



Bleeding & Clotting Disorders Institute

Family-oriented care for persons with bleeding, clotting and other blood disorders

Hypofibrinogenemia/Dysfibrinogenemia is a lifelong bleeding disorder that affects a person's clotting process. Individuals with hypofibrinogenemia do not produce enough fibrinogen and individuals with dysfibrinogenemia have enough fibrinogen but it does not work correctly. Fibrinogen (factor I) is a protein in the blood that is an essential part of the clotting process:

*Your Hemophilia Treatment Center staff will educate you on whether you have hypofibrinogenemia or dysfibrinogenemia at the time of diagnosis.

✓ You have been diagnosed with _____

✓ Your primary Provider here is _____

Inheritance of hypofibrinogenemia/dysfibrinogenemia:

- affects both men and women equally
- is hereditary – not sex linked (meaning it occurs in males and females)
- may occur rarely through spontaneous genetic mutation
- may also be acquired (rare)

Common symptoms of hypofibrinogenemia/dysfibrinogenemia:

- Easy bruising
- Frequent nosebleeds
- Bleeding gums
- Heavy menstrual periods
- Prolonged bleeding after injuries or surgery
- In severe cases (rare): bleeding in stomach, intestines, muscles or joints

If you or a loved one has been diagnosed with hypofibrinogenemia/dysfibrinogenemia, it is important to know when you should contact BCDI.

Please call if the person with hypofibrinogenemia/dysfibrinogenemia has:

- been scheduled for **any** type of dental or surgical procedure
- prolonged (greater than 10 minutes) nose bleeding
- prolonged (greater than 20 minutes) gum or mouth bleeding
- blood in the urine or stool
- excessive or prolonged (more than 7 days) menstrual bleeding
- more frequent bruising or large, painful bruising with knots
- has suffered an injury to the head, neck, or stomach
 - **If loss of consciousness or significant bleeding – call 911 prior to making other calls.**

When in doubt, we ask that you call our office for recommendations.

- **To reach a nurse, please call (309) 692-5337.**
- **After regular business hours, please call (309) 677-6085 to reach the provider on call.**

*Any of the above situations **may** require a person with hypofibrinogenemia/dysfibrinogenemia to receive treatment. It is important to contact BCDI so that treatment recommendations can be discussed.



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Available treatment options for symptoms of hypofibrinogenemia/dysfibrinogenemia:

- **Aminocaproic Acid (Amicar™):**
 - Available in liquid and pill form
 - Used for mouth or nose bleeding
 - Will likely be necessary with dental procedures

- **Tranexamic Acid (Lysteda™):**
 - Available in pill form
 - Used for heavy menstrual bleeding

- **Fibrinogen replacement product:**
 - Given as intravenous infusion
 - Indicated with some surgical procedures and with major injuries/bleeding episodes

There are also certain medications that persons with hypofibrinogenemia/dysfibrinogenemia should avoid due to their ability to cause an increase in bleeding symptoms. Persons with hypofibrinogenemia/dysfibrinogenemia should avoid:

- Aspirin™
- Ibuprofen (Motrin™, Advil™, etc.)
- All other NSAIDS – excluding Celebrex™ and Meloxicam™



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Staying active and activities that should be avoided:

- Although you have been diagnosed with hypofibrinogenemia or dysfibrinogenemia, it is still important for you to stay active and participate in the activities that you enjoy. Persons with hypofibrinogenemia and dysfibrinogenemia have few limitations when it comes to sports, but there are some select activities that are too dangerous and should be avoided.
 - **Activities to avoid:**
 - Contact sports
 - Tackle Football
 - Hockey
 - Boxing, or any other contact sports
 - Riding roller coasters
 - **Refer to “Playing it Safe” Manual for more details on activity safety**
 - **Please inform your or your child’s coach of the bleeding disorder diagnosis**
 - **An emergency treatment plan should be in place when playing organized sports**

*If you are interested in a specific activity and are unsure if it is safe, please do not hesitate to contact BCDI for formal recommendations.

How to inform others about your diagnosis:

- BCDI has outreach staff that is available to come to your child’s school, local emergency department, and/or other important areas to do education on hypofibrinogenemia/dysfibrinogenemia. These services are offered by our clinical staff.
- Once diagnosed, a piece of medical alert jewelry should be worn at all times. Your first medic alert tag can be provided by BCDI.
- BCDI can provide you with informational travel letters, wallet cards, and other important documentation that explain your diagnosis and emergency treatment options. These documents should be carried with you or in your vehicle at all times.