

Bernard-Soulier Syndrome



The Facts

- A person with Bernard-Soulier Syndrome has blood that does not clot like it should.
 - It affects males and females equally.
 - Very rare platelet disorder.
 - The only cure is a bone marrow transplant.
 - It is a life-long condition.
- People with Bernard-Soulier Syndrome do not bleed faster than normal but have a harder time stopping the bleeding.
- Bleeding can range from mild to very severe.
- It may take medicine to help control the bleeding.
- People with Bernard-Soulier Syndrome cannot make a strong clot.
- People with Bernard-Soulier Syndrome may not have a normal number of platelets.



Common Bleeding Issues

- Frequent and prolonged nosebleeds
- Nosebleeds that are difficult to stop
- Bleeding after invasive procedures
- Bleeding into joints or muscles
- Bleeding with minor cuts and scrapes
- Heavy bleeding during menses for females



School Considerations

- Some people with Bernard-Soulier Syndrome require frequent intravenous medications and/or blood products (because of low platelets) to prevent bleeding episodes.
- Please allow for a 504 plan to be in place to help with making up assignments.
- Patients may also require oral medications to help treat or prevent bleeding. This medication may need to be taken at school.
- Please allow for frequent bathroom breaks for females with this disorder because of heavy or irregular periods.



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.



*Bruising is
a common
occurrence for
people with
congenital
bleeding
disorders*

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