

CVS Specialty
1-866-RxCare-1 (1-866-792-2731)

CVS Specialty™
Hemophilia
School Preparedness Kit

Glossary

The following are terms you will read about in this School Preparedness Kit.

Hemophilia Treatment Center (HTC): A health care center for people with bleeding disorders. Run by the federal government, HTCs are located across the country and feature specialists including hematologists, nurses, social workers and physical therapists. These health care providers are specially trained to care for patients with bleeding disorders.

Individualized Education Plan (IEP): A written document that details a school's plan to provide special instruction or accommodations for eligible students. Regulations of the IDEA (see below) specify how school personnel and parents, working together, develop and implement an IEP.

Individualized Health Plan (IHP): A plan that you and your health care team put together that informs school personnel of what to do in case of an emergency, and how to handle other situations involving the health of your child with a bleeding disorder.

Individuals with Disabilities Education Act (IDEA): A law that provides federal funds to assist state educational agencies and, through them, local educational agencies, in making special education and related services available to eligible children with disabilities.

Plan 504: A collaborative, written document created to outline services that can help meet the educational needs of your child. These services can include providing a place for a student to administer factor, and allowing more time to get to class. This plan is made per Section 504 of the Rehabilitation Act of 1973, which prohibits recipients of federal funds from discriminating against people on the basis of disability.

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Section 1

Introduction

This School Preparedness Kit from CVS Specialty is a reference tool for parents and guardians who are transitioning their child to school for the first time, or whose child is new to a school environment. For parents of children with a bleeding disorder, preparing a child for school requires some basic education, smart planning, and a healthy amount of communication. It is a team effort involving you, your child, teachers, school administrators, the school nurse, your child's medical treatment center staff and other caregivers in your support network.

With the three pillars of preparation—planning, education and communication—you can set the stage for a safe, happy and rewarding educational experience for your child.

Planning

Much of the planning for your child's transition back to school or to a new school takes place before the school year actually begins. This kit will provide you with tools and information to help you anticipate some of the new issues you might face.

Some questions you might have include:

- When and where will infusions happen, and who will administer them?
- Where will clotting factor and other medications be stored?
- How will your child and school personnel respond to a bleed?
- What is your emergency plan of action?
- What will be the make-up plan for missed schoolwork?
- What activities will your child take part in during gym class?
- What preparations do you and your child need to make for field trips?
- Does the school have wheelchair accessibility if needed?
- Who will be told about your child's bleeding disorder?
- What rules need to be set about confidentiality?

The enclosed booklet, "Suggestions for an Individualized Health Plan," is designed to help you and your child's medical treatment team and school personnel address these issues. You will find more information on Individualized Health Plans (IHPs) on page 10.

Education

Educating and informing school staff about your child's medical condition can help clear up misconceptions and reduce anxiety for you, your child and school personnel. When appropriate, you and your child may also want to educate your child's friends and classmates. CVS Specialty can supply specialized presentations and educational materials to help explain the facts. For further information, simply contact your Hemophilia CareTeam at 1-866-RxCare-1 (1-866-792-2731).

Your hemophilia treatment center (HTC) may also be prepared to provide educational conferences to your child's school personnel. Be sure to contact your HTC nurse coordinator or social worker for information about what materials and services they can provide. Coram® CVS Specialty™ Infusion Services can work in conjunction with you and your HTC staff to expand the resources available.

Communication

Open communication between you, your child, the school, and your treatment team is the best way to make your child's school years go as smoothly as possible. Regular communication between parents and school personnel ensures that both parties are kept informed of bleeds, behavioral changes, or other signs from your child.

The School Preparedness Guide (page 6) and School Preparedness Timeline (page 12) provide an overview of some of the topics to discuss with your school and HTC.



For additional questions about the School Preparedness Program, contact your Hemophilia CareTeam.

School Preparedness Guide



Preparing a child for school is a team effort involving you, your child, your school, and your health care providers. As you are the leader of this team, it is important that you reach out to others and approach the process in the spirit of cooperation. After all, your child may be at the same school for years to come.

It is also important for you to stand firm when necessary. Your mission is to create a safe and supportive learning environment for your child. Ultimately, your child's bleeding disorder should not get in the way of opportunities for academic achievement and social development.

The following outline is a step-by-step guide to prepare a child with a bleeding disorder

for school. As everyone's needs are unique, this outline should be considered a guide only—not exact instructions. Use this guide in conjunction with the following School Preparedness Timeline (page 12) to help plan for the exciting year ahead.

1. Visit the school in advance.

Make a trip to the school the year before your child starts. This will give you an opportunity to assess the environment, meet the staff and make them aware of your child's special needs.

Schedule a date.

- Call the school to determine a good time for an informal visit while school is still in session. Make sure the full staff is available.

- Explain that your child, who will be attending school there, has a bleeding disorder and that you would like to introduce yourself to the principal, teachers and staff.
- Invite your child to go with you.

Meet the school staff.

- On the day of your visit, stop by the front office and meet the principal and administrative staff.
- Let the principal know that you would like to set up an educational conference approximately six weeks before the next school year begins to educate the staff about your child's bleeding disorder. (If possible, determine a date to schedule the conference.)
- Ask someone to introduce you to the teachers (including the gym teacher), school nurse, guidance counselor, playground monitor, hall monitor and other staff members who might have responsibility for your child.
- Get a list of the names and titles of the people you meet before your visit is over. (Someone in the administration office should be able to provide a list.) Also, be sure to get the names and titles of those you did not have a chance to meet but who may also have responsibility for your child. This list of names will help you plan for your conference.

2. Tap into your resources.

Take advantage of the resources available to you within the bleeding disorders community. There are many experienced people who are ready to help.

Consult your regional hemophilia treatment center (HTC).

- Call your HTC and ask the nurse coordinator or social worker what services the HTC offers to help with school preparation. Most likely, the HTC staff has helped other families prepare for school and can save you a lot of work. To find an HTC in your area, visit the website of the Centers of Disease Control and Prevention at cdc.gov/ncbddd/hemophilia/HTC.
- Set up a planning meeting with the HTC about three months before school starts.

Contact your regional hemophilia foundation.

- For a list of foundations in your state, contact the National Hemophilia Foundation (1-800-42-HANDI, hemophilia.org) or the Hemophilia Federation of America (1-800-230-9797, hemophiliafed.org).
- Call your hemophilia foundation and ask for any information or support it can offer to help you prepare your child for school. Most hemophilia foundations can provide a variety of resources and free educational materials.

Consult CVS Specialty

- Contact your Hemophilia CareTeam to participate in the CVS Specialty Hemophilia School Preparedness Program. With advance notice, your CareTeam can work with you and your HTC to conduct an educational presentation for your child's school. Refer to Section 3 of this booklet for more information on requesting a presentation from CVS Specialty.
- If requested, CVS Specialty can also provide educational materials and can discuss advocacy services.



3. Educate yourself about the laws and educational programs that protect your child's rights.

If your child requires special accommodations at school due to his bleeding disorder, it is important that you be able to speak knowledgeably about the school's responsibilities under federal, state and local laws.

Understand federal disability laws (see Section 4 of this booklet).

- Be familiar with Section 504 of the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act (IDEA). If your child will be attending a private school that receives no federal funding, be familiar with the rights afforded your child under the Americans with Disabilities Act.

Research laws and education programs in your state and local community.

- Consult your local school district, regional hemophilia foundation, and HTC for information on other laws and education programs in your state or local community that may apply.

4. Meet with the hemophilia treatment center (HTC).

Talk with their staff about your educational conference and discuss any accommodations or support that your child may need at school.

Discuss your plans for an educational conference.

- Ask if the HTC would be able to support you with a presentation to the school about your child's bleeding disorder. This presentation would be delivered at the educational conference you set up before the school year begins. If you prefer to deliver the presentation yourself, you may still want someone from the HTC available to answer questions, either in person or over the telephone.
- Decide together who will deliver the educational presentation. If you will be giving the presentation, make sure you practice and become familiar with the content. If someone else is giving the presentation, make sure you review and approve the content of the presentation.
- Discuss what information you will bring to the conference, including educational materials and your child's relevant medical history.
- Decide on a convenient time to schedule the conference at the school, approximately six weeks before school begins.

Discuss the need for an Individualized Health Plan, or IHP (see page 10).

- Let the HTC staff know you would like their help in developing an IHP for your child. (This should be done in cooperation with the school nurse or another designated school staff member, and can be discussed in more detail with the school after the educational conference.) Refer to the enclosed booklet, "Suggestions for an Individualized Health Plan." Decide if you would like to use this document to help you develop an IHP with the school.
- Discuss your child's specific health care needs at school.
- Decide on the information you would like to see included in the IHP.

Discuss the need for a 504 Plan or an Individualized Education Program, or IEP (see page 10).

- Ask for guidance regarding any accommodations or specialized instruction your child might require at school. Determine if you should ask the school for a 504 Plan and/or an IEP. To qualify, your child must meet certain eligibility requirements.
- Refer to Section 4 of this booklet for additional information on 504 Plans and IEPs.

5. Set up an educational conference at the school.

The educational conference is the most important part of the process. Schedule a time that works best for key people at the school and the HTC.

Request a meeting.

- Write to or call the school principal to set a date and time for an educational conference. Putting your request in writing may get more attention than making a phone call. It may also help to have your physician or HTC representative co-sign the letter.
- If you have already discussed a date with the principal (during your introductory visit), confirm this date in your letter. If possible, schedule the conference about six weeks before school begins. This will allow you time to develop an IHP, 504 Plan, or IEP with the school. Coordinate the date and time with the HTC and/or CVS Specialty, depending on who you want to accompany you.
- In your letter, explain that the purpose of the educational conference is to educate the staff on bleeding disorders and make them aware of your child's special needs.
- Explain that the conference will include an educational presentation and will also provide the staff with an opportunity to ask questions.
- If your HTC nurse or social worker will be attending or needs conference call access on the day of the conference (if he/she cannot attend in person), mention this in your letter as well.
- List the key school personnel you would like to have attend the meeting, but leave the invitation open for others to attend as appropriate. The more people you can educate, the better.
- Finally, ask the principal to designate someone at the school who can work with you and your HTC to develop an IHP for your child.

6. Conduct the educational conference.

The educational conference is your chance to clarify misconceptions about bleeding disorders and share information about your child's special needs.

Present information about your child's bleeding disorder.

- Describe what it means to have a bleeding disorder.
- Discuss your child's specific needs.
- Discuss the responsibilities of the school, parents/guardians, and child.
- Stress the importance of confidentiality (see page 24).
- Invite questions from the staff and listen to their concerns. Respond with honesty and confidence.

Leave copies of educational materials.

- Contact your CVS Specialty Hemophilia CareTeam in advance for copies of educational materials.

7. Develop an Individualized Health Plan (IHP).

An IHP provides information to school personnel that they might need in case of an emergency or other situation affecting your child's health or well-being.

Approach the school nurse (or other designated personnel) to begin the IHP process.

- Work with staff from your HTC and designated school personnel to complete the IHP before school begins. The process may take more than one meeting with one or more members of your IHP team, so be sure to begin the process soon after the educational conference. By involving staff

from your HTC, the school will know that your medical team supports the information in the IHP.

Refer to the enclosed booklet, "Suggestions for an Individualized Health Plan," to help jump start the process.

8. If necessary, develop a 504 plan or an Individualized Education Program (IEP).

If your child qualifies for protections under Section 504 of the Rehabilitation Act or the Individuals with Disabilities Education Act (IDEA), you may decide to ask the school to develop a written plan to meet those needs.

- Identify the school's 504 or IDEA coordinator. Usually schools will have a designated staff member responsible for developing these programs.
- As appropriate, work with the school to develop a timeline for completing a 504 Plan or IEP for your child.

9. Maintain ongoing communication with the school.

After school begins, monitor your child's progress. Stay informed and keep lines of communication open with school staff.

Update written plans as needed.

- Arrange to review and update your child's IHP, 504 Plan or IEP as often as necessary, but at least once a year.

Encourage two-way communication.

- Identify a point person at the school who can report on your child's progress. This person might be a homeroom teacher, guidance counselor or other person who comes into frequent contact with your child. Set up a recurring monthly call with this person to "catch up" on things at school.



- Continually ask staff members to contact you with any questions or concerns. Ask for feedback on your child's behavior and performance in class. Schedule additional educational conferences as needed to educate new staff or review information with existing staff.
- Let the principal's office and teachers know of any planned days off for your child (such as for doctor appointments, diagnostic tests or rehabilitation).
- Identify key dates of school assignments and tests so you can plan around them.
- Share any concerns you might have regarding issues such as make-up work, confidentiality, untreated bleeds, or suspected bullying. Work out a plan to address them.

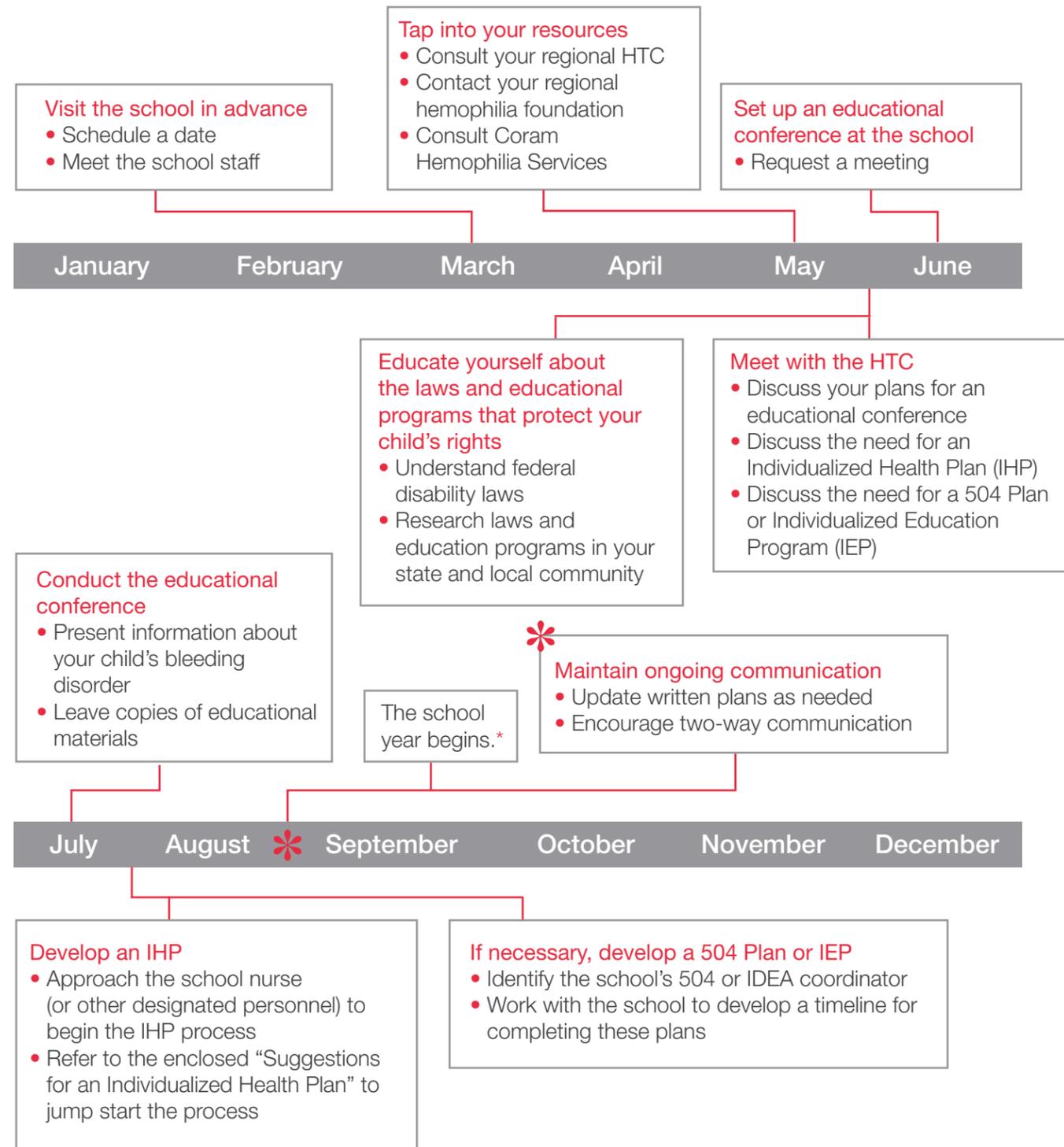
Remember, you are not alone in preparing your child for school. Take advantage of the resources available to you through your HTC, hemophilia foundation and CVS Specialty.

Whenever you need help along the way, call your CVS Specialty CareTeam. They are available to assist you in any way they can.



For more information on 504 Plans and IEPs, please see Section 4 of this booklet.

School Preparedness Timeline



* This timeline is for demonstration purposes only and may not necessarily apply to your situation. If your child's school year begins or ends at a different time, or if your child attends school year-round, adjust your planning accordingly.

Section 2

Overview for Schools

The Student with a Bleeding Disorder

The following is basic information for school personnel who are caring for a child with a bleeding disorder. This information is intended to be used in conjunction with the enclosed "Suggestions for an Individualized Health Plan," part of the School Preparedness Program from CVS Specialty.

These materials are designed for educational purposes only and are not intended to substitute for medical advice. Do not use this information to diagnose or treat a health problem or disease without consulting with a qualified physician. Never disregard medical advice or delay in seeking it because of something you have read in these materials.

About Hemophilia and Related Bleeding Disorders

Hemophilia is a rare, genetic coagulation disorder ("bleeding disorder") affecting approximately 18,000 people in the United States—almost exclusively males. It is characterized by delayed or deficient clotting of the blood, resulting in episodes of prolonged bleeding, usually into joints, muscles and internal organs.

Those born with hemophilia lack the ability to create enough of an essential clotting protein, or "factor," to stop some bleeds. In people without hemophilia, each clotting factor in the blood acts sequentially within a "cascade" of clotting proteins to form a complete blood clot. In people with hemophilia, due to a

missing or deficient factor, clotting may take longer, or may not occur at all without an infusion of replacement clotting factor.

There are a number of clotting factor proteins present in everyone's blood. The most common factors missing or under-produced in people with hemophilia are factor VIII and factor IX. Factor VIII deficiency is more prevalent than factor IX deficiency (80 percent vs. 20 percent). A deficiency of factor VIII is known as "hemophilia A." A deficiency of factor IX is known as "hemophilia B."

Hemophilia, whether A or B, is categorized further by its severity—mild, moderate or severe—which depends on the level of circulating clotting factor in the bloodstream.

Von Willebrand disease (VWD) is a genetic bleeding disorder that is similar to hemophilia but usually milder. Those with VWD are missing a related protein called von Willebrand factor, named after the physician who first discovered it.

VWD affects an estimated 1 to 3 percent of the U.S. population, though it is largely undiagnosed.

Unlike hemophilia, VWD affects males and females equally. Therefore, not all people with bleeding problems are males.

What Schools Need to Know

Quick Facts

- Hemophilia is a genetic condition.
- Hemophilia affects all races, nationalities and socioeconomic groups.
- Hemophilia is not related to mental illness or learning disabilities.
- Children with hemophilia do not bleed more or faster than anyone else, just longer.
- Hemophilia is not contagious.

Bleeding Episodes

- Bleeds requiring treatment usually are the result of a slight or serious trauma.
- Bleeds occur most often internally, in joints or muscles, but can occur anywhere.
- The child will not bleed to death from a minor cut or scratch.

Recognizing a Bleed

- Children can usually detect an internal bleed before signs are visible.
 - The child may report a tingling/bubbling sensation, warmth, pain or stiffness.
- Joint bleeds may appear swollen and/or red.
 - The joint may appear normal and may only be detected by the child reporting abnormal sensations.
 - Mouth bleeds seldom stop bleeding without treatment.
- Nose bleeds and surface cuts should be visible.

Clotting Factor

- Product should be stored in a secure location and may need to be kept refrigerated.
 - School personnel should determine if storage at school is permissible.
- The student or caregiver prepares the dose and infuses it intravenously.

Preventive Therapy (Prophylaxis)

Ongoing Preventive Therapy

- With this treatment, factor VIII or IX is infused regularly on a pre-determined schedule to prevent bleeds. This allows the child to participate in activities. Be sure to check with the parent/guardian for the student's specific activity list.
- Infusions are usually given in the morning before going to school so the child has the highest factor activity during the day.
- If the child has an injury on any day, including the day of a prophylaxis infusion, call the parent or guardian immediately.

Planned Preventive Therapy

- Preventive infusions are given at home on the day of a planned activity to avoid potential bleeds.
- Discuss this with the child's parent or caregiver when a school event or trip is planned.

Confidentiality and Psychosocial Issues

- Be aware of any limitations the child may have, but do not discriminate or "single out" the student.
 - Special treatment can impair peer acceptance.
- Allow self-infusion at school.
- Listen to the student and parents regarding the need for treatment and which activities he can participate in.
- Check with the student and parents to decide which, if any, of the child's peers will know about his condition.

Social Development

- A child's relationship with his peers is an important developmental issue. The student will let you know who he wants to know about his bleeding disorder.



- Participation in team sports builds bonds with peers.
- Peer acceptance can have long-lasting effects on a child's self-image and ability to learn.
- Remember that self-esteem can be fragile.

Sports and Physical Activity

Physical Education Goals

- Improve physical fitness, strength and motor control.
- Build strong muscles, which can reduce the risk of joint bleeding.
- Forge social bonds with peers.

How to Accomplish Physical Education Goals

- Avoid high-risk activities and contact sports.
 - Allow student to participate in a non-contact way when contact sports are being taught (for example, as referee or score keeper).

- Develop a plan with the student, family and physician regarding which sports are appropriate for the child's participation.
- Allow self-limitations during and after a bleed. Allow the student to determine when he is ready for full participation.
- Maintain expectations for this student around the self-limitations.
- Encourage strength-building exercises.
- Allow the use of assistive devices and protective gear as needed, such as crutches and splints.

Absenteeism and Make-Up Work

- Occasionally a bleed may require a few days of recuperation. The student may need crutches to return to school.
- Parents should notify the school in advance of any anticipated days off for the student (such as for doctor visits or tests) in order to plan for make-up work.
- Appoint someone at the school to be in charge of collecting assignments for the student or plan this with the student to maintain confidentiality.

Responsibilities

The Student's Responsibilities

- Report active bleeds immediately to a teacher or nurse.
- Be open about concerns, problems and needs with teachers and other trusted individuals.
- Don't take unnecessary risks (self-limit activities).
- Stay focused on academics. You are responsible for your own grades.

The Parent's Responsibilities

- Communicate the child's conditions and needs.
- Give the school your emergency contact information.
- Alert teachers about potential missed school days well in advance.
- Follow up on missed work assignments.
- Provide the school with needed products, supplies, and a disposal system for related materials.

The School's Responsibilities

- Report changes to the parent/caregiver in the student's behavior, personality and performance.
- Recognize the importance of treating this student as you would any other.
- Work with the student and parent(s) on physical education class and make-up work.
- Allow treatment of bleeds at school.
- Respect privacy and confidentiality.
- Be aware of school activities that may increase the risk of bleeds. Include physical education teachers and/or coaches in the student's activity plan.



Types of Bleeds and How to Manage Them

General note for all types of bleeds:

Always call the emergency contact (parent or caregiver). Call 911 as you would for any other student who is injured.

If you call 911 and factor is kept at school, send it with the paramedics, along with a copy of a letter from the student's doctor. (See the "Physician Letter Template" included in the back pocket of this CVS Specialty School Preparedness Kit.)

Life-Threatening Bleeds (Usually due to injuries in the areas listed below.)

Immediately call 911 and the emergency contact!

What to do for life-threatening bleeds

- **DO NOT DELAY TREATMENT.**
- **CALL 911.**
- **CALL THE EMERGENCY CONTACT. If unavailable, call the student's physician.**
- **Report details of the injury collected from the student or a witness.**
- **Follow the child's emergency plan as set by the parents and physician.**
- **Allow the student or caregiver to infuse factor.**

Major sites of serious bleeding that threaten life, limb or function:

Central Nervous System Bleed (all head and spinal cord injuries)

Early signs/symptoms: Sleepiness, nausea, vomiting, headache, blurred vision, shock, loss of consciousness.

Action: Call 911 and the emergency contact.

Abdominal Bleed

Early signs/symptoms: Acute abdominal pain, paleness, rigidity of the abdomen, decreased blood pressure, increased pulse.

Action: Call 911 and the emergency contact.

Neck/Throat Bleed

Early signs/symptoms: Acute pain, swelling, difficulty breathing or swallowing.

Action: Call 911 and the emergency contact.

Major Bleeds

Note: A child can usually detect an internal bleed before signs are visible. If a child says he is bleeding and needs treatment, listen to him. He may report a tingling or bubbling sensation, warmth, pain, stiffness or decreased motion in any limb. The area may appear swollen and/or feel warm to the touch. The child may limp or appear to favor one arm or leg. Even if there are no symptoms, the child knows best—be sure to listen to him.

What to Do for Major Bleeds

- **Follow the child's emergency plan as set by the parents and physician.**
- **Allow the student or caregiver to infuse factor if needed.**
- **Notify the emergency contact.**
- **If in doubt, call 911.**

Sites of major bleeds:

Eye Bleed

Early signs/symptoms: Blood showing over the white part of the eye; sense of fullness in the eye, or mild irritation.

Action: Call the emergency contact and have the student or caregiver infuse factor.

Deep Laceration

Common sites: Anywhere on the body.

Early signs/symptoms: Bleeding should be visible.

Action: Apply pressure and a dressing to the area. Notify the emergency contact; call 911 as deemed necessary.

Joint Bleed

Common sites: Knee, elbow, ankle, shoulder and hip.

Early signs/symptoms: Tingling, pain, limited range of motion, limping or lack of use of affected extremity. There may be no symptoms. Listen to the student if he mentions feeling unusual.

Action: Ice the area and elevate the extremity. Allow the student or caregiver to infuse factor. Notify the emergency contact.

Muscle Bleed

Common sites: Upper arm, forearm, thigh and calf muscles.

Early signs/symptoms: Warmth, pain, swelling. There may be no symptoms.

Action: Apply ice and elevate. Allow the student or caregiver to infuse factor. Notify the emergency contact.

Nose Bleed

Action: Tilt the head forward and press the sides of the nose together firmly. If holding

the nose does not work, try putting an ice pack over the bridge of the nose. Allow the student or caregiver to infuse factor if needed. Notify the emergency contact.

Mouth Bleed

Early signs/symptoms: These bleeds may appear worse than they are because the blood mixing with the saliva gives the appearance of excessive bleeding.

Action: Apply ice or cold compress, if possible. If the bleed is a result of biting the tongue or the inside of the cheek, or the loss of a tooth, the child may apply pressure to the site by using a 2" x 2" gauze pad. Allow the student or caregiver to infuse factor. Notify the emergency contact.

Scrapes/Cuts

Early signs/symptoms: Bleeding at the site of injury.

Action: Normal first aid care.



Section 3

Request a Presentation for Your School

Hemophilia is a lifelong condition that affects every aspect of life, as well as the lives of family members and caregivers. That's why CVS Specialty has developed a series of presentations available to families to help educate school personnel in caring for their children.

The first presentations in the CVS Specialty School Preparedness series are titled, "The Student with Hemophilia—An Introduction for Teachers, School Nurses and Administrators" and "Hemophilia—A Presentation for Students." Each presentation was developed under direct oversight of trained hemophilia treatment nurses. The student presentation is written for students in grades K through 5.

How It Works

CVS Specialty works in partnership with your family and your child's hemophilia care team to develop the most appropriate program to meet your needs. With adequate notification, a CVS Specialty representative can be available almost anywhere in the country to conduct a presentation on your behalf. Should a child, parent, or hemophilia care professional wish to deliver the CVS Specialty educational program, a CVS Specialty representative will review the program with the designated instructor in advance of the scheduled presentation date. In addition, CVS Specialty may request the opportunity for a representative of the company to attend the presentation in order to observe and support the proprietary content of the program, as well as collect feedback for continuous quality improvement. Hemophilia

treatment centers (HTCs) can request a copy of the presentations for their own use by contacting CVS Specialty at 1-866-RxCare-1 (1-866-792-2731).

For further information or to request a date for the CVS Specialty School Preparedness Presentation, please contact your CareTeam at 1-866-RxCare-1 (1-866-792-2731).

Available Programs

The Student with Hemophilia: An Introduction for Teachers, School Nurses and Administrators

Goals:

- To increase school personnel's understanding of hemophilia and to clarify misconceptions.
- To reduce anxiety for school personnel, parents and children.
- To improve acceptance of the child at school.
- To open communication between the school, student, parents and HTC.

Hemophilia: A Presentation for Students

Goals:

- To dispel myths and increase fellow students' understanding of hemophilia.
- To improve acceptance of the child among peers.
- To encourage open communication and questions from fellow students.
- To reinforce the student's self-esteem and reduce anxiety.

Section 4

School Responsibilities Under Federal Disability Laws

Children with bleeding disorders may not be “disabled” in the traditional sense of the word; however, some children who attend school may qualify for special protections under federal law. Some children might have disabilities unrelated to their bleeding disorder that are also covered by these laws.

The federal laws described in this section apply to a school’s responsibility to help students manage a bleeding disorder. A particular student with a bleeding disorder could be covered under several laws. It is important to be aware of these laws if you feel your child requires accommodations or special instruction at school, or is being discriminated against. Your hemophilia treatment center (HTC), area hemophilia foundation or home care provider can be a great source of additional information and advocacy on your behalf.

Section 504 of the Rehabilitation Act of 1973 (Section 504) and Americans with Disabilities Act of 1990 (ADA)

Section 504 prohibits recipients of federal funds from discriminating against people on the basis of disability. Title II of the ADA prohibits discrimination on the basis of disability by public entities, regardless of whether the public entities receive federal funds. Public school districts that receive federal funds are covered by both Title II and Section 504. The obligations of public schools

to students with disabilities under each law are generally the same. For schools, these laws are enforced by the office for Civil Rights (OCR) in the U.S. Department of Education.

Section 504 outlines a process for schools to use in determining whether a student has a disability, and in determining what reasonable accommodations a student with a disability needs. This evaluation process must be tailored individually since each student is different and his needs will vary. Students with bleeding disorders are usually covered by Section 504, but may not be depending on the degree to which the condition limits the learning process.

Under Section 504, students with disabilities must be given an equal opportunity to participate in academic, non-academic and extracurricular activities. The regulations also require school districts to identify all students with disabilities and to provide them with a free appropriate public education (FAPE). Under Section 504, FAPE is the provision of regular or special education and related aids and services designed to meet the individual educational needs of students with disabilities as adequately as the needs of non-disabled students are met.

However, a student does not have to receive special education services in order to receive related aids and services under Section 504. Providing a place for a student to administer



clotting factor, allowing more time to get to class, and loaning an extra set of textbooks for home use are a few examples of related aids and services that schools may have to provide for a particular student with a bleeding disorder. The most common practice is to include a list of these related aids and services, as well as any needed educational accommodations, in a written document. This document is sometimes referred to as a “Section 504 plan” or simply a “504 plan.” Each school or school district should have a designated “504 coordinator” who is responsible for handling Section 504 needs.

Private schools that receive federal funds may not exclude an individual student with a disability if the school can, with minor adjustments, provide appropriate education to that student. Private, nonreligious schools are covered by Title II of the ADA.

The ADA Amendments Act (ADAAA) became effective on January 1, 2009. The ADAAA focuses on the discrimination at issue. It makes important changes to the definition of the term “disability” by rejecting the holdings in several Supreme Court decisions and portions of the Equal Employment Opportunity Commission’s (EEOC) ADA regulations. The Act retains the ADA’s basic definition of “disability” as an

impairment that substantially limits one or more major life activities, a record of such an impairment, or being regarded as having such an impairment. However, it changes the way that the statutory terms should be interpreted.

Most significantly, the ADAAA:

- Directs the EEOC to revise the portion of its regulations that defines the term “substantially limits”;
- Expands the definition of “major life activities” by including two non-exhaustive lists:
 - The first list includes many activities that the EEOC has recognized (e.g., walking), as well as activities that the EEOC has not specifically recognized (e.g., reading, bending, and communicating);
 - The second list includes major bodily functions (e.g., “functions of the immune system, normal cell growth, digestive, bowel, bladder, respiratory, neurological, brain, circulatory, endocrine, and reproductive functions”);
- States that mitigating measures other than “ordinary eyeglasses or contact lenses” shall not be considered in assessing whether an individual has a disability;
- Clarifies that an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active;
- Provides that an individual subjected to an action prohibited by the ADA because of an actual or perceived impairment will meet the “regarded as” definition of disability, unless the impairment is transitory and minor;
- Provides that individuals covered only under the “regarded as” prong are not entitled to reasonable accommodation; and
- Emphasizes that the definition of “disability” should be interpreted broadly.

Individuals with Disabilities Education Act (IDEA)

IDEA provides federal funds to assist state educational agencies and, through them, local educational agencies in making special education and related services available to eligible children with disabilities. The Office of Special Education Programs (OSEP) in the Office of Special Education and Rehabilitative Services (OSERS) in the U.S. Department of Education administers IDEA.

Under IDEA, a child with a disability must meet the criteria of one or more disability categories and require specially designed instruction to benefit from education. The IDEA category of “other health impairment” includes hemophilia. To qualify under IDEA, the student’s bleeding disorder also must adversely affect educational performance to the point that the student requires special education and related services, as defined by state law. A qualifying condition is one that results in limited strength, vitality or alertness to the educational environment. An example of a child with hemophilia who may qualify under IDEA is a student who is unable to attend school regularly due to hospitalizations, thereby limiting his alertness to the educational environment.

IDEA requires school districts to find and identify children with disabilities and to provide them a free appropriate public education (FAPE).

Under IDEA, FAPE means special education and related services that meet state standards and are provided in conformity with the Individualized Education Program

(IEP). An IEP is a written document detailing a school’s plan to provide special instruction or accommodations for eligible students. The IDEA regulations specify how school personnel and parents, working together, develop and implement an IEP.

In the Individuals with Disabilities Education Improvement Act of 2004 (the 2004 reauthorization of the IDEA), the Congress required the U.S. Department of Education to publish and widely disseminate “model forms,” that are “consistent with the requirements of [Part B of the IDEA]” and “sufficient to meet those requirements.” Specifically, the reauthorization required the Department to develop forms for the: (1) IEP; (2) notice of procedural safeguards; and (3) prior written notice.

Each child’s IEP must include the supplementary aids and services to be provided for, or on behalf of the child, and a statement of the program modifications or supports for school personnel that will be provided for the child to make progress and be involved in the general curriculum. Providing a place for a student to administer clotting factor, allowing more time to get to class, loaning an extra set of textbooks for home use, and altering the education curriculum are a few examples of related services, supplementary aids and services, or program modifications that schools could provide for a particular student with a bleeding disorder who is eligible under IDEA.

With regard to IDEA, it is also helpful to know the policies of your state and local school district. States must meet the minimum federal requirements of IDEA, but they can

also give students and parents more rights and services. Call or write to your state department of education (or your local school district) and ask for a copy of your state (or local) special education regulations. There may also be a special education handbook or parent guide available from your state or local district.

The term “special education” under IDEA does not necessarily relate to a child’s placement at school (i.e., special education classroom or “regular” classroom). It means that a child is entitled to specially designed instruction to address difficulties caused by his disability. Generally, if a child with a bleeding disorder needs only a related service and not special education services as defined by state law, that child is not a child with a disability under IDEA and therefore is not eligible for any services under IDEA. Such a child might still be eligible for services under Section 504.

How Can I Get Copies of the Federal Laws?

The statutes are found in the United States Code (U.S.C.). The regulations implementing the statutes are found in the Code of Federal Regulations (CFR).

- Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794, implementing regulations at 34 CFR Part 104. Available at ed.gov.
- Title II of the Americans with Disabilities Act of 1990, 42 U.S.C. 12131 et seq., implementing regulations at 28 CFR Part 35. Available at ed.gov.
- Information on the ADA Amendment Act is available at eeoc.gov.
- To obtain copies of the Section 504 and Title II regulations, you also may contact the Customer Service Team of the Office for Civil Rights, U.S. Department of Education,

1-877-433-7827, or at edpubs.gov. For TTY, call 1-877-576-7734.

- Individuals with Disabilities Education Act, 20 U.S.C. 1400 et seq., implementing regulations at 34 CFR Part 300. Available at ed.gov.
- For copies of the IDEA regulations, you also may contact EdPubs at 1-877-433-7827, or visit edpubs.gov.

What Are the Differences Between Section 504, ADA and IDEA?

Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act are civil rights laws. The obligations of public schools to students with disabilities under each law are generally the same. The Individuals with Disabilities Education Act is a federal funding statute that provides financial aid to states in support of special services for students with disabilities and special education needs. Section 504 and the ADA do not provide federal funds to states but do require states to carry out their obligations under these laws at their own expense. Generally speaking, Section 504 and the ADA prohibit discrimination and remove barriers to achievement for all citizens, whereas the IDEA provides services to students whose disabilities adversely affect their educational performance and require special education. Together, these laws help all students benefit from an education regardless of their ability.

Qualifying for an Individualized Education Program (IEP) under IDEA is more involved, and eligibility requirements more restrictive than for a Section 504 plan. Different procedures are required to evaluate a child and implement a plan. In addition, different services are available through each plan, as well as different safeguards. Children who

qualify for protections under Section 504 may not necessarily qualify for special education services under IDEA. However, children who qualify under IDEA are automatically protected by Section 504.

Confidentiality

The protection of confidential health information is a patient's right and every health care provider's responsibility. Disclosing a bleeding disorder is ultimately a decision for the parent and affected student to make. As a parent, while you need to share your child's health information with the school to help ensure his well-being, sharing this information with fellow classmates is a decision the child must make.

A child's relationship with his peers is an important developmental factor. Peer acceptance can have long-lasting effects on a child's self-image and ability to learn. Therefore, when parents organize an educational conference with school staff to prepare them to care for their child, it may be necessary to strongly emphasize the importance of confidentiality.

During kindergarten and grade school, disclosing a child's condition to fellow classmates and teachers may not be as big of a concern as it is during junior high or high school. And for some children, it may never be a concern. Everyone's environment and circumstances are unique, but the important thing to remember is to do what is best for your child's self-image while protecting his general health and well-being.

For some students, presenting information about hemophilia (or a related bleeding

disorder) to their friends and classmates can be an effective way to clarify misconceptions and "clear the air." For others, it might not be the right time, or it might even be old news. It all depends on your child's circumstances.

While communication is good, confidentiality also has its place. If appropriate, have the child and teachers work out special signals so that, if the child has a bleed that needs to be treated, he can leave the classroom without calling attention to himself. Decide ahead of time which of his peers, or buddies, will know about his condition so he can talk to someone if he needs to. Make sure the teachers and support staff have been taught to be discreet and to avoid singling out your child. With your child, choose a faculty member who will be the "go to" person for sharing concerns or needs; this could be the guidance counselor, school psychologist, or even a favorite teacher.

A child's self-image and self-esteem can be fragile. Fortunately, most school personnel understand this, but you and your child may have different standards of confidentiality. By discussing your child's individual needs with his teachers and caregivers at school, the stage will be set for a comfortable and confident learning environment.

The Family Education Rights and Privacy Act (FERPA) is a federal law that generally prohibits schools from disclosing personally identifiable information in a student's education record unless the school obtains the consent of the student's parent(s) or the eligible student (a student who is 18 years old or older or who attends an institution of post-secondary education). FERPA does allow schools to

disclose this information, without obtaining consent, to school officials, including teachers, who have legitimate educational interests in the information, including the educational interests of the child. Schools that do this must include in their annual notification to parents and eligible students the criteria for determining who constitutes a school official and what constitutes a legitimate educational interest. Additionally, under FERPA, schools may not prevent the parents of students or eligible students themselves from inspecting and reviewing the student's education records.

For more information on FERPA, visit the U.S. Department of Education website at ed.gov/policy/gen/guid/fpco. Parents and

eligible students who need assistance or who wish to file a complaint should do so in writing to the Family Policy Compliance Office, sending pertinent information concerning any allegations to the following address:

**Family Policy Compliance Office
U.S. Department of Education
400 Maryland Avenue, SW
Washington, D.C. 20202-5920**



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