



# THE CHILD WITH HEMOPHILIA IN SCHOOL

## MARYLAND STATE SCHOOL HEALTH SERVICES GUIDELINE

**DECEMBER 2007**

Maryland State Department of Education  
Student Services and Alternative Programs  
Branch  
200 West Baltimore Street  
Baltimore, Maryland 21201  
Phone: 410-767-0311  
TTY/TDD: 410-333-6442

Maryland Department of Health  
and Mental Hygiene, Center for  
Maternal & Child Health  
201 West Preston Street  
Baltimore, Maryland 21201  
Phone: 1-877-463-3464  
TTY/TTD: 1-800-735-2258



## MARYLAND SCHOOL HEALTH SERVICES GUIDELINE

### Foreword

There is a strong relationship between academic achievement and a child's physical, emotional and mental health. This link is the foundation for providing school health services as an important component of a school program. School health services provide primary prevention aimed at keeping students in schools through appropriate screenings, early identification of children at risk for physical, emotional and mental health concerns, and case management of students with chronic health concerns.

The Annotated Code of Maryland, Education Article, § 7-401 requires the Maryland State Department of Education (MSDE) and the Maryland Department of Health and Mental Hygiene (DHMH) to jointly develop public standards and guidelines for school health programs. The following guideline is developed in accordance with that requirement and is based on the expressed needs of the local school health services programs. These guidelines contain recommendations for minimum standards of care and current best practices for the health service topics addressed. It is intended that these guidelines will be used by the local school systems in developing local school health services policies and procedures as a means to assist local school health services programs in providing consistent and safe care to the students of Maryland. Specific laws and regulations that direct school nursing practice or other health services are identified in the guidelines.

## The Child With Hemophilia in School

### Introduction

Children with hemophilia attending school require a thorough nursing assessment of their health needs and specific plans that take into consideration special accommodations that may be required in school. All students have the right to fully participate in educational activities. Any student with a chronic condition such as hemophilia cannot be denied access to any school activity based upon their needs related to the medical condition. Parents are an integral part of their child's care and should be involved in health care planning. This comprehensive guideline outlines considerations that must be addressed as the school nurse develops an individualized care plan for the student with hemophilia in conjunction with the family, the primary care provider, and the hemophilia care specialist.

Children with hemophilia generally do not necessarily require daily care in the health suite and are encouraged to participate in all school activities. Hemophilia is an inherited bleeding disorder that affects approximately 17,000 people in the United States. It predominantly affects males and results in prolonged bleeding, usually into the muscles and joints. Persons with hemophilia bleed longer than people who are unaffected, unless they receive the appropriate treatment. It is important to note they do not bleed at a faster rate.

When a student with hemophilia enters school or a student is diagnosed with hemophilia, the school nurse is responsible for assessing their health needs, performing a nursing appraisal/assessment, and developing a care plan to meet their needs in the school setting. The school nurse should refer to the *Maryland State School Health Services Guideline on Nursing Appraisal* for general guidance on conducting a nursing assessment and to Appendix A (Nursing Appraisal and Assessment of Student with Hemophilia) for specific issues related to the student with hemophilia. The school nurse is also responsible for informing appropriate school personnel of the special health needs of students with hemophilia and providing guidance regarding their need for accommodations (i.e., physical education, school-sponsored events). Additionally the school nurse may provide health education to students with hemophilia.

### Definition

Hemophilia is an inherited disorder characterized by a deficiency or absence of one of the clotting proteins in plasma resulting in poor blood clotting, or coagulation, and continued bleeding. The two types of hemophilia are factor VIII deficiency (hemophilia A) and factor IX deficiency (hemophilia B) or Christmas disease. Hemophilia is carried in the X chromosome, and generally females are carriers and males are affected.

The severity of the clotting disorder is proportional to the degree of clotting factor deficiency. Mildly affected individuals have prolonged bleeding with surgery or significant trauma; moderately affected persons may bleed after minor trauma (such as a

playground fall). Severely affected children may have frequent, spontaneous bleeding into muscles and joints as well as bleeding from trauma.

## **Purpose**

The purpose of this guideline is to provide school health staff with information and resources that will enhance planning for the management and coordination of care of the student with hemophilia in schools and to enable a child with hemophilia to attend school regularly and fully participate in educational programs.

## **Planning and Intervention for Students with Hemophilia in School**

Upon completion of the assessment, the school nurse shall develop a plan that addresses both routine and emergency care. The plan shall outline what will be done if the nurse is not available. The plan should also address participation in physical education classes, recess and school-sponsored activities. See the sample in Appendix B, Johns Hopkins Hemophilia Treatment Center Sports Guidelines for Hemophilia. Copies should be shared with the parents/guardians, physician, and appropriate school staff. Barriers or obstacles to participation and care in school should be identified and addressed in the care plan. It is important to remember that the goals for the student are safety and independence in controlling this lifelong chronic condition to enable full participation in the educational process.

The following should be considered when developing health care plans for the student with hemophilia:

- Developmental considerations
- Family concerns
- Student concerns
- Student's understanding of Hemophilia management and ability to identify potential crises and to perform needed interventions
- Equipment needed
- Psycho-social issues
- Classroom strategies and accommodations
- Medication/Blood clotting factor administration and dose
- Extent of participation in physical education, recess
- Emergency care
- Staff training
- Educational planning
- Coordination with other team members including the parent, the health care provider, and hemophilia care specialist
- Safety considerations
- Disaster preparedness: Lockdown, In-Place, Sheltering and Evacuation (refer to the Maryland State School Health Services Guideline for Emergency Planning for School Nurses)
- Level of severity
- History of type and severity of bleeds

- Handling body fluids (refer to the Maryland School Health Services Guideline for Handling Body Fluids in the School Setting)

## **Emergency Protocol/Plan**

When a student is identified as having hemophilia, the school nurse will develop an individualized emergency protocol/plan with parent and health care provider input. Hemophilia is treated with replacement of the missing clotting factor by intravenous infusion. A school nurse in compliance with the nurse practice act (COMAR 10.27.20) may infuse factor concentrate, or the parents/guardians may be called in to administer the blood-clotting factor. Prompt treatment for minor bleeds allows the child to return to class quickly. It also decreases the time necessary for an injury to heal, and lessens the complications resulting from delayed intervention. A more serious bleed will generally require transport to an emergency room. The following should be considered when developing an emergency protocol/plan:

- The emergency protocol/plan will address types of injuries, the health care providers' emergency orders, and when to call 911.
- The student's symptoms of excessive bleeding.
- Bleeding symptoms can progress to a serious medical emergency and should be monitored closely, treated promptly and have appropriate follow-up.
- Accommodations so that a student is never unattended after an injury.
- The daily responsibility for the management of the student's hemophilia.
- A plan for access to medication and equipment.
- Emergency supplies for treatment:
  - Missing clotting factor as ordered
  - Infusion equipment
  - Clearly marked location/storage of medication and equipment

## **Orders**

The health care provider will submit necessary order forms as determined by local policy. Parents/guardians are responsible for providing the completed order forms to the school.

## **Equipment**

The school should provide the following:

- Sharps container
- Locked storage for medication and equipment including refrigerator for the factor
- Sharps that meet OSHA guidelines, if the school nurse is administering the blood clotting factor
- Gloves

The parent/guardian will provide when needed:

- Medications and all supplies for intravenous infusion
- Student's medical alert identification such as bracelets, necklaces, shoe tags, etc.

- Protective gear such as helmets, knees and elbow pads

## **Daily Accommodations and Educational Planning**

### ***Physical Activity***

Good physical conditioning is particularly important for the child with hemophilia. Strong muscles protect joints and may decrease the number of bleeding episodes. Most children with hemophilia are able to judge what they can do safely. A physical education program should be adapted and based on physician recommendation in consultation with adaptive physical education or motor development specialists and parental input. See the sample in Appendix B, the Johns Hopkins Hemophilia Treatment Center Sports Guidelines for Hemophilia, which should be completed by the student's health care provider.

Low impact sports such as swimming are usually recommended. High impact activities such as contact sports are not advised. If a child seems to be sustaining frequent injuries, it is important to consult with the parents and physician regarding appropriate levels and types of activities.

### ***Psychosocial Issues***

In addition to dealing with the usual developmental issues of childhood, the child with hemophilia faces the challenge of living with a life-long condition. The child may feel different, stigmatized, or isolated. Physical limitations may restrict career choice to the more sedentary occupations.

Reasonable rules are important for all students. Physical altercations should be handled according to school policy as they are for all students. Persistent behavioral issues can be referred to the school administrator, parent/guardian, and the school counselor.

### ***Transportation***

The health care plan may need to address transportation needs for the student with hemophilia. In general, a student with hemophilia should not require special transportation. Each student's needs should be evaluated individually. It is recommended that the school nurse provide consultation regarding any requests for special transportation for the student with hemophilia.

### ***Field Trips/School Sponsored Activities***

All students have the right to participate in a field trips or school-sponsored activities. Participation cannot be denied because of the need for medication/treatment or requirement of additional assistance. If a field trip is planned, the teacher should give sufficient notice to the school nurse so that a plan can be put into place for the student. In some cases, a nurse may be needed to accompany a student. Plan for the field trip should include emergency supplies. Prior to the field trip, the school nurse should provide to the teacher/staff member in charge copies of the care plan for the student.

## Coordination and Case Management

School team members are responsible for implementation of the emergency protocols/plans. Team members' responsibilities include:

<b>Administrators:</b>	Overall responsibility for the education and safety of the student.
<b>Bus Drivers:</b>	Responsibility for student on bus. Communicates health problems or concerns to school official, school nurse, and parent.
<b>Pupil Personnel Worker:</b>	Assistance with transportation issues, home teaching and attendance issues.
<b>School Counselor:</b>	Disability awareness, assistance with support groups/counseling needs.
<b>School Nurse:</b>	Coordination of the school related management of the student with hemophilia. The school nurse is the liaison between the health care provider, school staff, administration, pupil service staff, parents/guardian, and student. The school nurse can also refer the student and/or family for counseling, support groups, access to medical care, and provision of direct nursing services.
<b>School Psychologist:</b>	Assistance with any behavioral strategies.
<b>Teachers/Physical Education Teachers:</b>	Responsibility for student in class and communication of health problems/concerns or injuries to school nurse, school official, and parent/guardian.

For students who participate in field trips and other school-sponsored activities, the school nurse is a resource to evaluate and plan for student health needs.

## Staff Training

Training of appropriate school staff should include:

- Definition of Hemophilia
- Confidentiality
- Symptoms to report to the school nurse
- Field trip and school sponsored activity accommodations
- Physical activity or physical education restrictions

- Role in the implementation of the Emergency Protocol/Plan
- Substitute plans (teacher, school health staff, transportation)
- Student's functional limitations
- Available resources

## **Evaluation**

Evaluation is an ongoing process and should include the following:

- Orders reviewed with family and health care provider annually and as necessary
- Documentation of medications and treatments given
- Communication with the health care provider and family
- Need for staff training
- Effectiveness of the plan to meet the student's health and educational needs
- Assessment and documentation of student's response to the management plan



## **APPENDIX A: THE NURSING APPRAISAL/ASSESSMENT FOR A STUDENT WITH HEMOPHILIA**

### **Data Collection**

It is essential that the school nurse be well informed on the medical, educational, and psychosocial issues regarding students with hemophilia. The school nurse will collect information from a review of medical and educational records (i.e., the school health record, the Student Record Card, emergency health card, and the student cumulative education record). Additional information should be obtained from:

- Parent interviews and/or home visits
- Student interview
- Physician/health care provider
- Hematologist
- Teaching staff
- Classroom observations

### **Assessment**

The school nurse should assess the student with hemophilia for special needs using standard appraisal procedures developed by the jurisdiction and the procedures outlined in the *Maryland State School Health Services Guidelines: Nursing Appraisal/Assessment of Students with Special Health Needs*. The school nurse should be cognizant of policies regarding record releases, information sharing, and confidentiality.

Assessment of the student with hemophilia should include but not be limited to the following:

#### ***Nursing Appraisal/Assessment Outline for Students with Hemophilia***

##### **1. Identifying Information/Contact Information**

- Name of parent/guardian, address, phone number, and emergency contacts
- Name and phone number of primary care provider
- Name and phone number of hemophilia care provider

##### **2. Personal Health History/Hemophilia History**

- Concurrent medical conditions
- Family history of hemophilia
- Initial diagnosis, progress of disease
- History of hemophilia emergencies, hospitalizations, emergency room visits, previous blood clotting factor administration, date of last administration
- Number of days of school missed in the past year
- Limitation of activities
- Physical education restrictions
- Recess activities restriction
- Student awareness of symptoms of excessive bleeding
- Hemophilia disease and related complications
- Medications in addition to blood clotting factor

- Need and regimen for prophylactic factor

### **3. School Hemophilia Management**

- Blood clotting factor
  - dose
  - type(s), frequency, indications
  - method of administration
- Administration of blood clotting factor at school
  - how dose is administered
  - will be administered at school
  - self administered by student; amount of supervision required
  - administered by school nurse
  - administered by parent
- Equipment used
- Student's level of understanding and independence

### **4. Educational Information/Considerations**

- School performance, grade level
- Need for or existence of a 504 plan, IEP
- Participation in special programs, e.g. work study program, vocational program, evening high school, alternative education program, field trips, school-sponsored activities, etc.
- Transportation issues, e.g., bus rider, length of ride; walker, length of walk
- Availability of emergency supplies
- Location of emergency supplies

### **5. Psycho-social Considerations**

- Family status, support available
- Family stresses and student's concerns
- Ability of student and family to cope with disease
- Student's and family understanding of the condition
- History of hemophilia education
- Developmental issues
- Disability awareness needed in the classroom
- Involved in disease related support groups
- Issues related to access to health care and hemophilia supplies, health insurance needs, any additional resources
- Cultural Issues
- Adherence with the hemophilia management plan

## **Health Care Plan**

Upon completion of the assessment, the school nurse shall develop a plan that addresses routine and emergency care. The plan will address what will be done in the absence of a school nurse. Copies of these plans are shared with the parents/guardians, physician, and appropriate school staff. Barriers or obstacles to participation and care in school should be identified and addressed in the care plan.

## APPENDIX B: RESOURCES

- ❑ Children's National Medical Center  
Christine Guelcher, Pediatric Nurse Practitioner  
Department of Hematology/Oncology  
cguelch@cnmc.org  
<http://www.dcchildrens.com/dcchildrens/about/ProgramDisplay.aspx?ProgramId=286>
- ❑ Hemophilia Foundation of Maryland  
(410-288-3955)
- ❑ Johns Hopkins Hospital, Baltimore, Maryland
- ❑ Johns Hopkins Hemophilia Treatment Center Sports Guidelines for Hemophilia  
Pediatric Hematology – Contact Patricia Underland, Hemophilia Coordinator,  
Johns Hopkins Hospital (410) 955-6132 or (410) 614-0834 (Appendix C)
- ❑ National Hemophilia Foundation, New York  
800-842-HANDI; [www.hemophilia.org](http://www.hemophilia.org)

**APPENDIX C**

**SAMPLE GUIDELINES  
Johns Hopkins Hemophilia Treatment Center  
Sports Guidelines for Hemophilia  
Pediatric Hematology**

(Adapted from the Johns Hopkins Hemophilia Treatment Center Sports Form)

Treatment Center: \_\_\_\_\_

Name: \_\_\_\_\_ DOB: \_\_\_\_\_

Physician: \_\_\_\_\_ Phone: \_\_\_\_\_

Nurse Coordinator: \_\_\_\_\_ Phone: \_\_\_\_\_

Hemophilia is a chronic bleeding disorder affecting approximately 20,000 individuals in the US. People with hemophilia have low levels or complete absence of a blood protein that is necessary for normal blood clotting. Trauma and injury may cause bleeding into soft tissue, joints and muscles. Individuals with hemophilia are affected at varying levels of severity, requiring different approaches to treatment and restriction of activities.

For the child with hemophilia, physical exercise strengthens muscles and increases joint stability. Studies by orthopedists and physical therapists have shown that children whose joints are supported by well-developed muscles are better able to withstand the traumas of daily living. Participating in sports increases independence, confidence and self-esteem. The physical, social and psychological benefits of sports will outweigh the potential risks of these activities in many cases.

Low impact sports such as swimming, bicycling and golf are usually recommended, whereas high contact/impact activities, such as football, lacrosse and wrestling are not advised. Boxing is strictly prohibited. Protective gear appropriate to the sport, such as helmets or elbow pads, is required. In addition, activity/sports recommendations will vary according to a child's particular treatment regimen, e.g. prophylactic therapy vs. on demand treatment.

The decision to participate in sports and activities is primarily the decision of the parent/guardian, with input from health care providers and physical education staff. The following are our specific recommendations for the current school year, as discussed with the patient and his family.

Sport	Yes	No	Competitive	Non-competitive Instructional only	Special Equipment or Procedures	Prophylactic Rx Before Participation
Aerobic Dance						
Archery						
Badminton						
Baseball						
Basketball						
Bicycling						
Bowling						

MARYLAND SCHOOL HEALTH SERVICES GUIDELINE

Sport	Yes	No	Competitive	Non-competitive Instructional only	Special Equipment or Procedures	Prophylactic Rx Before Participation
Crew (Rowing)						
Fitness Calisthenics						
Dodgeball						
Fencing						
Flag Football						
Golf						
Gymnastics						
Hockey-Field						
High Beam						
Handball						
Horseshoes						
Lacrosse						
Martial Arts						
Parallel Bars						
Racquetball						
Rope Jumping						
Running						
Shuffleboard						
Skating (Ice)						
Skating (Roller)						
Skiing						
Soccer						
Softball						
Swimming						
Table Tennis						
Tennis						
Track and Field (excluding pole vaulting)						
Trampoline						
Volleyball						
Walking						
Weightlifting						
Wrestling						
Other						

If you would like to review these recommendations or have any questions, please call me at \_\_\_\_\_ Evenings and weekend beeper: \_\_\_\_\_.

Nurse Coordinator \_\_\_\_\_ Phone \_\_\_\_\_

Physician Signature \_\_\_\_\_ Date \_\_\_\_\_

Physician (name printed) \_\_\_\_\_ Expiration Date \_\_\_\_\_