Inherited Bleeding Disorders in the Schools: 
Information for School Healthcare Providers, Teachers, and Families

The Care Team: Working Together to Support Students

Note: This information is applicable to students with hemophilia and other inherited bleeding disorders.

Hemophilia is managed with a team approach. There are three parts to the care team for students in school: the Family, the Hemophilia Treatment Center Staff, and the School Nurse or other School Healthcare Provider. This page tells about their roles.

👉 Families: Families manage their children’s hemophilia care, including administering IV clotting factor medication at home (at school or on-the-go). So, students with hemophilia are often treated for bleeding events without seeing a doctor.

Families:
• Play a critical role in sharing information about hemophilia with school staff.
• Are trained to treat students’ hemophilia themselves or with home nurse support.
• Should be aware of the resources and plans available to support students so they can work with the school to best support their child’s health and education.
• May be concerned for students’ safety at school because school involves a whole new set of activities and people who may be unfamiliar with hemophilia.

👉 Hemophilia Treatment Center (HTC) Staff: Children with hemophilia receive comprehensive care in a specialized center. There are 146 of these federally-funded centers in the US, and there are three in Virginia. Some families in Virginia may visit HTCs in other locations (like Washington D.C. or Tennessee) because they are closer.

HTC Staff:
• Usually include a Hemophilia Nurse Coordinator, Social Worker, Education Consultant, Physical Therapist, and Hematologist.
• Train families to manage children’s care and work closely with families on day-to-day care management.
• Provide free staff development for K-12 schools, so schools have the most current information available about care of children with hemophilia in the school setting.

👉 School Healthcare Providers: Most school healthcare providers will not see children with hemophilia during their career because it is rare, occurring in 1 of every 5000 births (CDC). For those who do, it is important to remember that even though these children may not “look sick,” hemophilia is serious and can be life threatening.

School Healthcare Providers:
• Provide nursing care for bleeding events at school.
• Work with the family and HTC to educate school staff on hemophilia.
• Are key advocates to ensure students have the right plans (such as IEPs, IHPs, and 504 Plans), services, and accommodations to be safe and successful in school.

Updated August 2016. Information provided is intended for educational purposes. Consult healthcare providers for medical advice.
