Hemophilia Treatment Centers: Comprehensive Care for People with Bleeding Disorders

In 1974, Congress authorized and funded the national network of hemophilia treatment centers (HTCs) within the Maternal and Child Health’s (MCH) Special Projects of Regional and National Significance. Since then, the hemophilia program’s patient-centered, multi-disciplinary care provided by HTCs has been a model for patients with special needs. The Veterans Health Care Act of 1992 (PL 102-585) designated HTCs as original covered entities eligible to participate in the 340B program. The 340B program provides significant value to HTC patients by enabling access to lower cost prescriptions with reduced out-of-pocket spending and to medical, dental, and psycho-social services and educational programs that HTCs provide using 340B proceeds.

What are Hemophilia and Other Bleeding and Clotting Disorders?

- Hemophilia is a rare, chronic bleeding disorder affecting about 20,000 people in the US, who require life-long infusions of high-cost clotting factor therapies that replace missing or deficient blood proteins to prevent and treat debilitating and life-threatening internal bleeding.
- Individuals with hemophilia are trained to assess their needs and self-infuse factor at home since rapid time-to-treatment is critically important to prevent complications.

What are Hemophilia Treatment Centers?

- HTCs provide multi-disciplinary care furnished by a team of hematologists, pediatricians, nurses, social workers, physical therapists, orthopedists and dentists, all with specialized training in treating individuals with bleeding disorders.
- The HTC network is comprised of a regionalized system of care: 8 highly-specialized regional centers in major cities work with more than 130 HTCs across the country to facilitate access to appropriate care for patients. Over 70% of the hemophilia population receives their care at an HTC.
- A Department of Health and Human Services report\(^1\) highlights HTCs as providers of cost-effective, coordinated care that improves quality outcomes. Appropriate treatment can also decrease emergency room visits and inpatient hospital days. Mortality and morbidity rates are 40% lower in people who use HTCs than in those who do not, despite the fact that more severely affected patients are more likely to be seen in HTCs.
- Hemophilia Treatment Centers with 340B programs integrate clinical and pharmacy services resulting in better management of patient care and utilization of costly treatments, resulting in improved patient adherence and compliance, innovative therapeutic approaches to treatment, and better patient outcomes.

Why the 340B Program is Important to the Hemophilia Community

- Continued access to the 340B program is critically important to the national network of HTCs and the patients they serve. Only $4.9 million in MCH funding for services is spread among the 130 federally-funded HTCs nationwide. The approximately 105 HTCs participating in the 340B program use program revenues to meet the needs of their growing patient population.
- HTCs comply with significant Federal reporting requirements and limitations on the use of 340B program income funds as defined in HRSA Guidance to stretch scarce Federal dollars to reach more patients and provide more comprehensive services. Strict oversight of HTCs participating in the 340B program occurs through the Maternal and Child Health Bureau.
- HTCs provide very specialized healthcare, education, and support services to a patient population easily defined by a diagnosis of hemophilia or other bleeding or clotting disorders.

Find more information on Hemophilia Treatment Centers and the 340B Program at [www.hemoalliance.org](http://www.hemoalliance.org).

---