

MCHB National Hemophilia Program Coordinating Center Update

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The National Hemophilia Program

History

- Funding for hemophilia care through hemophilia treatment centers (HTCs) was authorized under Title V of the Social Security Act (Maternal and Child Health Services (MCH) in 1976.
- Historically funded 12 regions, but reorganized the program in 2012 to shift from 12 to eight regions and adding the National Hemophilia Program Coordinating Center.

Funding

- **Regional Hemophilia Network:** eight regional grants; 5-year awards.
 - New England: **Icahn School of Medicine, Mt. Sinai** - CT, ME, MA, NH, RI, VT, NJ, NY, PR, USVI
 - Mid-Atlantic: **Children's Hospital of Philadelphia** - PA, DE, DC, MD, VA, WV
 - Southeast: **Hemophilia of Georgia** - AL, FL, GA, MS, KY, NC, SC, TN
 - Great Lakes: **Hemophilia of Georgia** - OH IN, MI, OH
 - Northern States: **Great Lakes Hemophilia Foundation** - IL, MN, ND, SD, WI
 - Great Plains: **University of Texas Health Science Center at Houston** - AR, LA, OK, TX, IA, KS, MO, NE
 - Mountain States: **Oregon Health & Science University** - AK, ID, OR, WA, AZ, CO, MT, NM, UT, WY
 - Western States and Territory: **Center for Comprehensive Care and Diagnosis of Inherited Blood Disorders** - CA, HI, NV, Guam
- **National Hemophilia Program Coordinating Center:** one cooperative agreement; 5-year award.
 - **The American Thrombosis and Hemostasis Network (ATHN)** (virtual)
- **340B Program:** Recipients of the RHN grants, and their subrecipient HTCs are eligible entities of the 340B Pharmacy Program, which allows them to earn program income through the purchase and resale of factor. All program income is considered additive, and must go back to the purpose of the grant.



NHPCC Purpose and Goals

- To support a center that will coordinate a collaborative national infrastructure of regional hemophilia networks to promote and improve comprehensive quality care for individuals with hemophilia and related bleeding or clotting disorders such as thrombophilia.
- Establish a national infrastructure to improve access to coordinated and comprehensive systems of care for patients with hemophilia and related blood or clotting disorders; strengthen the capacity of the Regional Hemophilia Network (RHN) and the hemophilia treatment centers' (HTC) integrated care teams; increase the evidence base on care for patients with hemophilia and related blood or clotting disorders; and track national, regional, and patient-level data to assess patient and health outcomes.



Program Requirements

Awardees must:

- Provide an infrastructure that provides technical assistance and supports the work of the RHNs which results in a uniformity of practice and developing standards of care, accessible care for all patients and their families, improved quality of care, and the dissemination of bleeding and clotting disorder services and information.
- Coordinate and support national QI projects carried out by the RHNs. National QI projects will focus on the entire system of care for hemophilia patients and their families ***over the course of the project period*** and should address:
 - Transition (e.g., from pediatric care to adult care, education to employment, etc.)
 - Increasing patient/family engagement in care decisions and HTC, Regional, and NHPCC program activities.
 - Ensuring access to a medical home and integrating hemophilia treatment with other systems of care.



Quality Improvement

Transition QI projects have been underway for two years.

- Patient Experience Survey should be distributed to patients at comprehensive care clinics at HTC's, regardless if they are actively participating in a QI pilot project.
- Survey responses comply with HRSA grant requirement to report on Healthy People 2020 DH-5: Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care.

NHPCC is responsible for providing technical assistance, data analysis, and assisting in dissemination of materials and results.

To determine how best to operationalize quality improvement around ensuring patients have a medical home and increasing patient and family engagement, HRSA will be providing TA to grantees and decisions will be made by consensus.



Program Requirements – cont'd

- Support a national patient-level hemophilia database by collecting regional specific data, including supporting regional and national QI projects and data reporting for HP2020.
- Develop and maintain a national online repository of evidence-based articles, best practices and standards of care, and educational materials for regional and HTC subawardee staff and patients.
- Work with RHNs to identify, prioritize, and address emerging issues of importance, including increasing access to, and the improvement of, hemophilia and related bleeding and clotting disorder services through outreach to underserved populations.
- Support and fund at least one in-person meeting annually for all RHNs and identified staff.



Program Objectives– Page 1

The awardee will be expected to report annually on program objectives, which include:

- The number and type of technical assistance services provided to RHN and HTC staff.
- The number of active NHPCC workgroups/committees, the charter, and membership.
- The number of patients/families serving on NHPCC workgroups/committees and which committees.
- The number of HTC staff quality improvement (QI) trainings that were available to HTC subawardee staff.
- The number of HTC staff that completed QI trainings.
- The number of regions and HTC subawardees participating in reportable national NHPCC activities.
- The number and titles of educational materials/reports/articles disseminated from NHPCC workgroups/committees.



Program Objectives– Page 2

- The number and types of submissions of materials to NHPCC public and private access website.
- By the fourth quarter in Year two, the percent increase from baseline in the # of submissions/materials to NHPCC online repository.
- The number and type of annual RHN leadership in-person meetings.
- National QI project data results on transition survey, increased patient/family engagement/tracking medical homes of patients for each RHN and their HTC subawardees.
- The number of HTC subawardees (and their regions) submitting data for Healthy People 2020 (HP2020) measures.
- Analysis on the RHN results for the following measures:
 - Discretionary Grant Information System (DGIS) CSHCN measure 2 – Medical Home
 - DGIS CSCHN measure 3 – Transition
 - DGIS CSCHN measure 1 – Family Engagement
- Analysis on the number of annual comprehensive visits recorded by Regional Hemophilia Networks (RHNs) and their HTC subawardees.



DGIS Measures

The new DGIS system will not be online until ~January 2018.

Link to Measures and Forms:

<https://mchb.hrsa.gov/data-research-epidemiology/discretionary-grant-data-collection>



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