STUDENTS WITH BLEEDING DISORDERS

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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 bleeding disorder care provider

2. Personal Health History/Bleeding Disorder History

- Family history of bleeding disorder
- Initial diagnosis, progress of disease
- Concurrent medical conditions
- History of bleeding disorder 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 Bleeding Disorder Management

- Medication (e.g., factor concentrate)
  - > Brand name
  - > Dose, frequency, indications
  - > Method of administration
  - > Storage of factor at school
- Administration of factor at school
  - > How dose is administered (e.g., port or other device, peripheral infusions)
  - > 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 (e.g., crutches, wheelchair)
- Student's level of understanding and independence
- Access to the school nurse's office (e.g., case-by-case basis, permanent pass for the year)
- Student's medical alert identification, such as bracelets, necklaces, or shoe tags

4. Educational Information/Considerations

- School performance, grade level
- Need for 504 plan or IEP *(see "Your child has a bleeding disorder: Now what?" for more information on 504s and IEPs)*
- Participation in special programs (e.g., field trips, school-sponsored activities, evening high school, alternative education program, work study, and vocational programs)
- Transportation issues (in general, a student with a bleeding disorder 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 healthcare and bleeding disorder supplies, health insurance needs, any additional resources
- Cultural issues
- Adherence with bleeding disorder management plan

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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 and standards that promote a student's health and educational goals.
- Avoids unnecessary risk, restriction, stigma, illness and 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 healthcare 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 if required and 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: Miscellaneous

- 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 bleeding disorder
  - 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

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