

# Ensuring You Get the Best Care for Your Bleeding Disorder

Hemophilia treatment centers (HTCs) specialize in the management of bleeding disorders and are recognized by the US Government as “centers of excellence” in providing high-quality care, including pharmacy access to clotting factor replacement therapy. People with bleeding disorders may encounter potential issues related to their health coverage, and they should be aware of new means that employers and insurers use to manage the cost of specialty drugs. The National Bleeding Disorders Foundation’s (NBDF) Comprehensive Care Sustainability Collaborative (CCSC) and your HTC are available to assist you in ensuring access to the best care for your bleeding disorder.

## HTCs Offer Comprehensive Care from Experts in Bleeding Disorders

### Some HTCs Feature an Integrated Pharmacy to Manage Your Factor and Other Treatment Needs



#### Core Team

- Hematologist
- Nurse Coordinator
- Social Worker
- Physical Therapist

#### Additional Specialists

- Pharmacist
- Orthopedist
- Dentist
- Psychologist
- Genetic Counselor
- Nutritionist or Registered Dietician

#### Services

- Expert care for bleeding disorders
- Early detection and diagnosis
- Individual treatment plans
- Preventive medicine
- Patient education
- Access to specialists from different fields of health care

#### Pharmacy Services at Specific HTCs

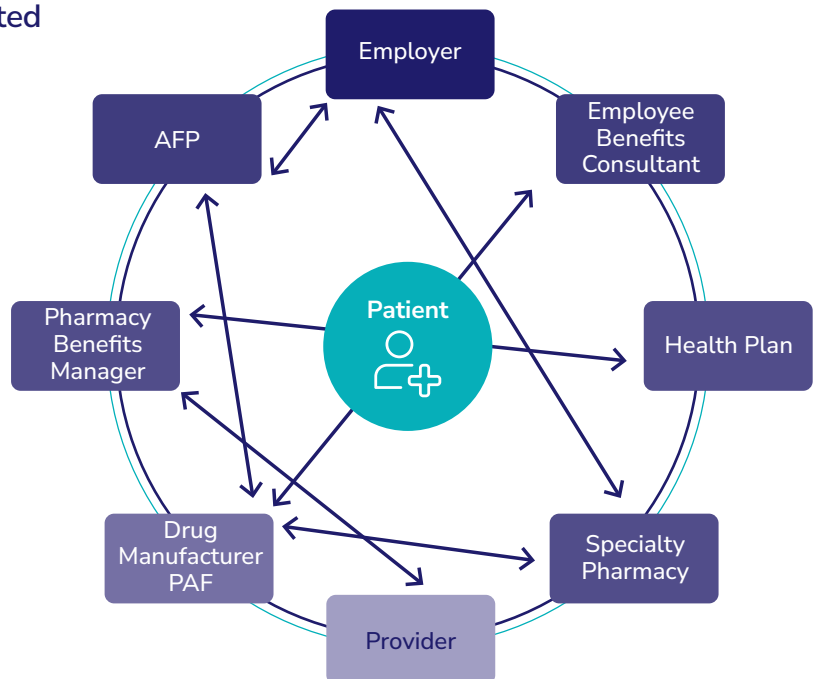
- Management of prescriptions
- Dose and inventory management
- Monitoring and supporting adherence
- Home support
- Ancillary medicines, supplies, and waste disposal
- Emergency clotting factor supply when needed

**Patients treated at HTCs visit the emergency room less often and are less likely to be hospitalized or experience severe complications.**

## Your Employer or Health Insurance Provider May Ask You to Enroll in an Alternative Funding Program (AFP)

### AFPs Put Patients at the Center of a Complicated and Time-Consuming Interaction Between Different Organizations

- These programs may exempt clotting factor and other specialty pharmaceuticals from coverage and require you to apply for patient assistance
- The process can affect your care and have potentially serious or negative consequences:
  - ✗ Delayed access to life-saving treatments
  - ✗ Greater financial responsibility for the patient/family regardless of income
  - ✗ Limited direction and communication
  - ✗ Greater confusion or misinformation
  - ✗ Limited or no right to appeal
  - ✗ Negative impact on patient and caregiver mental health



## What Steps Can You Take To Ensure Access to the Best Care For Your Bleeding Disorder?

- 1 [Find an HTC near you.](#)
- 2 Contact your employer's human resources department or your insurance company to see if the nearest HTC is covered in the plan's network.
- 3 Work with your healthcare provider to determine the most appropriate therapy, including prophylactic vs on-demand treatment.
- 4 Pharmaceutical companies and nonprofit organizations often provide financial assistance, copay support, and free medication programs for eligible patients.
- 5 Reach out to NBDF via the [CCSC e-mail hotline](#) if you encounter any issues with your nearest HTC being out-of-network.
- 6 If an organization outside of your health plan asks you to sign a contract or power of attorney or complete patient assistance forms to enroll in a program for drug coverage, contact your employer's human resources department for more information before you enter any agreement.
- 7 Reach out to NBDF via the [CCSC e-mail hotline](#) for alternatives to enrolling in an AFP that you can consider.

Provided by



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