



STUDENTS WITH BLEEDING DISORDERS

This guide is meant as a starting point for discussions about how to best address the unique healthcare needs of students who have a bleeding disorder. It is important that YOUR hemophilia treatment center (HTC) be involved in these conversations from the start so that – together – you, the HTC team, and the school staff can appropriately address your child’s individual needs.

Step 1: Nursing Assessment

Should include but not be limited to....

1. Identifying Information / Contact Information

- Name of parent/guardian, address, phone, 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

- Family history of hemophilia
- Initial diagnosis, progress of disease
- Concurrent medical conditions
- History of hemophilia emergencies, hospitalizations, ER visits
- Number of days of school missed in the past year
- Limitation of activities
- Physical Education restrictions
- Recess activities restrictions
- Student awareness of symptoms of excessive bleeding
- Complications (target joints, inhibitors, etc.)
- Other medications in addition to factor
- Need and regimen for prophylactic factor



3. School Hemophilia Management

- Factor Concentrate
 - Brand name
 - Dose, frequency, indications
 - Method of administration
 - Storage of factor at school

- Administration of factor at school
 - How dose is administered (i.e., port or other device, peripheral infusions, etc.)
 - When factor will be administered at school
 - Self-administered by student – amount of supervision required
 - Administered by school nurse ***(Is it an option? Not all school systems will do this)***
 - Administered by parent or visiting nurse
 - Ancillary supplies needed

- Equipment used (i.e., crutches, wheelchair, etc.)
- Student's level of understanding and independence
- Access to the school nurse's office (i.e., case-by-case basis, permanent pass for the year)
- Student's medical alert identification such as bracelets, necklaces, shoe tags, etc.

4. Educational Information / Considerations

- School performance, grade level
- Need for 504 plan or IEP ***(see separate handout with more information on 504s and IEPs)***
- Participation in special programs (i.e., field trips, school-sponsored activities, evening high school, alternative education program, work study, vocational programs, etc.)
- Transportation issues (in general, a student with hemophilia should not require special transportation, but each student's needs should be evaluated individually)
- Availability and location of emergency supplies

5. Psycho-Social Considerations

- Family status, support available
- Family stresses and student's concerns
- Student's and family's understanding of the condition and ability to cope
- Developmental issues
- Disability awareness and/or bleeding disorder education to be provided to peers
- Involvement in community support groups
- Issues related to access to health care and hemophilia supplies, health insurance needs, any additional resources
- Cultural issues
- Adherence with hemophilia management plan



Step 2: Individual Healthcare Plan (IHP or IHCP)

- A formal written agreement developed through a collaboration by the school staff, the student's family, and the student's health care provider(s)
- Identifies your child's health needs, and creates solutions to potential health problems that can occur in a school environment
- Provides a safe environment that helps your child learn and makes goals for your child's healthcare
- The plan should address both routine and emergency care
- The plan should document what steps to take if the nurse is not available as well as what interventions the nurse will provide
- The plan should outline any classroom accommodations that may be needed, as well as guidelines regarding participation in PE, recess, field trips, etc.
- The plan should include information related to training school staff and educational planning

"Hallmarks" of a Good Individual Health Plan

Contains information, guidelines & standards that promote a student's health & educational goals.

Avoids unnecessary risk, restriction, stigma, illness & absence.

Step 3: Emergency Care Plan

(Some schools may include the Emergency Care Plan as part of the Individual Healthcare Plan)

- Types of injuries – when to call parents, when to call the HTC, when to call 911
 - Explain the difference between joint bleeds, muscle bleeds, soft tissue bleeds, mucous membrane bleeding
 - Emphasize areas that require immediate attention: head trauma, blow to neck or abdomen, eye injury
 - Educate on the signs and symptoms of a head bleed, which in rare cases can happen without known trauma or external manifestations
- Treatment of bleeds
 - Explain the difference between early onset symptoms and late onset symptoms
 - Emphasize the importance of early treatment
 - Obtain orders from the student's health care provider on appropriate Medication Authorization Form – parents should be responsible for providing the completed forms to the school
 - Identify a clearly marked location/storage of medication and equipment
- The school should provide the following:
 - Sharps container and gloves
 - Locked storage for medication and equipment including refrigerator for the factor if requested
- 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



Step 4: Misc.

- Field Trips / School Sponsored Activities
 - All students have the right to participate – 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 two weeks-notice to the school nurse so that a plan can be put into place for the student. The plan should always include factor and emergency supplies
 - In some cases, a nurse or parent may be needed to accompany a student
 - Prior to the field trip, the school nurse should provide to the teacher/staff member in charge copies of the student's care plan

- Staff Training - training of appropriate staff should include:
 - Definition of Hemophilia
 - Confidentiality
 - Symptoms to report to the school nurse
 - Field trip and school sponsored activity accommodations
 - Physical activity or PE restrictions
 - Staff roles in the implementation of the Emergency Protocol Plan
 - Student's functional limitations
 - Available resources

- Evaluation
 - It's 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 at a minimum of every two to three months
 - Assessment and documentation of student's response to the management plan at a minimum of every six months.

SOURCE: *The Child With Hemophilia in School*. Baltimore, MD: Maryland State Department of Education; 2007 <http://cl.k12.md.us/depts/HEALTH/Guidelines/HemophiliaGuidelines.pdf>