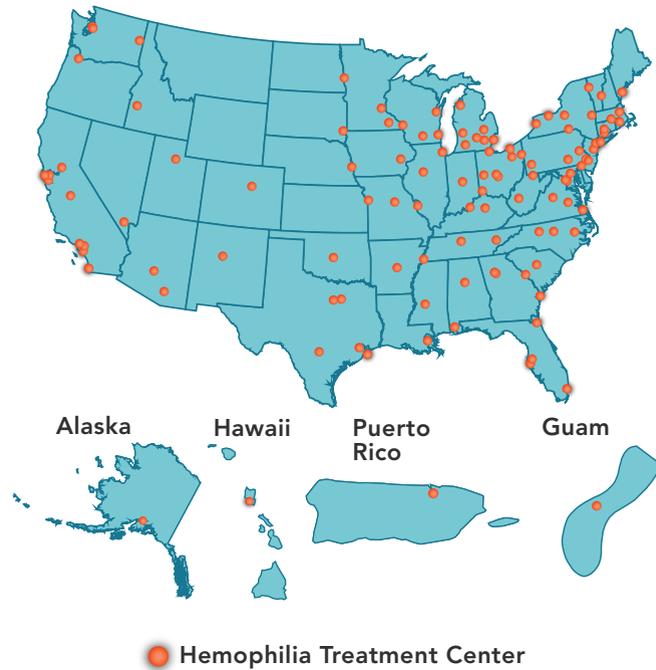




## Hemophilia Treatment Centers



### Resources

To locate an HTC or outreach clinic please visit:  
<http://www.cdc.gov/ncbddd/hemophilia/HTC.html>

### To reach the:

National Hemophilia Foundation, contact:  
[information@hemophilia.org](mailto:information@hemophilia.org) or 1-800-42-HANDI.

Hemophilia Federation of America, contact: [info@hemophiliafed.org](mailto:info@hemophiliafed.org) or 1-800-230-9797

National Institutes of Health, National Heart, Lung, and Blood Institute, contact: [nhlbiinfo@nhlbi.nih.gov](mailto:nhlbiinfo@nhlbi.nih.gov) or 301-592-8573

American Thrombosis and Hemostasis Network, contact: [info@athn.org](mailto:info@athn.org) or 1-800-360-2846

# Hemophilia Treatment Centers



Delivering integrated, multi-disciplinary experienced care and improving health for people with genetic bleeding disorders since 1975

*A Guide for Providers and Insurers*



Hemophilia is an inherited bleeding disorder that can lead to spontaneous bleeding as well as bleeding following injury or surgery. Currently, about 20,000 males in the United States are living with the disorder, where care and treatment cost an estimated \$3.5 billion annually.

### National Network

The national network of over 130 Comprehensive Hemophilia Diagnostic and Treatment Centers (HTCs) provides comprehensive specialty health care to people with rare inherited bleeding disorders and their families throughout the United States and its territories. HTCs are organized within regional networks partially funded by the Health Resources Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC). Regional leadership provide fiscal and programmatic oversight, capacity building, clinical education, technical assistance, evaluation, and advise public and private health agencies at the local, state, and federal levels.

The U.S. HTC network (USHTCN) serves as a model for improving health outcomes and quality as well as reducing costs and health care access disparities for people with complex rare bleeding disorders. This network successfully partners with consumers, other health care providers and governmental agencies to offer a healthcare delivery system that provides access to the best possible bleeding disorders clinical care and prevention services. HTCs collect nationally uniform information using the American Thrombosis and Hemostasis Network's secure database to track patient health.

## Comprehensive (Integrated) Care

The HTC model of care is a systematic, multidisciplinary, and integrated team-based approach. HTC staff provide services in a coordinated, proactive manner to improve health and quality of life. HTC services include specialized diagnostics, evaluation, treatment, rehabilitation, outreach, education and research. The HTC team includes a hematologist, nurse, social worker, physical therapist and may include a pharmacist, psychologist, genetics counselor, dentist, orthopedist, obstetrician/gynecologist, reimbursement specialist or other professionals. Information technology (IT) experts, research personnel and data managers help make data collection and telemedicine clinics possible. Comprehensive HTC services strive to meet the physical, psychosocial, and educational needs of people with bleeding disorders. HTCs provide care regardless of age, sex, race, gender, religion, culture, and in some cases even ability to pay.

Comprehensive (Integrated) care includes diagnostic work up, clinic visits, elective or emergency procedures and inpatient hospitalizations. HTCs work with schools, insurance companies, and employers to help promote attendance at work or school and to maintain access to care.

## A Proven Track Record

The comprehensive (integrated) care model has a proven record of keeping people healthy so that they can attend school and work. This model has resulted in patients having fewer and shorter hospital stays, and fewer emergency room visits.

**CDC studies show that people with hemophilia who get HTC care are 40% less likely to be hospitalized and less likely to die because of bleeding complications.**

## Oversight

In each HTC, a medical director with expertise in bleeding disorders leads the health care team and is accountable to regional network leadership. HTCs are monitored through site visits and evaluations to ensure that treatment and prevention services are provided according to the standards and guidelines of the National Hemophilia Foundation and federal goals. Regional HTC programs advance national public health policy and quality goals and objectives for people of all ages with these medically complex disorders.

## Benefits of the USHTCN

HTC clinicians are experts in diagnosing and treating rare and under-recognized bleeding disorders. The regional network structure facilitates the rapid adoption and spread of innovation and best practices throughout the U.S. The network of HTCs allows for easy transfer of care between HTCs. Here are some compelling reasons to get HTC care:

**Health care quality:** HTCs offer high-quality care that includes medical and psychosocial services and genetic counseling. HTCs encourage physical fitness and activity to strengthen joints and muscles, which further reduces hemophilia complications, vital to good health outcomes. HTC comprehensive (integrated) care provides access to the latest treatments, information, research, and clinical trials. HTCs engage in quality improvement initiatives and participate in national patient satisfaction surveys, using data to drive service enhancements.

### Customized Medicine and Diagnostic Services:

HTC specialized diagnostic services include coagulation laboratories, personal and family medical histories, viral testing and hepatitis vaccinations, and genetic testing and counseling. HTCs are experienced in adapting clotting factor replacement therapies to individual bleeding phenotypes, variable activity levels and use of pharmacokinetic-tailored prophylaxis regimens. These services and technologies are essential for appropriate utilization of expensive therapeutics and treatment plan effectiveness.

**Improved access and outreach:** HTCs offer extensive outreach to reduce access barriers posed by distance, language, and insurance. HTCs provide care to underserved populations living far from the HTC, or in states with no HTCs through physical outreach clinics and/or telemedicine clinics. HTCs have access to language translators to improve communication; some HTC staff are multi-lingual. HTCs work with case managers at other healthcare facilities to coordinate care.

**Medication management:** Many HTCs offer bleeding disorder medications, including factor replacement products, at prices much lower than commercial pharmacies through the federal 340B outpatient drug discount program. HTCs reinvest savings back into the HTC, and hire staff so they can expand services and serve more patients. Some HTCs have clinical pharmacists as part of their team who attend comprehensive clinic and advise patients in medications management.

**Family-centered care:** Patients and families are the center of the HTC team sharing decision making about treatment and effective management of a chronic disorder. The HTCs help build family support networks and reduce isolation by pairing people with bleeding disorders and their families with mentors for peer support. HTCs teach home infusion to eligible patients. This maximizes health and functioning by facilitating prompt treatment or prevention of bleeding episodes, thereby reducing clinic and emergency room visits and hospitalizations, as well as lowering school and work absenteeism.

**Research:** HTCs participate in CDC surveillance programs to monitor for blood-borne infections and measure illness burden and health outcomes. HTCs also conduct clinical trials, including gene therapy, to find new treatments for people with bleeding disorders.

**Advocacy and education:** HTC staff provide advocacy and education in a number of ways:

- Collaborate with local consumer advocacy organizations, the National Hemophilia Foundation, and the Hemophilia Federation of America
- Conduct community outreach to underserved populations
- Provide patient and community education on state-of-the-art bleeding management
- Offer financial counseling and advocacy with insurance payers – public and private



## What You Can Do:

### Primary Care Providers

- Partner with an HTC to coordinate care and get help when your patient has a bleeding disorder related complication
- Coordinate with the HTC including sending patients for a comprehensive (integrated) care visit each year

### Payers

- Include the HTCs in your network

