

Hypofibrinogenemia/ Dysfibrinogenemia

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.***

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

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



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.

MEDICATIONS TO AVOID:

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

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

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
- Please inform your or your child's coach of the bleeding disorder diagnosis
- Refer to "Playing it Safe" Manual for more details on activity safety
- 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.***

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:

- Bleeding symptoms including prolonged nose bleeding (more than 10 minutes)
- Prolonged gum or mouth bleeding (more than 20 minutes)
- Excessive or prolonged menstrual bleeding (longer than 7 days)
- Blood in urine/stool
- More frequent bruising or large painful bruising with knots.
- Any upcoming procedures or surgeries, including dental work.
- Any injury to head, neck or abdomen.
- If there are any concerning symptoms or doubt, please call for recommendations.

If loss of consciousness or significant bleeding occurs – 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.