

Edition:  
Winter/Spring  
2015

# Cure HHT newsletter

News & Information for the HHT Community

## THIS IS OUR YEAR OF TRANSFORMATION

**C**ure HHT could not be more grateful for the support you have shown over the last year! Because of your level of dedication, we've named 2015 the Year of Transformation. We plan to transform your continued engagement into major advances across the HHT field.

For 24 years, Cure HHT has been the driving force of a global initiative to promote awareness of HHT, inspire critical research, discover new treatments, advocate for families and patients and create lasting bonds within the HHT community.

This year will be no different, as we work together to achieve advancements we could only have imagined a few years ago. Though our ultimate goal is to find a cure for this disease, we aim to dramatically change its course in our lifetime as well.

So, what do we have planned for this next year? Research is already on the move across the United States in the form of focus groups, brain AVM study recruitment, clinical drug trials and the new outcomes registry to study HHT patterns in families.

Join us as we push the HHT movement forward into the future!

Together, we will witness as this transformational work increases access to and quality of expert care, and in turn, expands our understanding of HHT to fund further research and bring us even closer to finding a cure.

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The Cornerstone of  
the HHT Community

# TO THE CURE HHT COMMUNITY:



This is the year our community will partner to transform the face of HHT!

In my last message, I posed the challenge to **Join the Movement**. This is it, the movement forward.

Cure HHT has designated 2015 as The Year of Transformation, the year we will spark action toward a new era of HHT progress - leading awareness initiatives, increasing access to expert care and funding focused research.

And the Cure HHT organization and Board of Directors have a strategic plan in place to pursue these goals aggressively.

Our researchers now have the opportunity to submit proposals regarding vascular malformations to be considered for millions in grant funding by the Department of Defense's Peer Reviewed Medical Research Program. It is through our determined focus and your efforts reaching out to congressional representatives that we have achieved this notable success!

This year also holds major updates for clinical trials, new research, data analysis and treatment options. Through personalized medicine and funding dedicated to critical research, we can target therapeutic approaches to understanding AVM formation, reversing AVMs and even preventing them from forming.

Help us spread the good news and HHT awareness by sharing the monthly E-Newsletter, passing out online factsheets to physicians or contacting the local media about your HHT experience.

**Let's build the future that we want to together!**

Best,

Marianne S. Clancy  
Executive Director

# CONNECT WITH US



[facebook.com/hht.org](https://facebook.com/hht.org)



[@hhtawareness](https://twitter.com/hhtawareness)



[youtube.com/HHTFoundation](https://youtube.com/HHTFoundation)



The Cornerstone of  
the HHT Community

**Marianne Clancy, RDH, MPA**  
Executive Director

**James Gossage, M.D.**  
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**Marie Faughnan, M.D.**  
Scientific Research Director

## CURE HHT NEWSLETTER

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# NEW LEGISLATION AIDS HHT RESEARCH FUNDING



Big developments in HHT research are on the way now that millions in grant funding is available through the Peer Reviewed Medical Research Program (PRMRP).

This huge breakthrough came in December, when the Defense Appropriations Bill was passed, adding malformation-related conditions, including HHT, to the list of eligible research topics under the program.

“We have worked hard through the years to get into this program,” said Marianne Clancy, Executive Director of Cure HHT. “We anticipate there will be strong collaborations among our global HHT research community.”

It took two years of targeted advocacy efforts - meeting with the Department of Defense, working with congressional representatives, writing letters to legislators and conferences between HHT medical specialists - to achieve this breakthrough.

**This new legislation gives the HHT scientific community access to \$240 million available in grant rewards for research efforts over the next year.**

Program administration is expected to issue a final announcement on the availability of funding and the grant guidelines this spring.

## PROGRAM HISTORY

The Peer Reviewed Medical Research Program was established in 1999 to support research across a full range of sciences and medicines, with the underlying purpose of enhancing the health and well-being of currently and previously serving personnel and their families.

Congressional appropriations for the PRMRP totaled \$644.5 million through 2013, supporting nearly 550 awards in more than 100 different topic areas.

# ANNOUNCING NEW CLINICAL TRIALS FOR HHT RESEARCH

**We are pleased to announce our partnership with one of the most respected names in medicine - GlaxoSmithKline.**

Together we have begun a new clinical study designed to test whether bleeding episodes can be reduced in patients with chronic HHT-related bleeding, focusing on individuals with persistent anemia or who require iron infusions.

Specifically, the study will examine the effects of a drug called Pazopanib, which partially blocks the response to various vascular growth factors, including VEGF. Patients will participate in a baseline screening period along with up to three months of drug therapy and follow-up visits.

This new relationship will advance progress toward finding a cure for this disease! Our association to GSK will be instrumental as we seek to alter the face of this disease during the Year of Transformation.

## **Are you interested in getting involved?**

Participating HHT Centers of Excellence will be added to the

clinicaltrials.gov website once IRB approval is received. Visit [www.curehht.org](http://www.curehht.org) for the most current information on this and other clinical trials.

Choosing to participate in any clinical trial is an important personal decision that should be treated with care. Talk with your doctor and family before deciding to be a part of this study. To learn more, contact the study research staff with the contact information provided below. To answer general questions, visit the Learn About Clinical Studies page (<https://clinicaltrials.gov/ct2/about-studies/learn>).

When requesting information, please refer to this study by its Clinical Trial identifier: NCT02204371 Contact U.S. GSK Clinical Trials Call Center 877-379-3718 GSKClinical-SupportHD@gsk.com

Subscribe to our newsletter to receive the most current information regarding opportunities in the HHT community, or visit us online at [curehht.org/get-involved/](http://curehht.org/get-involved/) to learn about ways to participate.

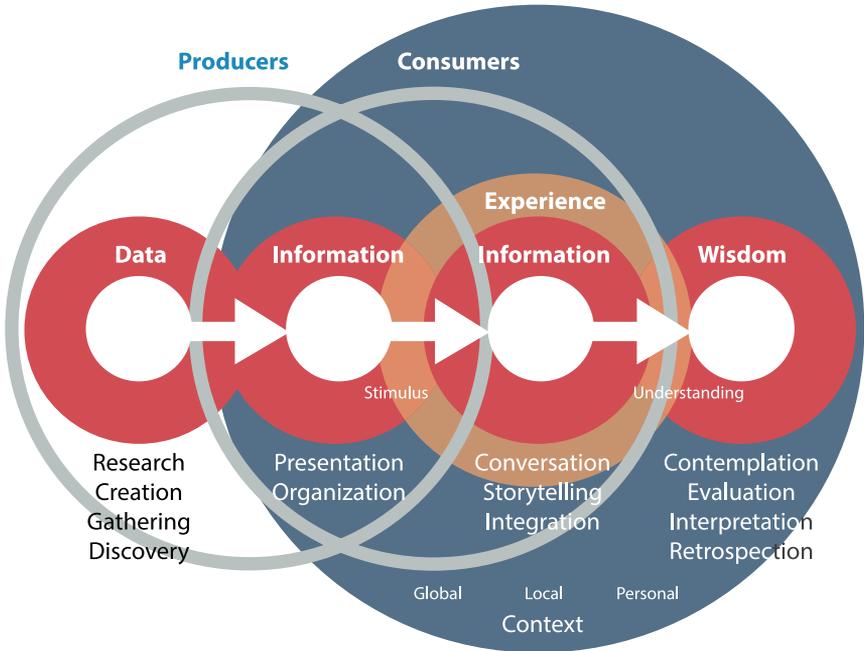
# CURE HHT LAUNCHES NEW OUTCOMES REGISTRY

Information available to physicians about HHT, treatments and outcomes will increase exponentially over the next several years thanks to the new Cure HHT Outcomes Registry. The goal is to collect enough patient data to allow scientists to create natural history studies of the disease for research use.

## How does it work?

The registry will include clinical, radiographic, genetic and treatment information of an expected 80,000 HHT patients who are evaluated at a North American HHT Treatment Centers of Excellence.

By linking all North American HHT Centers, the amount of patient data is increased 20 times over what any single HHT Center could gather and analyze!



## What will it be used for?

This information will be used for targeted clinical research studies of new therapies. Pharmaceutical companies have also indicated that access to this patient data is a determining factor in the decision to invest in HHT drug development.

## When does it start?

Cure HHT anticipates a pilot program of the registry, which was designed in part by Dr. Marie Faughnan, to begin this spring with involvement from two HHT Centers of Excellence. The short-term goal is to recruit 1,000 HHT patients in the first year with 500 data fields per participant.

## What is a research registry?

A research registry is an organized system that uses observational study methods to collect uniform data to evaluate specified outcomes for a population defined by a particular disease or condition.

Data collection typically includes:

- › Patient demographics
- › Family history
- › Risk factors, exposures
- › Disease characteristics
- › Disease testing
- › Treatment protocols

## Why are research registries important?

Research registries provide the ability to:

- › Capture standardized, quantifiable information about patients and disease
- › Collect population-based data, with enough subjects to scientifically draw conclusions
- › Ensure high data quality so outcomes are reliable
- › Collect longitudinal data, sometimes including decades of information
- › Measure or monitor safety and/or effectiveness of treatments
- › Springboard new scientific questions

## Examples of successful outcome registries:

### Colon Cancer Family Registry (C-CFR)

- › A resource for investigators to use in conducting studies on the genetics and molecular epidemiology of colon cancer
- › Investigators collect information on the patient, the patient's family, and incidence of cancer
- › Blood and tissue are collected to support ongoing molecular characterization of each family

### Infertility Family Research Registry (IFRR)

- › Helped to improve the health of people and families who have faced a diagnosis of infertility or dealt with infertility treatments
- › The IFRR population has provided enough information to launch three research studies

# CURE HHT TO AWARD YOUNG RESEARCH SCHOLAR GRANTS



New research is one of the most crucial aspects of our mission to find a cure for HHT. To attract the best new talent into the HHT area of study, Cure HHT is providing five \$30,000 grant awards to young scholars this year.

We invited Ph.D. scholars to submit applications for HHT-related projects, which are to be conducted under the supervision of an established investigator with an active research program.

And by our January deadline, we received 25 outstanding proposals from young scholars at universities and hospitals all around the world! We received submissions from the United States and Canada, as well as ones from as far as the Netherlands, United Kingdom, Belgium, France and Spain.

**WINNERS OF THE GRANTS WILL BE ANNOUNCED ON APRIL 18<sup>TH</sup>!**

**In the meantime, Cure HHT has begun working to double the number of awards. With so many amazing proposals, it's difficult to eliminate projects that could truly help the future of HHT. If you're interested in sponsoring one of the projects, contact Nicole Schaefer at [research@curehht.org](mailto:research@curehht.org).**

## CURE HHT ENCOURAGED APPLICATIONS IN THE FOLLOWING AREAS:

- › Basic mechanism of AVM formation
- › Signaling downstream of Alk1 and Endoglin
- › Cellular crosstalk in HHT
- › Stem cells in HHT
- › Modifier genes
- › In vitro and in vivo HHT models

# HOW TO DISCUSS HHT WITH MEDICAL PROFESSIONALS

Cure HHT learns more about HHT all the time, and while there have been enormous strides in research and advocacy, many physicians around the world remain uninformed. While Cure HHT cannot make it to every doctor's appointment, you can certainly take us with you.

Here are some Cure HHT questions to reference when speaking to a medical professional.

## What questions should I ask my doctor?

- › Are you familiar with/knowledgeable about HHT?
- › Have you treated patients with HHT? What was your process?
- › Is there another patient I can talk to?
- › Are you willing to consult with HHT specialists?
- › Would you read the medical literature on HHT?
- › Are you comfortable taking care of a patient with HHT?
- › If you are not available will there be a doctor on call who is knowledgeable about HHT?
- › What is this drug and what does it do?
- › What are the side effects of this drug? Ask your pharmacist for a printout on the drug and on all the drugs you are taking to prevent interactions.
- › Be clear about the dosage. If you are uncertain, ask your doctor about how to take the drug.

## How do I get my doctor to listen?

- › Prepare a list of written questions before the appointment.
- › Bring someone else to take notes.
- › Schedule a telephone appointment to get follow-up questions answered.

## Diagnosing HHT

A physician can diagnose HHT using a set of four criteria. A definite diagnosis has at least three, whereas a possible diagnosis only requires two.

- › Recurrent and spontaneous nosebleeds
- › Multiple telangiectasias on hands, lips, face or inside the mouth
- › AVMs or telangiectasias in an organ
- › A first degree relative who shares these criteria or has been diagnosed

### WHAT'S NEW IN HHT EDUCATION?

Find more information on HHT treatment and management at [www.curehht.org](http://www.curehht.org). Access the 12 new Cure HHT Factsheets under the resources tab as well as publications listed by topics.

# CURE HHT GIVES DR. ROBERT I. WHITE, JR YOUNG CLINICIAN AWARD

**Dr. Serra, Coordinator of the Hospital Italiano de Buenos Aires HHT Center of Excellence has been named the recipient of the 2015 Dr. Robert I. White, Jr Award.**

Dr. Serra was instrumental in opening the multidisciplinary HHT center in Argentina, developing an institutional HHT patient database for research and organizing the first Latino American HHT meetings.

He has been part of the HHT field for more than five years, having worked at the Hospital Sierrallana in Spain and the Madrid HHT laboratory.

Dr. Serra also presented at the 10th International HHT Scientific Conference in Ireland and has published several HHT-related articles in international journals, including the prestigious journal *The Lancet*.

**The Dr. Robert I. White, Jr Award was established in 2004, in recognition of Dr. Robert I. White Jr's outstanding contribution to HHT care and to the mentoring of other clinicians in HHT development and research.**

This award is given annually to a clinician who embodies Dr. White's qualities as a compassionate and dedicated clinician, devoted to improving HHT care.

# NORTH AMERICA HOSTS SCIENCE CONFERENCE



## 11<sup>th</sup> HHT INTERNATIONAL SCIENTIFIC CONFERENCE

### North America Hosts Scientific Conference for First Time

The world's leading HHT research and clinical specialists are coming together for the 11th International HHT Scientific Conference, held in North America for the first time.

**Our goal is to accelerate progress toward a cure for HHT by strengthening collaborations between clinicians and scientists to encourage more investigation into treatment research.**

The four-day event, running from June 11 to 14, will focus on HHT diagnosis, treatment and mechanism of the disease through cross-disciplinary information sessions, presentations and poster views.

The bi-annual meeting sponsored by Cure HHT is considered a

### INVITED SPEAKERS INCLUDE:

- › Michael Fallon, M.D.
- › Mardi Gomberg-Maitland, M.D., MSc
- › Alan Guttmacher, M.D.
- › Akiko Hata, M.D., PhD
- › Edda Spiekerkoetter, M.D.
- › Rong Wang, M.D., PhD

“must-attend event” for both established and early-stage researchers, as well as clinicians experienced in treating HHT and those just entering the field.

The conference will be held at South Seas Island Resort on Captiva Island in Florida, along the gulf coast.

**Visit <http://hhtconference.curehht.org/> for more information or to register. Register before the early bird rate ends on May 1.**

# JOIN THE MOVEMENT

## Your Involvement Makes a Difference

Thanks to volunteers all over the country, Cure HHT boasts countless fundraising and networking events throughout the year. Your engagement makes all of this possible!



## Get Involved With an Event

### MAY 17

Stoner Golf Tournament in Kresgeville, PA

### MAY 17

Bay to Breakers in San Francisco, CA

### MAY 30

Cure HHT Team Walk in Rochester, MN

### JUNE 6

Cure HHT Team Walk in Washington, DC

### JUNE 11

Orioles vs. Red Sox in Baltimore, MD

### JUNE 12

Cure HHT Team Walk in Amity, AK

### JUNE 14

Cure HHT Team Walk in Memphis, TN

### JUNE 18

Mariners vs. Giants in Seattle, WA

### JUNE 19

Yankees vs. Tigers in New York, NY

### AUGUST 15

Agapi and Hope Gala in Cary, NC

## DON'T SEE AN EVENT IN YOUR AREA?

Contact Christine Kirkley at [christine.kirkley@curehht.org](mailto:christine.kirkley@curehht.org) or visit [curehht.org/get-involved](http://curehht.org/get-involved) to learn how to start your own.

Follow [@hhtawareness](https://twitter.com/hhtawareness) on Twitter or visit us at [facebook.com/hht.org](https://facebook.com/hht.org) for updates on events.

## It's All About Teamwork!



## It's Easy to Join Cure HHT Team

Our teams are going above and beyond with their fundraising efforts. They are helping to save lives and move the needle closer to finding cure for HHT. Sign up online at <http://goo.gl/NuiHPn> or email Christine Kirkley at [Events@CureHHT.org](mailto:Events@CureHHT.org) to start a team and invite your friends to join you.

**Each step and dollar you raise will make a difference.**

# WELCOME OUR NEW BOARD MEMBERS



**Julie Cooling** is CEO of RIA Database, a worldwide provider of financial data and software located in North Carolina. After graduating from Bucknell University in 1994 with a bachelor's degree in economics and a minor in finance, Julie founded RIA Database in 2005. She earned an award for the fastest growing company for her region in 2010.

Julie was diagnosed with HHT in 2001, and has had two PAVM embolization procedures since. After her diagnosis, her father, Bob Cooling, was diagnosed with the genetic disease, as were four other relatives.

Julie said she looks forward to rejoining the board, having previously served on the fundraising committee, to assist the foundation toward discovery of alternative treatment options for PAVMs. She also hopes to see the foundation secure consistent government funding.

Julie lives in Charlotte, N.C., with her husband, Chris, and two children, Jack (10) and Kate (8). She enjoys running, biking and playing soccer with her kids.



Though **Harry Chapman** is currently working as the director of special projects and gifts at Belmont University, he is better known as a television anchor for NewsChannel Five. After graduating from the University of Georgia in 1968, Harry went on to broadcast journalism, earning more than four awards for his work before retiring in 2006.

Harry has dedicated a large part of his time to volunteering with organizations like the Lymphoma and Leukemia Society, Muscular Dystrophy Association and The United Way. He has also served on the board of directors for six different groups.

Harry, who was diagnosed with HHT in 1966, hopes to use his role as a foundation board member to improve HHT research initiatives and create a stronger awareness within the medical community. Joining the board is the best way to protect his family, Harry said, adding that the majority of his three children and eight grandchildren have been diagnosed with HHT.

Harry lives in Tennessee with his wife, Angela.

# MONTREAL CENTER NAMES NEW DIRECTOR



Dr. Andreanne Gauthier has been named Director of the Montreal HHT Centre. As a pulmonologist, Dr. Gauthier has been training under Dr. Marie Faughnan since 2013, following a one-year fellowship in HHT under supervision at the Dutch HHT Centre.

**Dr. Gauthier attended and presented at the HHT Scientific Conference in Cork, Ireland (2013) and she also participated in the 2014 HHT Family and Patient Conference.**

Cure HHT is confident she will continue to be an important contributor to the international HHT scientific and clinical community as she has already begun to collaborate on several HHT research studies. She also plans to

## RESEARCH PARTNER BEGINS CLINICAL TRIAL OF AVASTIN

The Stanford School of Medicine Sinus Center is set to begin a clinical trial of bevacizumab injections, also known as Avastin, for the management of HHT-related nosebleeds. Cure HHT is funding this important research in partnership with the American Academy of Otolaryngology as a follow-up to the North American Study of Epistaxis (NOSE Study).

The purpose of the project is to determine if Avastin injections inside the nose at the time of nasal electrocautery surgery reduce nasal bleeding. To learn more about the study and participation eligibility visit our website at [www.curehht.org/medical-scientific/researchstudies/](http://www.curehht.org/medical-scientific/researchstudies/).

# HAVE YOU ATTENDED OUR WEBINARS YET?

YOU MIGHT BE MISSING OUT ON  
SOME VALUABLE INFORMATION

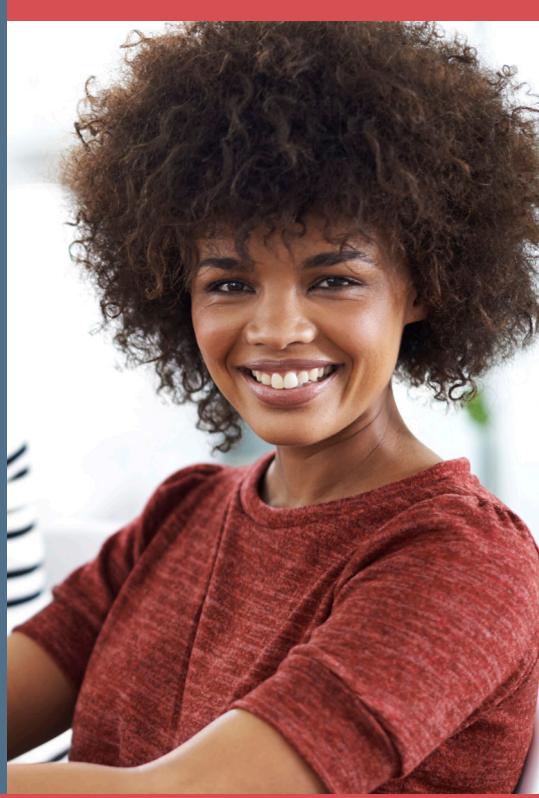
## UPCOMING WEBINARS:

### APRIL

Pathophysiology of HHT  
and New Research Grants

### JUNE

HHT Diagnosis: What does this  
all mean to me?



## WHAT PEOPLE ARE SAYING:

**“What a wonderful webinar tonight about HHT, and how it affects the liver and the heart. Awesome! Have to find out where they downloaded it.”**

MaryAnn Schill Lavery of Brookville, PA

**“I am a Nurse Practitioner and I learn so much from these webinars about my husband’s HHT. My two daughters have it as well.”**

Alice Davis of Kirksville, MO

## DID YOU KNOW WE POST ALL OUR PAST WEBINARS ONLINE?

Check them out at <http://curehht.org/resources/webinars/>

## PAST WEBINARS:

**OCT. 21, 2014** - HHT in Children: Talking to Your Nurse

**NOV. 5, 2014** - Our Recipe for Fundraising Success

**NOV. 25, 2014** - The Importance of Genetic Testing

**FEB. 11** - Brain AVM in HHT

**FEB. 26** - Cardiac and Liver Manifestation in HHT

**MARCH 12** - Treating Chronic Nosebleeds in HHT

# TRY SOMETHING NEW THIS WEDDING SEASON

Though life with HHT has its share of hard and trying moments, it can also be full of happiness, love and achievements. Celebrate those bright occasions with Cure HHT by giving an honorary donation or contributing a story to the new tribute wall. Family and friends can then sign your tribute guestbook and donate in honor of your experience.

**READ ON TO SEE HOW TWO WOMEN MADE CURE HHT A VERY BIG PART OF THEIR VERY SPECIAL WEDDING DAYS.**

## Gifts from the Heart

Submitted by Cate Lacy

When Jon and I were planning our wedding, we had the usual combination of excitement and slight trepidation at the amount of planning ahead. We felt so lucky to have found each other, and so rich to be surrounded by supportive and loving family and friends.



From a practical standpoint, we'd been living together for a year, so we already had a functional cooking pot and toaster. When it came to registering for gifts, we knew a charitable donation would make us much happier than any dishware.

We picked three charities close to our hearts - one supporting environmental conservation, one supporting Oaklands impoverished children and the HHT foundation.

Anyone reading this probably has had some friends or family affected by HHT, so it's enough to say that our family has felt the effects of loss, as well as what's possible with early detection and medical intervention.

**Every time we got a donation notification, we felt a little lighter in our hearts - and we never had to deal with all those waffle makers and lampshades.**

## To Love is to Give

Submitted by Amy Stoner

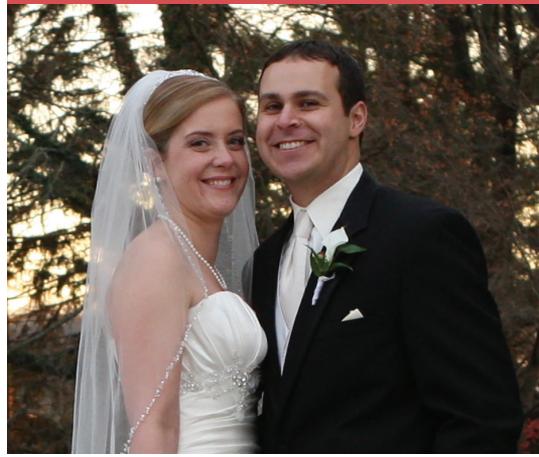
As more than 100 guests took their seats at the Stoner-Del Turco wedding reception, they found a small notecard sitting on their plate reading, "In lieu of favors, a charitable donation has been made to Cure HHT in your name."

Bride Amy Stoner wanted to use her happy day to give back to the HHT community, instead of spending money on a take-home candle, pack of cards or bag of candy as a favor.

"Cure HHT has done so much for my family in the past," Amy said, who has been happily married to her husband Matt for three years. "I thought the donation would be a wonderful way to represent the love of that day."

A special occasion, whether it is a birthday, wedding or graduation, provides a perfect opportunity to dedicate a special honorary donation and raise HHT awareness within those attending.

**"Giving back to Cure HHT was the perfect way to celebrate such a happy moment in my life," Amy said.**



HONOR A LOVED ONE WITH  
**THE MOST MEANINGFUL  
 GIFT OF ALL.**

**INTRODUCING THE  
 CURE HHT TRIBUTE WALL**

**Is there someone with HHT who has inspired you?**

**Someone with HHT who has left a lasting impression even if they aren't with you anymore?**

Remember them on the Cure HHT Tribute Wall. It's a place to keep those who have lost their fight to HHT part of the Cure HHT future.

Our simple form, available at <http://curehht.org/tribute-form/>, provides a place for you to share a story and photo of the person you wish to honor. And once your personal page goes live you can invited friends and family to sign the guestbook or donate in honor of your loved one.

# YEAR OF ACTION 2014 IN REVIEW

**HHT Foundation International took bold steps in 2014 to reposition and rebrand as a stronger, more assertive advocate for the HHT mission.**

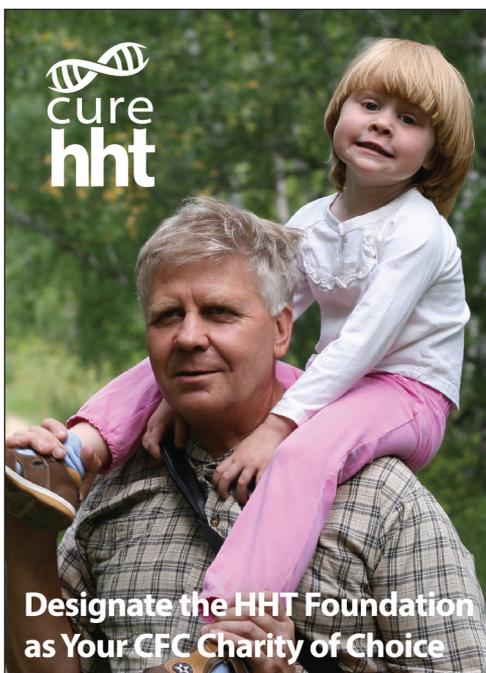
While this means we have a new name, logo and color chart, it's really the energy behind the new brand that continues to motivate Cure HHT toward the ultimate goal of finding a cure.

Over the past year, Cure HHT has been in the forefront of HHT advances, enhancing treatment, improving access to care and increasing awareness.



## **Here's a glimpse of what we accomplished together in 2014:**

- The HHT Diagnosis and Treatment Act was introduced to Congress (S.908 / H.R.4592).
- HHT was added to the Defense Appropriations Bill as a type of vascular malformation, opening new research grants for the HHT scientific community.
- A new HHT Center of Excellence opened at the University of California at San Francisco.
- The North American Study of Epistaxis, known as the NOSE Study, was completed with results anticipated in 2015.
- Cure HHT developed new relationships with bio/pharma companies to accelerate drug discovery and research efforts for HHT within the next year.
- The HHT Outcomes Registry is in its final stage of development to be used for creating natural medical history studies and follow patients on a long-term basis.
- Cure HHT launched the new Physician Directory online so patients can locate HHT Centers and knowledgeable doctors.
- The Cure HHT community organized and hosted Walks and Team events in 15 cities throughout North America.
- Cure HHT started a live webinar series to discuss common issues and challenges of HHT with experts in the field.
- The 17th National Patient and Family Conference was held in Santa Clara, CA with more than 200 patients and physicians in attendance.
- HHT education sessions were held at national medical and scientific conferences.



  
cure  
hht

Designate the HHT Foundation  
as Your CFC Charity of Choice



#10233

## OTHER WAYS TO DONATE

### WHO DOESN'T SHOP ONLINE THESE DAYS?

Shop till your hearts content  
and make a difference!

Below are website that provide  
a portion of their profits or  
sales to Cure HHT.

  
amazon  
smile  
You shop. Amazon gives.

  
goodshop

  
iGive.com

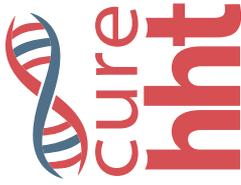


NOW OPEN!

## CURE HHT STORE

Our Cure HHT Store features Cure HHT  
shirts, coffee cups, kitchen aprons,  
phone cases and even a shirt for your  
pooch. By proudly wearing Cure HHT  
gear, you are helping create a brighter  
future for people with HHT.

Shop online at [Zazzle.com/CureHHTStore](http://Zazzle.com/CureHHTStore)



HHT Foundation  
International  
P.O. Box 329  
Monkton, MD 21111

### **Corporate Matching**

There are a lot of companies that double charitable donations!

Don't forget to check with your employer before preparing your Cure HHT donation.

A full list is available at [www.curehht.org](http://www.curehht.org) under the Donate tab.

If you no longer wish to receive this newsletter, please contact [hhtinfo@curehht.org](mailto:hhtinfo@curehht.org) or 410-357-9932.