



Cure HHT Leading the Way

Cure HHT has been working for over a decade to build relationships with scientists, physicians and pharmaceutical companies to alter the face of this disease and how it impacts 1.4 million people worldwide. Since 2003, **Cure HHT has invested more than \$1,300,000 in grant awards** to support global research, clinical trials, young scholars and scientific conferences.

2015, our Year of Transformation, is living up to its name as we start to see **a tremendous return on our HHT Research Investment.**

- **Funded six research grants** equaling \$230,000, which is the LARGEST single investment in the organization’s history.
- Five of our research seed grants have been **leveraged** to **\$5,300,000** from NIH, FDA and the European Research Agency. Within the last few weeks, Dr. Paul Oh (Univ. of Florida) and Dr. Rosemary Akhurst (Univ. of California, San Francisco), received a total of \$2.8 million in NIH funding to continue their HHT research originally funded by Cure HHT.
- **Five Young Scholar Research Grants** were awarded with a record number of 30 applications received; the HHT Scientific Community is growing as is the number of countries and institutions engaging in innovative HHT research projects.

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Message from Marianne

Last month, after an enormously successful 11th International HHT Scientific Conference, I found myself alone in an airport van finally able to reflect on the events of the week.

The driver had been shuttling people to and from the conference for several days and revealed to me that he had become a bit of an HHT expert himself. In fact, he was grateful for the opportunity to learn about the disease for the first time. After talking to countless doctors and scientists, he was able to call his sister-in-law in Colombia and diagnose her with HHT!

Because of the passion and dedication of our medical and scientific communities, a family who may never have known what was wrong can now be treated. Lives will be saved.

It isn't always easy to see the growth of awareness, but moments like this one reminds me of the impact our work and collaboration continue to have on the global community.

In January, we pledged to make 2015 our Year of Transformation. In recognition of that promise, we have made our greatest research investment to date, providing \$230,000 in research grants around the world. In addition to cultivating promising new breakthroughs, this investment will continue to grow our research community and encourage engagement with the brightest young minds in their fields.

With your continued support, we've come closer than ever to our goal for a cure, and we will not give up. *Together, we can change the face of HHT.*

Best,

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.
Scientific Research Director

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CURE HHT NEWSLETTER

Marianne Clancy, RDH, MPA
Editor

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Cure HHT Leading the Way

(continued from page 1)

- **Nine research papers** have been published from the preliminary findings of the Brain AVM Study; NIH has found value in the data being collected and renewed its grant to the Brain Vascular Malformation Consortium for another five years.
- **Two clinical trials** are being conducted by a pharmaceutical company and a renowned research institution to determine the impact of different drugs on bleeding in HHT patients. Several additional projects are currently being discussed.
- Development of the **HHT Outcomes Registry** is almost complete; Beta Testing will begin this fall at three North American HHT Centers of Excellence; data collected by the registry will relate to every aspect of the disease and will allow scientists to plan and target clinical research studies of new therapies and determine outcomes of treatment.
- Vascular Malformations are now an approved research topic through the Department of Defense Peer Review Medical Research Program (thanks to Cure HHT perseverance); **HHT researchers now have access to over \$247.5 million in federal grants** for projects that apply to laboratory, clinical, behavioral, epidemiological and other areas of research to advance knowledge in prevention, detection, diagnosis and treatment.

Cure HHT invests in research for you because we can't cure the disease if we don't understand how genes are behaving in HHT, how AVMs form and grow or what therapies have the most impact in reversing AVMs. **Investing in HHT research also raises awareness about the disease** in the medical community through research publications, clinical trials and conference presentations which translates into more timely diagnosis, better treatments and access to more knowledgeable doctors for you and your family.

We all share a common goal – better quality of life (short term) and to cure this disease (longer term). Both are possible! **An investment in HHT research is really an investment in your family's future health and well-being.** We are proud to say that not only is this a worthy investment but one that is seeing significant returns.

Global Awareness Campaign Will Save Lives Around the World



In June, we started a campaign to **Make the Invisible Visible** with the goal of educating physicians and doubling the diagnosis rate for HHT. The HHT community suffers from lack of awareness and from slow or incorrect diagnosis. By ensuring that doctors can recognize the symptoms of HHT, we can help ensure that patients are diagnosed as soon as possible and begin receiving the treatments they need. This in turn will save families all over the world from needless suffering and loss.

Our community came forward to contribute over \$50,000 to this critical initiative. More than **200 individuals** gave to the campaign, while **52 others** shared their hopes for the future of HHT. We are enormously grateful for the support that allows us to continue serving the global HHT community.

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Cure HHT Sponsors

11th International Scientific Conference

More than 220 physicians, scientists, nurses, genetic counselors and advocates represented 18 countries at the 11th International HHT Scientific Conference. Over four days, they heard 66 presentations and viewed 96 research posters. Attendees enjoyed hearing from HHT veterans while also welcoming young newcomers to the ever-growing scientific community.

Because we could not possibly include the details of each research presentation in this newsletter, we have provided explanations of the most prominent topics. A full **executive summary**, written by a committee of scientists, doctors and researchers, will be published in the journal Angiogenesis this October. In the meantime, the **clinical and basic science summaries** of notable talks can be found on the Cure HHT website at <http://curehht.org/get-involved/conferences/scientific-conferences>.

Lessons in Clinical Aspects of HHT

Presentations on new clinical lessons in HHT revealed encouraging progress in the contrast between HHT and general populations. Dr. Claire Shovlin, Director of the HHT Center in London, shared particularly promising research on controlling some of the symptoms of HHT that patients often cite as most disruptive to a normal life.

Discussions in Pediatrics

A discussion of pediatric care showed significant work is being done to ensure that children receive the most accurate screening for HHT. Further research revealed that doctors are finding ways to predict some of the more serious circumstances faced by children as a result of HHT and its symptoms.

Advances in Diagnostics

Several of our researchers presented critical information on advances in the diagnostics of invisible symptoms. These results will lead to faster and more accurate diagnosis of underlying problems, as well as safer methods for identification and treatment.

New Therapies for HHT

Our medical and scientific communities are committed to finding a cure for HHT, but in the meantime they work tirelessly to provide better treatments for their patients. Some of our top doctors shared the results of trials that showed exciting new procedures and drug therapies used to treat HHT. In particular, great strides are being made in the treatment of epistaxis, one of the most common and disruptive of all symptoms.

It was truly incredible to see so many brilliant people working for a single purpose, but perhaps even more impressive than the minds of our researchers is their passion. Our scientific community wants a cure for HHT just as much as the rest of us.



"This is my 10th conference and it's very nice to see my colleagues from over the years all together and seeing them enthusiastic about HHT research and care."

- Hans-Jurgen Mager, M.D., Director, HHT Center Netherlands

Growing the HHT Research Community

The Young Scholar Research Program, launched and funded by Cure HHT in 2015, was designed to attract new researchers into the field of HHT. The program was carried over into the HHT International Scientific Conference by funding travel awards that allowed a group of 22 young scientists, fellows, nurses and genetic counselors to attend the event and gain the knowledge needed to better study, diagnose and treat HHT. In addition, eight young scholars received recognition, along with a monetary award, for their outstanding presentations at the conference.

Travel Award Winners

Frank Baiden, MD
Stephanie Bowers, PhD
Andrea Cajal, MSc
Dan Dardik, MD
Melissa Dickey, NP
Pierre Guihard, PhD
Alexis Harrison, MD
Anna Hosman, BSc
Lawrence Huang, PhD
Saad Ibrahim, MD
Xuan Jiang, PhD
Amudhan Jyothidasan, MD
Yong Hwan Kim, PhD
Guiseppe (Joey) Latino, MD
Ross Allan Mendoza, MD
Roxana Ola, PhD
Valeria Orlova, PhD
Maria Elena Riccioni, PhD
Lynne Sekarski, RN
Marcelo Serra, MD
Karen Smith, RN
Veronique Vorselaars, PhD

Poster Presentation Award Winners

Freya Droege, MD (Germany)
Nasal Self-Packing for Epistaxis in HHT Increases Quality of Life

Xuan Jiang, PhD (United States)
Potential Association of Aberrant MicroRNA Biogenesis in HHT

Marcelo Serra, MD (Argentina)
Hypophosphatemia Induced by Intravenous Administration of Iron in Patients with HHT. A New Clinical Issue?

Pernille Topping, MD, PhD (Denmark)
Long Non-Coding RNA Expression Profiles in HHT

Oral Presentation Award Winners

Guiseppe (Joey) Latino, MD (Canada)
Diagnostic Yield of Rescreening Adults for Pulmonary AVMs

Valeria Orlova, PhD (The Netherlands)
Modeling HHT with Patient Specific Induced Pluripotent Stem Cells

Roxana Ola, PhD (United States)
Targeting VEGFR2 Signaling Recues AVMs in HHT Type2

Veronique Vorselaars, PhD (The Netherlands)
Follow-Up of the Pulmonary Right-to-Left Shunt with Transthoracic Contrast Echocardiography in HHT



"I really enjoy the collaboration and the ability to talk about all our different patients with different experts from around the world, and look at everyone's research and just learn."

- Miles Conrad, M.D., Co-Director, University of California San Francisco HHT Center

CURE HHT INVESTS \$150,000 IN YOUNG SCHOLARS

This year, Cure HHT launched and funded an HHT Young Research Scholar Award Program to attract new researchers into the field of HHT. Young scholars are typically hungry to make their mark on the research community; they have innovative ideas and are exposed to cutting edge technology which leads to new discoveries. HHT patients need more passionate scientists to be involved in this disease in order to find a cure, thus, it's important for Cure HHT to expose and engage high achieving PhD students who are in the early years of their career.

A record-breaking 30 researchers from around the world applied for the 2015 Young Scholar Research Grants. After an extensive selection process, the scientific research committee agreed on five projects that showed the greatest potential to advance HHT treatment while taking steps toward finding a cure. Each researcher received \$30,000 to fund their cutting edge research; all projects will be completed over the course of the next 12 months. This is Cure HHT's single largest investment in Young Scholars; each project impacts a different aspect of the disease but together the results will advance HHT treatment breakthroughs. "We are amazed at the passion and interest young researchers show for the Cure HHT cause," said Executive Director Marianne Clancy. "We expect great things to come from all of them. It's this level of dedication that will lead to a cure."



Chadwick Davis, PhD (Recursion Pharmaceuticals) is utilizing a high-content cellular imaging system to discover a known drug with the potential to be repurposed to successfully treat HHT. Dr. Davis will screen at least 2,727 known drugs and bioactive compounds against ENG, ACVRL1 and SMAD4 cell lines and he expects to find a minimum of one bioactive compound that fully or partially reverses the physical expression of the disease and can be repurposed for the treatment of HHT.



Hongyu Tian, PhD (Duke University) will determine endoglin's role in regulating the signaling and biology of vascular smooth muscle cells (VSMCs) during developmental angiogenesis, the formation of new blood vessels. Dr. Tian's study will provide novel insights into how endoglin in VSMCs regulates physiological development and how its disruption contributes to HHT.



Simon Tual-Chalot, PhD (Newcastle University Upon Tyne) is using a mouse model to investigate how endoglin maintains adult vasculature (blood vessels in an organ) to protect against high output heart failure (HOHF). This knowledge will help develop treatments for HHT patients with this condition (HOHF).



Whitney Wooderchak-Donahue, PhD (University of Utah and ARUP Laboratories) is focused on identifying additional genetic modifiers in HHT. Dr. Wooderchak-Donahue hypothesizes that the variability in HHT is caused by mutations in additional genes or genetic modifiers critical to blood vessel development. Her discoveries will lead to better diagnostics for HHT patients with the addition of new genes to the HHT NGS panel and better genetic counseling.



Wan Zhu, PhD (University of California, San Francisco) will investigate an innovative and noninvasive strategy for treating arteriovenous malformations (AVMs). Dr. Zhu believes that this strategy can be used to treat AVMS in the brain and other organs with less risk than current treatments and at a reduced cost.

Cure HHT Research Grant is Catalyst for NIH Funding

In June 2015 we learned that two scientists who originally received Cure HHT seed grants were awarded large research grants from the National Institutes of Health (NIH). The intent of the Cure HHT research grant program is to invest early in well-defined research projects that may not otherwise receive funding; our seed grant program fosters new areas of research and enhances research partnerships. Our goal for investing in research is to provide the investigator with the cash needed to generate initial data that will be of interest to a larger organization; the end result being larger funding for a long-term HHT research project.

In these two cases, NIH found the research of Dr. Rosemary Akhurst and Dr. Paul Oh worthy of further investment. **Together, they have been awarded \$3.3 million! That means that for every \$1 Cure HHT invested in research, the HHT community received an additional \$33 in research funds.** These results reaffirm that funding pilot projects can lead to HHT breakthroughs for patients around the world is a worthy investment.



In 2008, **Dr. Rosemary Akhurst** was awarded a \$50,000 grant from Cure HHT to begin determining which variant genes increase the risk of AVMs; if patients are at a higher risk of lung or brain AVMs based on genetics; and if doctors can personalize medicine for HHT patients. A few years later, **she has leveraged her Cure HHT seed funding into a \$1.8 million grant from the National Institutes of Health!**

Dr. Akhurst provided insight into how HHT funding impacted her project success.

Q: How instrumental was the \$50,000 Cure HHT grant?

A: The grant really acted as our seed money on the project to begin collecting preliminary data. Without that data there would have been no way to generate interest in the project or apply for federal funding. Without that initial grant, this project would not exist.

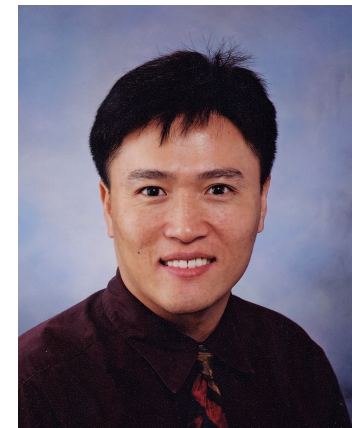
Q: How has Cure HHT continued to contribute to this important research?

A: Cure HHT is really what brought the team together for this project. I met both Chris Hughes and Marie Faughnan at the Family and Patient Conference in Los Angeles. We are each handling a specific aspect of this research within our expertise. The Foundation brought us together.

Q: Now that you have the funding, what are the next steps?

A: Over the last seven years we have written a few related publications and focused on research that lends itself to this study. But now that the funding has come in, we can begin to launch this project in full. We have already begun collecting blood samples and preparing mice for the study.

What began as a \$50,000 Cure HHT seed grant to kick-start **Dr. Paul Oh's** investigation entitled, "The Role of Macrophages in the Pathogenesis of HHT", **has been leveraged for an additional \$1.5 million in funding from the National Institutes of Health!**



"I thank you so much, the board of trustees and the donors for the trust and support during this drought season," Oh said. "This NIH fund is enough to quench the thirst, but I will continue to seek additional funding for more vigorous research. I will do my best to find the mechanism-based therapy for HHT."

Dr. Oh's current research project hypothesizes that ALK1 or ENG-deficient endothelial cells promote the recruitment of macrophages, cells of the immune system formed in response to infection or damaged cells, and differentiation of them plays a crucial role in the development of AVMs. It is anticipated that the results from his study will provide novel therapies with much lower potential side effects than current therapies. Dr. Oh's study will allow the repurposing of drugs not previously considered to treat HHT patients.

Dr. Oh is an Assistant Professor at the University of Florida where he has conducted HHT research since 2008. His primary research interest is to generate mouse models representing HHT for revealing the mechanisms of HHT pathogenesis and developing novel therapeutic reagents for treating HHT.

Special thanks to The Olitsky Family Foundation and The Jeffrey A. Blevins Memorial Fund for contributing to the funding of Dr. Oh's important research.

**Since 2004, Cure HHT has been funding research,
with your generous donations, to the following institutions.**

Funded by You & Cure HHT



www.CureHHT.org

In Memory of



Trish Linke

When you look a person in the eye, and talk heart to heart, you are making a direct connection. For many people with HHT, Trish Linke was their connection to life-saving guidance, a community of support and the Cure HHT organization.

Trish discovered HHT in the late 1980s when her mother began to have life-threatening GI bleeding. She was terrified and no one in the family knew what to do about it. When Trish went to the library to get books on genetics, hoping for information, she found "The HHT Patients Registry," with the name

and phone number for Bruce Jacobson, PhD, at the University of Massachusetts. He was the first person outside of her own family that she had known who had an HHT diagnosis.

Trish became one of the original members of the HHT Foundation Board of Directors, formed in 1990, and she took it upon herself to start the "Direct Connection" newsletter.

In the early days she created all of our publications and pamphlets, handled advertising, mailed information packages and entered new community members into the database. For more than a decade, she served on the Board of Directors in several capacities: vice-president, secretary, Internet and website coordinator and annual conference organizer.

She designed and moderated the HHT Message Forum to give people an open avenue to ask questions and seek advice. Trish dedicated countless volunteer hours guiding people who felt scared, misunderstood and alone to critical resources they needed. As the patient education liaison, Trish made it her personal challenge to correct the misinformation about HHT.

Trish was instrumental in advancing the Foundation's mission and creating the strong organization we are today. It is with great sadness that we say goodbye to one of the most passionate HHT advocates.

A Wife and Mother



Trish is survived by her husband of 54 years, Frank, her daughter, Kathy, her son, Matt, and granddaughter Courtney. Frank was a constant support to Trish. He was also a tremendous help in the early years of the HHT Foundation. During the patient conferences, he was always available to do anything that was asked of him. He assisted with planning and preparation for the meetings, helped with audiovisual needs, ran to make copies of materials, transported people and helped with the heavy lifting. Trish and Frank have supported the foundation through its entire evolution.

Matt remembers his mother as being a person who always advocated for him and encouraged him to follow his dreams. Kathy credits her mom for letting her children be free spirits – learning to ride horses, ride motorcycles, ice skate and sled.

A Lover of Life

In addition to being the international link to all those affected by HHT around the world, Trish was . . .

- ❖ A watercolor artist, calligrapher, musician, astronomer, equestrian and huge science fiction fan.
- ❖ An avid professional ice hockey fan.
- ❖ A collector of Star Wars, Star Trek, Stargate, Lord of the Rings and Queen Amidala memorabilia.
- ❖ An environmentalist who fought to protect the salmon population in the creek running through her family's property.
- ❖ A car enthusiast who owned two 1960 muscle cars - a Camaro and a Z-28.
- ❖ A teacher who instructed a variety of topics including Sunday school, folk singing and junior choir. Trish also worked for 22 years as a preschool teacher.

We will miss Trish dearly and offer our deepest sympathy to the Linke family.

In a gesture that encompasses her loyalty and generosity, Trish and Frank requested in lieu of flowers that those wishing to honor Trish's memory make a donation in her name to Cure HHT. We invite you to sign the guestbook for our tribute to Trish at <http://curehht.org/in-memory-of-trish-linke/>. You are welcome to share a story or fond memory, or simply express your condolences at this time.



"I will never forget the kindness, empathy and education that Trish showed me after I was diagnosed with HHT in 1996. All I was told was that I had a genetic disorder for which there could be life threatening consequences and no cure, diagnostic test or treatment. Trish directed me to an HHT Center who saved my life by closing my pulmonary AVMs." - Becki N.

"Trish was a tireless advocate for HHT. She was constantly scouring the web for information on HHT, sometimes out of personal interest and sometimes to answer a question for a patient in need. She would forward some of these queries to me as Medical Director and almost always her analysis was right on the money. She often found papers that I knew nothing about! I am grateful to have one of her lovely water colors hanging in our house to remember her by." - Dr. James Gossage

"Trish was not only a source of information, but also a good friend. At every conference we exchanged experiences, learned from her and had a great time. There was not a single question for which she didn't provide me with answers or consultation. The decades of effort by this knowing, caring and pleasant woman have forever left her in our hearts." - Meira Heiman, President of Israeli HHT Association

YOU can help advance HHT Research!

There are several HHT related research studies currently taking place. You or a family member may be interested in furthering the advancement of HHT research by participating in one of these clinical research studies. For more information, please visit our website at: <http://curehht.org/medical-scientific/researchstudies/>, call the Cure HHT office at 410-357-9932 or email research@curehht.org.

Cure HHT Partners with Stanford in Nosebleed Study

29 epistaxis patients needed - Nosebleeds are a common symptom of HHT with many patients reporting more than four episodes a day. The Stanford Sinus Center at the Stanford School of Medicine is conducting the first randomized, double-blind, placebo-controlled clinical trial of bevacizumab (Avastin) injection versus saline control for the management of HHT-related epistaxis.

What you need to know:

- Participants must travel to Stanford for the procedure
- The cost of the drug is covered
- The cost of the surgery will be billed to insurance
- There is no guarantee you will receive Avastin; you could receive the placebo
- Thanks to a generous donor, there is a travel reimbursement fund for participants willing to verify financial need.

These studies will advance our understanding of HHT and ultimately lead to better treatments. Just remember, none of these advances would be possible without the help of you and your family.

Cure HHT Recruiting Patients for Brain AVM Study

625 brain AVM patients needed - One of the major health risks to patients who develop a brain AVM is the possibility that the blood vessels within the AVM will break or rupture and cause a stroke. However, these risks have never been fully assessed for patients with HHT. The results of this study will help doctors make decisions about brain AVM treatment for individual patients and will drive further research in brain AVM therapies. So far, **nine research papers** have been published from the preliminary findings of this study covering topics such as predictors of HHT diagnosis, hemorrhage rates, neurovascular manifestations and more.

What you need to know:

- You are eligible to participate if you
 - Have a documented clinical or genetic diagnosis of HHT
 - Have a brain AVM whether its been treated or not
 - Live in the U.S., Canada or Netherlands
 - Are at least three years of age
- This is a data gathering study only
- No travel is required
- You will be asked to provide a blood or saliva sample
- There are 15 participating HHT Centers, along with Cure HHT, recruiting patients with Brain AVMs

Evaluation of Pazopanib on Bleeding in HHT

20 patients needed - Pazopanib partially blocks the body's response to various vascular growth factors (including VEGF), which might shrink or stabilize bleeding AVMs. GlaxoSmithKline is testing whether the drug Pazopanib can reduce chronic bleeding episodes in HHT patients who:
1) have frequent nosebleeds and require iron therapy, OR
2) have persistent anemia and require iron infusions, OR
3) have persistent anemia and require blood transfusions.

What you need to know:

- Visit Cure HHT website for details of inclusion and exclusion criteria : <http://curehht.org/medical-scientific/researchstudies/>
- Participants must be between the ages of 18 and 75
- Participation includes a baseline screening period and up to three months of therapy
- Travel to one of the seven participating HHT Centers of Excellence is required

A WORLD OF HHT AWARENESS



Cure HHT took it up a notch for HHT Awareness Month and set some serious goals! We launched the "Make the Invisible Visible" campaign in conjunction with HHT Awareness Month to double the HHT diagnosis rate. *Only 10% of people with HHT have been diagnosed, even though one in every 5,000 people has the genetic disease.*

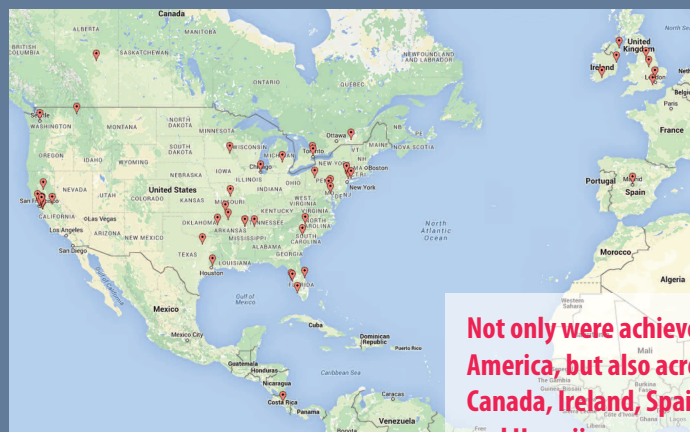


So, how did you help Cure HHT drive up the diagnosis rate? You created a World of HHT Awareness. Your efforts to increase HHT education and awareness were seen around the world during HHT Awareness Month!

It's time to #SeeHHT and make the #InvisibleVisible.

Some unique ideas:

- Passing a proclamation in honor HHT awareness
- Wearing an HHT shirt during a hospital visit
- Contacting television talk shows
- Organizing an HHT blood drive
- Creating a community-driven social media campaign
- Selling HHT bracelets and ribbons at a craft fair



Not only were achievements reported across America, but also across the globe, including Canada, Ireland, Spain, England, Costa Rica and Hawaii.

Check out the interactive awareness map:
<http://curehht.org/2015/06/a-world-of-hht-awareness/>

New Relationship Helps Build HHT Awareness Among Nurses

In an effort to double the diagnosis rate, Cure HHT was able to collaborate with the **Infusion Nurses Society (INS)** by providing an HHT speaker for their annual conference in Louisville, KY on May 20. INS is committed to providing the most current resources and information to all professionals involved with infusion therapy. Since many HHT patients depend on iron infusions, we were excited to be given the opportunity to expose a new professional group to HHT!



We are grateful that Dr. Raj Kasthuri, Hematologist and Director of the HHT Center of Excellence at UNC Chapel Hill, accepted Cure HHT's invitation to speak at the INS conference. According to Dr. Kasthuri, "we have done a little more to raise HHT awareness because of participating in this meeting."

Because of the growing Cure HHT prominence in the medical community, 80 infusion nurses are now able to take the best information on HHT treatments back to hospitals all over the country.

Attendees at the INS meeting had nothing but positive feedback on their experience learning about HHT.

"...definitely brings awareness in helping to identify these patients."

"I had not heard of HHT prior to your talk, I will be on the lookout for it now."

"I've never treated this patient population, but will now be more aware and have information for treating it if I ever do come across the illness."

"Very informative, interesting topic, excellent speaker - this was the best session I've attended at this conference."

Cure HHT will continue to partner with professional organizations in the future to double the diagnosis rate!

We need to make the Invisible Visible!

HHT DATA Act Gains Support in the U.S. House of Representatives



Jim Himes (D-CT)



Ed Royce (R-CA)

Jim Himes (D-CT) and Ed Royce (R-CA) introduced The HHT Diagnosis and Treatment (DATA) Act H.R. 1849 in the House of Representatives on April 16 as part of the 114th Congress. The Act would authorize the appropriation of **\$5 million per year for the next five years** to be used to improve early detection, screening, diagnosis and treatment of HHT.

We are excited to announce that Representatives **Zoe Lofgren (D-CA)** and **Rose DeLauro (D-CT)** have added their support of H.R. 1849! BUT, in order to become law, **we need a lot more sponsors**. *You can make this happen by asking your friends, family and colleagues to contact their House Representative at the link provided below.*

What does the HHT DATA Act mean for the future of HHT?

- It would transform HHT research and treatment by creating a federally led and financed initiative for early diagnosis and treatment of HHT that will prevent the premature deaths of HHT patients and lower health care costs.
- The Centers for Disease Control and Prevention (CDC) would provide comprehensive education on, and disseminate information about, HHT to health professionals, patients and the public.
- The CDC would conduct a population study to more accurately identify the prevalence of HHT and hemorrhagic strokes resulting from the disease.
- National Institutes of Health (NIH) would implement an HHT initiative to assist in coordinating activities to improve early detection, screening and treatment of people who suffer from HHT. The NIH initiative will focus on advancing research on the causes, diagnosis and treatment of HHT.
- It would authorize \$5 million for each fiscal year until 2020, offset by reductions to salaries and expenses at the Department of Health and Human Services.

Help us lay down the law for HHT by getting your representative involved!

Visit <https://popvox.com/bills/us/114/hr1849> to send a personalized email to your House Representative and ask them to co-sponsor this bill!

21st HHT Center of Excellence in North America UPMC and University of Pittsburgh Pittsburgh, PA



Medical Director: Christopher Faber, MD
Research Director: Beth Roman, PhD
Program Coordinator: Kathleen Lindell, PhD, RN
To make an appointment CALL 412-648-6161 (request a referral to UPMC HHT Center)

Dr. Faber and Dr. Roman have partnered with Dr. Madan-Khetarpal's pediatric team of specialists at Children's Hospital of Pittsburgh of UPMC who will care for patients less than 18 years of age. UPMC and the University of Pittsburgh has created a genuinely integrated health delivery system with one of the strongest ENT teams in the U.S. treating HHT. Led by Dr. Stella Lee, her team uses "state-of-the-art, high-definition video nasal endoscopy to target the multiple small telangiectases that line the nasal cavity, employing targeted laser therapy, cautery and topical injections of bevacizumab to control nose bleeds."



Dr. Faber is an Associate Professor of Medicine in the Division of Pulmonary, Allergy and Critical Care Medicine at the University of Pittsburgh School of Medicine and has been on staff at UPMC Presbyterian Shadyside since 2002. He is board certified in Internal Medicine, Pulmonary Medicine, and Critical Care Medicine.



Dr. Roman is a Cure HHT research grant recipient and an Assistant Professor in the Department of Human Genetics in the University of Pittsburgh Graduate School of Public Health. She is an avascular developmental biologist who has been studying the mechanisms involved in development of arteriovenous malformations, with a particular focus on HHT, since 2002.

HHT Specialties at UPMC - Pitt

Cardiology
Dermatology
Gastroenterology
Genetics
Hematology
Hepatology
Interventional Radiology
Neurology
Neurosurgery
Oral Surgery
Otolaryngology (ENT)
Pediatrics
Pulmonology

A major component of HHT's mission is to ensure that families have access to expert care. Our HHT Center review team was truly impressed with the strong group of specialists, nurses, genetics and medical professionals who are able to screen, treat and manage adults and children with HHT, said Marianne Clancy, Cure HHT Executive Director.

CHAMPIONS FOR CURE HHT

Did you know families and friends from around our community gathered to celebrate America's favorite pastime (three major baseball games for the Baltimore Orioles, New York Yankees and Seattle Mariners) to raise awareness during Global HHT Awareness Month? We only have 50% of your email addresses. If you missed out, sign up to receive electronic announcements by registering online at CureHHT.org or send us an email at hhtinfo@curehht.org and we'll add you to the list!

Finding a cure for HHT cannot be done alone. It has taken, and will continue to take the entire Cure HHT community to push toward the ultimate goal. Your support of the Cure HHT mission is driving forward awareness efforts and general understanding, leading to better research and treatment.

Together, you have raised more than \$120,000 toward finding a cure for HHT and helped fund some of our most important projects to date! We are grateful for your continued support. Special thanks to you all!



UNC Walk - Dr. Raj Kashuri, Dr. Charles Burke and Laurie Birdsong and HHT families



DC Walk - Roy Forey, Karakashian family, Weise family, Jody M., Lane family and the Craft family

"I'd like there to someday be a cure, so I am here today to walk, to educate and provide outreach."
- Jody M., New York



Bay to Breakers - Greg & Angela Brown



Stoner Golf Tournament - Steve Stoner and family



Night of Hope - Jody and Clay Nissan, Jenn Urbanek, Roz Youngert, Steve and Amy VanBrussel, Todd and Angela Schram, Bill Trail and the entire Hope Crew



Rochester Walk - Neeta and Nick Pai, Dr. Vivek Iyer, Verna S., Seema K., Shailaza S., Kargagam M., Asha J., Neeta K. Shyamala B. and Nisha K.



Zumba Event - Lori L.

"If we all learn about it, we can help others and we can actually help to raise more awareness and help cure this disease."

- Nicole W., Virginia



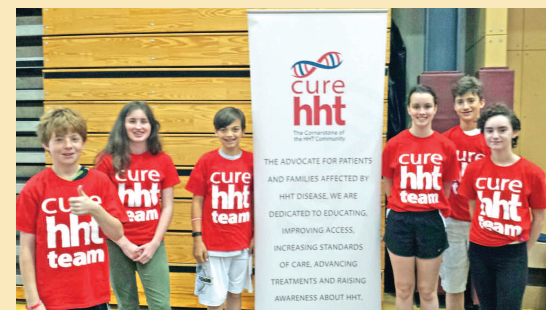
Memphis Walk - Sandra H.



Cleveland Walk - Denise Sherman and Sarah P.

"This is my Mother's Day gift. My son found out about the walk and donated over \$1000 for it. And now watching all of this, you have inspired us to have our own walk."

- Diane M., New Jersey



Seattle Academy of Art and Sciences Walk
- Rinn Family

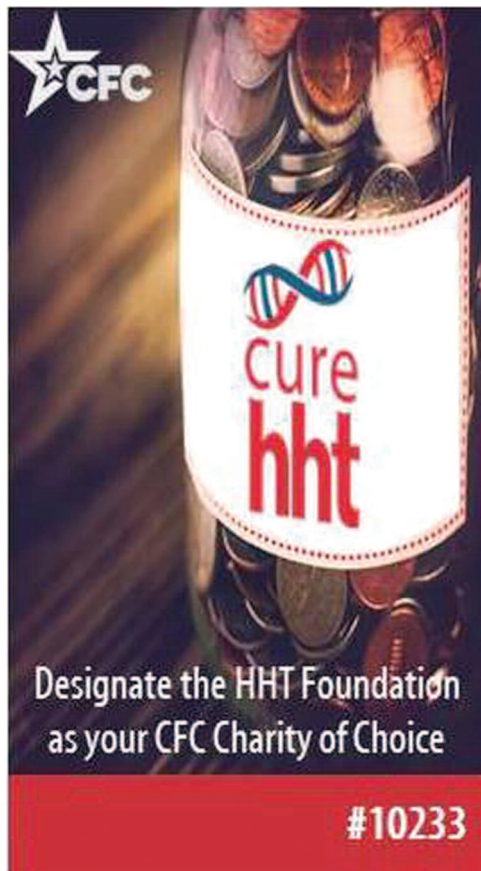


Arkansas Walk - Lindsay F.

Join us in spreading awareness and raising funds to continue our crucial goals of educating physicians, promoting research and increasing access to care.

Maine - Cure HHT Team Walk 10/11/15
Pennsylvania - Hershey Park in the dark 10/24/15
Georgia - Cure HHT Team Walk 10/25/15
Michigan - Night of Hope 3/12/16

Photo Credit: Night of Hope - Richard Sheff; Rochester Walk - Krishna Dhulipala; Memphis Walk - Nichole Park

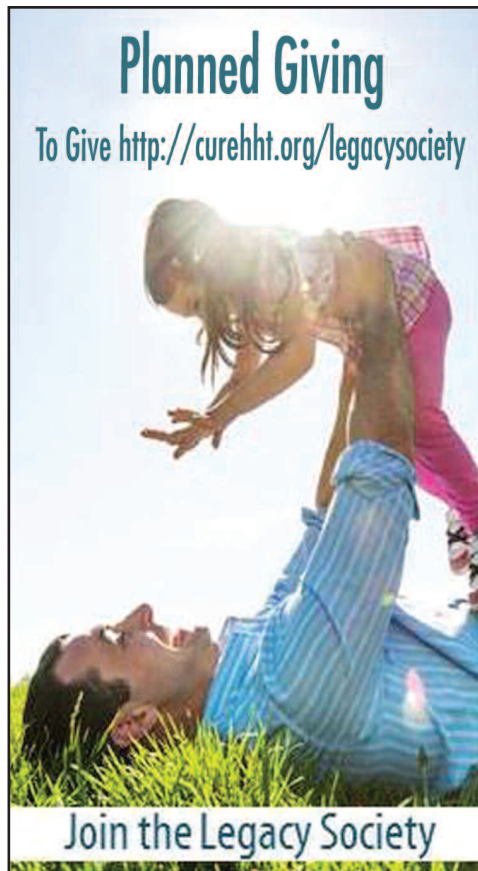


CFC

cure hht

Designate the HHT Foundation
as your CFC Charity of Choice

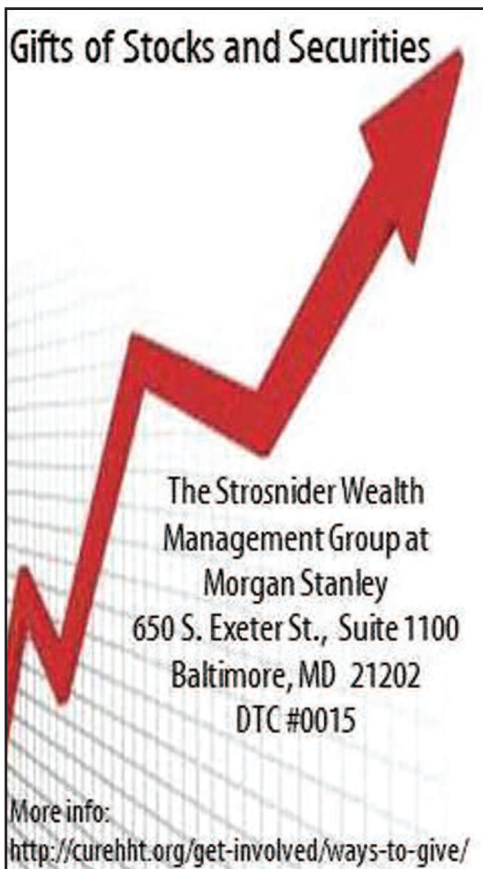
#10233



Planned Giving

To Give <http://curehht.org/legacysociety>

Join the Legacy Society



Gifts of Stocks and Securities

The Strosnider Wealth
Management Group at
Morgan Stanley
650 S. Exeter St., Suite 1100
Baltimore, MD 21202
DTC #0015

More info:
<http://curehht.org/get-involved/ways-to-give/>



Recurring Gifts

Monthly, Quarterly or Annually

Get Started:
<http://curehht.org/recurringgifts>

Save the Date

Join us in Boston . . .

HHT National Patient & Family Conference

October 28-30, 2016

Burlington, Massachusetts

As part of the HHT community, we each have been affected by HHT.

Whether you are newly diagnosed, a veteran patient, a sibling, a child or someone who provides treatment – we all have a stake in the future of this disease. We are returning to the Boston area for the National HHT Patient and Family Conference.

This is an unparalleled opportunity to hear about new HHT research breakthroughs, review the latest treatments and connect with others who have joined the fight. Cure HHT believes that education is the most important tool in managing the disease. We strive to teach people about the risks of ignoring symptoms and the benefits of taking proper action. By providing you with vital information, you will be empowered to more effectively manage HHT.

Location:

Boston Marriott Burlington

One Burlington Mall Road, Burlington, MA 01803

Cure HHT has negotiated discount guest rooms at a rate of \$125/night plus taxes. You can reserve your room now by calling 888-855-7741 and mention the Group Code "**HHT Patient and Family Conference**". Registration and the conference program schedule will be available in the coming months.

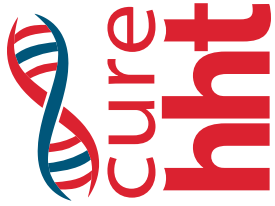
Volunteers and Auction Donations

You don't have to live in the Boston area to get involved in the National Patient & Family Conference. We need volunteers to help prepare conference materials a few days before the event, help with registration at the conference, be a conference ambassador to make first time attendees feel welcome, assist with the youth program, take photos and so much more.

Cure HHT requests donated items for the auction which will be held after dinner on Saturday night to benefit research, education and awareness. There will be a live auction, silent auction and raffle prizes so donated items will range from vacation packages, sports memorabilia, electronics, destination passes and jewelry to local / national eateries and gift cards. We welcome all types of donations; be creative and think outside of the box!

If you have the desire to get involved we have a place for you!

Contact catheleen.kinnear@curehht.org or 410-357-9932



Cure HHT
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Monkton, MD 21111

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*"I hope to inspire people to take action
in fighting to find a cure for HHT
through spreading awareness and
financial donations."*

This HHT hero is going the extra mile
to cure HHT and you can help! Donate at
www.curehhtteamanthonyanzell.causevox.com
to help Anthony reach his \$20,000 goal
for the **Dances With Dirt Ultra-Marathon**
on September 26.

If you no longer wish to receive this newsletter please
contact hhtinfo@curehht.org or 410-357-9932.