Factor XIII Deficiency

The Facts

- A person with factor XIII deficiency (pronounced as factor 13 deficiency) has blood that does not clot like it should.
  - It affects males and females equally.
  - Extremely rare genetic condition.
  - There is no cure.
  - It is a life-long condition.
- People with factor XIII deficiency do not bleed faster than normal but have a harder time stopping the bleeding.
- It may take intravenous and/or oral medicine to help control the bleeding.

Common Bleeding Issues

- Joint bleeds
- Bleeding into the brain with trauma
- Poor wound healing
- Bleeding after invasive procedures
- Heavy bleeding during menses for females

School Considerations

- Please allow for frequent bathroom breaks for students with this disorder.

If You Suspect a Joint Bleed

- Ask the student if s/he is having a joint bleed. (The student is trained to identify bleeds.)
- Look for warmth, pain, lack of use or guarding.
- Contact the parent and school nurse.
- Allow student to receive prescribed medication if instructed to by the parent or physician.

First Aid for Minor Bleeding

- Rest, Ice, Compression, Elevation
- Cuts and scrapes: clean, apply pressure, and bandage
- Nosebleeds: hold head straight (not back) and apply pressure
- Mouth bleeds: apply ice or cold compress
- Headache (not from injury): give Tylenol only. If not relieved in two hours or accompanied by other symptoms, contact the parent.

Emergency Bleeding

- Head: nausea, vomiting, headache, confusion, blurred vision, loss of consciousness
- Eye: trauma and bleeding into and around the eye
- Neck and throat: pain, swelling, difficulty swallowing or breathing
- Abdomen: trauma to abdomen, acute tenderness, pain or swelling

In an Emergency:

- Call 911.
- Inform the parent.
- Notify EMS the child has a bleeding disorder.
- Contact the Hemophilia Treatment Center.
Benefits of Physical Activity

- Promotes overall physical fitness by improving
  - Cardiovascular fitness
  - Muscular fitness
  - Bone health
  - Body composition/weight
  - Cognitive function
  - Academic performance
  - Sleep
  - Self-esteem
  - Self-confidence
  - Energy
- Reduces feelings of anxiety and depression
- Reduces fatigue
- Increases balance and coordination
- Promotes a spirit of participation and involvement
- Lowers the risk of
  - Spontaneous joint bleeds
  - Heart disease
  - Stroke
  - High blood pressure
  - Type 2 diabetes
  - Colon cancer

Which Sports Are Safe?

- **AVOID HIGH-IMPACT SPORTS** such as football, boxing, hockey, rugby, and wrestling.
- Encourage low-impact sports such as running, aquatics, and golf.
- Always consult parents regarding any participation in sports.
- Look for activity ratings in the Playing It Safe materials provided by the National Hemophilia Foundation.