

## HHT Foundation and HHT Centers

*A tale of separate institutions working toward a common goal.*

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Over the past year, the HHT Foundation has received several phone calls, emails, and letters asking about the differences between the HHT Foundation and the HHT Centers of Excellence. On the surface, we may look and act as one entity but the reality is that we are completely separate institutions.

The mission of the HHT Foundation is to find a cure for HHT while saving the lives and improving the well-being of individuals and families affected by HHT. We achieve this mission by funding research, advancing new therapies, educating patients and physicians, collaborating with HHT Treatment Centers, and engaging the scientific and medical community. All of these activities, especially the funding of research and educating patients and physicians, are made possible through your generous donations all year long.

**The HHT Foundation is the ONLY organization worldwide** that provides support to families and physicians through printed materials, website links, professionally monitored discussion forums, conferences, and legislative advocacy. The HHT Foundation initiates an application for an HHT Center of Excellence in the United States in an attempt to standardized the care received by HHT specialists at each institution, however, the hospital itself is an independent entity with its' own guidelines, standards of care, and liabilities. The **HHT Foundation** is reliant on the HHT Treatment Centers to take care of the patients we refer to them over the phone or through the internet, in addition to providing their expert medical presentations at our conferences. The **HHT Treatment Centers**, in turn, rely on the HHT Foundation to refer patients to their institution, provide initial contact with patients and answer non-medical questions and concerns about HHT, and produce mass materials on HHT that can be disseminated to patients and physicians alike. The HHT Foundation provides patient support, education, and research; the HHT Center of Excellence provides patient care.

Recently, we had an inquiry about donating to the HHT Foundation as compared to donating to an HHT Center of Excellence. While both institutions are working in partnership toward the same goal, improving

the quality of life for HHT patients, our funding comes from different sources. It is important that you, our members, understand this relationship. Here is the response I sent to a concerned member earlier this year:

*In response to your question, the HHT Centers of Excellence are completely independent from the HHT Foundation. An "HHT Center" is a group of physicians, nurses, and genetic counselors employed by a University Hospital (in most cases) that are knowledgeable in HHT and they join together to coordinate care for HHT patients at their institution. Donations made to an HHT Center, for instance, stays within that medical system. The HHT Foundation relies completely on private donations made primarily by our members and their families/friends through grassroots fundraising.*

*The HHT Foundation partners with physicians, scientists, and other rare disease organizations from around the world to advance therapies and a potential cure of HHT primarily through research and education. One of our more notable achievements is our collaborative work with the scientists who discovered the HHT genes. In addition to that study, we have funded 11 other research studies. Currently, our office, in coordination with the Foundation's Medical Director, is in the final stages of developing a multi-center clinical trial to test the effectiveness of 3 products on epistaxis (nose bleeds). Several HHT Centers will be participating in this study, while other HHT Centers have chosen not to participate. The HHT Foundation also funds regional and national education conferences for patients, CME accredited programs for healthcare providers, and we sponsor scientific meetings specific to HHT. In addition, we create educational materials that are distributed to patients and physicians who contact our office.*

*The HHT Foundation maintains a website full of resources for patients, physicians, and scientists, along with a discussion forum that allows HHT patients to talk in a monitored setting that provides factual information. In addition, we advocate for every HHT patient through programs with NIH and CDC, partnerships with other rare disease organizations, and a legislative initiative geared toward obtaining federal funding for this disease (we have already gained legislative language and a nationally recognized HHT Awareness month).*

*With relation to the HHT Centers specifically, the HHT Foundation identifies geographic area(s) with the greatest need for an HHT Center, communicates with key physicians in that area to gain interest in gathering a team of specialists, provides guidelines for what is expected from a center, and performs a site visit / makes suggestions on how the center should be organized. However, the HHT Foundation does not support the center financially nor do we have any control over their operation. We provide referrals to the HHT Centers and they donate their time to educate patients and physicians at our conferences. It is through this partnership that the HHT Foundation has been able to achieve many of its' successes. The money donated to each institution, however, stays within that institution.*

**We are coming into a season of giving. While there are many charities that are worthy of your investment, we ask that you make the HHT Foundation your first priority.**