cure hht

# 2025 IMPACT REPORT

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# THE POWER OF YOU

## A message from John Dunn, President, Cure HHT Board of Directors

Dear Friends,

As I look back on this past year, I feel grateful — and proud. The story of 2025 is not just Cure HHT's story. It is all of ours. Every milestone in this report was made possible because people like you stepped up — by giving, volunteering, sharing your story, or simply standing with us.

This has been a year of real momentum. We have seen breakthroughs in research, built new partnerships with doctors and scientists around the world, and watched families raise awareness in powerful ways. Each step forward proves what is possible when we come together.

At the heart of this progress is you. Your generosity fuels research. Your voices raise awareness. Your determination inspires scientists and doctors to keep pushing. Because of this community, the future we imagine is closer than ever — a future where treatments replace surgeries, where AVMs can be prevented or reversed, and where families do not have to live in fear of the next emergency.

As you read through this report, I hope you feel proud of what we have built together. This progress — and this hope — belongs to all of us.

With gratitude,
John Dunn
President, Board of Directors
Cure HHT

# BUILDING MOMENTUM: MILESTONES THAT MATTER

Before we take a look back at our year, let's first take a moment to reflect on our past. Over more than 30 years, we've driven wins that have reshaped what's possible for HHT — and we're just getting started. Here's a look at a few of our most notable milestones, each one setting the stage for even bigger breakthroughs ahead.

### FEDERAL FUNDING SECURED IN 2022

After nearly 15 years of advocacy, Centers of Excellence received federal support for the first time.

### FIRST INTERNATIONAL GUIDELINES

Created in 2009 and updated in 2020, setting the global standard for HHT care.

### GLOBAL PATIENT REGISTRY AND BIOREPOSITORY

Connecting patients worldwide, powering clinical trials, and opening doors to precision medicine.

### HHT GENE PATENTS RELEASED IN 2003

Enabling and funding genetic testing for patients across North America for the first time.

### PIONEERED NONPROFIT-SPONSORED CLINICAL TRIALS

One of the only nonprofits in the world to sponsor a drug through all phases of clinical trials through drug registration, advancing pazopanib to stabilize symptoms and improve lives.

### 55 GLOBAL HHT CENTERS OF EXCELLENCE

From just one in 1991, we've expanded access to expert care around the globe.

### $1.5 MILLION INVESTED IN SEED GRANTS

These grants fuel future breakthroughs and potential treatments.

### $42.5K AWARDED IN MERITORIOUS HONORS

These awards champion promising young investigators through the NIH Young Investigators Award and celebrate excellence in HHT clinical care through the distinguished Robert I. White Award.

### $600K INVESTED TO ADVANCE AND SUPPORT GLOBAL HHT CONFERENCES

These funds power international collaboration by supporting travel, awareness, hosting, and sponsorship of scientific meetings.

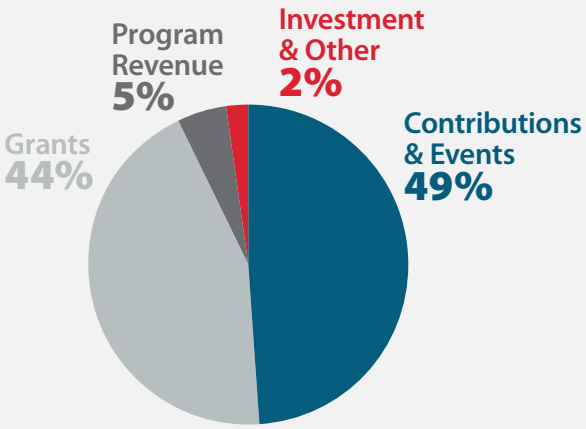
# EVERY DOLLAR DRIVES CHANGE

Every dollar fuels progress. In fiscal year 2025, 85% of expenses went directly to program services—with the vast majority powering research (75%), alongside education and awareness (10%). Just 9% supported management and 6% fundraising, ensuring donor gifts drive maximum impact.

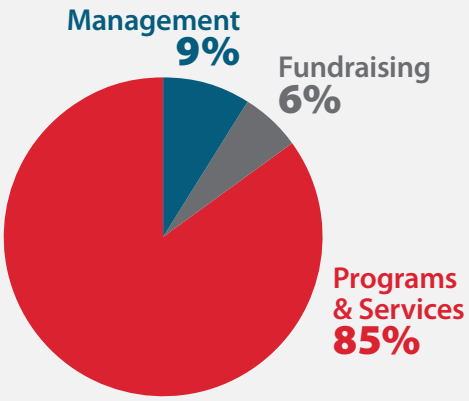
Together, our community generated $9.6 million in revenue, with 58% from contributions and 42% from grants. We invested $6.8 million into research, education, and patient resources worldwide, while growing our net assets to $7.15 million and increasing investments by 42%.

**Simply put: 85 cents of every dollar you give goes straight to mission impact.**

## FUNDING SOURCES




## EXPENSED ALLOCATION




## AN UPDATE ON CALLED TO CURE: OUR MOMENT TO END HHT

We're standing at a true turning point for HHT. After decades of research, advocacy, and persistence, the science has finally caught up with our determination. For the first time, the question isn't *if* we can deliver better treatments and curative therapies — it's *when*.

That's the driving force behind the **Called to Cure Campaign** — the boldest effort in Cure HHT's history. With a $12 million goal, this campaign is powering the research, partnerships, and infrastructure needed to bring life-changing therapies to patients faster than ever before.

The momentum is incredible. Together, we've already raised **more than $8.3 million**, fueling a focused research agenda that targets the root causes of HHT, not just its symptoms. These funds are supporting landmark studies, expanding our global patient registry and biorepository, and driving forward innovative projects aimed at true disease-modifying — even curative — treatments.

And this is just the beginning. The campaign is also helping us strengthen pediatric care, advance women's health research, and expand access through new Centers of Excellence gloablly.

This isn't just a fundraising goal — it's a defining moment. A shared stand to say *enough is enough*. Together, we're making history and moving closer than ever to a future where no family has to live in fear of HHT.


POWELL
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POWELL
POWELL

# FIND

# TURNING ADVOCACY INTO IMPACT

For more than a decade, Cure HHT and our community have worked tirelessly to have HHT recognized by Congress. In 2022, that persistence paid off. Lawmakers established the **National HHT Center Program** and dedicated federal funding through the US Department of Health and Human Services — a milestone years in the making.

This funding doesn't go to Cure HHT. It goes straight to multiple patient-support programs including our HHT Centers of Excellence across the country, where it's transforming care for patients and families. We're proud of the results we've helped drive throughout the 2025 fiscal year:

- **16 Centers of Excellence funded care coordination**, giving more families access to expert, coordinated care.
- **Patient volumes up more than 50%** at these Centers since funding began — meaning more people are getting the right care, sooner.
- **Nearly 900 patients enrolled** in the national HHT Outcomes Registry, creating the data needed to improve treatments and accelerate progress toward a cure.
- **Hundreds of providers educated,** with a 17% increase in knowledge about diagnosing and managing HHT.
- **Ongoing support from Congress**, thanks to Capitol Hill Days, briefings, and the powerful advocacy of our community.

Together, we've proven what persistence can do — turning awareness into action, and advocacy into measurable impact for every family living with HHT.

# **CONFERENCES THAT** CONNECT, EDUCATE, AND INSPIRE

In 2025, Cure HHT once again showed why we're the heart of this community—bringing patients, families, and physicians together in spaces that inform, uplift, and unite.

In March, **more than 160 members of the HHT community gathered in Denver** for a powerful weekend of learning and connection. Physicians earned Continuing Medical Education credits while gaining hands-on training in HHT diagnosis and treatment. Patients and families heard directly from experts, while children found a safe space to connect and share their stories. Everyone left empowered with knowledge—and strengthened by community.

These conferences are about more than education—they're about belonging. Each gathering reminds us that no one faces HHT alone. The insights shared and friendships formed create ripples of impact that extend far beyond the weekend, improving care and inspiring hope in every corner of the community.

We're excited to continue this momentum through our latest **2025 Patient & Physician National Conference, held in November in Dallas**. This event builds on the energy of Denver, offering new opportunities for patients and providers to learn, connect, and shape the future of HHT care together.

# KNOWLEDGE IS POWER: CONNECTING AND EMPOWERING OUR COMMUNITY

HHT care is rapidly evolving. At Cure HHT, we take seriously our role as the true connector of our community — ensuring that every patient, caregiver, and healthcare professional has access to the latest research, treatments, and expert perspectives. We recognize that not everyone can easily reach a Center of Excellence or stay up to date with the newest information. That's why we believe so strongly that knowledge in HHT is power. Our commitment is clear: to provide the education and resources that help our community make informed choices, advocate for better care, and find hope in the progress being made.

In fiscal year 2025, we expanded this commitment through a robust webinar series designed to meet people where they are. These free, accessible programs offered deep dives into both practical care strategies and cutting-edge science, bringing leading experts directly to patients' homes.

Topics included:

- **Caring for HHT Through Generations,** addressing unique challenges of HHT at every stage of life and strategies for how to manage.
- **HHT and Mental Health,** shining light on the emotional challenges of chronic illness.
- **Comprehensive Nosebleed Management,** including a special session on sclerotherapy, a promising new treatment option.
- **Entering the Age of Therapeutics,** providing an overview of innovation in the pipeline and the reasons for hope as new therapies move closer to patients.

The impact was clear: **nearly 3,000 community members attended our webinars in 2025**, representing one of the largest outreach efforts in our history. These conversations didn't just share knowledge — they built connection, reduced isolation, and empowered individuals to navigate HHT with greater confidence.

As treatments evolve and hope grows, Cure HHT will remain the trusted source of information and the bridge between patients, families, and the experts working to change the future of this disease.

# TURNING DATA INTO ACTION: MAKING HHT IMPOSSIBLE TO IGNORE

A groundbreaking partnership between **Cure HHT, Massachusetts General Hospital, and Diagonal Therapeutics** has produced the first comprehensive look at the true cost of hereditary hemorrhagic telangiectasia (HHT) — both for patients and for the healthcare system.

Published in the *American Journal of Hematology*, this landmark study confirms what families and advocates have known all along: HHT is a serious, high-impact disease with deep personal and economic consequences.

For the first time, we have hard data that shows just how significant that impact is — and it's giving Cure HHT powerful new tools to drive federal funding, research investment, and broader recognition of HHT as a public health priority. By documenting the full burden of the disease, this collaboration is transforming awareness into action and helping accelerate the path to targeted, life-changing treatments.

**This research is a turning point—making HHT impossible to ignore and impossible to overlook.**

## KEY FINDINGS

Average annual costs per HHT patient exceed

**$19,000**

20% higher than for sickle cell disease.

Mean annual costs for HHT patient with anemia—

**$27,000,**

—comparable to muscular dystrophy.

**60% of patients**

live with anemia, driving nearly 80% of total costs.

Patients requiring transfusions or iron infusions face costs near

**$40,000 annually,**

similar to cystic fibrosis.

Liver transplant prevalence in HHT is

**40x higher**

than in the general US population.

**Bleeding and its complications**

remain the leading drivers of cost.

*Download the related infographic.*

# COMPASSIONATE CHAMPION AWARD

A Compassionate Champion is someone whose dedication to the HHT cause extends far beyond fundraising — someone who leads with heart, inspires others to get involved, and turns awareness into meaningful action.

This year, we proudly honored **Steve Stoner**, founder of the *Stoner Open*, a charity golf tournament held each summer in honor of his uncle, Dave Stoner — the only member of his family diagnosed with HHT.

What began in 2010 as a family tribute has grown into a beloved community tradition. Over 16 years, the Stoner Open has brought together golfers, sponsors, and friends to raise an incredible **$338,000** in support of Cure HHT's mission. Each year, Steve and his team build on that success — combining competition, camaraderie, and compassion to make a lasting impact.

In **2025**, the 16th Annual Stoner Open continued that legacy, with **120 golfers, 14 sponsors, and 15 volunteers** all joining the effort to bring us closer to a cure.

Cure HHT is deeply grateful to Steve for his extraordinary leadership and unwavering belief in a future free from HHT. His compassion has truly become a driving force for change.

# GRASSROOTS COMMUNITY ACTION

Every movement grows stronger through the passion of individuals who turn their personal stories into action. Across the country, Cure HHT supporters are proving that every event, every stream, and every step taken in honor of loved ones brings us closer to a cure.

In 2025, the BDC Leaps campaign marked a milestone fifth year of dancing for a cause — **bringing their total money raised for Cure HHT to $19,000**. Led by beloved dance instructor and retired studio director Maria Mahoney, the event unites the BDC dance community in honor of Maria and her family, many of whom live with HHT. Maria was first diagnosed in 1988 at the Yale New Haven Hospital Center of Excellence, and ever since, she has been an unwavering advocate for awareness and early diagnosis. Her dedication continues to inspire students, families, and alumni to leap higher every year for the cause she holds close to her heart.

This year also brought a new voice — and a new platform — to the movement. Caito, a cozy gaming streamer and YouTuber who lives with HHT, hosted her first charity livestream in support of Cure HHT. In 12 hours, **her online community raised an incredible $10,000 while learning about the realities of life with HHT**.

> *"Hosting a charity stream for Cure HHT meant the world to me… My community went above and beyond! What really stuck with me were the messages people shared during and after the event. So many had never heard of HHT before, and others said it was moving to see everyone come together around such a personal cause."*

These grassroots fundraisers remind us that **awareness can start anywhere** — on a dance floor, in a livestream, or in a single conversation. Every act of generosity, every shared story, helps bring understanding, compassion, and hope to those living with HHT. Together, this community is not just raising funds — it's raising the future of HHT care.


# THE POWER OF COLLABORATION: OUR INTERNATIONAL SCIENTIFIC CONFERENCE

Every two years, the global HHT community gathers for our HHT International Scientific Conference—our organization's flagship event dedicated to accelerating research, strengthening collaboration, and inspiring innovation in HHT science and care.

Launched in 1996 with just 60 attendees, this conference has grown into the central meeting place for experts, scientists, and clinicians working to change the future of HHT.

The 15th International Scientific Conference, held in 2024 just outside Cannes, France, marked a record-breaking milestone. **Nearly 400 participants from 29 countries came together to share discoveries, inspire trainees, and set new directions for the years ahead**. With **49 oral presentations, 176 posters, and 72 early-career investigators**, the event reflected the extraordinary growth and momentum of HHT research worldwide.

Highlights included groundbreaking presentations from Diagonal Therapeutics, whose antibody therapy aims to reverse HHT at the biological level, and data from five clinical trials—clear signs of a new era where "therapies, not surgeries" are becoming reality.

Now, anticipation is building for the **2026 Cure HHT International Scientific Conference on Cape Cod, MA**. Expected to draw a record number of participants, this next gathering will showcase the latest breakthroughs, unite global experts, and continue driving progress toward a future free from HHT.

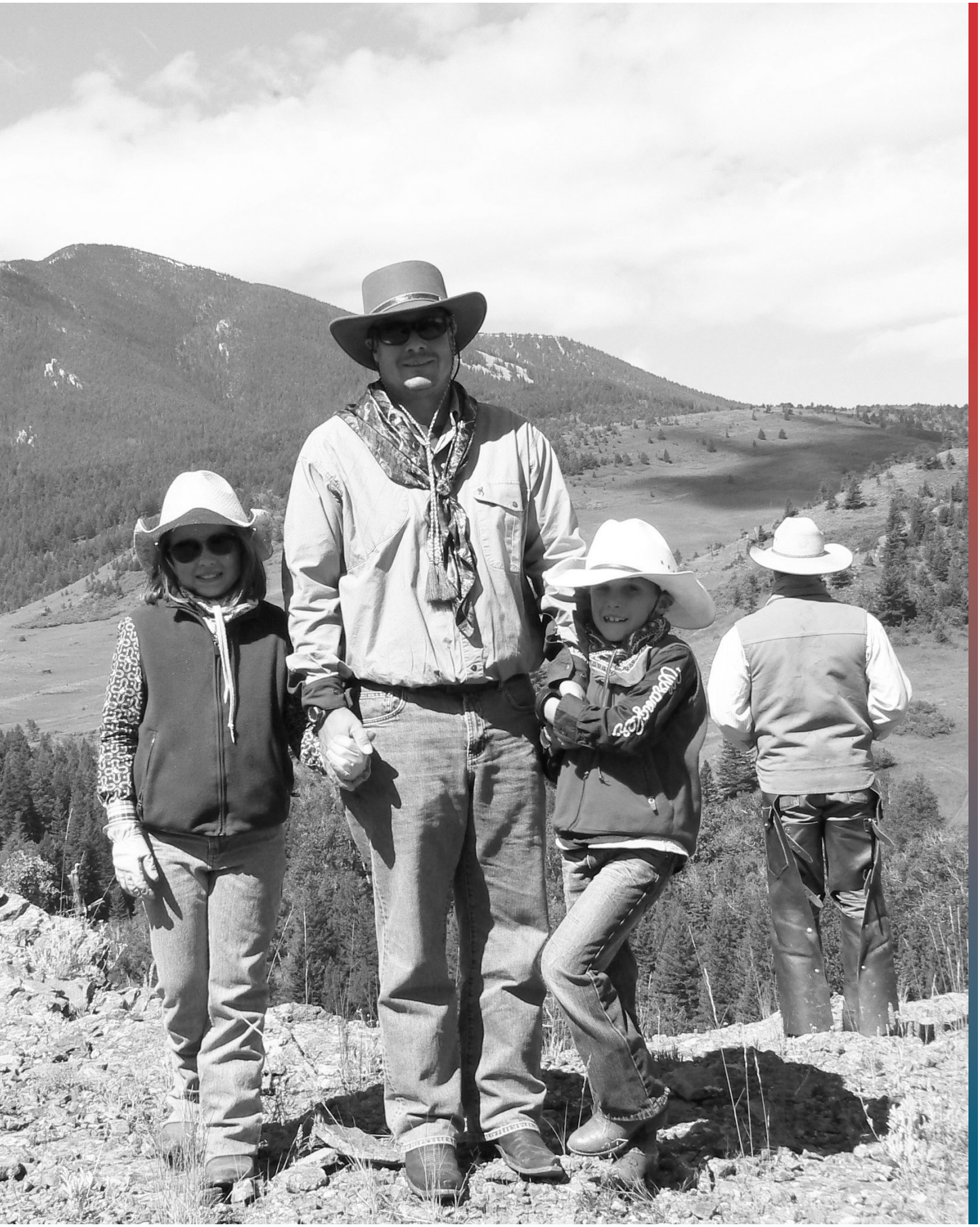
# RAISING THE PROFILE OF HHT ON THE GLOBAL STAGE

Cure HHT is making sure the world's leading scientists, clinicians, and industry partners understand—and act on—the urgent need to advance HHT research and care. By ensuring HHT is represented at major professional and scientific meetings, we're raising awareness, forging collaborations, and positioning HHT alongside other rare and inherited vascular diseases that command global attention.

This year, our presence spanned the globe—**from the North American Vascular Biology Conference (NAVBO) and Gordon Research Conferences to the World Orphan Drug Congress, Global Genes, and Chan Zuckerberg Initative Rare As One *"Science in Society"* gathering**. At each event, we shared our therapeutic development roadmap, highlighted breakthroughs in care, and invited new partners to join the movement to accelerate treatments for HHT.

These efforts are helping to change how the medical world sees HHT—moving it from an underrecognized condition to one that's increasingly studied, discussed, and prioritized for research funding and clinical innovation.

We're excited to continue this momentum at the **American Society of Hematology Annual Meeting this December**, where—for the first time ever—HHT will take center stage with a dedicated symposium and an oral presentation featuring findings from our Comprehensive HHT Outcomes Registry of the United States (CHORUS) Registry. It's another powerful step in ensuring HHT is seen, studied, and ultimately cured.



# TREAT

# TURNING ADVOCACY INTO IMPACT

Years of tireless advocacy from Cure HHT and our community led to a historic milestone: a federal Health Resources Services Administration grant establishing the National HHT Center of Excellence network. This bipartisan investment affirms that HHT deserves the same attention and resources as other major diseases.

Our advocacy has also helped secure nearly $60 million over the years in total federal research funding through the Department of Defense's Congressional Medical Research Program — fueling discovery and moving us closer to a cure.

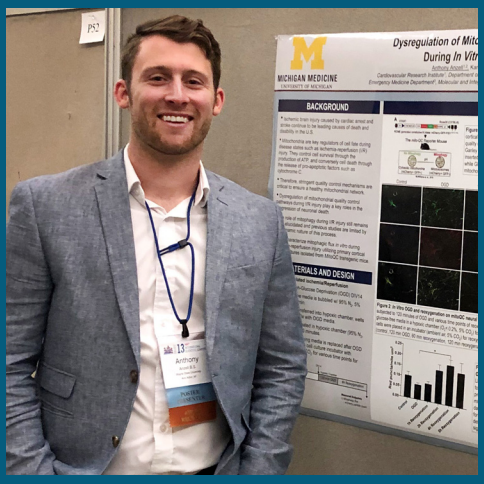
Together, these victories are transforming what's possible for families: faster diagnoses, better-educated providers, and more coordinated, compassionate care. We're building a national system where no patient faces HHT alone.

**3,181 new patients treated**
across 16 federally funded Centers of Excellence

**903 participants enrolled**
in the CHORUS research network

**4.9 / 5 average satisfaction**
among patients receiving care

# FUELING DISCOVERY, ACCELERATING CURES



Cure HHT invests strategically in discovery — awarding competitive seed grants that spark groundbreaking research and open the door to larger federal funding. These early-stage investments give scientists the data they need to compete for major grants from the NIH, CDC, DOD, and others.

The result is remarkable: **$715,000 in Cure HHT seed funding has generated more than $19 million in additional research support — a 2,668% return on impact.**

Each dollar invested doesn't just fund research — it fuels momentum, accelerates cures, and moves us closer to a future free from HHT.

**$715,000 invested**
through seed grants

**$19,795,886 leveraged in FY25**
from NIH, DOD, CDC, & others

**2,668%**
return on investment

# TURNING RESEARCH INTO IMPACT

Cure HHT is not only the cornerstone of the patient community — we're the bridge between scientific discovery and real progress for families living with HHT. In fiscal year 2025, our partnerships and advocacy helped turn breakthrough research into measurable impact. Three major milestones stand out:

## PATH HHT Trial

The NIH-sponsored PATH trial marked a historic milestone — the first large, randomized clinical trial in HHT to show positive results. Researchers tested pomalidomide, a cancer drug, as a treatment for HHT-related bleeding. **The results were so promising that the study concluded early** and was later published in the prestigious *New England Journal of Medicine*.

Cure HHT played a pivotal role in making this breakthrough possible — serving as a primary recruitment source for patients and advocating for the federal funding that launched the trial. This achievement puts HHT squarely on the global medical map.

## BLEEDING CONSENSUS PAPER

For decades, progress in HHT research has been slowed by the lack of standardized definitions for bleeding. In 2025, that changed. Cure HHT brought together an international team of experts to create **the first global consensus on how to measure bleeding in HHT**.

Published in the *American Journal of Hematology*, the report introduced two key tools — the Hematologic Support Score (HSS) and Hematologic Impact Score (HIS) — that will help researchers evaluate treatments more consistently, paving the way for faster clinical trials, regulatory approval, and improved patient care worldwide.

## BVMC: A 15-YEAR LEGACY

The Brain Vascular Malformation Consortium (BVMC), part of the NIH Rare Disease Clinical Research Network, concluded after 15 years of groundbreaking collaboration. Cure HHT served as both a Principal Investigator and key recruiting site, ensuring that patients' voices and experiences remained central throughout the study.

Over its **15 years, BVMC enrolled 2,261 patients, leading to 30+ published papers** — each advancing our understanding of HHT and shaping safer, more effective treatment decisions for years to come.

# **PAZOPANIB:** A BOLD STEP TOWARD FDA APPROVAL

For decades, people with HHT have lived without a single FDA-approved treatment. Cure HHT set out to change that.

The story of pazopanib reflects the spirit of our community — persistence against all odds. Originally approved in 2009 for kidney cancer, pazopanib's ability to block abnormal blood vessel growth offered new hope for HHT. Early studies, led by Dr. Marie Faughnan and HHT Centers of Excellence, showed encouraging results: shorter, less severe nosebleeds and significant improvements in quality of life.

When pharmaceutical companies declined to move forward with HHT-specific trials, progress could have stalled. **But Cure HHT refused to stop. Recognizing the urgent need, we made a bold and unprecedented decision — to take ownership of the pazopanib trial ourselves**.

Our community rallied behind that vision, raising nearly $1 million to launch the effort. Soon after came extraordinary wins: $5.2 million from the Department of Defense, $800,000 from the US Food and Drug Administration (FDA), and Breakthrough Therapy Designation, which speeds the review of promising new treatments. With these resources, Cure HHT built a complete research infrastructure — overseeing study design, lab coordination, and regulatory compliance — a role few patient organizations in the world have ever taken on.

**In early 2025, the pazopanib trial officially closed enrollment, marking a major milestone on the path to FDA approval.** If successful, this will mean more than just a new therapy — it will mean accessible, affordable treatment and insurance coverage for patients everywhere. **We are grateful to many individuals who helped make this bold achievement possible, but in particular must acknowledge contributions from Board member Dr. Dennis Sprecher — who provided 10 years of leadership on this project — and Dr. James Gossage, who served as principal investigator.**

Cure HHT has never accepted the status quo. Together, we're proving that bold action, backed by community, can change the future — and bring life-changing therapies within reach.

# BUILDING A WORLD WHERE EVERY PATIENT HAS ACCESS TO EXPERT CARE

For people living with HHT, finding a knowledgeable doctor can mean the difference between daily struggle and lasting relief. Cure HHT is breaking down barriers to expert care by equipping healthcare providers everywhere with the tools, training, and confidence to recognize and treat HHT effectively.

Through our HHT Continuing Education (CE) Program, launched in late 2023, **more than 200 healthcare providers have been trained across 650+ course completions**—covering everything from diagnosis and anemia management to pulmonary AVMs. Importantly, over half of these participants are unaffiliated with an HHT Center, and **79% say they're now more likely to refer or co-manage patients with one**. By transforming awareness into action, this program is expanding the reach of expert care into communities worldwide.

Meanwhile, our Sclerotherapy Training Program at Washington University is empowering ENTs to deliver a minimally invasive, highly effective treatment for nosebleeds that can dramatically improve quality of life. Since its launch, **12 otolaryngologists (ENTs) have been trained, enabling eight additional HHT Centers** to offer this procedure to their patients.

From education to hands-on training, Cure HHT is ensuring that wherever you live, access to knowledgeable, compassionate care is growing. Behind every new provider trained is a patient whose path to better health just got closer.


OFF
TO
MED
SCHOOL
FUTURE
M.D.

CURE

# CATALYST FOR SCIENTIFIC CHANGE

Cure HHT has long been the leading voice for patients — but today, we are so much more than an advocacy organization. To accelerate progress and push science forward, we made a bold and strategic move: launching our own **Therapeutic Development Arm** within the foundation.

This initiative brings scientific expertise directly in-house, allowing us to set a patient-driven research agenda, build partnerships with biotech and pharmaceutical companies, and actively shape new therapeutic opportunities. We're not waiting for change — we're leading it.

The impact has been remarkable. Since 2022, active **HHT therapeutic projects have increased by more than 300% because of this effort**. That growth means more innovation, more clinical trials, and more hope for families affected by HHT.

Cure HHT is now the catalyst driving scientific progress — ensuring that the needs of patients don't just inform the future of care, but define it.

"As a patient and board member, I've watched Cure HHT transform from advocate to innovator. We're not just pushing for change — we're making it happen."

***Terry Thompson, MBA***
*Board member and individual living with HHT*

# OUR ROADMAP TO END SUFFERING

Our vision is bold but simple: ***a future where no one suffers from HHT***. The Cure HHT Research Roadmap is our plan to make that vision real.

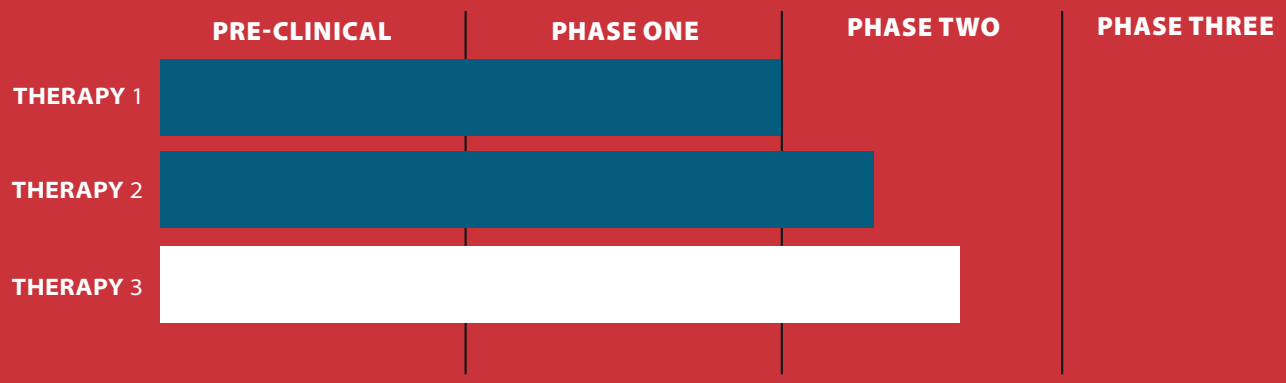
With support from the Chan Zuckerberg Initiative's Rare As One Project, Cure HHT developed the first-ever patient-driven research roadmap for HHT. **More than 1,200 patients, nearly 100 clinicians, and 40 scientists came together to define the priorities that matter most**. The result is a landmark plan that ensures patients' voices guide every step of discovery.

The roadmap outlines **31 key objectives to accelerate progress** — from uncovering how vascular malformations form, to advancing gene therapy, to standardizing screening for pulmonary, brain, and liver AVMs. It also focuses on urgent needs in diagnosis, access, and health equity, because every patient deserves the best chance at health.

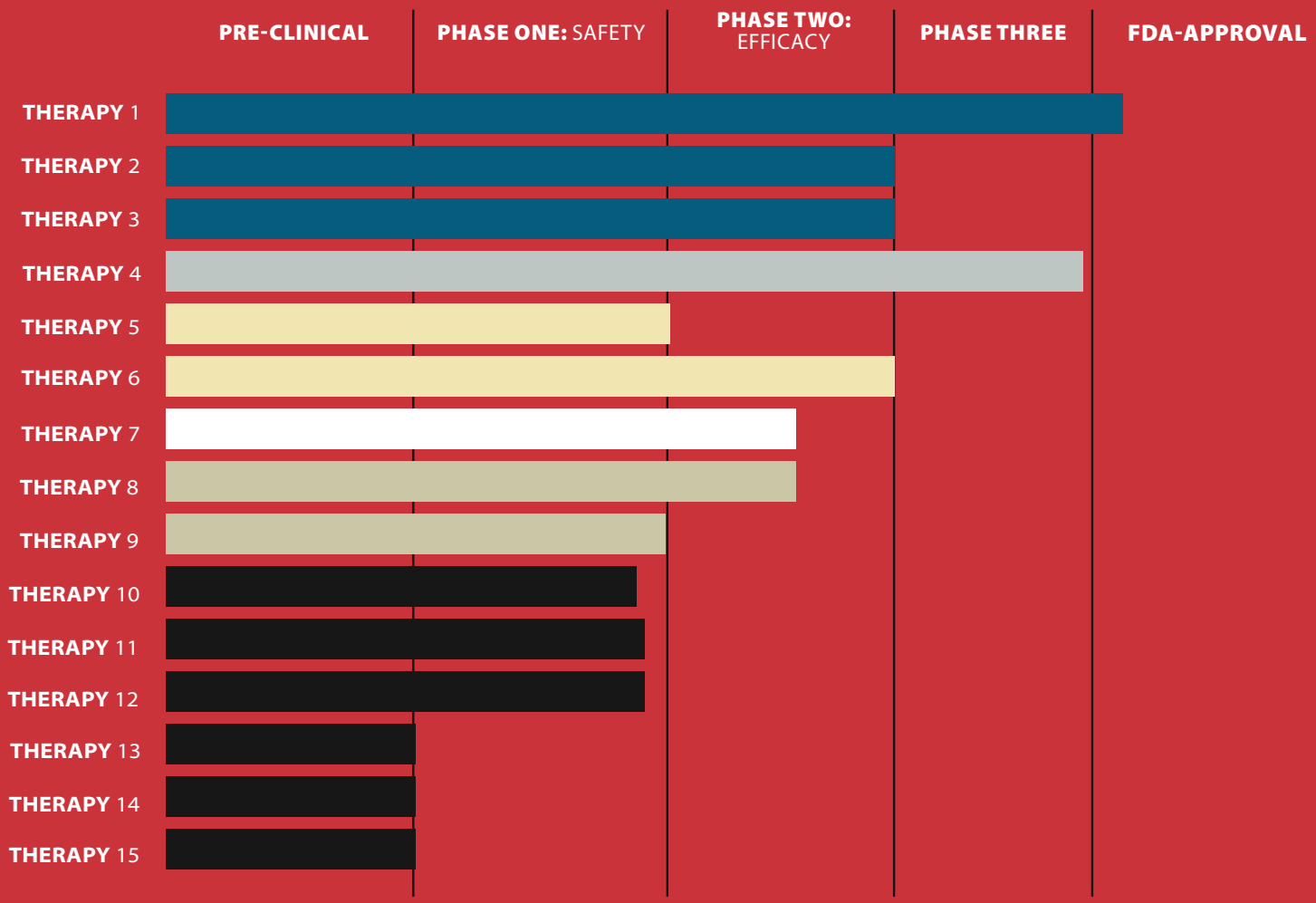
And it's not just a plan — it's already in motion. Biospecimen studies are underway. Drug development is advancing. The pazopanib clinical trial is fully enrolled with several new clinical trials planned in 2026. Each milestone brings us closer to a future where HHT no longer causes suffering — and where a cure is within reach.

# EVOLUTION OF THE HHT TREATMENT PIPELINE

## TREATMENT PIPELINE: 2018-2022




## CURRENT HHT TREATMENT PIPELINE




**Project names removed for confidentiality.*

# LAYING THE FOUNDATION FOR BREAKTHROUGHS

Breakthroughs don't happen by chance — they happen because we've built the foundation for them. Cure HHT is investing in the infrastructure that makes faster, smarter discoveries possible.

## BIOBANK

The Cure HHT Biobank provides researchers and industry partners with **high-quality patient samples, fueling genetic and biomarker studies** that deepen our understanding of how HHT works — and how to stop it.

## REGISTRIES

Across 16 Centers of Excellence, the **CHORUS Registry is capturing more than 2,400 data points on patient care and outcomes**, tracking how HHT progresses and how treatments make a difference. At the same time, **HHT Connect brings in the patient voice, collecting real-world data on symptoms, quality of life, and treatment experiences around the globe**.

Together, these resources form the foundation for tomorrow's therapies. Our goal is to expand this project to all HHT Centers of Excellence for full participation.

"Having an organization truly dedicated to curing and improving this disease means so much to families like mine. Donating my daughter's tissue was our way of helping move that work forward — so that one day, others might have faster answers and better treatments."

***Amanda H.,***

*HHT Caregiver*

# FORGING PARTNERSHIPS THAT DRIVE CHANGE

Patient-centered research. These three words are the foundation of Cure HHT's Therapeutic Development Arm — and they guide every partnership we build. From academic labs to biotech innovators and clinicians around the world, our role is clear: we are the catalyst bringing these efforts together, always with patients at the center.

Partnership takes many forms. We fund discovery through competitive grants that align with our patient-driven research roadmap and support rising scientists with travel awards to share their work on the global stage. By sponsoring HHT-focused sessions at major conferences — including the American Society of Hematology, North American Vascular Biology Organization, and the Gordon Research Conference on Angiogenesis — we make sure HHT research has a powerful voice in the broader scientific community.

We also partner directly with research teams and industry to move promising therapies forward. Whether serving as a study sponsor or research site — as we did with the Pazopanib trial, the Brain Vascular Malformation Consortium, and Diagonal Therapeutics — Cure HHT helps streamline recruitment, remove barriers, and accelerate progress.

Our infrastructure makes this collaboration possible. The Cure HHT Biobank, CHORUS registry, HHT Connect, and our new digital engagement app provide the real-world data and biospecimens scientists need to test new ideas and translate discovery into treatments faster.

This ecosystem thrives because each partner brings unique strengths — clinicians share expertise, scientists advance discovery, industry provides resources, and Cure HHT ensures the patient voice leads the way. Together, we're turning research into real-world treatments and delivering hope to families everywhere.

# THE FUTURE IS NOW

## A message from Marianne Clancy, CEO, Cure HHT

We are standing at the threshold of a new era for HHT. What once felt impossible is now within reach — therapies that treat this disease at its root, not just surgeries that manage its symptoms.

Over the past 30 years, together we've laid the foundation to Find. Treat. Cure. We've found answers through groundbreaking research and discovery. We've treated more patients than ever before through our expanding global network of Centers of Excellence. And we are moving closer each day to the ultimate goal — to cure HHT and end the suffering it causes.

This progress is the result of a community that never stops believing in what's possible. Through advocacy, generosity, and partnership, you have turned determination into action and hope into measurable impact.

As we look to the future, our vision is clear: a world where Cure HHT and our community not only survive — but thrive. A world where every family has access to expert care, every researcher has the tools to discover the next breakthrough, and every person with HHT can look ahead without fear.

With your continued partnership, we will get there. Together, we will finish what we started — and create a future free from HHT.

With gratitude and determination,

Marianne Clancy
CEO, Cure HHT

## DEDICATED TO YOU

This impact report is dedicated to the generosity of our loyal community. Without the support of our friends, family, and community we would not be here, at the precipice of breakthrough.

If you would like to make a tax-deductible gift, please visit **curehht.org/donate**.

curehht

The Cornerstone of the HHT Community

PO Box 329, Monkton, MD 21111

**Phone** 410-357-9932

**Fax** 410-472-5559

hhtinfo@curehht.org

**curehht.org**

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