HHT patient Carol sharing her HHT journey with Congressman Mark DeSaulnier

CURE HHT QUARTERLY

SPRING 2026 NEWSLETTER

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Need assistance or have questions about any of the content in this edition of Cure HHT Quarterly?
Please reach out to ***hhtinfo@curehht.org*** or call our Community Engagement team at **(410) 357-9932**.

VISIBLE TOGETHER

Celebrating 35 Years of Community and Progress

Every June, our community comes together to shine a brighter light on HHT. This year, we are inviting you to join us again for Visible Together, our HHT Awareness Month campaign, as we take last year's momentum one step further.

Visible Together was created from a simple but powerful truth: HHT can be invisible to the outside world, but the people and families living with it should never feel unseen. When we show up together — sharing our stories, raising awareness, and supporting the mission to find, treat, and cure HHT — we make this disease harder to overlook and easier to understand.

This year's campaign is especially meaningful because it also coincides with an important milestone: the 35th anniversary of Cure HHT.

For 35 years, this community has pushed awareness further, fought for better care, funded research, built Centers of Excellence, and created real hope for families living with HHT. That progress did not happen by accident. It happened because people like you chose to care, to speak up, and to act.

Now, we have a chance to build on that legacy.

Visible Together is about making HHT impossible to ignore — not just for one day, but all month long. It is about helping more people understand that HHT is not "just nosebleeds." It is a serious, whole-body disease that can affect the lungs, brain, liver, and gastrointestinal system. It is about helping families feel less alone. And it is about fueling the work that still lies ahead.

The good news? There are so many ways to be part of it.

You can raise money by creating your own fundraiser and inviting friends and family to support Cure HHT. You can make a direct donation to help fund awareness, advocacy, research, and patient support. You can share social media posts throughout June to help expand our reach and bring more voices into the conversation. You can educate your community by talking about HHT with your school, workplace, faith community, or local organizations. You can even shop the Cure HHT store, where every purchase helps spread awareness and support the mission.

And sometimes, getting involved is even simpler than that. It might just mean starting one conversation.

Vintage 2025 threads are leaving the Cure HHT store at the end of May!

Updated free resources releasing throughout June at curehht.org/awareness.

2026 CAPITOL HILL DAY

MARCH 17-18, 2026

"Your voice is powerful, and it is making a difference. By being here, speaking up, and standing together, you are helping change the future for everyone impacted by HHT."

MARIANNE CLANCY,
Chief Executive Officer, Cure HHT








SUCCESS IN WASHINGTON

This year, Cure HHT welcomed its largest and most diverse group of advocates to Capitol Hill with one goal in mind: To ask their elected officials for continued, and increased, federal support for the HHT Center of Excellence program. Our delegation included patients and caregivers, expert providers, dedicated research partners, and members of the Cure HHT team.

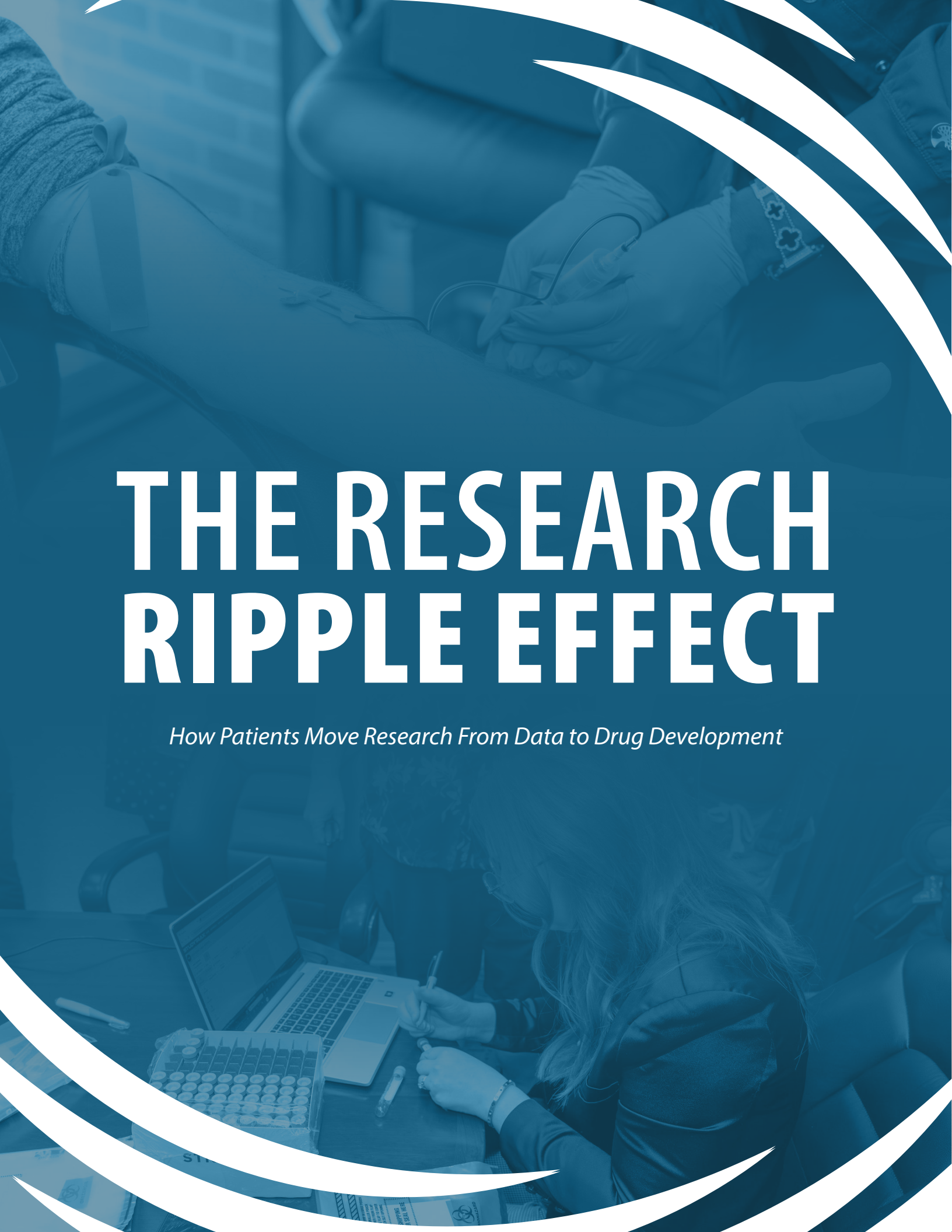
It was a cold day in DC, but that did not slow us down. Together, our group participated in more than 50 scheduled meetings with elected officials and congressional staffers. Across those conversations, our advocates shared personal stories, clinical expertise, and the real-world impact of HHT. They made the case clearly and powerfully: ***expert HHT care saves lives***.

Those conversations made an immediate difference. Several representatives signed the House Dear Colleague letter supporting HHT Center program funding soon after hearing directly from our community.

By the deadline we saw a 44% increase in letter signers compared to the previous year — a meaningful sign of growing awareness and support for HHT among Congress members.

Capitol Hill Day is always about more than meetings. It is about showing up for one another. It is about putting real faces and real stories in front of decision-makers. And it is about reminding Congress that HHT is not rare to the families living with its consequences every day.

We are deeply grateful to every advocate, provider, partner, and team member who helped make this year's day on the Hill such a strong success. Because of this community's commitment, HHT is gaining ground, and lawmakers are listening.



THE RESEARCH RIPPLE EFFECT

How Patients Move Research From Data to Drug Development

For many people living with hereditary hemorrhagic telangiectasia (HHT), research can feel distant. It lives in conference halls, journal pages, grant proposals, and scientific jargon that does not always sound like daily life. Patients live in a different vocabulary: nosebleeds that interrupt dinner, iron infusions squeezed between work meetings, unexplained fatigue, the anxiety of screening for AVMs, the quiet calculations families make about whether a symptom is "normal for us" or something more dangerous.

But in HHT, the distance between lived experience and scientific progress is not as wide, or far off, as it seems. In fact, one of the most powerful truths in this field is that patient experience is not just adjacent to research. It is the raw material for it.

That is the research ripple effect.

It begins with something deceptively simple: data. A patient enrolls in a registry. A clinician records what is happening in real life, not just in the neat confines of a tightly controlled trial. Bleeding patterns, anemia, transfusions, organ involvement, symptom burden, complications, demographics, treatment history, quality of life. At first glance, those entries may look like rows in a spreadsheet. In reality, they are pattern recognition waiting to happen. They are the inner most ring in a ripple that can eventually reach something every HHT family wants: viable treatments, stronger standards of care, and ultimately drug development built on the actual needs of this community.

For HHT, this matters immensely because HHT has spent too much of its history being underestimated. It is often introduced to the world through its most visible symptom: nosebleeds. But HHT is not only a nosebleed disorder, and reducing it to that has serious consequences such as delayed diagnosis and narrowed clinical understanding. Worse yet, it can make severe bleeding, iron deficiency anemia, gastrointestinal involvement, pulmonary AVMs, brain AVMs, liver involvement, and other serious complications seem secondary when they are, in fact, central to the disease burden many patients carry. Recent publications citing Cure HHT registry data and biobank biological samples are helping to prove these points in ways the medical community and general population cannot ignore.

CHORUS, the Comprehensive HHT Outcomes Registry of the United States, was built by Cure HHT to capture the real-world clinical impact of HHT. This is not abstract. This is the infrastructure that allows the field to move from anecdote to evidence at national scale. In 2025, CHORUS data reached a major milestone when an abstract based on the first 600 enrolled patients was selected for oral presentation at the American Society of Hematology (ASH) annual meeting. That alone was meaningful. Oral presentations at ASH are not participation trophies. They signal that a dataset has become important enough for the hematology field to pay attention. Then, in March 2026, those findings moved into a published paper in *Blood*, one of the most respected journals in hematology. The initial report described findings from the first 600 participants and helped quantify the real burden of bleeding, anemia, thrombosis, and other serious complications in HHT.

That sequence matters because publication is not just prestige. It is translation.

A registry becomes a dataset. A dataset becomes an abstract. An abstract becomes a publication. A publication becomes something clinicians cite, researchers build on, and drug developers can no longer dismiss as too small, too vague, or too fragmented.

For HHT, registries do something particularly important: they reveal burden that has historically been dispersed across specialties. A hematologist may see anemia. An ENT may see epistaxis. An interventional radiologist may see AVMs. A hepatologist may see liver involvement. A pulmonologist may see hypoxemia or paradoxical embolic risk. A gynecologist may see heavy menstrual bleeding. Patients, unfortunately, get to see all of it at once. Registries help the field catch up to what patients already know: HHT is cumulative, layered, and systemic. When those data are collected in one place, the disease stops looking like a collection of isolated complications and starts looking like what it is — a full-body vascular disorder with serious consequences and clear unmet therapeutic need.

That shift is where drug development begins to change.

No company develops a therapy simply because a disease exists. The uncomfortable truth is that therapeutic development follows evidence. Developers need to understand disease burden, prevalence of complications, treatment gaps, clinical endpoints, subgroup variation, and the size of the unmet need. They need to know what is happening to patients now, how current care falls short, and where a therapy could realistically change outcomes. Registries help answer exactly those questions. They make HHT legible to the systems that decide where research dollars, clinical trial infrastructure, and pharmaceutical attention will go.

In other words, registries do not sit on the sidelines of drug development. They help create the case for it.

This is especially important in HHT because many patients have long been treated through adaptation rather than purpose-built therapy. Clinicians manage bleeding. Replace iron. Perform procedures. Embolize AVMs. Monitor organ systems. Prevent catastrophe where possible. All of that work matters. It saves lives. But management is not the same thing as having a robust pipeline of therapies developed with HHT itself in mind. If the field wants more targeted treatments, it needs the kind of evidence base that tells a compelling story to researchers, funders, regulators, and industry partners. CHORUS is helping build that story.

And CHORUS is not the only registry effort strengthening that foundation. HHT Connect started by Cure HHT, the first global patient registry for HHT, is designed to collect health information from as many patients as possible so researchers and doctors can discover patterns and clues that may help them better understand HHT and develop new treatments. That global scope matters. Rare diseases are, by definition, limited by numbers. HHT research gets stronger when patients are not treated like scattered outliers but as part of a connected and visible

population. Every additional participant increases the power of the dataset, sharpens the patterns, and expands what the field can ask — and answer.

If HHT is going to move faster, the field needs more than awareness. It needs participation.

CASSI FRIDAY, PHD
Director, Research Programs and Grants
Cure HHT

"Behind every data point is a person or family doing their best to live with HHT every day. When patients choose to participate in research, they are helping us better understand what this disease really looks like and what it's asking of the people who carry it. That kind of participation is what moves better care and better treatments forward."

It needs patients and families willing to join registries, contribute samples, share their experiences, and help define the full reality of this disease. Because in rare disease research, visibility is not enough. Data drives action. Evidence drives investment. And investment is what helps move potential treatments from possibility to pipeline.

That is what makes patient engagement so powerful. It does not sit on the sidelines of discovery. It helps make discovery possible.

The burden of HHT is already being carried every day by patients, caregivers, and families. The next step is to make sure that burden continues to shape the research agenda, the clinical conversation, and the future of drug development. The ripple effect is real. Now it is up to all of us to keep it growing.

VALAREE MACHEN, MS
Senior Manager, Brand Strategy and Content
Cure HHT

ADVANCE RESEARCH

Your participation makes a difference. Cure HHT offers a variety of ways to make your mark in HHT research. Enroll in a registry, inquire about an ongoing study, donate a biological sample, or find information about clinical trials.

Learn more at ***curehht.org/participate*** or email ***research@curehht.org***.

RECENT PUBLICATIONS (AND WHY THEY MATTER)

CHORUS Study Underscores the Urgency of Earlier HHT Diagnosis
In this publication, researchers shared early findings from CHORUS. Data from the first 600 participants confirmed that HHT carries a high burden of bleeding, anemia, AVMs, and other serious complications.

CONCLUSION: The study reinforces that HHT is often diagnosed too late and underscores the need for earlier diagnosis, expert care, and continued research.

Read our summary at ***curehht.org/chorus-blood26***.

Study Offers New Insight Into How HHT Lesions Form
In this publication, researchers found evidence supporting a two-hit genetic mechanism behind HHT arteriovenous malformations.

CONCLUSION: Scientists found that HHT-related AVMs form when an additional genetic change happens in certain cells, improving our understanding of the disease and pointing toward new strategies to prevent or treat these malformations.

Read the publication at ***curehht.org/somatic-AVM***.

Study Explores a Potential Vaccine Approach for HHT AVMs
In this publication, researchers evaluated an angiopoietin-2–targeting vaccine in mouse models of HHT and found improvement in AVM pathology. Cure HHT biobank resources were also cited as research support for this work

CONCLUSION: This research points to a possible new therapeutic strategy for treating HHT.

Read the publication at ***curehht.org/avm-biobank***.

RESEARCH IN ACTION

Around the world, research is moving HHT forward. This map highlights clinical trial sites from Cure HHT's biotech partners and reflects something powerful: progress is no longer theoretical. It is happening in real places, with real researchers, clinicians, and patients helping move potential treatments closer to reality.

We're here to help you explore opportunities, answer questions, and stay informed about research progress in HHT.

To learn more about clinical trials or connect with our team, visit ***curehht.org/clinical-trials*** or email ***research@curehht.org***.

Alnylam - ALN-6400-001 Clinical Trial Site

A TRUE NIGHT OF HOPE

This past March, the Annual Night of Hope brought the HHT community together in Plymouth, Michigan for an unforgettable evening celebrating a Decade of Hope. Hosted by the incredibly generous Nissan family — Clay, Jody, Sydney, Sierra, and Jared — the event was filled with connection, gratitude, and a shared commitment to building a better future for everyone impacted by HHT.

One of the most powerful moments of the evening was a heartfelt speech from Dr. Anthony Anzell, an HHT patient, Cure HHT Board Member, and dedicated researcher working toward a cure. His words were a moving reminder of both how far we have come and why this mission matters so deeply. We were also honored to welcome Dr. Suman Sood of the University of Michigan and her team, whose presence meant so much to the community.

The evening also featured a lively cake auction led by Dr. Andy White, bringing fun, energy, and a little friendly competition to the celebration. Thanks to the extraordinary generosity of everyone who attended and gave so generously, Night of Hope made a meaningful impact in moving hope forward.

COMMUNITY
UPDATES & RESOURCES

TOWN HALL: CURE HHT CENTER OF EXCELLENCE PROGRAM UPDATES

JUNE 16 | 1-2PM ET

Cure HHT is committed to improving care, supporting providers, and helping ensure that more patients can access the specialized expertise they need. Join our National Healthcare Programs team for a crucial Town Hall about updates to US and Canadian HHT Centers. Patients, families, and community members will have a chance to ask questions in real time.

Join us for free by scanning the QR code or registering directly at curehht.org/TownHall-CoE to join this session live.

COMMUNITY WEBINARS

Missed a recent community webinar? Several of our latest sessions are now available on-demand, with more informative webinars on the way. Be sure to register for upcoming webinars to reserve your spot and get access to the recording one week before it is released publicly. Stay connected, keep learning, and join us for what's next.

See what is available now at ***curehht.org/webinars***.

DEDICATE YOUR BIRTHDAY TO A GREAT CAUSE

Looking for a simple way to make a difference? Facebook Fundraisers are an easy and meaningful way to support Cure HHT. Whether you're celebrating a birthday, honoring a loved one, or rallying your community around a cause you care about, creating a fundraiser helps raise both critical funds and awareness for HHT. Every fundraiser helps fuel research, patient support, advocacy, and progress toward better treatments and, one day, a cure.

GLOBAL EXPERTS, UNITED FOR A SHARED PURPOSE

Did you know Cure HHT has a Global Research and Medical Advisory Board? This exceptional group brings together leading experts in HHT research, medicine, and clinical care from around the world. Their guidance helps shape Cure HHT's medical and scientific priorities, strengthen global collaboration, and ensure our work is informed by deep expertise and a shared commitment to progress for the HHT community.

View our full roster at ***curehht.org/leadership***.

Cure HHT
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Marianne S. Clancy, MPA
Chief Executive Officer, Cure HHT

A FUTURE SHAPED BY 35 YEARS OF COMMUNITY

Standing alongside our advocates on Capitol Hill this year, I was struck not only by the strength of their voices, but by what those voices represent. In that moment, I found myself thinking about the patients, loved ones, and advocates no longer with us — the people whose lives, courage, and persistence helped build this mission. Their legacy is carried forward in every story shared, every breakthrough pursued, and every step this community takes together.

Because of the compassion, determination, and collective strength of this community, HHT is gaining long-overdue visibility.

Research is accelerating. Not just one, but multiple therapeutics are on the horizon, with more than a dozen additional initiatives in the pipeline. More healthcare professionals are recognizing this disease, and more patients are finding answers and expert care faster than ever before. That progress is not accidental. It is the result of a community that has refused to accept being overlooked.

That shared commitment is creating real momentum — and with it, real hope.