

Criteria for HHT Center of Excellence and Program Accreditation United States and Canada - 2026

The Cure HHT Organization Center Committee will consider an application for accreditation of an HHT Center of Excellence if it meets all criteria for care, education, research and advocacy.

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Abbreviations and Acronyms

AVM - Arteriovenous Malformation
BAVM - Brain Arteriovenous Malformation
CHORUS - Comprehensive HHT Outcomes Registry of the United States
CHRN - Cure HHT Research Network
CME - Continuing Medical Education
COE - Center of Excellence
CV – Curriculum Vitae
FTE - Full Time Equivalent
GRMAB - Global Research and Medical Advisory Board
HF - Heart Failure
HHT - Hereditary Hemorrhagic Telangiectasia
PAVM - Pulmonary Arteriovenous Malformation
PH - Pulmonary Hypertension

Care and Infrastructure

Program Description

A Cure Hereditary Hemorrhagic Telangiectasia (HHT) Center of Excellence (COE) is comprised of a multi-disciplinary medical team recognized by Cure HHT as possessing the personnel, expertise, commitment, and resources to provide comprehensive evaluation, treatment, and education to patients and families with HHT. Unless otherwise specified, all clinical, operational, and educational expectations described in this document apply to the care of adult and pediatric patients. **The following requirements must be met by the Center of Excellence and each of its component programs to establish and maintain COE accreditation.**

Clinical Care Guidelines

HHT accredited centers are expected to follow with the most recent [International Guidelines for the Diagnosis and Management of HHT](#) and develop a comprehensive and individualized implementation plan that aligns with the principle of personalized patient care. It is important to acknowledge that the application of specific recommendations may not be suitable for every clinical scenario, and adaptations should be made based on the unique needs and circumstances of each patient.

Guiding Principles

These principles articulate Cure HHT's commitment to ensuring that Centers of Excellence deliver consistent, equitable, and high-quality care for patients and families affected by HHT. Our mission is to find a cure for HHT while saving the lives and improving the wellbeing of individuals and families affected by HHT.

- Expand access: Increase equitable access to HHT care by addressing geographic gaps, minimizing barriers, and meeting diverse patient needs. Examples include, but are not limited to, collaboration with local providers, increased education and awareness.
- Maintain excellence: Ensure multidisciplinary staff, specialized facilities, and adequate resources to deliver comprehensive, patient-centered care.

- Implement guidelines: Adopt and actively implement the most recent International Guidelines for the Diagnosis and Management of HHT, while tailoring care thoughtfully to individual patients.
- Application discretion: Recognize that Cure HHT reserves the right to prioritize applications based on need, impact, and regional balance, and may decline applications from institutions in areas already served by established centers.
- Advance fairness and collaboration: Commit to reducing disparities and fostering collaboration across communities, patients, and providers to strengthen HHT care delivery.

Core Expectations

Centers of Excellence are expected to uphold the highest standards in patient care, research, and collaboration while maintaining a patient-centered approach to the diagnosis, treatment, and long-term management of HHT.

Centers are expected to:

- Provide education to patients, families, and healthcare providers about HHT.
- Collaborate with non-COE health care providers for shared management of HHT patients. Centers should maintain clear communication and coordinated care with non-COE health care providers to support evidence-based management, reduce care fragmentation, and ensure patients receive appropriate follow-up.
- Participate in HHT related research initiatives.
- Contribute to activities and programs including active participation in the HHT community with other COEs as organized by Cure HHT.

The care provided at the Center of Excellence must meet or exceed all consensus guidelines approved by the Global Research and Medical Advisory Board (GRMAB) of Cure HHT, as well as all local and national standards. It should align with published guidelines and the current medical literature. Centers must maintain a comprehensive, multidisciplinary approach and follow internationally recognized best practices to improve diagnosis, treatment, and patient outcomes.

Centers of Excellence are required to implement the most recent International Guidelines for the Diagnosis and Management of HHT, while allowing for individualized care based on patient needs. Clinical processes should be maintained to ensure consistency and actionable standards.

Centers must address the following areas of care, in adult and pediatric patients:

- Screening and management for pulmonary and brain AVMs
- Evaluation and management of hepatic AVMs
- Cardiopulmonary manifestations including HF and Pulmonary Hypertension management
- Comprehensive epistaxis management
- Evaluation and management of gastrointestinal bleeding
- Comprehensive management of iron deficiency with or without anemia
- Access to contemporary anti-angiogenic therapy
- Genetic testing and counseling
- Comprehensive reproductive care

Multidisciplinary Care Team and Other Specialists

The following designated HHT care team members are required to participate consistently in outpatient clinics and multidisciplinary team conferences. They must also be available to provide inpatient consultations and coordinate care with hospital staff to ensure adherence to established standards for the diagnosis, treatment, and management of HHT.

Personnel

The Center of Excellence must maintain the necessary personnel with expertise in HHT to coordinate the evaluation and treatment of patients and to respond promptly to patient inquiries. The multidisciplinary care team must be fully staffed to provide comprehensive education about HHT to patients, families, and health care providers. The time commitments for selected staff are minimum requirements and must increase with patient volume to ensure the highest standard of care.

It is recommended that each specialty service within the HHT Centers of Excellence is led by a single clinician rather than a group of clinicians. For example, one Hematology physician may provide more consistent and specialized care than several physicians sharing the role. This model allows for the development of deeper expertise in delivering HHT specialty care, in contrast to dispersing that experience across multiple providers. Distributing responsibilities among a group is most appropriate when a senior clinician is training a successor or in an established Center with a large patient population. It is also appropriate to have backup clinicians available to cover for the primary specialist during absences or in emergencies.

Centers are strongly encouraged to maintain clear algorithms for the intake and management of both adult and pediatric patients. Applications from prospective Centers of Excellence seeking pediatric-only or adult-only status will be evaluated individually, considering local and regional needs as well as available expertise.

Core Team

Mandatory

Each HHT Center of Excellence must maintain a clearly defined Core Team consisting of multidisciplinary clinicians who are essential to the evaluation, management, and longitudinal care of patients with HHT. Core Team members are those whose expertise is required to address the common and ubiquitous clinical issues in HHT, including but not limited to epistaxis, iron deficiency anemia, genetic testing and counseling, and screening and treatment for pulmonary and brain AVMs. These clinicians must be readily available to coordinate comprehensive assessment, deliver evidence-based treatment, and ensure continuity of care for all individuals with HHT.

The presence and active participation of the designated Core Team are required to achieve and maintain COE accreditation. **All Centers of Excellence must provide written notification to Cure HHT of any anticipated changes to Core Team members at least 30 days prior to the effective date and must submit a plan outlining the replacement or transition of the role.**

Definition and Distinction

- Core Team Members are clinicians whose involvement is fundamental and consistently required for the routine evaluation and management of HHT patients. Their expertise is integral to initial assessment, longitudinal oversight, and coordination of multidisciplinary services.

- Additional Team Members are specialists whose expertise is important and accessible but not required for the routine evaluation of every patient. These clinicians provide targeted evaluation or intervention based on specific clinical findings or complications and support the Core Team as needed.

Under this framework, some specialties, such as Pulmonology or Cardiology, may be classified as Additional Team Members, unless they are part of the center's leadership structure (e.g., Medical Director or Associate Director) or are routinely required by that center's specific patient population.

Leadership Consideration

The Medical Director, and where applicable, an Associate Director, are designated Core Team Members within the leadership structure of the Center of Excellence.

The Medical Director should have a background in Adult or Pediatric Medical Management to ensure comprehensive expertise in the evaluation and management of patients with HHT. Medical Management is defined as the ability to provide comprehensive evaluation and management of patients across organ systems and does not mandate that a physician is from a particular medical or surgical specialty.

For new Centers of Excellence, either the Medical Director or Associate Director should have a background in Internal Medicine or Pediatrics.

This requirement applies only to newly applying Centers of Excellence and does not apply to currently accredited or established Centers of Excellence.

Medical Director

The Medical Director must possess specialized knowledge of the manifestations of HHT and have significant experience in their management, as outlined in the most current International Guidelines and supported by current published literature. **A key responsibility of this role is dedicating focused time to coordinating the multidisciplinary diagnosis and treatment of patients referred to the Center of Excellence.** For a newly accredited center this individual is expected to see all new patients at the center and serve as the primary HHT provider for all HHT-related issues, distinct from the patient's primary care provider.

The Medical Director role should not be equally shared between co-directors, although an Associate Director may be appointed to provide support. This applies to **newly applying and to currently accredited or established Centers of Excellence.**

As patient volume grows, additional colleagues may assist in fulfilling the role of primary HHT provider. For currently accredited Centers of Excellence, an Associate Director with a Medical Management or related background may work closely with the Medical Director to support patient care and expand the center's clinical capacity.

The HHT COE Medical Director role may be held by a physician with a background in Medical Management. In the instance this physician is not available to lead the adult HHT clinical component, the role may also be held by a physician trained in Pediatrics, provided that clear pathways exist for adult medical oversight through collaboration with appropriate adult medicine specialists. The intent of this structure is to ensure appropriate expertise and continuity of care across both pediatric and adult

HHT populations and not restrict leadership opportunities while maintaining flexibility for different institutional models.

Pediatric HHT care remains an essential component of the COE model, and pediatric leadership, including Director level leadership, continues to be valued and supported within this framework.

Criteria

- Doctor of Medicine (MD) or Doctor of Osteopathic Medicine (DO) degree or equivalent.
- Board certified in the relevant specialty, or board eligible with certification expected within the timeframe set by the specialty board.
- Physicians who have completed clinical training at an HHT Center of Excellence may qualify for a leadership role sooner, provided they have a formal recommendation from the COE Director. This pathway is intended to recognize physicians who have gained substantial, structured HHT experience during training. Physicians who did not train at an HHT Center of Excellence may also qualify but are expected to build their HHT specific expertise over time through independent clinical experience, mentorship, and demonstrated competency in the evaluation and management of HHT patients.
- **It is required that Centers dedicate protected time for the Medical Director proportional to the annual patient volume. Centers must clearly document how protected time is allocated for administrative responsibilities.**
- **Administrative Program Oversight Protected Time:**
 - Time dedicated to program leadership and operational responsibilities, including oversight of multidisciplinary coordination, adherence to Cure HHT standards, participation in registry and research initiatives, team communication, quality improvement efforts, reporting requirements, strategic program development, and accountability for clinical quality.

The FTE ranges below reflect the total annual required protected time allocation for oversight and administration, inclusive of both the Medical Director and, where applicable, the Associate Director.

- **<50 patients** = 0.05–0.1 FTE
- **50-100 patients** = 0.1–0.15 FTE
- **101-250 patients** = 0.15–0.2 FTE
- **>250 patients** = 0.2–0.25 FTE or higher, adjusted based on patient volume

- **The full-time equivalent allocations outlined above represent the required protected time necessary to maintain an effective multidisciplinary HHT program.** These allocations are intended to support both direct clinical care and the administrative and leadership responsibilities required to operate a Center of Excellence. **Cure HHT uses these guidelines in the review and accreditation of Centers of Excellence.**
- For initial certification, a Center of Excellence must demonstrate care of a minimum of 35–50 unique patients with HHT annually over the preceding 4-year period.
- For renewal, a Center of Excellence must demonstrate sustained clinical activity and continued access to care for patients with HHT. This may be demonstrated by meeting at least one of the following criteria:

- Care of a minimum of 150 unique patients with HHT over the preceding 4-year period, or
- Demonstration of at least 20% growth in the number of unique patients with HHT over the preceding 4-year period.

In evaluating renewal, consideration will also be given to factors such as catchment area, regional prevalence, referral infrastructure, and program maturity.

A “unique patient” may only be counted once within the applicable reporting period, regardless of the number of visits during that time. Patient volume may include adult and pediatric patients and may reflect the collective experience of all Center of Excellence faculty.

Responsibilities

- Lead and coordinate multidisciplinary care for HHT patients.
- See all new patients entering the COE and serve as the HHT primary provider for every patient’s HHT-related care.
- Manage HHT-specific issues for patients throughout their care.
- Oversee adherence to the most recent International Guidelines for the Diagnosis and Management of HHT.
- Organize and lead multidisciplinary team conferences and participate in outpatient clinics.
- Serve as the primary point of contact for clinical decision-making related to HHT.
- Collaborate with backup clinicians to ensure continuous patient care during absences or emergencies.
- Obtain a letter of support from the Medical Director’s Department Chair documenting institutional commitment.
- Attend an HHT-focused conference (regional, national, international) at least every other year.

Coordinator

The Coordinator plays a central role in ensuring seamless care for patients with HHT. **This position is responsible for managing all patient contact, determining the necessary tests and specialty consultations for the initial visit to the Center of Excellence, and coordinating every aspect of that visit.** The Coordinator must have sufficient knowledge of HHT to make informed decisions about patient care needs and must be able to respond promptly and accurately to patient inquiries.

The Coordinator’s responsibilities extend beyond the initial visit and include overseeing the coordination of ongoing care for HHT patients. This includes follow-up appointments, ongoing communication with referring providers, and ensuring that diagnostic and therapeutic plans are carried out effectively over time. In some Centers of Excellence, the Coordinator role may align with a patient navigator function. The core responsibilities of the Coordinator as outlined above must be maintained.

In addition to direct patient care coordination, the role involves administrative duties that support the clinical mission of the Center. These may include obtaining insurance preauthorization for medical examinations, specialty consultations, and specialized medications such as bevacizumab and other therapeutics, scheduling appointments and preparing itineraries, arranging urgent therapeutic procedures, facilitating communication among multidisciplinary care team members, and working with patients’ local care teams to ensure effective collaboration and

communication to avoid any care gaps. Certain administrative tasks may be delegated or shared with an administrative assistant, depending on the operational structure of the Center.

Criteria

- A degree of Registered Nurse (RN), Bachelor of Science in Nursing (BSN), Advanced Practice Registered Nurse (APRN), Adult Nurse Practitioner (ANP), Physician Assistant (PA), Certified Genetic Counselor (CGC), or Respiratory Therapist (RT) or equivalent.
- **It is required that Centers dedicate protected time for the Coordinator proportional to the annual patient volume. Centers must clearly document how protected time is allocated for administrative responsibilities.**
 1. **Administrative Program Coordinator Time:** Time dedicated to operational and programmatic responsibilities, including maintenance of patient registries, participation in CHORUS and research activities, quality improvement initiatives, team communication, compliance with Cure HHT standards, preparation of required reports and coordination of internal and external program communications.

The FTE ranges below reflect the total annual required protected time allocation for the Coordinator.

- <50 patients** = 0.25 FTE
- 50-100 patients** = 0.5 FTE
- 101-250 patients** = 0.75–1.0 FTE
- >250 patients** = 1.0–1.25 FTE or higher, adjusted based on patient volume

- **The full-time equivalent allocations outlined above represent the required protected time necessary to maintain an effective multidisciplinary HHT program including administrative and operational oversight (day-to-day operations, scheduling and workflows, documentation and reporting, and coordination). Cure HHT uses these guidelines in the review and accreditation of Centers of Excellence.**

Responsibilities

- Obtain insurance preauthorization for medical exams, specialty consultations, and medications.
- Coordinate specialty consultations within and outside the Center of Excellence.
- Facilitate the provision of medications and secure prior authorizations when required.
- Schedule patient appointments and prepare detailed itineraries for clinical visits.
- Arrange and coordinate the scheduling of therapeutic and diagnostic procedures.
- Work with the research coordinator to ensure accurate input and ongoing maintenance of the CHORUS database.

Geneticist or Genetic Counselor

A physician (or a genetic counselor) with expertise in providing HHT specific counseling to adults, children, and families. This includes the ability to interpret genetic test results, assess family risk, and provide supportive counseling to facilitate informed decision making in HHT patients as outlined in the most current International Guidelines and supported by current published literature.

Hematologist

A physician with expertise with intravenous iron supplementation to treat iron deficiency (with or without anemia), anticoagulation when indicated and administration of advanced medical therapies, including anti-angiogenic inhibitors (e.g., bevacizumab), to manage arteriovenous malformations (AVMs) and bleeding, as outlined in the most current International Guidelines and supported by current published literature.

Interventional Radiologist

A physician with expertise in the diagnosis and treatment of embolization procedures for PAVMs and other HHT related vascular abnormalities as outlined in the most current International Guidelines and supported by current published literature.

Otolaryngologist (ENT)

A physician with expertise in the evaluation and management of epistaxis in HHT patients, using both medical and procedural interventions. The otolaryngologist should be familiar with treatment approaches as outlined in the most current International Guidelines and supported by current published literature.

Pediatric Specialist

A Pediatric physician with expertise in the evaluation and management of HHT in Pediatric patients, responsible for evaluating and coordinating pediatric care and ensuring alignment with the Center's broader care model for adult and pediatric patients, as outlined in the most current International Guidelines and supported by current published literature.

Additional Team Members

In addition to the Core Team, each Center of Excellence must ensure access to a network of Additional Team Members who can provide specialized expertise as needed. These clinicians are not required for the routine evaluation of every HHT patient but must be readily available to support the Core Team through consultation, targeted evaluation, or management of condition specific findings.

An individual with HHT expertise must be accessible for referral when indicated.

Cardiologist

A physician with expertise in the management of cardiovascular HHT complications, including but not limited to pulmonary hypertension, high-output heart failure, and atrial fibrillation in HHT patients as outlined in the most current International Guidelines and supported by current published literature.

Gastroenterologist

A physician with expertise in the management of bleeding from gastrointestinal telangiectasias, including the use of therapeutics, performance of endoscopy, and laser when actively bleeding, as outlined in the most current International Guidelines and supported by current published literature.

Hepatologist

A physician with expertise in the management of symptomatic complications from liver AVMs in HHT patients as outlined in the most current International Guidelines and supported by current published literature.

Neurovascular Specialist

A physician with expertise in the diagnosis and treatment of brain and spinal cord AVMs and other cerebrovascular lesions in HHT patients as outlined in the most current International Guidelines and supported by current published literature.

Obstetrics and Gynecology

A physician with expertise in managing HHT patients with heavy menstrual bleeding and during pregnancy, as outlined in the most current International Guidelines and supported by current published literature. It is also recommended that Centers have access to a Maternal Fetal Medicine (MFM) specialist for patients who are pregnant or planning pregnancy.

Pulmonologist

A physician with expertise in the diagnosis and management of pulmonary arteriovenous malformations (PAVMs), and pulmonary hypertension, including the use of imaging modalities, and other interventions to prevent complications including brain abscess formation, as outlined in the most current International Guidelines and supported by current published literature.

Facilities and Services

A Center of Excellence must have the facilities and services required to perform all procedures necessary to evaluate and treat the manifestations of HHT as outlined in the most current International Guidelines and supported by current published literature.

Criteria

The Center must have direct access, or referral access, to facilities and services for the following:

- Agitated saline contrast echocardiography
- Capsule endoscopy and extended upper GI endoscopy (e.g., double balloon enteroscopy)
- ENT procedural area
- Gamma knife or another stereotactic radiosurgery
- Genetic testing for the diagnosis of HHT
- Heart catheterization
- Infusion center
- Interventional radiology suite
- MRI and CT imaging
- Neurointerventional radiology suite

Additional Support Services

Centers are encouraged to have direct or referral access to the following support services to support comprehensive HHT care.

Dermatologist

A physician with expertise in the management of skin telangiectasias in HHT patients as outlined in the most current International Guidelines and supported by current published literature.

Mental Health Professional and/or Social Worker

A professional with experience in supporting patients with chronic disease, including counseling, coping strategies, and access to community resources, in HHT patients as outlined in the most current International Guidelines and supported by current published literature.

Pharmacist

A pharmacist with experience in specialty pharmacy services, drug interactions, and pharmacogenomics (strongly recommended). in HHT patients as outlined in the most current International Guidelines and supported by current published literature.

Patient Volumes

For initial certification, a Center of Excellence must demonstrate care of a minimum of 35–50 unique patients with HHT annually over the preceding 4-year period.

For renewal, a Center of Excellence must demonstrate sustained clinical activity and continued access to care for patients with HHT. This may be demonstrated by meeting at least one of the following criteria:

- Care of a minimum of 150 unique patients with HHT over the preceding 4-year period, or
- Demonstration of at least 20% growth in the number of unique patients with HHT over the preceding 4-year period.

In evaluating renewal, consideration will also be given to factors such as catchment area, regional prevalence, referral infrastructure, and program maturity.

A “unique patient” may only be counted once within the applicable reporting period, regardless of the number of visits during that time. Patient volume may include adult and pediatric patients and may reflect the collective experience of all Center of Excellence faculty.

Administration of an HHT Center of Excellence

The effective administration of an HHT Center of Excellence is essential for delivering coordinated, high-quality care to patients while ensuring that the center operates efficiently, meets patient needs, and adheres to recognized clinical standards. Achieving these goals requires deliberate planning, structured processes, and active engagement from the entire care team.

Centers should adopt the following administrative strategies:

- Develop and implement clearly defined clinic workflows that support all stages of patient care, from initial intake through follow-up and coordination across medical specialties.
- Adopt standardized protocols and clinical algorithms tailored to adult and pediatric patients to ensure consistent, evidence-based management of care.
- Conduct regular multi-disciplinary meetings with the core HHT care team at least quarterly to review emerging scientific and clinical knowledge, discuss ongoing and potential research projects, and evaluate overall center performance.
- Conduct pre-clinic review of records to facilitate an efficient, comprehensive and individualized evaluation of new patients.
- Support ongoing professional development by encouraging all staff to participate in HHT Continuing Education programs and other relevant training opportunities.
- Develop a leadership succession plan to ensure continuity, especially if the Medical Director anticipates retirement within the next five years, preventing disruptions in care delivery.
- Engage with the institution’s financial leadership to secure sustainable program funding, including dedicated staff time and infrastructure support.

- Maintain active communication with Cure HHT regarding staffing changes, service updates, and the timely resolution of any patient concerns.
- Provide age-appropriate care for adult and pediatric patients by ensuring a structured transition from pediatric to adult services between the ages of 18 and 21, with active coordination between programs and completion of the transition by the patient's 21st birthday unless a specific clinical contraindication exists.
- Administer the Patient Experience Survey to patients on a routine basis, clearly explaining its purpose and emphasizing its role in improving services. Staff should actively encourage participation, ensure accessibility for all patients, and review results regularly as part of the center's quality improvement efforts.
- Findings should guide workflow adjustments, service enhancements, and program priorities.

By following these administrative strategies, HHT Centers of Excellence can strengthen operational performance, enhance patient outcomes, and maintain the standards required for ongoing accreditation.

Education, Research and Advocacy

Advancing the quality of care for individuals with HHT depends on active collaboration among Centers of Excellence and meaningful engagement with Cure HHT. By participating in education, research, and advocacy efforts, COEs enhance professional expertise, foster collaboration across centers, and contribute to the growth of knowledge and resources that benefit the entire HHT patient and provider community.

Education

Education is a cornerstone of excellence in care. COEs are expected to remain current on best practices in HHT management and to contribute to the education of patients, colleagues, and the public. Participation in educational activities helps ensure consistent, high-quality care across centers and provides opportunities for professional growth and collaboration.

Mandatory Educational Activities

Centers must actively participate in the following mandatory educational activities:

- Directors must participate in the Cure HHT COE All Directors conference calls, on a quarterly basis (minimum attendance of 3 calls per year).
- Coordinators must participate in the center coordinator calls on a quarterly basis (minimum attendance of 3 calls per year).
- Complete Cure HHT Continuing Medical Education (CME) program online courses:
 - For new Centers applying, all Core Team members must complete all required CME program online courses prior to the site visit. Additional Team members are strongly encouraged to complete these courses.
 - This requirement does not apply to currently accredited Centers of Excellence; however, any newly appointed Core Team members must complete relevant CME program online courses, as determined by Cure HHT.
- Delivery of HHT related presentations, by the Medical Director and/or another member of the Core Team, in grand rounds and/or to local community groups.
- Attend the biennial HHT International Scientific Conference:

- Attendance for the Medical Director is mandatory; if that is not possible, the Co-Director or Associate Director (if applicable) or at least one Core Team member must attend (additional team members are encouraged to also attend).
- Ensure every core team member is enrolled in Cure HHT's Listserv and the Cure HHT Research Network (CHRN) Hub.
- Attendance at a Cure HHT Patient and Family Conference within the first year of initial COE certification is mandatory.
- Host, participate in, or attendance by Medical Director, Coordinator or other Core Team member, at least once every two years, a National or a Regional HHT Patient and Family Conference or education forum.

Optional Educational Activities (Strongly Encouraged)

Centers are strongly encouraged to:

- Deliver HHT-focused presentations at specialty society meetings.
- Host or attend Cure HHT or partner organization webinars. Develop or contribute to HHT-focused training modules or educational materials for medical students, residents, or fellows.

Research

Research participation is essential for advancing the scientific understanding of HHT, developing new treatments, and improving care delivery. Centers of Excellence are encouraged to actively engage in HHT related research, including participation in patient registries, clinical trials, basic science investigations, and translational research initiatives.

All research protocols involving human subjects must receive approval from the local institutional review board (IRB) or equivalent human subjects' assurance committee prior to initiation.

Mandatory Research Activities (subject to funding and infrastructure availability)

To maintain accreditation, each HHT Center of Excellence is required to demonstrate active participation in research involving HHT patients and document completion of at least three (3) of the following 9 activities within the preceding three years:

- Enroll and contribute patient data to the CHORUS registry (Comprehensive HHT Outcomes Registry of the United States).
- Maintain active participation in the Cure HHT Research Network (CHRN) Hub.
- Facilitate and track patient contributions to the HHT Biorepository.
- Conduct or serve as an enrolling site for clinical trials or natural history studies focused on HHT.
- Submit and present abstracts or posters at least once every other national or international scientific conference on HHT.
- Identify and refer eligible patients for participation in clinical trials, with referrals documented.
- Publish peer-reviewed manuscripts on HHT-related topics in recognized scientific journals.
- Engage in multi-center research collaborations with other accredited Centers of Excellence.
- Design, implement, and disseminate quality improvement projects related to HHT care, with outcomes presented or published at a national or international scientific meeting.

Advocacy

Advocacy is an essential responsibility of HHT Centers of Excellence (COEs) and plays a critical role in raising awareness, improving access to specialized care, and securing funding for HHT research and treatment. Active advocacy efforts at the local, regional, and national levels strengthen the visibility, sustainability, and long-term impact of the HHT community and its care infrastructure.

Mandatory Advocacy Activities

- Host, participate in, or attend, at least once every two years a National or a Regional HHT Patient and Family Conference or educational forum.
- Participate in collaborative programming with Cure HHT and community-based events.

Encouraged Advocacy Activities (Strongly Recommended)

- Advocate for HHT through the institution's government relations staff.
- Promote the HHT program with national legislators, including both the Senate and the House of Representatives.
- Participate in Cure HHT Capitol Hill Day, in accordance with the policies of the institution.
- Engage in legislative advocacy efforts that support HHT research, secure funding for COEs, and strengthen rare disease care infrastructure.

Additional Expectations for a Center of Excellence

COE Engagement with Cure HHT

Centers of Excellence are expected to maintain active engagement with Cure HHT leadership and collaborative initiatives. This includes consistent participation in scheduled quarterly meetings for COE Directors, which serve as a forum for sharing updates, developments, and addressing challenges in HHT care delivery.

Attendance at quarterly meetings for COE Directors is essential for sustaining the center's designation and may be tied to continued funding support. **Centers receiving financial support are expected to prioritize participation, as repeated absences may jeopardize funding eligibility.**

Annual Status Reports

Submitting an annual status report is a **mandatory requirement for maintaining ongoing accreditation as a Center of Excellence.**

Each COE must submit its first annual report by March 31 and annually thereafter. The report should provide a comprehensive review of the center's activities, staffing, services, and outcomes from the previous calendar year.

Timeliness of Communications

Centers of Excellence are expected to maintain timely and responsive communication with patients, families, and referring providers. Urgent phone calls should be returned within one business day, while non-urgent phone calls should be returned within three business days.

Staff Changes

All Centers of Excellence must provide written notification to Cure HHT of any anticipated changes to Core Team members at least 30 days prior to the effective date and must submit a plan outlining the replacement or transition of the role. In the case of a proposed change in the

Medical Director, the Center must provide a formal letter from the Department Chair identifying the proposed new Director and include the candidate's curriculum vitae (CV). The appointment of a new Director must receive approval from Cure HHT leadership before the change is implemented.

A change in the Medical Director or the loss of any critical service will result in a site visit from Cure HHT leadership.

Any change in staff will require HHT-specific education, such as completing Cure HHT CME online modules, and staff are encouraged to attend a patient and family conference.

Continued certification will be contingent upon staff changes meeting the established COE criteria.

Centers are also encouraged to update COE and staff information in the Cure HHT Physician Directory at least every six months, or as soon as changes occur. Cure HHT staff are available to assist with this process if needed.

Sustainability

Ensuring the long-term sustainability of each Center of Excellence is essential to maintaining access to high-quality care for individuals with HHT.

Centers should actively engage medical trainees in the operations of the COE to cultivate future specialists and expand the pool of providers with HHT expertise.

COEs should work closely with institutional leadership to demonstrate the center's clinical, academic, and community impact, thereby securing continued or increased institutional support.

Compliance with COE Criteria

Cure HHT Centers of Excellence are expected to maintain full adherence to the standards and requirements outlined in this document for the duration of their certification. While Cure HHT recognizes that unforeseen challenges may occasionally impact a center's ability to meet all criteria, maintaining compliance remains essential to preserving accreditation.

If a COE becomes noncompliant with any required criteria prior to its scheduled renewal, including the unexpected departure of the Medical Director, Coordinator, or another Core Team member, the Center must provide written notification to Cure HHT within 30 days of the change.

In such cases, Cure HHT reserves the right to review the circumstances, assess the potential impact on patient care, and advise on an appropriate plan of action or next steps. This process will involve collaboration with the Cure HHT Center Committee to identify solutions and ensure a timely return to full compliance. Ongoing communication and updates will be expected until the matter is resolved.

Failure to meet the required COE criteria, or failure to make satisfactory progress toward resolving deficiencies, may result in the revocation of the center's designation.

Fee Schedule

This fee schedule recognizes and partially funds the increasing administrative burden on Cure HHT to certify and maintain high-quality Centers of Excellence. Fees are based on the costs of application processing, site visits, new COE announcements, and the ongoing monitoring and administrative support provided by Cure HHT during the designated period following certification or renewal.

Type	Item	Amount (USD)
Certification	Interest Form Submission & Review Fee	\$500
	Application Form Submission & Review Fee	\$2,000
	Site Visit (in-person)	\$2,500
	Four-Year Certification Fee	\$3,000
	Certification Total	\$8,000
Type	Item	Amount (USD)
Renewal <u>Without</u> Site Visit	Application Form Submission & Review Fee	\$1,500
	Four-year Renewal Fee	\$2,500
	Recertification Total	\$4,000
Type	Item	Amount (USD)
Renewal <u>With</u> Site Visit	Application Form Submission & Review Fee	\$1,500
	Site Visit (in-person)	\$2,500
	Four-Year Renewal Fee	\$2,500
	Recertification Total	\$6,500

Renewal Without Site Visit:

Applies to Centers of Excellence in good standing that are meeting all current criteria requirements and remain in compliance. An in-person site visit is not required. Cure HHT reserves the right to conduct a virtual site review if deemed necessary.

Renewal With Site Visit:

Applies to Centers of Excellence that are not fully meeting current criteria requirements or are not in compliance. An in-person site visit is required as part of the renewal process.

Funding Sources

Potential funding sources include Department and Division funds, especially from procedure-based areas benefiting financially from COE participation

- Hospital funds, especially from departments related to patient safety, quality of care, outreach, and rare diseases.
- Local fundraising events (e.g., golf outings) with or without Cure HHT assistance. If Cure HHT helps organize the event, profit-sharing arrangements may be considered.

Executive Committee

The Executive Committee advises Cure HHT on clinical, operational, and program strategies to strengthen the COE network, with members representing diverse expertise in HHT care. The Committee reviews policies, advises on best practices, addresses emerging challenges, and supports the ongoing accreditation and development of COEs.

Membership Composition

- Cardiology representative
- Coordinator representative
- Cure HHT representatives
- Hematology representative
- HHT Patient representative
- Interventional Radiology representative
- Pulmonology representative
- Subspecialty representative relevant to HHT (to be identified as needed)
- Recently established, high performing COE Medical Director representative (past 2 years)

Supporting Resources

Centers of Excellence are encouraged to utilize resources to support clinical care, professional education, and collaborative research. These tools provide access to the most current guidelines, expert networks, and educational materials to ensure consistent, high-quality care for HHT patients.

- [Cure HHT Continuing Education Program](#)
- [Cure HHT Physician Directory](#)
- [Cure HHT Research Network](#)
- [Second International Guidelines for the Diagnosis and Management of HHT](#)