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CureHHT.org

Dear HHT Research and Clinical Community,

We know these are challenging times for biomedical research among other things. Ongoing shifts in government priorities, budget uncertainties, and increasing demands on your time and resources can make it feel like the ground is constantly shifting beneath your feet.

Please know that Cure HHT is here with you—and for you.

We remain steadfast in our mission to support your work in understanding, diagnosing, treating, and ultimately curing HHT. We're closely monitoring federal funding decisions, NIH budget developments, and other policies that affect the future of rare disease research. We're advocating at every level to ensure that HHT remains a priority in this changing landscape.

In the meantime, we want to remind you that Cure HHT is working on offering resources that can help accelerate your work:

- **CHORUS has enrolled over 650 participants and will be open soon and accepting data proposals.** We are currently finalizing a manuscript that will describe the data available. Once published, we will be able to provide this descriptive report along with the data available for querying. You will be able to access these (timeframe July 2025) on the Cure HHT Research Network Hub and submit your proposals to receive natural history data.
- **The Cure HHT Biorepository** is still collecting tissues and will also accepting proposals in the coming months. Whether you're investigating biomarkers, novel therapies, or pathophysiological mechanisms, the biobank will be available to support your studies. As we finalize the tissue request details, look for more information on the Hub.
- We're always open to **collaborative conversations**—whether you need help navigating grant applications, forming research partnerships, or identifying funding opportunities.

Above all, we want you to know: we see you. We appreciate the passion, brilliance, and tireless effort you bring to the HHT field every day. We believe in your work, and we're honored to stand beside you as your partners and advocates.

With gratitude and support,

Cassi Friday, PhD
Director of Research, Cure HHT

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