGENCY

- **NOTE:** These injuries can be life- or limb-threatening
- If there are injuries to:
 - Head
 - Neck
 - Throat
 - Back
 - Chest
 - Abdomen
 - Groin
 - Eye injury
 - Broken bones
 - Cuts requiring stitches
 - Joint or muscle bleed

CONTACT NUMBERS

- See “Contact List for School Worksheet”
- Contact parents/guardians first
- If parents/guardians are unavailable, contact the Hemophilia Treatment Center or physician
- Follow the school’s policies for emergency notification

WHILE WAITING FOR EMERGENCY ASSISTANCE

- Stay calm and remain with the student
- Help decrease the student’s anxiety
- Keep the student comfortable and quiet
- Provide privacy for the student’s caregiver
- Reassure the student that help is on the way
- Use compression and elevation on the injured area
- If possible, ice may be used to decrease pain and slow bleeding
- Do not give aspirin or aspirin-containing products to a student with hemophilia



An Emergency Care Plan

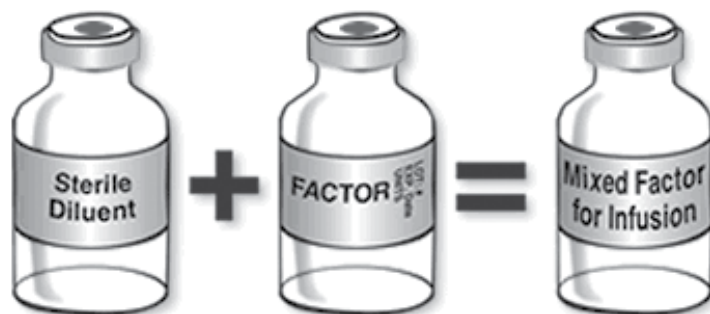
An Emergency Care Plan is important if a student with hemophilia has a serious injury or hemorrhage. Use these reminders to help get the best outcome.



Factor Facts

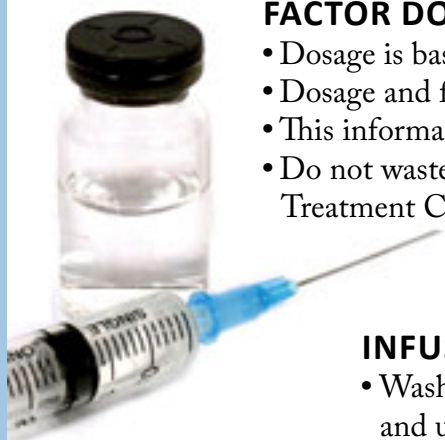
FACTOR FACTS

- Factor concentrate is mixed with a diluent, a solution that dilutes the factor, before being administered to the student
- Factor is injected with a syringe into a vein, usually in the arm or on the hand



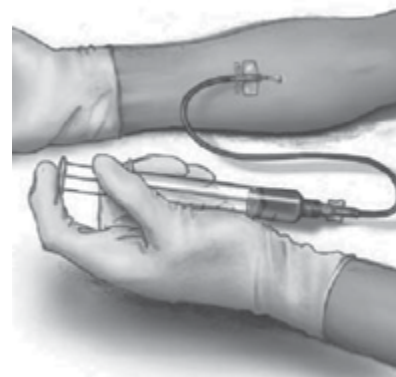
FACTOR DOSAGE

- Dosage is based on the weight of the student with hemophilia
- Dosage and frequency of infusion varies from one student to another
- This information will be specified by the student's physician
- Do not waste the factor once it is mixed. Ask the student's family or Hemophilia Treatment Center if you have any questions



INFUSING AT SCHOOL

- Wash hands thoroughly before beginning, and use gloves
- Have a plan in place—what to do when it is time for infusion. See the “Treatment Plan Worksheet”
- Provide an area for storage of supplies for infusion, as well as a container for sharps disposal
- Provide a private area for infusion process



STORAGE OF FACTOR

- Some factor concentrate needs to be refrigerated, while others can be stored at room temperature. Check with the student's family, Hemophilia Treatment Center, or pharmacy if factor will be stored at school
- Do not refrigerate factor after mixing it
- Never freeze factor
- An adequate supply of factor should be kept at home in case of an emergency

Check with the student's parent/guardian or Hemophilia Treatment Center regarding any questions about the use of factor, factor storage, dosage information, or factor infusion.

The Definition of Factor

Product made from human blood or non-blood sources that helps the blood clot.

Venous Access and Infusion

MOST COMMON TYPES OF VENOUS (IV) ACCESS

• Peripheral venous access

- ♦ *Butterfly needle*: needle with tubing attached for one-time use; removed after infusion

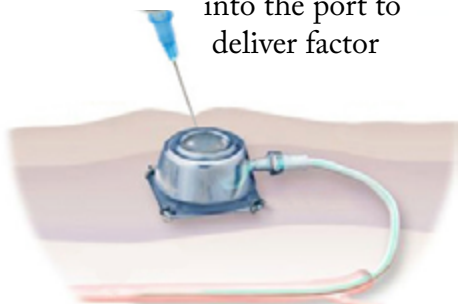


- ♦ *Heparin or saline lock*: a small plastic tube with a cap on the end to lock (close) it; may be left in for a few days

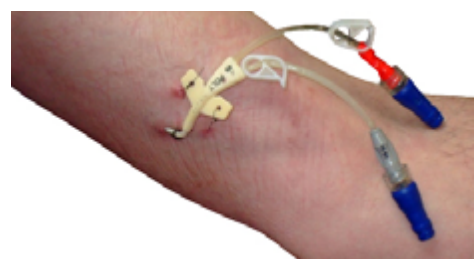


• Central venous access

- ♦ *Port*: a small device placed under the skin and threaded into a large vessel by a doctor in the operating room; the needle is inserted into the port to deliver factor



- ♦ *External catheter*: tubing threaded into a large vessel by a doctor in the operating room; one end of the tubing comes out through the skin for infusion
- ♦ *Peripherally inserted central catheter (PICC line)*: tubing threaded into a large vessel, but does not require surgery; usually in for a short period of time



STEPS OF FACTOR INFUSION



- Clean the work area, gather the supplies, and wash hands



- Get the factor into the syringe



- Fill out the infusion log



- Mix the factor with sterile diluent, (keeping everything sterile)



- Find a vein; infuse the factor



- Clean up the work area

REMINDERS

- If administration of factor is required, allow time and location for the student or parent to infuse
- Respect the confidentiality and privacy of the student and family during factor administration



School Emergency Contact List

Student: _____

Homeroom teacher or counselor: _____

CONTACT NAME	ADDRESS	TELEPHONE
Parent / Guardian (circle one):		Home: Work: Cell:
Comments:		
Hemophilia Treatment Center (HTC):		
Contact name:		
Comments:		
Student's Physician:		
Comments:		
Other contact:		
Relationship to student:		
Comments:		

Parents/Guardians: Emergency Contact List

Student: _____
 School Name: _____
 School Address: _____
 School Phone: _____

CONTACT NAME	TELEPHONE	COMMENTS
Principal:		
School office contact:		
School nurse:		
Teacher(s):		
PE Teacher/Coach:		
School Counselor:		
Other:		
Other:		

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Insurance Information

Student Name: _____

Policy Holder: _____ Date of Birth: _____

Insurance Name: _____

Policy Number: _____ Group Number: _____

Contact Person/Title: _____

Address: _____

Telephone: _____ Fax: _____

Policy Holder: _____ Date of Birth: _____

Insurance Name: _____

Policy Number: _____ Group Number: _____

Contact Person/Title: _____

Address: _____

Telephone: _____ Fax: _____

Medicaid: _____

Number: _____

Contact Person/Title: _____

Address: _____

Telephone: _____ Fax: _____

BCMH Number: _____

Contact Person/Title: _____

Address: _____

Telephone: _____ Fax: _____

Medicare Number: _____

Contact Person/Title: _____

Address: _____

Telephone: _____ Fax: _____

Other: _____

Contact Person/Title: _____

Address: _____

Telephone: _____ Fax: _____



Physical Education Activity Worksheet

Student: _____

Grade level: _____

Homeroom teacher or counselor: _____

What physical activities are recommended or acceptable? List any limitations (example: no heading in soccer).

Protective gear to be used (if appropriate):

What activities are inappropriate or unacceptable?

If injured, what action should be taken?

Limitations after a bleed:

For questions, contact: _____

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Treatment Plan Worksheet

Student: _____

Type of hemophilia: ☐ Hemophilia A (Factor VIII) ☐ Hemophilia B (Factor IX) ☐ Other

Severity level: ☐ Mild ☐ Moderate ☐ Severe Factor % _____

Inhibitor: ☐ Yes ☐ No (as of ____/____/____)

Do not give student any aspirin or aspirin-containing products.

What are student's common bleeding sites? _____

Allergies/other medical conditions: _____

Will factor be infused at school: ☐ Yes ☐ No

If so, who will infuse factor when needed? _____

Where is factor stored? _____

Preferred treatment product: _____

Recommended treatment dosage: _____

Use R.I.C.E. (rest, ice, compression, elevation)? ☐ Yes ☐ No

Special considerations/instructions: _____

In case of an emergency, notify:

Name: _____

Phone number: _____

If not available, contact: _____

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