



Year of Empowerment

This year, **Cure HHT** is celebrating **25 years** of commitment to awareness, advocacy and education, and we want you to join us.

It's because of your dedication and support that the last 25 years have been full of discoveries and advances. Because of you we are closer to a cure than ever before, and because of you we are able to save lives around the world every day.

Two years ago we pledged to take action, last year we pledged to transform your support into progress and in 2016 we pledge to further empower our community to become stronger advocates. **This is the Year of Empowerment.**

For 25 years we have been the cornerstone for HHT families, providing resources and support. Take action with us this year and join the HHT movement.

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Message from Marianne

As our Year of Transformation comes to an end, I've been taking some time to recall my own transformation within this incredible community.

I came to Cure HHT as many of you have – 21 years ago, I was newly diagnosed with a disease I knew nothing about. I had three young children and had seen my mother and a sister pass away suddenly with no explanation. I was terrified.

My family and I were fortunate that an organization, still in its infancy, was able to offer us comfort, resources and direct us to the best doctors in the country. But my relief was tinged with frustration – so few people knew about HHT, and even experts lacked the support and funding they needed to improve diagnosis and treatment. For 10 years a small group, all of us affected in some way by HHT, worked every day to spread awareness and advocate for our families and ourselves. In 2001, I was asked by the board to become the Executive Director, and nearly 15 years later it's still an enormous privilege to serve this community.

Since I was diagnosed, I have seen HHT transformed, its course changed more drastically than any of us could have hoped 25 years ago. Back then, collaborating with experts, pushing for legislative change and securing research funding through the Department of Defense were impossible. But now we have achieved the impossible.

For 25 years, Cure HHT has been the foundation supporting and guiding our community. Moving forward, we are your partner, and it is your voice that needs to be heard, your story that needs to be told and your actions that will drive our mission. **Let's make 2016 the Year of Empowerment!**

You are the future of HHT.

In partnership,

Marianne S. Clancy, RDA, MPA
Executive Director



Marianne Clancy, RDH, MPA
Executive Director

James Gossage, M.D.
Medical Director

Marie Faughnan, M.D., M.Sc.
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Stay current on HHT clinical trials, education programs and community events. Sign up to receive electronic announcements by registering at www.curehht.org or send us an email at hhtinfo@curehht.org.

CURE HHT NEWSLETTER

Marianne Clancy, RDH, MPA
Editor

Sponsorship and/or advertisement in the Cure HHT newsletter does not constitute endorsement of any treatment or product by Cure HHT.

Cure HHT Welcomes New Board Members

Join us in welcoming Sara Palmer, Jim Lapidès and Alyson Conger to the Cure HHT Board of Directors, a role dedicated to guiding the HHT community toward new levels of awareness and a cure.



"Joining the board is a way to deepen my involvement and work closely with other committed volunteers to improve education and awareness as well as to support research that leads to better treatments for HHT."
-Sara Palmer, Ph.D.



"I am fighting for a better life for me, my family and everyone else who suffers from this disease. Our organization is ready for a major leap forward, and we are closer to a cure than ever before."
-Jim Lapidès



"Our family has suffered great tragedies with HHT, but I have seen firsthand the progress in screening, treatment and awareness for HHT patients. I look forward to being part of the movement for a cure and continued advances to benefit my children, grandchildren and the entire HHT community."
-Alyson Conger

HHT Champion Reflects on 25 Years of Research



After more than 20 years of dedication to the Cure HHT community, Dr. Alan Guttmacher is retiring from his role at the National Institutes of Health.

He has been a tireless champion for HHT research since the 1990s, leading the team that discovered the Endoglin and Alk genes. Dr. Guttmacher served on the Cure HHT Scientific and Medical Advisory Board, helped establish HHT Clinical Guidelines and co-chaired the first HHT Scientific Research Funding Program.

How did your knowledge of HHT influence your NIH career?

My career at NIH would not have happened without my HHT connections. I was working as a geneticist in Vermont, finding and tracing HHT families, when I became involved with the NIH. I happened to be in the right place at the right time to help.

How have you seen the HHT community grow?

The researchers, clinicians and patients form a community – something that is true for relatively few diseases. Because Cure HHT is the only organization focused on HHT, there is one strong and solid voice advocating for the entire community.

What advancements are possible with the Personalized Medicine Initiative?

As we have a better understanding of disease biology and how HHT mutations create clinical problems, there will be more therapies available. Diagnosis will be more effective and real prevention made possible.

What do you see as your new role in the future of HHT?

As someone who knows HHT and its effect on the lives of individuals and families, I hope to become an unbiased advisor for the community.

Dr. Robert I. White Becomes Professor Emeritus at Yale After Decades of Service

Before Cure HHT was even an idea, there was one champion for HHT - Dr. Robert White, Jr. He was an interventional radiologist at Johns Hopkins Hospital when he devised a surgical method method for treating arteriovenous malformations in the lungs. Dr. White treated HHT patients from all over the country, providing comfort, resources and in many instances saving lives.

When Dr. White learned Dr. Bruce Jacobsen, a biochemist at the University of Massachusetts, had formed an HHT patient registry, the two teamed-up to change the future of HHT. After Dr. White accepted a position as chair of the Department of Radiology at Yale School of Medicine, he established the first HHT Center of Excellence. In 1991, Drs. White and Jacobsen gathered a group of patients to form the first Board of Directors and a year later they established the Medical Advisory Board.



Dr. White has now retired from Yale after more than four decades of incredible service to the HHT community. Cure HHT would not be the organization it is today had Dr. White not cared so deeply about the families who needed his help: "I'd like to express special thanks and gratitude to Pat Kelly-White who shared the vision."

The Cure HHT staff is enormously grateful for the work Dr. White has done on our behalf, and we wish him a long and joyful retirement.

"HHT owes each of these visionaries much gratitude. I can't imagine a world without this organization, and the advances in partnerships that have been built over this quarter century."

-Marianne Clancy

"I very much appreciate the recognition for my earlier work in the foundation. It took a lot of people and their hard work. I am humbled to be given recognition."

-Dr. Bruce Jacobson

22nd HHT Center of Excellence in North America University of Chicago Medicine Chicago, Illinois



THE UNIVERSITY OF
CHICAGO
MEDICINE

Medical Director: Issam Awad, MD, MSc, FACS

Program Coordinator: Shannon Love, RN, BSN

Make an Appointment: administrative assistant # 773-702-4452

Website: www.uchospitals.edu/hht

"We are delighted that HHT multidisciplinary care will now be a reality in Chicago and the surrounding states," said Cure HHT Executive Director Marianne Clancy.

The University of Chicago Medicine is the only facility in Illinois that specializes in the diagnosis, evaluation and treatment of HHT. This newest HHT Center of Excellence features a multidisciplinary team, led by Dr. Issam Awad, which coordinates care for adult and pediatric patients. Whether a patient needs genetic screening or a complex procedure, Dr. Awad's team of specialists has the knowledge, resources and expertise to provide advanced and comprehensive care.

Dr. Awad is an internationally recognized leader in neurosurgery. As the John Harper Seeley Professor of Surgery, and Director of Neurovascular Surgery at The University of Chicago Medicine, he specializes in surgical management of neurovascular conditions affecting the brain



and spinal cord, including 30 years of experience with managing HHT related problems. Dr. Awad is looking forward to a fruitful and contributive partnership with Cure HHT and the HHT patient community.

HHT Specialties at U Chicago Medicine

Cardiology
Dermatology
Gastroenterology
Medical Genetics
Hematology/Oncology
Neurointerventional Surgery
Neurology
Interventional Radiology
Neurovascular Surgery
Otolaryngology (ENT)
Pulmonology/Critical Care
Pediatric Cardiology
Pediatric Dermatology
Pediatric Neurosurgery
Pediatric Pulmonology
Pediatric Surgery

25 years – Together We Stand

In 1909, Dr. Frederic Hanes named a distinct new disease that he called Hereditary Hemorrhagic Telangiectasia, also known as Osler-Weber-Rendu syndrome. His conclusion of the disease was derived from descriptions documented by three other men within the past 13 years, each of whom focused on a different aspect of the condition.

1896: Dr. Henri Rendu produced a detailed clinical description.

1901 and 1907: Dr. William Osler described the familial associations.

1907: Dr. Frederick Parkes Weber identified the dermatological manifestations.

Over the next 80 years, while progress was made in treating symptoms, the discoveries of Rendu, Osler and Weber were all that was known about the cause and effects of HHT. Then, in 1991, a group of patient families and concerned physicians decided to band together for a better future.

They founded **HHT Foundation International** with one mission in mind: *to raise awareness, promote education and save lives.*

25 years later, those goals are still the driving force behind the **Cure HHT** organization and community. And now, we are capable of so much more. The strides made in research, legislative advocacy, fundraising, physician education and community events are made possible by two-and-a-half decades of mutual commitment.

What was once impossible is now within reach, and this is only the beginning.

A Year in Review

Our recent progress as an organization is no mystery. In the past two years, engagement from our community has **doubled**, allowing information and education a greater reach than ever before. As awareness continues to grow, so does our ability to focus efforts on three primary goals: to find, treat and cure HHT.

2015 FIND

- HHT has been covered on Fox News Detroit and in the "New York Times Magazine."
- Executive Director Marianne Clancy presented on HHT at the DIA Conference for Rare Diseases in Bethesda, MD, and at the Vascular Anomalies Meeting in New York City.

2015 TREAT

- 22 Centers of Excellence are now open across North America.
- H.R. 1849, the HHT Diagnosis and Treatment Act was introduced in the U.S. House of Representatives

2015 CURE

- **Cure HHT** invested \$230,000 in research grants, leveraged to \$1.5 million through NIH.
- The Department of Defense Peer Review Medical Research Program approved vascular malformations as research topics, allowing HHT researchers access to \$247.5 million in grants.

What does this mean for you?

Imagine a future where your HHT doctor won't be 100, 300 or 1000 miles away, but in the next town over. Imagine speaking to a doctor about the disease and they know what you're talking about and how to treat it. The increased funding for research and government recognition is bringing that world closer. National news coverage and representation at medical and scientific meetings is spreading the knowledge of HHT to people in all walks of life.



The founding members of HHT Foundation International at the first organizational meeting in 1991.



A panel of HHT doctors speaking at the first HHT Conference in 1992.



A roundtable discussion involving the future of HHT Foundation International at the first HHT conference in 1992.



A presentation on the scientific history of HHT during the first HHT International Scientific meeting in 1996.

Because you know about HHT, you can Advance HHT Research!

These studies will expand our understanding of HHT, ultimately leading to better treatments. You have the ability to further HHT research by participating in one of these research studies.

ACT NOW to make research advancements possible.

- **Pomalidomide** – Drug therapy study at Cleveland Clinic for HHT patients with GI bleeding or HHT-related nosebleeds requiring ongoing transfusion or iron replacement therapy.
- **Bevacizumab (Avastin)** – Evaluation of nosebleeds at Stanford University; involves nasal bipolar cautery and intranasal injection of bevacizumab vs. placebo.
- **Pazopanib** – Drug therapy study at seven HHT Centers of Excellence for patients who require iron therapy or blood transfusions from nosebleeds or anemia.
- **Timolol** – Topical drug therapy study at Johns Hopkins to determine effectiveness of reducing or eliminating skin telangiectasia.
- **Brain AVMs** – Information gathering study to determine the genetic and clinical factors which signal high risk for hemorrhage from brain AVMs in HHT patients.

For more information, visit:

<http://curehht.org/medical-scientific/researchstudies/>,

call **Cure HHT** at 410-357-9932 or email research@curehht.org.

How does clinical research work?

Scientists work with cells and animal models to learn about the mechanisms which cause HHT to develop. Based on these mechanisms, drugs are proposed that might stop or reverse the disease. A research study is then designed, with FDA approval, in which people with HHT receive a drug under close supervision to monitor for benefits and side effects.

Why should I participate?

- Your participation may help someone else in your family or future generations.
- The drugs are typically free of charge to participants.
- You are helping other HHT patients - it is a small contribution to a big cause!

Dr. Dennis Sprecher Receives Robert E. Berkman Leadership Award

"Dennis has provided wise guidance through the years as a valued board member and has led collaboration with GlaxoSmithKline for breakthroughs we hope will transform HHT therapy. He also served on the Research Review committee, providing invaluable guidance with HHT research grants considered for funding."

– Executive Director Marianne Clancy



Dr. Dennis Sprecher and his mother.

Dr. Dennis Sprecher is the Senior Director of Discovery Medicine and Drug Development at GlaxoSmithKline, the company currently leading the study on pazopanib and its effect on chronic bleeding. He co-chairs the company-wide protocol review board and heads the drug development teams in heart failure and acute coronary syndromes, advancing ideas generated in animal models and translating them into human trials. He is also currently on staff at the University of Pennsylvania cardiology department as a practicing physician.

The Cure HHT webinar series

keeps patients and physicians informed of the latest information in HHT treatment, medicine and research.

They are led by physicians and scientists specializing in HHT, with each segment including a Q&A period.

January – Legislative Advocacy

February – HHT and Pulmonary Hypertension; Pregnancy and HHT

March – Research Talk: The Role of Notch and Ephrin Signaling in Brain AVM

April – Anemia, Iron Therapy and Iron Rich Foods

May – TBD

June – Pediatric Screening and Treatment

ACT NOW by providing cathleen.kinnear@curehht.org your email address to receive information on future webinars.

Remember, all webinars are recorded and available online at

<http://curehht.org/resources/webinars/>

SHARE this link with your family and local doctors.

Millennial Takes on HHT Advocacy

Savanah Schott's first date was not the experience she had been hoping for. Instead, at 16-years-old, she spent the day being nervous only to choke when he showed up – literally. Her nose started bleeding, and all of a sudden she coughed up a blood clot.

She was transported to the ER, bleeding from both her nose and mouth. The episode lasted for 45 minutes before doctors had to manually cauterize the epistaxis with silver nitrate sticks.



"Have you ever bled for 45 minutes straight, bleeding so hard it comes out both nostrils and down your throat," Savanah asked. "Nearly filled a sink up with your own blood? Contemplating the thought that you might die? It's awful."

Now at 23-years-old, Savanah is leading the advocacy charge in Iowa to introduce an act similar to the **HHT Diagnosis and Treatment Act** in the Senate. She has contacted Senators **Chuck Grassley** and **Joni Ernst** as well as Representative **Rod Blum**.



Her voice was one of many that secured Representative **Dave Loebsack** as a co-sponsor of the **HHT DATA Act**.

"If you don't educate others and advocate for your disease, it's just going to spiral," Savanah said. "It's our responsibility to increase awareness."

Join Savanah and ACT NOW

by clicking "Support This Bill" at

<https://www.popvox.com/bills/us/114/hr1849>

It only takes two minutes to get your voice heard!

Events



Georgia Walk

"People from different families walking as one family for one cause: a cure for HHT... which makes us all part of a larger family. We are a community and we want to be heard. We need help and funding! I left feeling empowered and hopeful."

– **Mary McGee**

"One of the greatest concerns our mother had was the impact HHT would have on her children and grandchildren. She would have been elated, and not only proud of her family, but of the efforts of **Cure HHT** and all of the other participants, volunteers and donors."

– **Nancy Buttimer Adams**



Maine Walk:

A group from Augusta, Maine came together in October 2015 to support the **Cure HHT** mission. They created a community of HHT patients, families and friends dedicated to raising awareness about HHT and inspiring others to get more involved in the New England area.

Anthony Anzell Ultramarathon:

HHT patient Anthony Anzell took on the Dances with Dirt 100 Mile Ultramarathon in Michigan this past September. His drive to represent the HHT community garnered local media support and spread awareness in households across Michigan.



Game On Marathon:

Red Hat Games dedicated an entire weekend in August 2015 to playing 30 video games in three days to raise awareness and funds for the **Cure HHT** mission. This was the first totally global event for **Cure HHT** as the marathon was broadcasted online.



**October 28-30, 2016
Burlington, Massachusetts**

HHT is the "Great Masquerader," disguising itself as many common illnesses (i.e., brain abscess, asthma, fatigue, anemia, etc.).

Join Cure HHT this Halloween weekend for an empowering conference to unravel the mysteries of HHT and learn to take charge of your own health.

ACT NOW!

Reserve your room - Boston Marriott Burlington, 888-855-7741
(Group Code "HHT Patient and Family Conference")
\$125/night plus taxes.

Donate your time or an auction item by contacting
cathleen.kinnear@curehht.org or call 410-357-9932.

Registration and conference program schedule will be available in the coming months

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**BECAUSE YOU KNOW ABOUT HHT
WILL YOU ACT TODAY?**

HHT is a hereditary disorder affecting 1 in 5,000 people, ninety percent of whom are undiagnosed. If left untreated, the abnormal blood vessels characteristic of HHT patients can lead to serious, life-threatening complications.

Cure HHT's mission is to find a cure for HHT while saving the lives and improving the well-being of individuals and families affected by HHT.

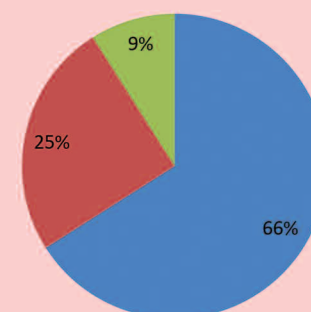
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Financial Report

2014 - 2015 Financial Highlights

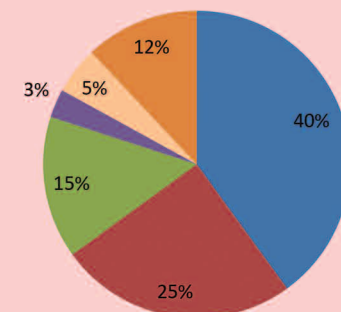
Income

■ Donations ■ Conferences ■ Fundraising Events



Expenses

■ Research ■ Public Outreach ■ Education ■ Advocacy ■ Administrative ■ Fundraising



Help Cure HHT continue to grow!

- Tell one person about HHT this year.
- Send us a note about how involvement with Cure HHT has touched your life. lauren.linhard@curehht.org
- Consider a first-time financial gift or an increase in your giving this year. www.curehht.org/donate



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Meet Jody Nissan, who is
ACTING NOW for Cure HHT by
hosting an annual gala in Michigan.
Visit www.curehht.org and click
“Get Involved” to hear about more
upcoming events.
**How will you ACT TODAY for
Cure HHT?**

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