

About Hemophilia

Approximately 20,000 people in the United States have hemophilia, a genetic disorder that affects predominately males. Hemophilia, which can be inherited, is caused by a deficiency or reduced level of one of the plasma proteins that function as a clotting factor.

- About 60 percent of persons with hemophilia have the severe type. Individuals with severe hemophilia experience bleeding episodes after dental work, surgery or trauma. They also may experience frequent spontaneous internal bleeding with no trauma or injury, and without apparent cause. Repeated joint bleeds can result in chronic joint problems and loss of range of motion.
- About 15 percent of persons with hemophilia have moderate hemophilia. These individuals are at risk for bleeding after surgery or trauma, and, rarely experience spontaneous bleeds.
- Twenty-five percent of people with hemophilia have mild hemophilia. Their disease may be so mild that it may go undetected until bleeding occurs after trauma or surgery. Regardless of the severity, individuals with hemophilia rarely have problems with surface cuts and do not bleed faster than someone without hemophilia.

Treatment

Currently there is no cure for hemophilia. While research is ongoing to identify a cure, people with hemophilia are treated with infusions of the clotting factor that is missing in their blood. Appropriate medical management and prompt treatment of bleeding episodes can limit pain, prevent joint complications, and allow individuals to resume normal activities more rapidly.

The National Hemophilia Foundation recommends that individuals with a bleeding disorder have annual checkups at a hemophilia treatment center for the following reasons:

- A longer, healthier life
- Blood safety testing and monitoring
- Coordinated care and advocacy for added services
- Counseling and support
- Early detection of complications
- Fewer hospitalizations
- Home infusion instruction
- Latest products, treatments and specialized lab tests
- Participation in research studies
- Physical therapy and an individualized exercise plan

To contact the New England Hemophilia Center at UMass Memorial Medical Center, call 800-955-8252.