Steps for Living
National **Bleeding Disorders** Foundation

SCHOOL INFORMATION: BLEEDING DISORDERS

stepsforliving.bleeding.org

Health and Safety in Schools

An essential part of school inclusiveness is recognizing the importance of offering care to young people with chronic illnesses, particularly since a major part of childhood is spent attending school. This toolkit gives you an overview of bleeding disorders, resources, and how to best support a student with a bleeding disorder.

Students with bleeding disorders have protections from two federal laws while at school: the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act. These do the following:

- Prohibit discrimination on the basis of disability.
- Allow for reasonable accommodations. For example:
    - An extra set of books at home or school to avoid having to carry heavy bags
    - Extra time to complete assignments when absent due to hospital stays or health care provider visits
    - Modified physical education
- Provide early intervention, special education, and related services to children with disabilities.

What is a Bleeding Disorder?

A bleeding disorder is a condition in which a person tends to bleed longer (not faster) before a blood clot forms to stop the bleeding. A bleeding disorder can be caused by a defect in the blood vessels or from an abnormality in the blood itself. The abnormality may be in blood clotting factors (proteins called coagulation factors) or in platelets (small protein-containing blood cell elements, called fragments). The clotting factors are numbered from 1 through 13, using roman numerals (such as I, IV, or X).

Bleeding Disorder Basics

The Most Common Types of Bleeding Disorders are:

- Hemophilia A (Factor VIII deficiency)
- Hemophilia B (Factor IX deficiency)
- von Willebrand disease

Hemophilia

Hemophilia is the most well-known bleeding disorder and is caused when there is a lack or decrease of clotting factor VIII (8) or clotting factor IX (9). There are two main types of hemophilia. Hemophilia A happens if there is a problem with clotting factor VIII (8) and hemophilia B happens if there is a problem with clotting factor IX (9). Hemophilia A and B can be mild, moderate or severe.

There are between 30,000 to 33,000 people living with hemophilia in the US. Common signs include bleeding into the joints, prolonged bleeding from cuts or injuries, nosebleeds, and bruising.

How common is hemophilia?

- Hemophilia A: 1 in 5,000 male births
- Hemophilia B: 1 in 30,000 male births

Von Willebrand disease (VWD)

VWD is the most common bleeding disorder. VWD affects approximately 1 in every 100 people. A person with VWD is either missing or low in von Willebrand factor (VWF) or they have VWF that doesn't work properly.

Several different types of VWD have been identified, including Type 1, Type 2, and Type 3, as well as subtypes 2A, 2B, 2M, and 2N. The most common signs include heavy periods that last longer than 7 days, frequent nosebleeds, easy bruising, and bleeding from gums.

How common is von Willebrand disease?

- von Willebrand disease is estimated to be present in 1% - 2% of the population

Rare Factor Deficiencies

VWD is the most common bleeding disorder. VWD affects approximately 1 in every 100 people. A person with VWD is either missing or low in von Willebrand factor (VWF) or they have VWF that doesn't work properly.

Several different types of VWD have been identified, including Type 1, Type 2, and Type 3, as well as subtypes 2A, 2B, 2M, and 2N. The most common signs include heavy periods that last longer than 7 days, frequent nosebleeds, easy bruising, and bleeding from gums.

Rare Platelet Disorders

Platelets play an important role in blood clotting. When an injury occurs and a blood clot is needed, platelets become sticky and help plug the site of the injury. A person with a platelet disorder has too many platelets, too few platelets, or the platelets they have do not work well. Rare platelet disorders include Bernard-Soulier Syndrome (BSS), Glanzmann's Thrombasthenia (GT), and Platelet Storage Pool Deficiency (PSPD).

How Does Someone Get a Bleeding Disorder?

While there are many different and rare bleeding disorders, generally bleeding disorders are inherited genetically.

Some people may acquire a bleeding disorder like hemophilia or VWD later in life.

Others may get a bleeding disorder not from genetic inheritance but due to a change called spontaneous mutation in the gene. This change can prevent the clotting protein from working properly or the protein may be missing altogether.

Treatment for Bleeding Disorders

In general, small cuts and scrapes are treated with usual first-aid measures: clean the cut and then apply pressure and a bandage. There are different types of treatments that can be given including through a needle in the vein (called infusion), orally, or by a nasal spray. Many children learn to self-treat at a young age, and can selfinfuse even in early elementary school.

What types of bleeding should I expect in a person with a bleeding disorder?

- Joint bleeding (internal bleeding into the joints)
  - Symptoms
    - Tingling or bubbling sensation
    - Stiffness
    - Warmth
    - Pain
    - Unusual limb positions
- Muscle bleeding (internal bleeding into the muscles)
  - Symptoms
    - Same as joint bleeding
- Soft tissue bleeding (internal bleeding marked by excessive bruising or swelling)
- Life threatening bleeding (head injuries, eyes, neck/throat, abdominal/stomach, kidney/bladder)
- Other common bleeding (nosebleeds, mouth/teething bleeds)

Medical Emergencies for Bleeding Disorders

Prevent bleeding as soon as possible; treat immediately when it occurs

Depending on the severity of the underlying bleeding disorder, bleeding episodes may be frequent to rare. When possible, prevention of bleeding is the goal in managing people with a bleeding disorder. However, when bleeding does occur, it is important to recognize the signs and symptoms at the earliest possible time and treat it appropriately.

What happens if a person with a bleeding disorder is left untreated?

- Continued or repeated bleeding into the joints can cause:
  - Flexion contractures
  - Joint arthritis/arthopathy
  - Chronic pain
  - Muscle atrophy
- Continued or repeated bleeding into muscle can cause:
  - Compartment syndrome
  - Neurological impairment

Some bleeds are more serious than others

Common bleeds, such as bruises, nosebleeds, mouth bleeds and heavy periods generally do not require emergency medical attention. If a person with a bleeding disorder has a bleed and is not on a home-therapy program, be sure to consult immediately with the student's parents who will most likely contact a health care provider or hemophilia treatment center (HTC) to determine whether treatment is required.

Potential bleed sites are:

- Mouth
- Urinary Tract
- Nose
- Joint
- Muscle
- Soft Tissue
- Head (911!*)
- Eye (911!*)
- Spinal cord (911!*)
- Neck or throat (911!*)
- Deep cuts or lacerations (911!*)
- Gastrointestinal (GI) (911!*)

** 911! Bleeding from these sites is life threatening. If a person has bleeding at one of these sites, call 911 immediately, notify the student's parents and, if protocol indicates, also the hemophilia treatment center (HTC). Bring the person's bleeding disorder medication with them to the emergency room.*

Treatment for Bleeding Disorders

Individualized Health Plan (IHP):

All students with bleeding disorders should have an individual health plan. The IHP allows for all parties involved, medical team, parents, and school staff, to be assured that the correct information regarding the student is being distributed, while allowing for a quick reference guide in the event an issue arises. Many hemophilia treatment centers (HTC) or local bleeding disorder organizations will work with school staff to create and explain an IHP. Individual health plans may vary slightly but tend to cover:

- General description
- Diagnosis and treatment
- Preventive measures to keep the student well at school
- Arrangements, if any, for giving medication to the student
- What constitutes an emergency and what to do
- Key contacts
- Specific information related to the student's daily life at school.

The plan should be updated each year and reviewed with staff the student is likely to meet during their academic year.

School Absences:

It is important for schools to have strong support for students with bleeding disorders to account for school absences. Despite a student's adherence to treatment, breakthrough bleeds occur, and may cause the student to miss school in increments from hours to days, and even weeks. There is the risk that the student will have absences beyond the school corporation's allotted missed days.

It is important that the student not be penalized when such occasions arise due to serious bleeding episodes.

Discuss with school administrators how the student may plan for and make amends for days of absence, from the teacher sending schoolwork to the home with a sibling or friend, to special tutors.

Physical Activity:

Physical activity is any activity that causes your body to work harder than normal. Such activities are beyond the daily routine of sitting, standing, and walking up stairs. Everyone can benefit from increased physical activity. Some physical activities are considered safer than others for people with bleeding disorders. Avoid contact sports and other forms of hard, physical exercise involving strenuous exertion that could precipitate a bleed. Encourage moderate exercise. Over time the young person will come to know their own safe limits of physical activity. The IHP should address which activities are suggested for this individual student.

Do not refuse requests if a young person with a bleeding disorder asks to be excused or stop participating in an activity because of pain or a bleed. It is important to listen to the student and parent, and follow advice from their health care provider or Hemophilia Treatment Center (HTC) about physical activity.

Pain

When a young person has a bleed it can be quite painful. The IHP needs to be created with each individual student in mind, with input from teacher, school nurse, health care provider, student and parents. It is very important that the policy includes instructions about how to handle a painful bleed.

Adaptive Devices:

From time to time the student may need to use adaptive devices such as crutches or a wheelchair. School staff should be aware to not draw undue attention to the student while at the same time making sure that ample exceptions are afforded the student, as needed.

Treatment:

A key part of the individualized health plan should include arrangements for administering treatment. Treating early is key with bleeding disorders to avoid continued bleeding and further damage. Listen to the student and follow the individualized health plan. Students eventually learn to self-treat, and the IHP should list the student's ability and what provisions have been made for treatment including parent/guardian permission, and delivery/storage of bleeding disorder medication, among other information. If there is any doubt contact the student's parents.

Teacher Awareness:

Each parent and student may have a particular desire regarding who to tell and how much to tell about the student's bleeding disorder, but generally, especially for younger students, all staff that has regular contact with the student should be made aware of their bleeding disorder. Staff needs to know what to do if the student has a bleed and needs to learn to listen to the student if they are feeling unwell.

Abuse:

Bruises on a student can easily be misinterpreted as a sign of physical abuse. Even trained health care providers may have difficulty determining whether the bruising they see is associated with abuse or a medical condition, such as a bleeding disorder. Having a bleeding disorder does not exempt a child from abuse. School officials should look for specific bruising patterns such as slap marks or the outline of an object, such as a paddle or belt. A thorough investigation should occur before any accusations are made.

Additional information and resources available at:
www.stepsforliving.bleeding.org

This document was developed through the support of NBDF's Community Education Program sponsors: https://www.stepsforliving.bleeding.org

NATIONAL
BLEEDING DISORDERS
FOUNDATION