

The Complex World of Hemophilia Care

Last edited: 3/29/2022

This is a reference. There are nuances at each HTC. HTC's may operate differently regionally and nationally.

What is a federally funded Hemophilia Treatment Center?

Hemophilia is a complex disorder. Fortunately, there are centers of excellence for hemophilia care called Hemophilia Treatment Centers (HTC). HTCs are specialized health care centers that bring together a team of doctors, nurses, and other health professionals experienced in treating people with hemophilia, making them the best choice for hemophilia care.

Each HTC provides access to multidisciplinary health care professionals:

- Hematologists (doctors who specialize in blood)
- Nurses
- Social workers and other mental health professionals
- Physical therapists
- Lab medical technologists and pathologists
- Other specialists available by referral, (e.g., dentist, nutritionist, genetic counselor, orthopedist, OBGYN)

HTC Affiliates:

- 8 regional hemophilia networks
- Each network has a core center with a regional coordinator who applies for, monitors, and then distributes grants from HRSA and the CDC to the HTCs in the region
 - **NHPCC** (National Hemophilia Program Coordinating Center) <https://nhpcc.org>
 - Created to identify gaps in services and coordinate grant-sourcing efforts between regions
- These grants typically have requirements to fulfill Quality Improvement projects (transition, patient/family engagement, etc); the grants also require you to meet annually with your region – hence the regional meetings

Funding for HTCs comes from:

CDC: Centers for Disease Control and Prevention	<ul style="list-style-type: none">• Provides funding for research, patient education
HRSA: Health Resources and Services Administration	<ul style="list-style-type: none">• The grant is through the Maternal and Child Health Bureau (MCHB)• Provides government grant funding to support comprehensive care at hemophilia treatment centers• Administers 340b pharmacy programs
NIH: National Institute of Health	<ul style="list-style-type: none">• Funding for research

The Complex World of Hemophilia Care

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Data Collection:

ATHN (American Thrombosis and Hemostasis Network)	<ul style="list-style-type: none">• Data network - 146 hemophilia treatment centers (HTCs) across the United States to build a national data set: ATHNdataset (many statistics are gathered and used for reporting purposes)• Your center might have research assistants who collect data to submit to ATHN for studies and grant purposes• ATHN hosts an annual data summit (social workers do not typically attend, unless they are responsible for data entry and/or research)
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How patients get their medications:

<p>Specialty Pharmacies</p> <ul style="list-style-type: none">• Specialty pharmacies provide medications used to treat rare or complex medical problems. Factor, alternatives to factor, and infusion supplies are distributed through a specialty pharmacy.• Patients can usually choose whatever specialty pharmacy they would like to use. Sometimes, insurance dictates which pharmacy they can use.• Home infusion services administered by a home care company may be provided (i.e. when patient is unable to self-infuse). <p>340b Pharmacy Programs: https://www.hrsa.gov/opa/index.html</p> <ul style="list-style-type: none">• 340B pharmacies can purchase hemophilia medication from a manufacturer at a discounted rate. Profits from these medications goes back into funding of hemophilia treatment centers, which is how we have access to services like social work, physical therapy, etc. This is how many standalone centers are funded.• 340B's bring in money to help subsidize the services that benefit patients provided by your HTC.• Approximately 100 of the 141 HTCs have elected to participate in the 340B program.
<p>Hemophilia Alliance: https://hemoalliance.org/</p> <p>A not-for-profit organization that comprises federally funded hemophilia treatment centers (HTCs) that either have, or are seeking to have, pharmacy programs under Section 340B of the Public Health Service Act.</p> <ul style="list-style-type: none">• Many, but not all, HTCs with 340b's are members of the Alliance. Please check with your institution/director.• The Alliance has auditors who will come out to talk to your HTC about various issues around compliance.

Patient Advocacy/Education Groups:

National Hemophilia Foundation (NHF): <https://www.hemophilia.org/>

The Complex World of Hemophilia Care

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The Foundation's mission is dedicated to finding better treatments and cures for inheritable bleeding disorders and to prevent the complications of these disorders through education, advocacy and research.

- Offer guidelines on care, advocacy, patient and provider educational opportunities
- Oversee local chapters
 - Local bleeding disorders chapters function in various ways to provide advocacy, support, and community engagement to those with bleeding disorders and their families
 - Some chapters are integrated into HTC's and some are stand alone
- Funding: ~30-40% from pharma, remaining funding from various grants
- Oversees MASAC (the scientific advisory council)
- Oversees the various working groups under MASAC including the Social Work Working Group

The social work working group (SWWG)

- Comprised of a social worker from each of the federally designated HTC regions, plus "at large" positions
- Primary purpose is to organize the Social Work Track for the annual Bleeding Disorders Conference. They take on various other tasks – writing articles, collaborating on research, participate in various other committees, etc.
- Meets monthly
- Nursing and Physical Therapy also have working groups

Hemophilia Federation of America (HFA): <https://www.hemophiliafed.org/>

- Patient education, services, and advocacy organization serving the bleeding disorders community
- Offer financial assistance and scholarships

Platelet Disorder Support Association (PDSA): <https://pdsa.org/>

- Dedicated to enhancing the lives of people with immune thrombocytopenia (ITP) and other platelet disorders through education, advocacy, research and support
- College scholarship opportunity available

The Complex World of Hemophilia Care

Last edited: 3/29/2022

Annual Events for providers: Access your regional SWWG representative for more info

NHF Bleeding Disorders Conference (<https://www.hemophilia.org/events/bleeding-disorders-conference>)

- Hosted in a different city every year
- Typically ~2,000-2,500 attendees including HTC staff, patients, pharma, specialty pharmacies, chapters, etc. There are tracks and programming for each group
- The three-day social work track is organized by the social work working group (SWWG) and us focused on issues pertaining to social work practice in HTC's
- You can receive SW CEUs
- Some HTC's pay for their staff to attend. If you are a SWWG member, NHF funds your conference trip
- Patients can and are encouraged to attend

NHF Insurance and Reimbursement Conference:

- Annual conference typically held in Baltimore
- Two days of programming relating to insurance and reimbursement updates
- NHF pays for the conference, flights, hotels, food entirely
- No CEUs offered

The Hemophilia Alliance Linda Gammage Social Work Conference

- Annual conference for social workers hosted in different parts of the country
- Two days of programming relating to social work and hemophilia
- CSL Behring pays for the conference, flights, hotels, food entirely
- You can receive SW CEUs
- Organized by a committee of HTC social workers

Partners in Bleeding Disorders Education Program (<https://partnersprn.org/>)

- Offers both in person and online discipline specific programming
- Programs include Basic Partners (introduction to bleeding disorders and care), Advanced Partners, Presentation Skills Workshop, Motivational Interviewing, and PartnersPRN online learning activities
- You can receive SW CEUs
- Located at the Indiana Hemophilia and Thrombosis Center (IHTC)
- Supported through an educational grant (flight, hotel, transportation, meals)

Hemophilia Alliance Hill Day (<https://hemoalliance.org/events/>)

- HTC staff and people from the Hemophilia Alliance advocate for various issues facing the bleeding disorders community
- Social workers can and are encouraged to attend
- Patients can and are encouraged to attend

NHF Washington Days (<https://www.hemophilia.org/events/washington-days>)

- Annual event held in Washington DC to advocate with legislators
- SW encouraged to coordinate with your chapter and attend
- Patients can and are encouraged to attend

NACCHO (<https://www.arizonahemophilia.org/naccho/>)

- Sponsored by the Arizona Hemophilia Association
- Camp planning conference that focuses on the work of bleeding disorder summer camps

Helpful Resources for Patients:

Support

- Local chapter of bleeding organizations

The Complex World of Hemophilia Care

Last edited: 3/29/2022

- <https://www.hemophilia.org/community-resources/resources-near-you/nhf-chapters>
- <https://www.hemophiliamed.org/home/our-role-and-programs/what-is-hfa/member-organizations/>
- National Youth Leadership Institute (NYLI)
 - <https://www.hemophilia.org/educational-programs/training/youth-leadership-nyli>
 - NYLI is a two-year leadership program for young people (18-24 years old) in the bleeding disorders community designed to assist in becoming well-trained, recognized leaders
- Comprehensive Health Educational Services (CHES)
 - [ches.education](https://www.ches.education)
 - Provides on-site patient programming, education, and the latest information on research and treatment specifically for bleeding disorders (i.e. inhibitor, women, and rare disorders)
- Steps for Living
 - [stepsforliving.hemophilia.org/resources](https://www.stepsforliving.hemophilia.org/resources)
 - Part of the National Hemophilia Foundation online education program
 - Provides education and links to bleeding disorder resources across the life span including the online Playing It Safe guidelines
- YETI
 - [pnwbd.org/yeti](https://www.pnwbd.org/yeti)
 - Created by the Pacific Northwest Bleeding Disorders chapter
 - Offers free hands-on experiential training in Oregon for HTC and chapter staff focused on the development of teen/young adult programs
- Kelley Communications
 - [Kelleycom.com](https://www.kelleycom.com)
 - Web site includes the online newsletter Communiqué, archives of Parent Empowerment Newsletter (PEN), books, and other publications free to families of children with bleeding disorders
- Bleeding Disorders Camps
 - [hemophilia.org/community-resources/resources-near-you/bleeding-disorders-camps](https://www.hemophilia.org/community-resources/resources-near-you/bleeding-disorders-camps)
 - Most state hemophilia chapters run weeklong overnight hemophilia camps for children and adolescents with bleeding disorders. Some camps allow siblings of children with BD to attend as well. Many of the counselors are former campers.
- Empact Parenting
 - [https://empactparenting.com/about/](https://www.empactparenting.com/about/)
 - Empact Parenting is a program designed for parents of children with a bleeding disorder. With multi-dimensional content and exercises, this program provides educational material and tools to strengthen parenting skills focusing on children to becoming independent, capable adults.
- Got Transition
 - [Gottransition.org](https://www.gottransition.org)
 - Federally funded national resource center on health care transition.

Women specific support

- Victory for women (NHF): <https://www.victoryforwomen.org/homepage>
- VWD Connect: <https://www.vwdconnect.org/about/>
- National Outreach for von Willebrand (NOW): <https://www.arizonahemophilia.org/now/>
- Hemophilia Foundation of Michigan (HFM) National Conference for Women and Teens <https://www.hfmich.org/national-conference-for-women-and-teens-with-hemophilia/>
- Foundation for Women & Girls with Bleeding Disorders LANs: [fwgbd.org](https://www.fwgbd.org)

The Complex World of Hemophilia Care

Last edited: 3/29/2022

- The Women/Girls Learning Action Networks (LANs) are the home for collaboration, education, and resources for clinics specifically devoted to the care of women and girls with bleeding and other blood disorders. Hold a yearly conference for providers who treat women and young girls with bleeding disorders and sickle cell disease.

Financial

- Hemophilia Federation of America (HFA)—“Helping Hands” program
 - HFA provides assistance with urgent basic living expenses, medically necessary items, plus medical travel and educational support for people with inhibitors
 - [Helping Hands - Hemophilia Federation of America](#)
- Patient Services, Inc. (PSI)
 - Our programs provide financial assistance with health insurance premiums, infusion and nursing services, ancillary costs, travel costs, and more
 - [Patient Services Inc.](#)
- PAN Foundation
 - The PAN Foundation helps federally and commercially insured with out-of-pocket costs for their prescribed medications.
 - [PAN Foundation](#)
- The Assistance Fund (TAF)
 - The Assistance Fund (TAF) helps patients and families facing high medical out-of-pocket costs by providing financial assistance for their copayments, coinsurance, deductibles, and other health-related expenses.
 - [The Assistance Fund - TAF \(tafcares.org\)](#)
- United Healthcare Children’s Foundation (UHCCF)
 - UHCCF provides medical grants to help children gain access to health-related services not covered, or not fully covered, by their family’s commercial health insurance plan.
 - [United Healthcare Children's Foundation \(uhccf.org\)](#)
- Copay assistance/free trial/patient assistance programs specific to product
 - Refer to manufacturer website

Scholarship

- <https://www.hemophiliafed.org/scholarships>
- <https://www.hemophilia.org/Community-Resources/Scholarships>
- <https://www.scholarships.com/financial-aid/college-scholarships/scholarship-directory/physical-disabilities/hemophilia>
- www.colkeen.org/beth-carew-new/
- <https://www.hemophiliavillage.com/scholarship-program>
- <https://livebellasoul.org/>