

# Hemophilia at School



*Developed by:*  
**Hemophilia Federation of America**  
210 7th St SE Suite 200 B  
Washington DC 20003  
202-675-6984  
[www.hemophiliafed.org](http://www.hemophiliafed.org)

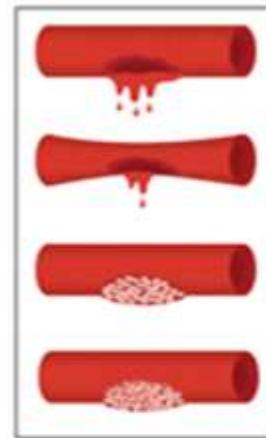
## Definition of Hemophilia

- A group of hereditary bleeding disorders in which there is a deficiency of one of the factors necessary for coagulation of blood

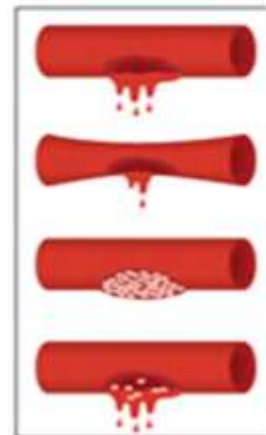
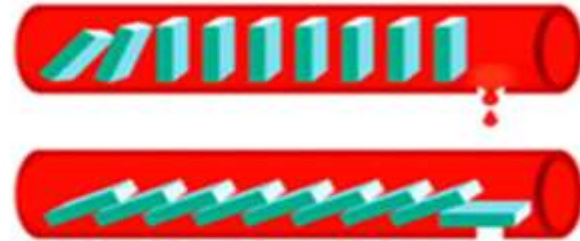
## Types of Hemophilia

- Hemophilia A - absence or deficiency of Factor VIII; also known as Classic Hemophilia
- Hemophilia B - absence or deficiency of Factor IX; also known as Christmas Disease
- Other rare missing clotting factors can include factors II, V, VII, X, XI, XIII

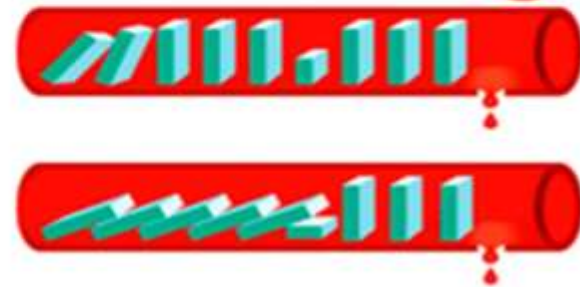
They are missing or have low levels of a clotting factor – this makes it difficult for the blood to form a clot



Normal Clotting Process



Clotting in Hemophilia



## Incidence

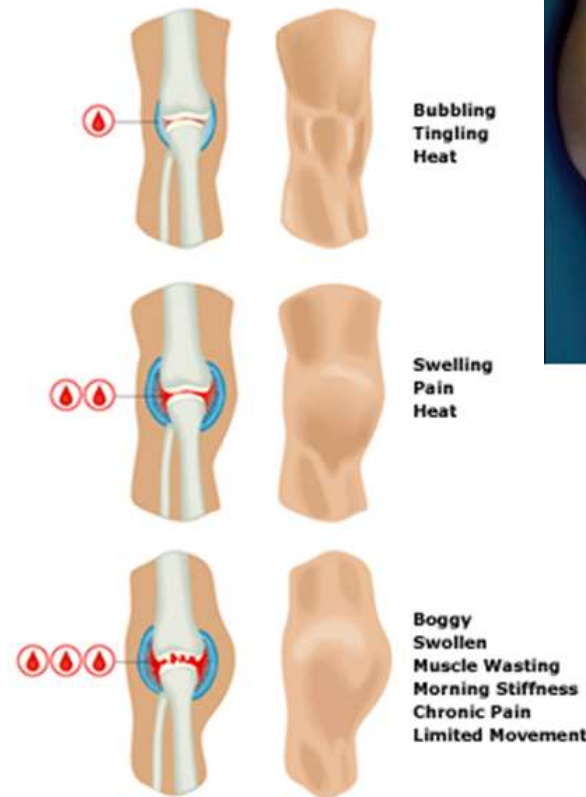
- One in 7500 live male births
- Affects approximately 17,000 males in the U.S.
- All races and socioeconomic groups are equally affected
- X-linked disorder, females carry gene, males are affected. 30% cases genetic mutations

## Degrees of Severity

- Normal factor VIII or IX level = 50-150%
- Mild hemophilia
  - factor VIII or IX level = 6-50%
- Moderate hemophilia
  - factor VIII or IX level = 1-5%
- Severe hemophilia
  - factor VIII or IX level = <1%

- Joint bleeding
- Muscle hemorrhage
- Soft tissue - bruising
- Life threatening - bleeding
- Others - mouth, nose, scrapes, minor cuts

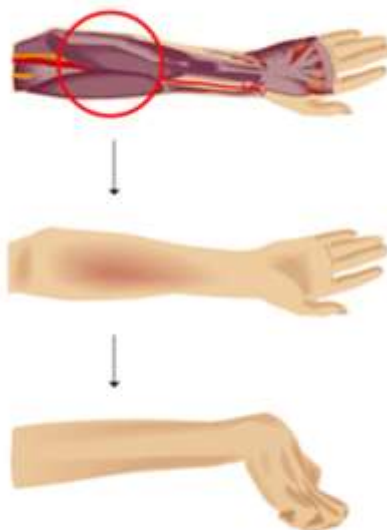
- Early signs of joint bleeding include bubbling, tingling and heat at the joint  
*(This is the best time to start treatment)*
- Swelling and pain set in
- As the joint swells, it feels boggy, and range of motion is limited. Child may not be able to bear weight or move a limb. Very painful in later stages of a bleed
- Knees, Ankles & Elbows most often affected
- **KEY POINT: Child can feel a joint bleed LONG before anyone sees any outward symptoms**



knee bleed

Photo Credit: National Hemophilia Foundation

- Signs and symptoms very similar to joint bleeding, but also can include tightness and/or shininess of skin
- Muscle bleeding is very painful
- Usually happens in arms and legs
- Significant blood loss can happen quickly
- Leg, thigh, calf, forearm and groin most affected areas
- **KEY POINT: Child can feel a muscle bleed LONG before anyone sees any outward symptoms**





Graphic Credit : Wilkes family

- Soft tissue bleeding is primarily characterized by bruising and hematomas (raised bruises)
- Many children with hemophilia have significant bruising all over their bodies
- Treatment is generally not needed, but ice can help with comfort



- **Head/Intracranial**
  - Nausea, vomiting, headache, drowsiness, confusion, visual changes, loss of consciousness
- **Neck and Throat**
  - Pain, swelling, difficulty breathing/swallowing
- **Abdominal/GI**
  - Pain, tenderness, swelling, blood in the stools
- **Iliopsoas Muscle**
  - Back pain, thigh tingling/numbness, decreased hip range of motion

- Mouth bleeding
  - Looks like more than it is, as it is mixed with saliva
  - Child may vomit
  - Feces may be black (from swallowed blood)
- Nose bleeding
  - Sit up, pinch bridge of nose, cool pack on back of neck
  - If longer than 20 minutes, call parents
- Scrapes and/or minor cuts
  - Wash, pressure, dressing
  - Call parents if bleeding persists

Early and appropriate treatment of each bleeding episode is critical to minimize complications.

REPLACEMENT OF DEFICIENT CLOTTING FACTOR IS  
THE SINGLE MOST IMPORTANT STEP IN  
ANY INTERVENTION

The recognition of bleeding episodes and treating bleeds as early as possible can help prevent complications such as the lost of range of motion, arthritis and muscle atrophy



- Factor concentrate is administered intravenously (IV)
- It should be administered as close to the time of the bleed as possible



- Parents should notify the appropriate medical staff at the school about their child
- Classroom teachers, PE/Gym teachers, playground supervisors should be aware that there is a child with hemophilia under their supervision
- A care plan should be made with the medical staff, school personnel and parents
- Key people should be made aware of the plan

People on prophylaxis infuse their treatment on a regular schedule to prevent bleeds from occurring. Prophylaxis is recommended for children with severe hemophilia.

There are two types of prophylaxis:

- Primary – This type of treatment is usually started in young children to reduce or prevent joint disease and it is continued indefinitely.
- Secondary – This type of prophylaxis is usually short term and it is started when a bleed has occurred and continued on a regular schedule for a defined period of time.

Advantages:

- Reduced risk of joint damage
- Ability to participate in sports and other physical activities
- Reduced risk of spontaneous bleeding

# How Does the Child Handle School?

- Should not be treated differently than any other child in the classroom
- Leave it up to the parents and/or the child to share with others that he has hemophilia
- There are no learning disabilities that are associated with hemophilia
- Could have frequent absences
  - Hard to catch up
  - Hard for peers to understand
- Pain
  - Could have acute or chronic pain
  - Medication side effects

- Unless recovering from a bleeding episode
  - Should participate in regular gym class
  - Should go on all planned field trips
  - Should play at recess with classmates
- Some activities restrictions
  - No contact sports
  - May need immobilization during or after a bleed
  - May need some alternative activities for inclusion in physical education, recess, etc.



- If a child says he is having a bleed or is limping or not using an arm
  - **Contact parents immediately**
  - Have the child elevate the body part that is bleeding
  - Apply ice to the area
  - Remember, the child can feel a bleed before there are any outward signs
- Superficial cuts or scrapes
  - Wash the area with an antiseptic soap
  - Apply firm pressure
  - Apply a dressing
  - Contact parents if bleeding persists
- Could have bleeding at port site

- Can play along with other kids and do the same activities as others
- Parents ask that he NOT run indoors or on cement.
- Pay careful attention at recess & PE
- No rough-housing with other kids
- Playground
  - Does not have to wear helmet as of now, but that could change
  - Prefer that he only run on grass
  - No running on cement
  - No jumping off equipment
  - Careful consideration when walking near swing
  - Use equipment properly (no going up the slide, don't come head first down slide, no jumping off play-sets, etc)

- May be covered in excessive bruising
  - Some older bruises may become lumpy or hard
- May come to school “accessed”
  - Needle inserted into his port. Will be covered by tape and his clothing
- May come to school wrapped in ACE bandage or Coban, or other device
- Medication will be kept in (nurse’s office)

# How Much do Others Need to Know?

- If other parents ask about student they can be told:
  - He has a medical condition
  - He has Hemophilia
  - He has a bleeding disorder
- Encourage them to talk to the student's parent/guardian if they have more questions.
- If the kids notice bruising, helmet, Medic-Alert bracelet:
  - The student can tell the other kids :
    - “I have special blood”
    - “My blood doesn’t work right”
    - “I’m missing something in my blood”
    - “I get pokes”
    - “I get infusions”

- Treat student normally
  - Don't label him
  - Don't overprotect
  - Don't exclude him
  - Don't overreact
- Believe him if he says something hurts
- CALL if you have any questions!

- If the student says something hurts
- Fever
- Injury to joints
- ANY head or neck injury
- Non use of a limb or swelling, warmth or redness in a limb
- Broken bone
- Cut requiring sutures
- Injury to torso (especially chest wall) or kidney area

# Responsibilities

## Student

- Learn to communicate
- Tell someone when they are bleeding
- Do your schoolwork on time
- Make the same amount of effort as someone without hemophilia

## Parent

- Communicate child's condition, activity level & treatment
- Help obtain makeup work
- Help the child have a positive attitude about school
- Work with school staff & nurse to develop a factor treatment plan

## School

- Monitor student achievement & inform parents of any change to personality, performance
- Communicate to parent/child any observable sign of a bleed
- Stress the importance of completing assignments
- Promote ability and success, not inability
- Respect privacy and confidentiality

- Remember that the student is a normal child who happens to have a bleeding disorder
- Understand what type of bleeding disorder he has and the type of treatment he receives
- Be aware of the emergency action plan
- If you have questions or have ANY questions, ANY time, call the parents!