ADVOCACY / COMMUNITY / RESEARCH / AWARENESS

WINTER 2026 ***NEWSLETTER***

HHT patient Lance and his wife

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INSIDE THIS EDITION

CONTENTS

2026 ★ ★ ★

CAPITOL HILL DAY

MARCH 17-18, 2026

INVITATION: 2026 HHT Capitol Hill Day in Washington, DC

Over the last decade, HHT has finally started breaking through the noise. More research. More trials. More recognition from national leaders and institutions that once overlooked us entirely. And as inspiring as this progress is, I need to say something plainly: ***none of it happens without you.***

Every advancement we've made has been fueled by patients and families who stepped forward — who told their stories, who demanded better, who refused to let HHT remain invisible.

And in 2026, we have a chance to make the loudest impact yet.

We are heading back to Washington, DC for a **Congressional Breifing on Tuesday, March 17, 2026** and **Cure HHT's Capitol Hill Day on Wednesday, March 18, 2026**, and I cannot overstate how pivotal this moment is. We are working through a time of shifting federal priorities, tighter budgets, and increasingly competitive funding. This is our moment to stand in front of lawmakers and advocate for what HHT families need — and why continued federal support is not optional.

Hill Day has power because of one thing: **people showing up.** When 10 patients walk into an office, it's moving. When 50 walk in, it's undeniable. And here's the piece we cannot forget: ***even our smaller advocacy efforts in past years have led to meaningful change*** — increased awareness, new partnerships, and early congressional champions who are still with us today. **If that's what we accomplished with small groups, imagine what could happen when we arrive as a true crowd.**

When the hallways fill with families, caregivers, and clinicians speaking with one unified voice, priorities shift. Legislators ask follow-up questions. Staff lean in. Doors that were once shut begin to open. That's when funding becomes possible.

And the urgency is real. We're entering a phase where research and clinical trials are accelerating, but policy has not kept pace. We need congressional support for data infrastructure, for programmatic initiatives, for expanding access to specialized care. Decisions made in the next few years will determine whether families nationwide receive timely diagnoses, effective treatments, and the healthcare networks they depend on.

Your presence helps determine that future.

Participating is easier than you might think. You don't need to be a policy expert. You don't need a polished speech. You simply need to show up, walk with us into meetings, and — if you're willing — share even a small piece of your experience living with, caring for, or loving someone with this complex disease. Those are the moments lawmakers remember long after we leave the room.

I've seen the impact firsthand. Offices that once said, "We'll look into it," became champions after meeting real people. Members of Congress referenced personal stories in committee discussions months later. And soon, your voices were echoing far beyond the buildings on Capitol Hill.

If you've ever wished for better care. If you've ever waited years for answers. If you've ever felt alone in this journey. If you want the next generation to inherit something better…

This is your moment.

Join us in Washington. Stand up for the HHT community. Help make HHT impossible to overlook — and impossible to delay.

Let's make 2026 the year lawmakers finally recognize the urgency we live with every day and commit to the progress we know is possible.

I hope you'll be there with us!

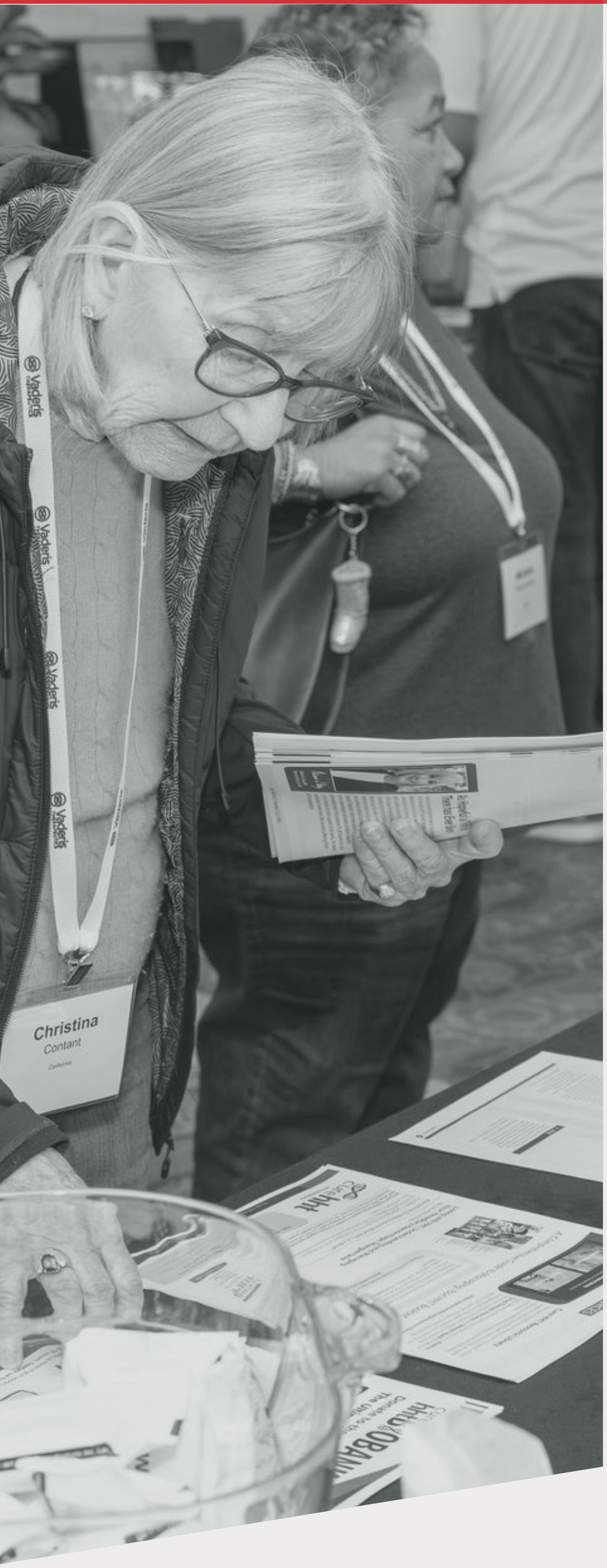
CRYSTAL COTTRILL
National HHT Coordinating Center
Grant Manager, Cure HHT

Become an HHT advocate:
curehht.org/advocacy26

PATIENT RESOURCES

Navigating a medical condition can be challenging, but it shouldn't have to be. We are constantly collecting and sharing helpful information, tools, and support resources for the HHT community.

See what's new below or reach out to us at hhtinfo@curehht.org for individualized help.



NEW TOOL: IAMRARE REGISTRY MOBILE APP

We're excited to announce that the National Organization for Rare Disorders has launched a new IAMRARE mobile app, available to all participants in the HHT Connect Registry! Advance research for the HHT community by sharing your data anytime, anywhere.

Download the IAMRARE mobile app today.

Apple App Store

Google Play

ACCESS: Official HHT Guidelines

Developed by an international panel of HHT experts and patients, the second International HHT Guidelines for Diagnosis and Management of HHT are available for download online.

Read more at ***hhtguidelines.org***

DOWNLOAD IT NOW: 2025 Impact Report

Progress doesn't happen by accident — it's built by people who show up. Our 2025 Impact Report is now available and highlights the research advances, advocacy wins, and community growth made possible by your support. Inside, you'll find key milestones across clinical research, education, and access to care, along with the measurable outcomes driving momentum forward.

See how your involvement is shaping the future of HHT care: ***curehht.org/impact25***

As the cornerstone of the HHT community, we believe in being proactive when it comes to raising awareness, driving research, and providing support to those impacted by this disease.

Looking for more information, programs, or access to the HHT guidelines? Visit curehht.org.

CURE HHT
PROGRAMS

ADVANCE RESEARCH

Your participation makes a difference. By joining one or more of these initiatives, you can help researchers collect the information needed to improve treatments, accelerate discoveries, and bring us closer to a cure.

HHT BioBank

Our biobank is committed to securely collecting, storing, and distributing tissue samples to qualified researchers who are working tirelessly to develop new treatments and therapies for HHT.

Learn more about how you can contribute to this important cause, contact ***research@curehht.org***

HHT CONNECT

We're asking patients around the world to participate in HHT Connect, a global patient registry that looks to equip researchers with data from as many patients as possible so they can better understand and treat this disease.

CHORUS

We invite you to learn more about "CHORUS," our patient outcomes registry. Our goal is to have more than 10,000 patients participate in this survey, which will allow us to follow a large cohort of patients over time—helping us better understanding the impact the disease has, and the factors that influence them.

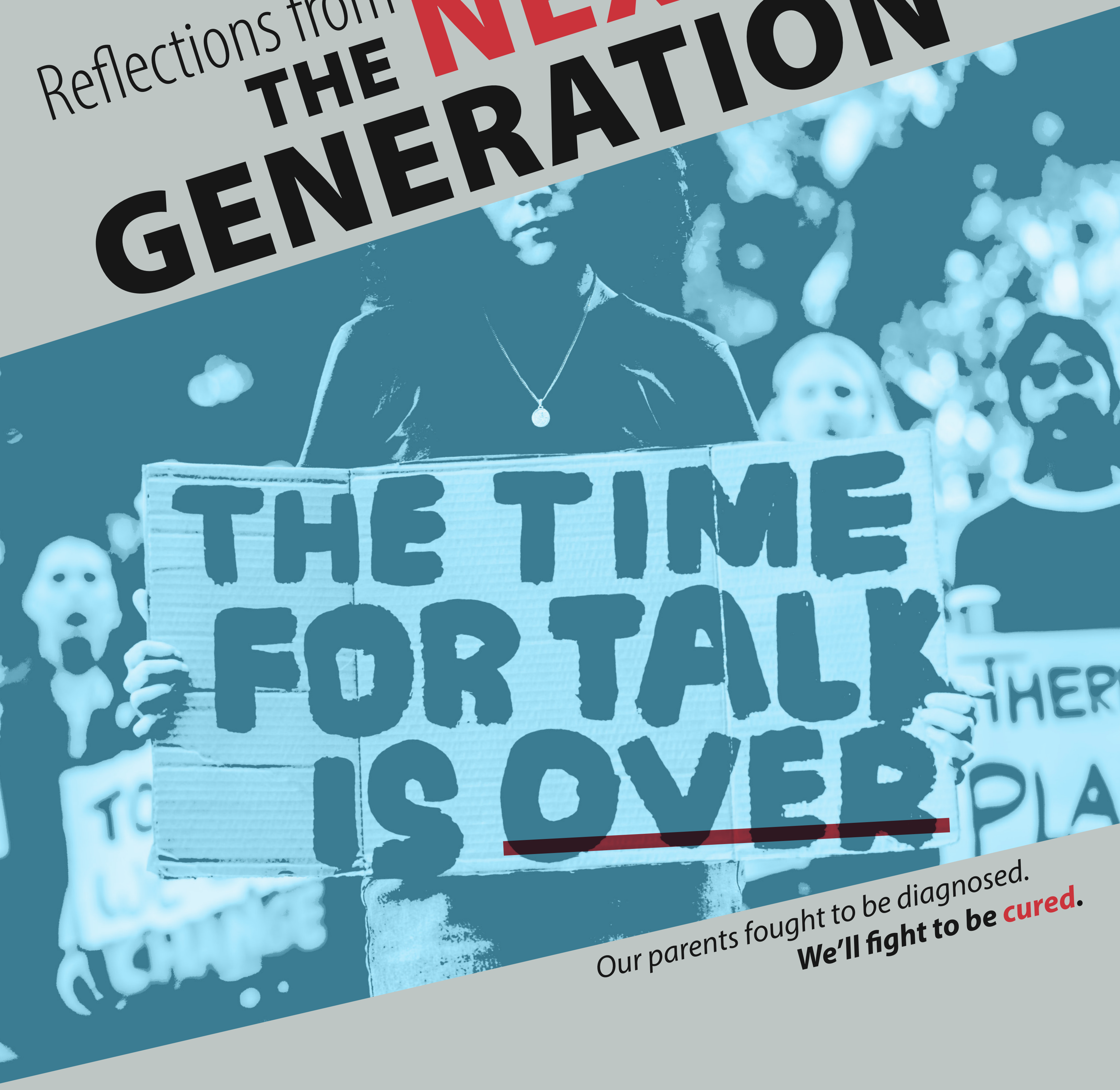
Learn more at ***curehht.org/participate***

ADDITIONAL OPPORTUNITIES

New studies are opening throughout the year — and every participant moves us closer to better treatments. Check our website regularly for the latest clinical trial opportunities with Cure HHT partners. Your involvement matters more than you know.

Learn more at ***curehht.org/clinical-trials***

Reflections from THE NEXT GENERATION



Our parents fought to be diagnosed.
We'll fight to be cured.

There is a particular kind of inheritance within the HHT community — one that passes through DNA and dinner-table stories, through memories of unexplained nosebleeds, iron infusions, and years spent searching for a diagnosis that could name it all. For many families, hereditary hemorrhagic telangiectasia (HHT) was once a shadowy presence, recognized only in hindsight, stitched into generations who carried symptoms without answers.

But could that legacy be shifting?

A new generation is coming of age with a different kind of awareness — earlier, clearer, and supported by a community their parents never had. They are growing up not only with the vocabulary of HHT, but with the conviction that understanding this disease is the first step toward changing its future.

They carry their families' history, yes — but they also carry a determination that is uniquely their own.

The Weight of What They Inherited

Before we talk about the next generation, we must honor the ones who came before.

For decades, families navigated HHT without the words to describe it. Parents recognized patterns but not diagnoses. Grandparents endured symptoms quietly, believing their struggles were simply "how things are." Generations carried a condition they didn't know how to name, let alone challenge.

Their persistence — their advocacy, their insistence that something deeper was happening — built the foundation on which today's progress stands.

This new generation is not starting from scratch.
They are starting from a legacy carved out by courage.

And with that foundation beneath them, their story begins differently.

A New Awareness, Arriving Sooner

We know the diagnostic odyssey for HHT has always been too long. In fact, it takes nearly **five times longer** to diagnose HHT than the average rare disease — a journey that can stretch across decades, filled with intense symptoms and contradictory answers.

Cure HHT has been working to change this trajectory through a multi-layered approach: publishing international screening guidelines, certifying institutions as HHT Centers of Excellence, raising public awareness, and educating clinicians with targeted continuing education.

Those initiatives have begun to bear fruit. Early studies show that today's patients are receiving accurate diagnoses faster than any generation before them.

"I was 13 when I realized my life was going to be different," said Daniella, 22. "Endless appointments. Taking my health seriously. That was the moment I knew HHT wasn't going away."

Another young adult, Morgan, 18, shared, "Knowing earlier changed my experience. It meant I had answers. I knew why I was getting nosebleeds; I learned more specialized ways to treat them, and I learned what to avoid to protect my health."

Earlier awareness doesn't erase hardship — but it does shift the terrain. Instead of wandering through uncertainty, young adults are stepping onto a clearer path, lined with resources, community, and a language for what they've lived through.

Growing Up in the Age of Possibility

To grow up with HHT today is to live at the intersection of fear and possibility.

These young adults wrestle with questions their parents didn't know to ask — about screening, genetic testing, pulmonary shunts, iron levels, anesthesia risks — yet they also hold tools their parents never had.

This clarity doesn't remove the weight HHT carries, but it reframes it. Knowledge becomes a kind of armor. Connection becomes medicine. Community becomes constant.

They are growing up in an era where hope isn't abstract — it's measurable, visible in trial announcements, research publications, and medical conferences now filled with providers eager to learn.

This is the age of possibility — and they know it. And in a world where answers no longer feel out of reach, connection has become one of the most powerful tools they have — especially the kind found in unexpected places.

The Digital Village

You've heard the saying, "It takes a village." For those living with underrepresented medical conditions, this phrase takes on a whole new meaning. And unlike the generations before them, Generation Z is not navigating HHT in isolation. Online communities have become the modern village — bringing a lifeline straight to their phone, tablet, or computer screen.

Layla, 17, shared, "Seeing everyone share their stories online — finding others with similar experiences — helped me feel less alone in this battle. It gave me hope that more discoveries and better treatments are coming."

And for AnnMarie, 26, online connection transformed into activism. She launched a jewelry business and donates part of her sales to Cure HHT. "I wanted patients to know awareness is happening," she said. "I wanted to create a safe place for others like me."

*AnnMarie modeling designs from her jewelry company **Killer Sweetpea Co.**.*

In these digital spaces, young people are finding not only solidarity, but courage — a reminder that the burden they carry is shared, understood, and never borne alone.

A Generation That Refuses to Stay Quiet

Where their parents fought for a diagnosis, these young adults are stepping into the next chapter: advocating for equitable, affordable access to care and a future shaped by research, not luck.

"I talk about HHT to everyone," Daniella said. "If my story helps even one person get answers, it's worth it."

Layla learned the stakes early, watching her younger brother suffer up to eight nosebleeds a day while doctors struggled to connect the dots. "I don't want any more kids to be told they just have to deal with it," she said.

And for AnnMarie, advocacy is a response to her family's silence. "I feel responsible for raising awareness," she said. "I will stand and talk about my experience for those who can't or won't."

If previous generations survived HHT quietly, this one is determined to speak loudly — not out of desperation, but out of hope for what is possible.

Looking Ahead — With Hope That Feels Earned

When asked what these young advocates hope HHT care will look like ten years from now, their responses are bold and deeply hopeful.

"**A cure**," Daniella said simply.

Morgan hopes for **widespread awareness** — among clinicians, schools, and families — so no one waits years for answers.

Layla hopes **genetic testing and screening become affordable** and routine.

AnnMarie imagines a future where **HHT treatment is accessible to all**: "We've made remarkable progress in the last decade. I truly believe we'll get to a cure — one everyone can access."

Their optimism isn't naïve. It's grounded in the momentum they see: expanding Centers of Excellence, new clinical trials, stronger guidelines, smarter technology, and a community that is finally being heard.

A Call from the Next Generation — and to the Rest of Us

For every young advocate stepping forward today, there are generations behind them who carried this mission long before it had a name — parents who insisted something wasn't right, grandparents who endured symptoms in silence, families who fought for care when the world didn't yet recognize HHT.

Their persistence — and every victory won along the way — created the foundation this generation now stands on.

Now, the next generation is ready to pick up that torch.

They are asking all of us — young and old, newly diagnosed and long familiar — to step into this moment together. To honor the work that brought us here by pushing the future even further.

Because the progress we celebrate today was built by those who came before — and the breakthroughs of tomorrow will be shaped by all of us choosing to keep going, side by side.

Together, we can build the world every generation before us hoped to pass down: A world where HHT is recognized early. Where care is equitable. Where research is fully funded. And where a cure is no longer a distant hope, but available to all.

VALAREE MACHEN
Senior Manager,
Marketing and Communications,
Cure HHT

Share your HHT experience with us:
curehht.org/share-your-story

CONFERENCE SPOTLIGHT

KNOWLEDGE IS POWER: The 5 Biggest Changes in HHT Care Over the Last 5 Years

If you've lived with an HHT diagnosis for a while, you know how heavy the uncertainty can feel — the nosebleeds that interrupt your day, the well-intentioned health care practitioners who don't always know what to look for, the worry that comes with every new symptom. I see that every week in clinic, and it's one of the reasons I'm so committed to this work.

So I want to say this as clearly as I can: **the world of HHT care is changing, and it's changing fast.**

At this year's HHT Patient and Physician National Conference in Dallas, I walked through the five biggest shifts we're seeing right now in HHT care. And as someone who's dedicated his career to this field, I can tell you honestly — the momentum we're seeing right now is unlike anything I've seen before, and I'm grateful to be part of it.

New Doors Are Opening at HHT Centers of Excellence

More families now have access to coordinated, multidisciplinary care that looks at all of HHT — lungs, liver, genetics, ENT, hematology, pregnancy, and everything in between thanks to the growth of HHT Centers of Excellence.

For patients who get care from one of our 55 global Centers, they are ensured that their entire condition is being treated as one connected system rather than a series of isolated problems. That alone is a game changer.

Guidelines Have Finally Caught Up to What Patients Really Need

Updated International HHT Guidelines are giving clinicians a clear, evidence-based roadmap for the surveillance and management of nosebleeds, anemia, GI bleeding, pediatric care, pregnancy, and more. For patients, this means fewer missed diagnoses, fewer contradictions, more consistent surveillance, and improved care around the world.

Sclerotherapy Is Offering Relief Many Thought They'd Never Find

Nosebleeds are one of the toughest and most frustrating symptoms of HHT. Office-based sclerotherapy is giving many patients long-lasting improvement, even if they've already tried cauterizations, lasers, or medical therapy. Patients have been able to get their lives back — and their iron levels back — because of this option.

Systemic Therapies Are Helping Stabilize the Toughest Cases

Thanks to the work Cure HHT and its partners are driving forward, we're seeing real benefits with medications like bevacizumab and pomalidomide, and newer investigational therapies such as pazopanib. These treatments are giving patients who feel out of options a new pathway forward.

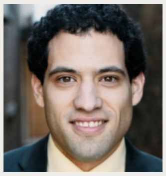
And maybe the biggest shift of all:

The World Is Finally Paying Attention

Over the last five years, biotech companies, research groups, and clinical teams have engaged with the HHT community with a level of seriousness that simply didn't exist before. This includes the HHT treatment pipeline expanding from three therapeutics trials in 2022 to fifteen as of December 2025.

If you take one thing away from this update, let it be this: **progress isn't theoretical anymore — it's happening right now.**

I'll be covering this topic in an upcoming webinar held on **Thursday, February 26, 2026 at 7PM ET**. Please register to attend and hear more about these exciting changes. A Q&A session will follow.



PETER HOUNTRAS, MD
Center Director, HHT Center
University of Colorado Hospital

Register for the webinar:
curehht.org/webinar

COMMUNITY RESOURCES

Discover the latest breakthroughs, inspiring personal stories, and vital updates within the HHT community right here!

The actions we take today can change the future.

COMMUNITY QUESTIONNAIRE: Make Your Opinion Known!

Use your voice to help shape what comes next. We invite you to take part in a short questionnaire designed to guide Cure HHT's communications, community engagement, programming, webinar topics, and future resources. Your feedback will directly inform how we show up for the HHT community — ensuring our work reflects what you need most.

Take a few minutes to share your perspective with us ***curehht.org/survey26***

RARE DISEASE DAY 2026

The countdown to Rare Disease Day 2026 is on! On February 28, the HHT community will stand alongside the global rare disease community to raise awareness, share knowledge, and celebrate the strength of those living with rare conditions. This year's international focus centers on uplifting youth voices and examining what equity looks like in everyday life for individuals. There are many ways to take part and make your voice heard.

Interested in getting involved? Reach out to us at ***hhtinfo@curehht.org***

SHOP CURE HHT

Support the mission — and spread awareness — with official Cure HHT merchandise. Every item purchased from the Cure HHT Store helps fund research, advocacy, and programs for the HHT community. Shop now and help turn everyday moments into awareness-building opportunities.

Learn more ***curehht.org/store***

COMMUNITY **EVENTS**

Our community events are designed to foster learning and connection. Participate in educational webinars, connect with peers, advocate on the hill, or get involved online.

Read below about what we've been up to lately.

CELEBRATING A SUCCESSFUL WEEKEND AT ASH

For years, the HHT community has called for faster diagnosis, meaningful treatment options, and healthcare professionals equipped to manage this complex disease. At the 2025 American Society of Hematology (ASH) Annual Meeting, we saw clear evidence that those calls are being heard.

This year marked the largest presence of HHT-related content ASH has ever seen. Across multiple standing-room-only sessions — including several featuring research conducted by or in partnership with Cure HHT — the global hematology community showed unprecedented engagement. New data was shared. Novel therapeutic insights were discussed. New collaborations began to take shape.

The message was unmistakable: HHT has reached a turning point.

To every investigator, clinician, partner, and advocate who helped elevate HHT at ASH this year — thank you. Your work is reshaping what's possible for this field and this community. And a special thank you to Pharmacosmos and Alnylam for helping make our Friday Satellite Symposia a reality.

UPCOMING EVENTS

16TH HHT INTERNATIONAL SCIENTIFIC CONFERENCE

We're proud to announce the dates and location for the next HHT International Scientific Conference, bringing together leading researchers, clinicians, and industry partners from around the world. This conference serves as a critical forum for sharing emerging data, advancing collaboration, and accelerating progress toward better treatments and cures for HHT. As momentum across the field continues to grow, this convening represents an important moment to align science, strategy, and impact.

We can't wait to see everyone this October 12-16, 2026 in Cap Cod, MA!

CELEBRATING 10 YEARS OF DRIVING HOPE AND AWARENESS

The Nissan Family invite you to be part of this extraordinary, black-tie evening in support of Cure HHT's mission to find, treat, and cure HHT. This milestone event offers a night of dinner, dancing, and reflection on a decade of progress — and the future we're building together. Featuring a special anniversary champagne toast, meaningful stories of impact, and opportunities to support life-changing programs and research, this unforgettable evening honors how far we've come and the hope that lies ahead.

Learn more at ***curehht.org/NoH26***

2025

HHT PATIENT AND PHYSICIAN NATIONAL CONFERENCE

NOVEMBER 8-9, 2025 • DALLAS, TEXAS

RECAP: 2025 HHT Patient & Physician National Conference

This year's HHT Patient and Provider National Conference in Dallas felt especially meaningful — not only was it my first opportunity getting to meet many members of our community, but it was a gathering overflowing with connection, discovery, and a whole lot of joy.

From the moment attendees arrived, there was an unmistakable buzz in the air. Patients and families were eager to learn. Providers were ready to engage. Advocates who've been with us for years met those who were as recently diagnosed as the week prior. But, no matter where you looked, you could feel a sense of belonging almost instantly.

Our educational sessions kicked off with standing-room-only crowds, a clear sign of how hungry our community is for information, tools, and clarity. Patients asked thoughtful questions, compared experiences, and shared the kind of real-world wisdom that only those living with HHT can offer. Families connected in hallways and breakout rooms, swapping stories that made others feel seen, supported, and far less alone.

And on the provider side? We made history. This conference welcomed a record number of healthcare professionals, filling our physician track like never before. To witness so many clinicians — pulmonologists, ENTs, interventional radiologists, geneticists, nurses, and more — dedicating their time to deepen their understanding of HHT was powerful. Their engagement, curiosity, and commitment to improving patient care showed us that the momentum in the medical community is real and growing.

Of course, no Cure HHT conference would be complete without a celebration of community — and our Welcome Reception delivered. Line dancing the night away at the Austin Ranch was a highlight for everyone, whether you were an expert, a brave first-timer, or someone cheering from the sidelines. The room was full of laughter, two-stepping, and joyful connection. Watching patients, caregivers, providers, and staff dancing together reminded me that hope isn't only found in data and research — it's found in moments like these, when community becomes family.

Across the weekend, what stood out most was how deeply people showed up for one another. Parents who came seeking answers found reassurance. Patients who felt isolated met others who shared their same experiences. Providers who treat HHT every day told us they were leaving with new tools, new knowledge, and a renewed commitment to their patients.

This conference wasn't just a series of lectures or workshops — it was a living example of what happens when a community gathers with purpose, curiosity, and heart. Our staff left Dallas with a deeper understanding of your needs and a true sense of possibility for the future of HHT care.

To everyone who joined us — **thank you**. Your presence made this conference one of our most successful yet. And to those who couldn't make it, we hope to see you at the next one. Our community is stronger because of you, and we truly can't wait to continue this journey together.

Here's to the momentum we built in Dallas — and everything we'll accomplish next!

HELLEN TECLE
Manager, Community Events & Education, Cure HHT

UPCOMING WEBINARS

Thursday, January 29 | 2-3pm ET
Comprehensive Guide to Managing Your Nosebleeds

Thursday, February 26 | 7-8pm ET
Knowledge is Power: The 5 Biggest Changes in HHT Care

March 2026 | Details Will Be Released Soon
Discovering the HHT Genes: A Fireside Chat

Learn more at ***curehht.org/webinars***

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The Cornerstone o
the HHT Communi

THANK
YOU

Celebrate the progress that's possible thanks to the generosity of our sponsors! Their support powers research, education, and advocacy efforts that bring hope to the HHT community every day.

Together, we are transforming challenges into opportunities and moving closer to a future free of HHT.

We are looking for adults with HHT to take part in the ALN-6400-001 study

We need adults, who, in addition to other criteria:

- Are aged 18 years and over
- Have been diagnosed with HHT
- Are experiencing frequent nosebleeds

How can I learn more?

If you, or someone you know, are interested in taking part, please contact the study team at:

clinicaltrials@alnylam.com

Alnylam

ALN-6400-001

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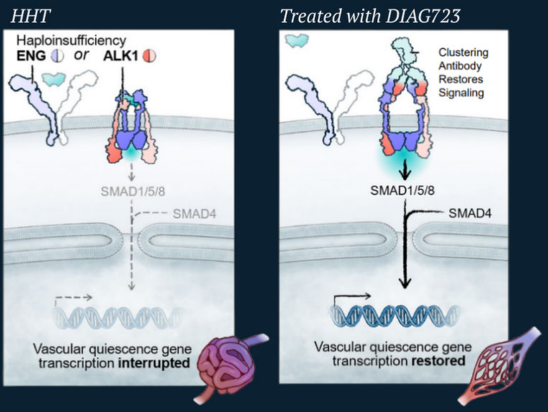
diagonal Therapeutics

DIAG723 a novel, targeted approach specifically designed to treat HHT.

DIAG723 is a bispecific antibody designed to restore normal ALK1 signaling that is disrupted due to loss-of-function mutations in key genes that cause HHT. Preclinical studies have shown that DIAG723 can:

- *prevent and reverse AVMs*
- *prevent HHT-associated anemia*
- *improve survival*
- *restore normal signaling*



Advancing **clustering antibodies** *to correct the root cause of genetic diseases*

Phase 1/2 Clinical Trial

Phase 1/2 trial that will initiate in the first half of 2026.

To stay connected on upcoming clinical trial updates, visit us at:

www.diagonaltx.com
clinicalinfo@diagonaltx.com

SUPPORT PROGRESS THROUGH A PARTNERSHIP

Cure HHT offers partnership opportunities that connect sponsors with impactful programs advancing awareness, education, and research for HHT.

With 1.4 million people affected worldwide, support is critical to expand initiatives such as HHT Academy Patient & Physician Conferences, International Scientific Conferences, awareness campaigns, and online resources.

Partnerships help bridge the gap between industry and treatment, bringing life-changing progress to the HHT community.

Scan the QR code to read more or email us directly at ***hhtinfo@curehht.org***

Marianne S. Clancy

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

Turning Awareness into Action in the Year Ahead

As we step into 2026, I'm struck by how far our community has carried this mission forward. Awareness of HHT is no longer limited to a small group of specialists — it's reaching policymakers, biotech leaders, and healthcare systems around the world. Over the past year, we've seen significant advances in research, numerous publications from studies we helped launch, progress toward therapeutic trials, and a strengthening network of HHT Centers of Excellence standardizing how HHT is recognized and treated.

But awareness alone isn't enough. To meet this moment, we need deeper engagement from our entire community — patients, families, clinicians, and partners. Every shared story, every study enrollment, every act of advocacy brings us closer to our goal: ***a future where no family is left without answers or access.***

There is real hope on the horizon, and it grows clearer every day. But bringing it fully into view will take all of us.

Thank you for your continued commitment. I'm honored to lead this organization into a year where our collective impact will matter more than ever.