**TEMPLATE LETTER TO CONGRESS**

**Subject: Support FY26 Funding for HHT Centers of Excellence – Sign Dear Colleague Letter by May 19**

Dear [Senator/Representative] [Last Name],

My name is [Your Name], and I am a constituent from [Your City, State]. I am writing to respectfully urge you to sign onto a Dear Colleague letter in support of **$4 million in FY25 federal funding for the Hereditary Hemorrhagic Telangiectasia (HHT) Centers of Excellence program** through the Health Resources and Services Administration (HRSA). This bipartisan letter is being led by [choose one: *Senator Richard Blumenthal* in the Senate OR *Representative Valerie Foushee* in the House], and the deadline to sign is **May 19, 2025**.

**HHT (Hereditary Hemorrhagic Telangiectasia)** is a **serious and often overlooked** genetic blood vessel disorder that affects approximately **70,000 Americans** and 1.4 million people worldwide. Though many have not heard of it, **HHT is twice as common as hemophilia and cystic fibrosis**. It causes abnormal blood vessel formation in major organs such as the lungs, brain, and liver, where ruptures can result in sudden hemorrhage, stroke, heart failure, and death. Tragically, many individuals remain undiagnosed or misdiagnosed due to limited awareness among healthcare providers.

Thanks to bipartisan Congressional support in recent years, the HHT community has seen transformative progress. In partnership with HRSA, Cure HHT has been able to provide funding to a national network of Centers of Excellence that has already:

* Increased the number of **new patients seen at funded Centers by 54%**, far exceeding the original goal of 15%. Each of these patients now has access to coordinated, expert care that can prevent catastrophic outcomes.
* Expanded the ability of Centers to deliver early screening, accurate diagnosis, and life-saving treatment by multidisciplinary care teams.
* Advanced a **national patient registry** to fuel future research, inform clinical practices, and improve long-term outcomes.
* Built capacity to educate healthcare professionals and close critical gaps in knowledge across the medical community.

Despite this remarkable progress, only **15 of the 29 Centers of Excellence** currently receive federal support. Many centers are overextended, and patients are still experiencing long wait times or traveling hundreds of miles for specialized care. An appropriation of $4 million in FY26 would allow HRSA to fund more centers and ensure that every patient in need has access to appropriate, timely, and expert treatment.

[**Insert your personal story here** – Share how HHT has affected you or your family. How long did it take to get diagnosed? What has expert care meant to your health, safety, and peace of mind?]

**Investing in the HHT Centers of Excellence will not only save lives — it will reduce emergency room visits, costly hospitalizations, and the overall economic burden on the healthcare system, which currently stands at nearly $500 million annually for diagnosed HHT patients.**

Please sign the Dear Colleague letter in support of continued funding for this life-saving program before the May 19 deadline. Your support will directly impact families like mine — and help move us closer to a future where no one living with HHT is left undiagnosed, untreated, or unheard.

Thank you for your leadership and for standing with the rare disease community.

Sincerely,
[Your Name]
[Your Address or ZIP Code]
[Your Email Address]
[Your Phone Number]