

## **CRITERIA FOR A NORTH AMERICAN CURE HHT CENTER OF EXCELLENCE**

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### **DEFINITION OF A COE**

A Hereditary Hemorrhagic Telangiectasia (HHT) Center of Excellence (COE) is a medical team recognized by Cure HHT as possessing the personnel, expertise, commitment, and resources to optimally provide comprehensive evaluation, treatment, and education to patients and families with HHT.

### **GUIDING PRINCIPLES**

These criteria were developed in consensus over a period of 2 years by 15 members of the Cure HHT Center Committee (Appendix 1), which consisted of HHT clinicians representative of a mix of recently and longer-established COE, patients, and Cure HHT Board of Director members. The HHT Board of Directors and all current HHT COE directors reviewed and made recommendations, keeping in mind these “guiding principles.”

- Intention to increase patient access to high quality HHT care.

- Intention to ensure that COE have the necessary staff and facilities to provide high quality care.
- Belief that continuing education of COE staff, patients, families, and non-COE health care providers is critical to maintaining high quality care.
- Recognition that it may be challenging for a prospective COE to gain the optimum level of expertise until certified as a COE and realize increased patient volume as a result of this designation. Therefore, the rigor of these criteria should strike a balance between: 1) the level of expertise that can be attained by interested HHT clinicians practicing outside of an established COE, and 2) the level of expertise that is necessary to provide high quality care.
- Cure HHT does not have the resources or obligation to process applications from every hospital interested in becoming a COE, especially in geographic areas that are already well served by an established COE.
- Cure HHT does not currently have the resources to review and visit COE outside of North America. Additionally, appropriate criteria for COE may differ from one country to another depending on many issues such as that country's health care system, financial resources, and public expectations of health care. Accordingly, this certification process only applies to COE in North America.

## **GENERAL COE EXPECTATIONS**

COE are encouraged to:

- Educate patients, families, and health care providers about HHT.
- Interact with the non-COE health care providers of HHT patients.
- Engage in HHT research.
- Participate in Cure HHT activities.

The standard of care provided at COE must be equivalent to or exceed all consensus guidelines approved by the Global Research and Medical Advisory Board of Cure HHT and all local and national standards.

## **COE CRITERIA**

The required criteria to initially obtain and maintain COE certification are detailed below in 4 sections:

- A. Personnel
- B. Facilities and Resources
- C. Education, Research, and Advocacy/Administration
- D. Other COE expectations

### **A. Personnel**

COE must have sufficient personnel with knowledge of HHT to coordinate the evaluation and treatment of patients, and respond to their inquiries, in a timely manner. COE must also have sufficient personnel to provide HHT education for patients, families and health care providers. The recommended time commitments for selected staff are a minimum estimate and will likely increase with time.

At most successful COE, specialty services are best served by one clinician as opposed to a group of clinicians (e.g. one ENT physician as opposed to several). This is because the experience of managing a rare disease can be focused on one clinician and allow for development of greater expertise in contrast to diffusing that experience over a group. Spreading the experience across a group is most appropriate when a senior clinician is training his or her replacement or with an established COE that has a large volume of patients. Of course, it is appropriate to have back up clinicians who can fill in when the main specialist is out of town or in case of other emergencies.

COE are strongly encouraged to have algorithms for the intake and management of both pediatric and adult patients. Applications from prospective COE requesting stand-alone pediatric or adult COE status will be considered on a case by case basis according to local/regional needs and expertise.

### **Core Staff**

The following personnel must be designated and available at a COE.

1. Medical Director. The Medical Director must have specialized knowledge of the main organ manifestations of HHT and experience in their management. An important part of this role is having the time and ability to coordinate the multidisciplinary diagnosis and treatment of patients referred to the COE. Accordingly, this person is expected to see at least 90% of patients new to the COE and serve as the “HHT primary provider” for issues related to HHT (not to be confused with the patient’s PCP who manages all things not HHT). At some point the volume of HHT patients may exceed what one person could reasonably manage and one or more colleagues may need to assist the Medical Director in their role as the HHT primary provider. Serving as the HHT primary

provider includes spending a significant proportion of practice time devoted to: seeing patients in clinic, screening for visceral manifestations, following patients on other services while they are receiving inpatient care at the COE, and dealing with complex issues leading to referral and follow-up.

The Medical Director position for new COE cannot be evenly shared between Co-directors, though an Associate Director is encouraged. For example, a junior clinician with limited experience in HHT might be appointed as Medical Director as long as he or she has a senior clinician with extensive HHT expertise acting as mentor in the role of Associate Director. As another example the Medical Director might be adult focused while the Associate Director is pediatric focused (or vice-versa).

Criteria include:

- a. A degree of DO or MD.
  - b. Experience with at least 15 unique HHT patients during the past 5 years. This criterion can be shared between the Medical Director and Associate Director.
  - c. An available time commitment of at least 0.1 FTE in year 1 after COE certification. At most centers, the Medical Director will eventually need a time commitment to HHT of 0.15 to 0.5 FTE. This criterion can be shared between the Medical Director and Associate Director.
  - d. Attendance at one or more HHT focused conferences in the past 4 years (regional, national, or international).
  - e. An active Professional Membership in Cure HHT.
  - f. The Medical Director for an initial COE certification or a new Medical Director at an established COE must have visited or previously worked at an established COE in the past 4 years.
2. Coordinator. The Coordinator is typically responsible for the initial patient contact - determining what tests and consults are necessary for the initial visit to the COE and coordinating all aspects of that visit. Accordingly, the Coordinator must have sufficient knowledge of HHT to make these decisions and must be able to respond to patient inquiries in a timely fashion. Other key components to this position include: obtaining insurance preauthorization for tests and specialized medications (e.g. bevacizumab); scheduling appointments and preparing itineraries; scheduling urgent therapeutic procedures; maintaining a local database; etc. Some of these duties might be reasonably shared with an administrative assistant.

Criteria include:

- a. A degree of APRN, ANP, BSN, CGC, PA, RN, or RT. At most successful COE the Coordinator has an advanced degree as listed above. However, if the

Medical Director shared in the clinical decision making aspects of this position, a less advanced credential (e.g. Medical Secretary) may be considered acceptable upon review.

- b. Clearly identified financial support to allow at least a 0.25 FTE commitment to HHT. (Coordinators at most established and successful COE have a time commitment of 0.5 to 1.0 FTE).
3. Otolaryngologist (ENT). A physician with experience and expertise in the treatment of recurrent epistaxis in HHT patients. This physician should be identified early in the formation of the COE and ideally should visit an ENT at an established COE. At many COE the ENT focuses on the surgical management of epistaxis while the Medical Director or other staff direct the medical management. In any case, optimal management of epistaxis in HHT requires a collaborative effort that includes surgical and medical management.

Criteria include:

- a. Experience with advanced cautery techniques (including bipolar cautery, laser cautery, and Coblation) in at least 10 HHT patients. Chemical cautery does not qualify. This involvement can include both personal participation (primary proceduralist or first assistant) and observed cases (e.g. cases in which the ENT physician observed a senior ENT physician at a well-established HHT COE). Personal participation must include at least 6 patients with at least 3 of those as primary proceduralist. Flexibility with this criterion may be considered if the ENT physician were to be closely mentored by a senior colleague who meets this criterion.
  - b. Experience with and/or referral pathways for advanced procedures to treat epistaxis such as sclerotherapy, Young's nasal closure, or nasal septal dermoplasty.
4. Interventional Radiologist. A physician with experience and expertise in the treatment of pulmonary AVM. The interventional radiologist ideally should visit a well-established HHT COE for understanding the complexities of treating PAVM such as the treatment of pregnant patients and re-perfused PAVM.

Criteria include:

- a. Involvement in the embolization of at least 15 PAVM in the past. This involvement can include both personal participation (primary proceduralist or first assistant) and observed cases (e.g. cases in which the IR physician observed a senior IR physician at a well-established HHT COE). Personal participation must include at least 10 PAVM with at least 5 of those as primary proceduralist. Flexibility with this criterion may be considered for an IR physician with personal experience with embolization in other body areas or if

the IR physician were to be closely mentored by a senior colleague who meets this criterion.

5. Gastroenterologist and/or Hepatologist. This person/s should have experience in the management of symptomatic complications from liver AVM and bleeding from gastrointestinal telangiectases including performance of endoscopy with cauterization of telangiectases.

### **Additional Staff**

In addition to the core staff above, a COE should ideally have ready access to the following personnel. Please note that for many of these personnel, it is acceptable for their duties to be performed by another member of the HHT team. For example, the Medical Director may be fully qualified and comfortable with the management of iron deficiency anemia and therefore a hematologist may not be necessary.

1. Associate Director. This person should be able to coordinate patient care and direct COE operations in the absence of, or to assist, the Medical Director (within the scope of their qualifications). This person must have a degree of APRN, ANP, CGC, DO, MD, NP, PA, or RN.
2. Neurovascular team. Typically, a team of Interventional Neuroradiologist and Neurosurgeon with experience and expertise in the diagnosis and treatment of brain and spinal cord AVM and other cerebrovascular lesions.
3. Genetic counselor or Geneticist. This person should have expertise to provide HHT-specific genetic counseling to patients and families.
4. Hematologist. This person should have expertise in the use of iron supplementation to treat iron deficiency anemia and administration of medical therapies including angiogenic inhibitors (e.g. bevacizumab) to manage AVM and bleeding.
5. Pulmonologist. This person should have experience in the management of pulmonary AVM and their complications, including hemoptysis.
6. Cardiologist. This person should have experience in the management of cardiovascular HHT complications including pulmonary hypertension, high output heart failure, and atrial fibrillation.
7. Dermatologist and/or Oral Surgeon/Dentist. This person/s should have experience in the management of non-nasal mucocutaneous telangiectases.

### **B. Facilities and Resources**

A COE must have the facilities and resources required to perform all the procedures necessary to evaluate and treat the manifestations of HHT.

Criteria include facilities to perform the following:

1. MRI imaging of the brain.
2. Agitated saline contrast echocardiography.
3. CT imaging of the brain and body.
4. Interventional radiology service for angiography and percutaneous embolization therapy.
5. Advanced cautery equipment such as KTP laser, YAG laser, bipolar electrocautery, and/or Coblation.
6. Iron infusion center.
7. Access to obtain genetic testing for the main HHT causing mutations.
8. Adequate record keeping system.
9. Local access to gamma knife is encouraged but not mandatory.
10. Local access to capsule endoscopy and extended upper GI endoscopy (e.g. double balloon enteroscopy) is encouraged but not mandatory.
11. Right heart catheterization.

### **C. Education, Research, and Advocacy/Administration**

Patient care and understanding of HHT are optimized when COE are collaborating with each other and with Cure HHT to provide education about HHT, conduct research, and participate in a wide spectrum of advocacy and administrative activities. Accordingly:

- Centers applying for initial certification are encouraged to progressively participate in the following activities, but these are not required criteria for initial certification.
- For recertification, COE must demonstrate engagement with Cure HHT initiatives, and must meet minimum criteria in at least 2 out of the following 3 sections: Education, Research, and Advocacy/Administration.

#### **1. Education**

Educational activities are an important component of a COE and are necessary to maintain an up to date understanding of the management of HHT and to inform others about HHT.

*Excellence in Education must be demonstrated by one or more COE staff collectively fulfilling at least 4 of the following criteria.*

- a. Participation on the planning committee for a Cure HHT Patient or Scientific conference in the past 4 years.
- b. Participation in at least 50% of North American Center Director conference calls or face to face meetings in the past 4 years. A COE representative may attend in the Director's absence.
- c. Presentation of 2 or more HHT related talks in your regional area (e.g. support group or Grand Rounds) in the past 4 years.
- d. Presentation of 1 or more HHT related talks at a national or international meeting in the past 4 years.
- e. Presentation of 1 or more HHT related webinars in the past 4 years.
- f. Attendance at an HHT Scientific meeting in the past 4 years.
- g. Attendance at a Cure HHT Patient and Family conference in the past 4 years.
- h. Attendance in 3 or more HHT related webinars in the past 4 years.
- i. Hosting a regional HHT conference in the past 6 years.
- j. Development of HHT related curricula at your local medical school, residency training program, or fellowship program in the past 6 years.
- k. Preparation of educational materials for Cure HHT (e.g. Newsletter information, educational brochures, etc) in the past 4 years.
- l. Posting on the Cure HHT Professional Forum at least 6 times in the past 4 years
- m. Other meaningful educational activities may be considered on a case by case basis.

## 2. Research

COE are encouraged to participate in HHT related clinical and/or basic science research. Research protocols involving human subjects must be approved by the local institutional human assurance committee.

*Excellence in Research must be demonstrated by one or more COE staff collectively fulfilling at least 2 of the following criteria.*

- a. Coauthor of at least one HHT related publication in a peer reviewed journal in the past 4 years.
- b. Submission of an HHT related grant in the past 4 years (PI or Co-PI).
- c. Participation in at least one HHT related research project in the last 4 years (including registries).

- d. Presentation of results of research conducted at your COE in the past 4 years (oral or abstract).
- e. Participation in an NIH study section that reviews HHT related grants in the past 4 years.
- f. Other meaningful research activities may be considered on a case by case basis.

### 3. **Advocacy/Administration**

*The Advocacy/Administration criterion must be fulfilled by one or more COE staff collectively fulfilling at least 3 of the following criteria.*

- a. Membership on a Cure HHT committee in the past 4 years.
- b. Membership on the Cure HHT GRMAB in the past 4 years.
- c. Membership on the Cure HHT Board of Directors in the past 6 years.
- d. Participation in a site visit to a prospective COE in the past 4 years.
- e. Hosting an Applicant Center to visit your COE in the past 4 years.
- f. Hosting or participating in a fundraising event for a local HHT group or Cure HHT in the past 4 years.
- g. Assisting Cure HHT in general fundraising activities in the past 4 years.
- h. Meeting with your local government representatives to advocate for HHT in the past 4 years.
- i. Visiting Capitol Hill to promote legislative activities for HHT in the past 4 years.
- j. Visiting the NIH to promote support of HHT related research in the past 4 years.
- k. Meeting with your Cure HHT COE liaison at least 2 times in the past 4 years (in person or by phone).
- l. Other meaningful advocacy/administration activities may be considered on a case by case basis.

## D. **Other COE Expectations**

### 1. **Patient volume**

- For initial certification, a COE must have seen at least 25 unique patients in the past 5 years. This includes new referrals and return patients, though each return patient can only be counted once during the 5-year period.

- For recertification, a COE must have seen at least 100 unique patients during the past 4 years.
- NOTE: Volume can be based on the collective experience of all COE faculty.

## **2. Timeliness of communications**

- Urgent phone calls should be returned within 1 business day.
- Non-urgent phone calls should be returned within 3 business days.

## **3. Staff changes**

- All COE must notify Cure HHT of changes in Core Staff within 30 days – for example a change in Medical Director or Coordinator, or loss of IR services. This cannot wait until the annual status report and needs immediate attention so that we may ensure that new personnel have the necessary expertise.
- Continued certification will be contingent upon staff changes meeting the above COE Criteria.
- The COE are encouraged to update COE and staff information on the Cure HHT Physician Directory at least every 6 months (see <https://directory.curehht.org>). Cure HHT can assist with this process if desired.

## **4. Annual Status Reports**

- Each COE will submit an on-line annual status report that will include a limited data set such as personnel changes, number of patients seen, number of PAVM embolization's, etc.
- The first annual report for all COE will be due 18 months from the effective date of these Criteria, and annually thereafter. This will provide COE the necessary lead-time to collect this information in a prospective fashion, while spreading the burden over time.

## **CENTER CERTIFICATION PROCESS**

The above criteria cannot foresee every possible circumstance that may occur at prospective or established COE. Therefore, the Cure HHT Center Committee reserves the right to be judiciously flexible in the interpretation of these criteria when reviewing applications for initial COE certification and established COE for recertification. For example, an unmet criterion might be waived at a prospective COE that would improve access in an underserved geographic area, especially if a viable plan was proposed for meeting that criterion in the future.

The fee schedule for initial certification and recertification is presented in Appendix 2.

### **Initial Certification**

- In general, Cure HHT discourages more than one COE in the same geographic area. Given that development of expertise in the management of HHT is almost certainly correlated with patient volume, and since HHT is a rare disease, 2 COE in the same geographic area would likely not maintain sufficient volume. Secondly, Cure HHT has finite resources to evaluate, certify, monitor, and recertify COE, and is obligated in the foreseeable future to focus on certifying COE in underserved areas. However, COE in the same geographic area can be considered on a case by case basis if, for example, there are compelling reasons such as significant insurance exclusion issues or areas of unmet expertise at the established COE (e.g. expertise in management of brain AVM). Such situations are anticipated to be fairly uncommon.
- The process of initial certification is estimated to require 4-6 months on average and is outlined below.

### **Process of Initial Certification**

- Applicants interested in becoming a COE should thoroughly review the above COE Criteria and then complete the online application (available at CureHHT.org). The initial application fee is nonrefundable unless the application is rejected by Cure-HHT due to the presence of a well-functioning COE in the same geographic area (e.g. same or nearby city).
- Upon review of the application, Cure HHT will assign a Mentor Center to arrange for a visit by the Applicant to the Mentor Center within 60 days. The reasons for this visit are two-fold: 1) So that the Applicant team may learn from how an established COE functions, and 2) So that Cure HHT may better evaluate the “HHT expertise” of the Applicant team. There is no fee for this visit but the Applicant will be responsible for any travel costs.
- Within 60 days of the visit to the Mentor Center, Cure HHT will arrange a site visit to the Applicant Center. This visit will include visiting key facilities, interviewing core staff, and reviewing selected patient charts. Within 30 days of the site visit, a report will be prepared for review by the Cure HHT Center Committee.
- Key considerations for the Cure HHT Center Committee during this process include:
  - Does the Applicant Center meet the essential criteria for being a COE?
  - Are key personnel available at the Applicant Center?

- Has the Applicant Center seen a sufficient number of patients in the recent past to qualify as a COE?
- Are HHT patients receiving care according to current guidelines?
- Does the Applicant Center have a comprehensive plan for the medical and surgical management of epistaxis?
- Does the Applicant Center have a cohesive plan for the management of both pediatric and adult patients?

### **Outcome of Initial Certification Evaluation**

A written summary of the center evaluation will be provided to the Applicant. Possible outcomes of the evaluation are outlined below.

#### **1. Certification granted**

- The Applicant meets COE criteria, no significant issues are identified, and all applicable fees have been remitted (Appendix 2).
- Following certification, Cure HHT will work with the new Center's public relations department to coordinate press release, announcement to the HHT community and all publicity announcements.
- Cure HHT will re-evaluate in 4 years.

#### **2. Certification is on hold**

- If recommendations are made upon which certification is contingent, the Applicant will be allotted 3-12 months (specified depending on the issue) to make corrective action and report back for reconsideration, prior to disposition of the application.
- Please note that applications that are incomplete will likely lead to an "on hold" status unless the deficiencies are clearly explained in the application.

### **Recertification**

- The overarching goal of the recertification process is to ensure that COE are providing comprehensive, state-of-the-art care to HHT patients. This process will provide a mechanism to ensure that all Centers continue to meet COE standards. It will also provide an opportunity for COE to help each other provide HHT care that meets our common, agreed-upon standards.
- The purpose is not to be punitive towards any COE and/or to revoke accreditation unless in extreme cases as discussed below.

- The process of recertification is expected to take 2-3 months on average and is outlined below.

### **Process of Recertification**

- Recertification of established COE will occur every 4 years.
- For COE that were originally certified more than 4 years prior to the effective date of this document, the recertification process shall be divided so that approximately 25% of COE undergo the recertification process during each of the next 4 years.
- Each COE should complete an on-line application collecting information intended to provide a detailed snapshot of the COE. This will take the place of the annual report for that year, and will be due 3 months prior to recertification.
- The recertification application will be reviewed by a team of 2-3 members of the Cure HHT Center Committee, and may include a Cure HHT COE liaison.
- In general, the reaccreditation “site visit” will occur via teleconference between key personnel at the COE and those performing the evaluation. On occasion, a local site visit may be necessary if major areas of concern are noted during the review process; the expense associated with a local site visit will be assumed by Cure HHT.
- The review criteria for recertification are outlined in the Section above – COE Criteria. They include the initial certification criteria except where noted, and in addition include the section on Education, Research, and Advocacy/Administration.
- Key questions asked by the review Committee during this process include:
  - Does the COE continue to meet the essential criteria for being a COE?
  - Are key personnel still available at the COE?
  - Does the COE see a sufficient number of patients each year to maintain HHT expertise?
  - Do COE personnel participate in the HHT community?
  - Are there systematic issues at the COE that are otherwise not identified in the written criteria, e.g. variable care given by a specialty group, long delays in getting appointments, etc.

### **Outcome of Recertification Evaluation**

A written summary of the COE reevaluation will be provided to the Applicant. Possible outcomes of the evaluation are outlined below.

### 1. Recertification granted

- COE criteria continue to be met, no significant issues are identified, and all applicable fees have been remitted (Appendix 2).
- Cure HHT will re-evaluate in 4 years.

### 2. Recertification on hold

- Recertification will not be granted until the issue(s) is resolved but neither will the COE be delisted from the Cure HHT website.
- Reasons could be due to one or more significant issues such as lack of key personnel or insufficient patient volume.
- The Cure HHT Center Committee and Cure HHT will work with the COE to help resolve the issue(s) as soon as possible.
- In case of lack of key personnel, it is understood that resolution can take time. The center will be granted 6-12 months to replace key personnel. A reevaluation will be performed 1 year later to ensure this has been addressed.
- In case of insufficient patient volume, Cure HHT may be able to help by increasing center advertising or referrals, as appropriate.

### 3. Certification rescinded

- Recertification is not granted. The COE will no longer be designated as such, and will be delisted from the Cure HHT website COE roster. Individual clinicians can continue to be listed in the HHT Physician Directory if they desire to continue seeing HHT patients.
- This action would only be used if all steps taken have not been sufficient to meet established criteria for a COE.
- Potential examples of when this might occur would be: a COE that refused to place a recertification application or a COE that lost its Medical Director and had no plan or interest in finding a replacement.
- Recertification could be granted after successfully addressing the original issues that led to decertification.

## **COMPLIANCE WITH COE CRITERIA**

1. All COE that have Co-Medical Directors (as of 1/1/2017) will be allowed to maintain that structure as long as problems do not develop related to that structure (e.g. lack of accountability).
2. COE that no longer meet COE criteria (for example, if the Medical Director steps down) before the next recertification date will be granted a grace period of 6-12 months (depending on the issue) to re-establish consistency with COE criteria. This process should involve discussion with the Cure HHT Center Committee to come up with a mutually agreeable plan to correct the deficiency. COE status will be rescinded if criteria are not fulfilled in a satisfactory and timely manner.

## Appendix 1 – Cure HHT Committee members

James Gossage, MD, Chair

Robert Berkman

Murali Chakinala, MD

Harry Chapman\*

Mark Chesnutt, MD

Marianne Clancy, MPA

Miles Conrad, MD

Marie Faughnan, MD

Kate Henderson, CGC

Edward Jurevic, BSChE, MBA

Raj Kasthuri, MD

Mollie Meek, MD

Scott Olitsky, MD

Beth Plahn, RN

Kevin Whitehead, MD

\*Ad hoc member for preparation of these Criteria.

## Appendix 2 – Certification and Recertification Fee Schedule

This fee schedule recognizes and partially funds the ever increasing administrative burden by Cure HHT to certify and maintain high quality COE. These fees are based on the costs of application processing, site visits, new COE announcements, and the costs incurred by Cure HHT in the process of monitoring and administratively supporting the COE for the 4-year period following certification or recertification.

### Initial Certification

- The total fee for a successful certification process will be \$5,000.
- The fees are to be paid piece-meal as various milestones are reached during the application process as noted below:
  - Application fee \$500
  - Site visit \$2,500
  - 4 year certification fee \$2,000
- Note that the 4 year certification fee can be paid in two installments if desired.

### Recertification

- The total fee for a successful recertification process will be \$2,300.
- The fees are to be paid piece-meal as various milestones are reached during the application process as noted below:
  - Application fee \$300
  - 4 year recertification fee \$2,000
- Note that the 4 year certification fee can be paid in two installments if desired.

### Funding Sources

Below is a partial list of sources that COE might consider to pay these fees:

- Department and Division funds, especially those that are procedure based and gain much revenue by participating in the COE.
- Hospital funds, especially from departments involved with patient safety, quality of care, outreach, and rare diseases.
- Local fundraising events (e.g. golf outings) with or without help from Cure HHT. If Cure HHT is enlisted to help set up such events, profit sharing arrangements might be made.

- \$1,000 “in kind” credit from Cure HHT for hosting Mentor visits by Applicant Centers or going on site visits to Applicant Centers.
- “In kind” credit from Cure HHT for some advocacy work/involvement