

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