Edition:
Summer/Fall
2014

Cure HHT newsletter

News & Information for the HHT Community

Say Hello to Cure HHT

Our new Cure HHT brand – the result of a comprehensive rebranding – was first introduced to more than 200 patients, families, medical and scientific professionals at the 17th National Patient & Family Conference on July 18, 2014.

Taking more than nine months, the rebranding, represents a significant transformation for the organization and plays a vital role in helping to expand efforts and reach more people. During the process it became immediately apparent that everything we do helps those affected by HHT. While our mission and core values will always serve at the forefront to guide our path to finding the cure for HHT disease.

Our new logo and tag line, The Cornerstone of the HHT Community, is a perfect union of past and present and honors our accomplishments and propels our commitment to the millions of people who are suffering from HHT and living in fear of the unknown consequences of HHT disease – each and every HHT patient deserves to have a chance to live a healthy and normal life.

The new brand will help advance many aspects of the organization's work, from patient and physician education to improving treatments. Cure HHT also serves as the platform that will help raise greater awareness about the disease.

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cure hht
The Cornerstone of the HHT Community
www.CureHHT.org

In Clancy's Corner

Meet our new organization! Our new brand, Cure HHT, includes a refreshed logo and tag line that we feel better reflects who the organization is today. Our new name activates our mission and enhances our efforts to advance therapies NOW, increasing access to expert care and dramatically increasing awareness.

Why the change? It was time to reflect the organization that we are striving to be in the future. We continue to be your trusted resource where you can find the latest research advances and educational materials to share with family and your doctors to help you live a full and healthy life. We are busy preparing a treasure trove of resources and information that you will be able to download on our website **CureHHT.org.**

Every week, I read stories in the media about rare and uncommon disorders uncovering incredible breakthroughs:

- Cystic Fibrosis drug therapies that extend life expectancy beyond what it was 30 years ago.
- Duchenne Muscular Dystrophy "End Duchenne" has 15 drug therapies in their pipeline.
- #ALSIceBucket Challenge is an example how social media can translate into over $79 million for crucial research and awareness.
- Autism awareness began with brave families who gave a face to the diagnosis accelerating research.
- Multiple myeloma has truly became the poster child for dynamic change.

So I ask, "Why not us? How do we create a powerful positive movement?" What do all of the disorders I mentioned have in common? They have an energized constituency that steps up to "Join the Movement."

"Is this disease important enough to you and your family to become engaged and step forward to transform this disease?" Together, we can accelerate progress. We can connect our families, the medical community and our superstar scientists. The time is now. We are ready and waiting to assist and support you in joining us!

All the best,

Marianne S. Clancy

Marianne S. Clancy, RDH, MPA
Executive Director, Cure HHT

DID YOU KNOW?

Cure HHT has more than 2,000 friends and fans on our Facebook page who are actively supporting each other and helping raise awareness about HHT disease?

Join the online conversation today!

Cure HHT IN ACTION

#CureHHT Don't wait for an emergency, go to an HHT Center and get tested! **#hhtconference #livingwithHHT**

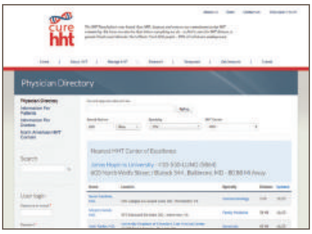
#CureHHT The eye doesn't see what the brain doesn't know. Great doctors may not diagnose #HHT b/c they don't know what 2 Look for! **#learnHHT**

@hhtawareness

facebook.com/hht.org

DIGITAL HIGHLIGHTS

Do you need help finding a doctor that specializes in treating HHT disease in your area?



Our new **Cure HHT Physician Directory** is designed to help patients, like you and your family, find a medical professional who is knowledgeable about HHT.

Our directory contains all the doctors, genetic counselors and staff associated with the HHT Centers of Excellence as well as other doctors and medical personnel that have been referred to us by other by HHT physicians and other HHT patients.

Searching for doctors near you is easy! Just type your location in the address field click the refine button. Directory listings include the physician's name, specialty, contact information, training history and procedural expertise.

Visit our website CureHHT.org and click on the "Directory" tab to get started.

> *I am excited about the new directory! I had no idea there were doctors in Jacksonville and Gainesville FL who dealt with HHT! – Cathy L., Ormond Beach, FL*

Disclaimer: All of the information in our database, including that of the Centers of Excellence, is self-reported and the HHT Foundation International makes no warranties about the credentials of any of the people listed herein.

For Doctors and Specialists

If you are listed in our directory, please make sure to update your information with any relevant changes.

If you would like to be added to the directory, click on the "create new account" button and enter your profile information. You will be contacted when your information is published.

HHT FOUNDATION INTERNATIONAL

BOARD OF DIRECTORS

Cure HHT newsletter

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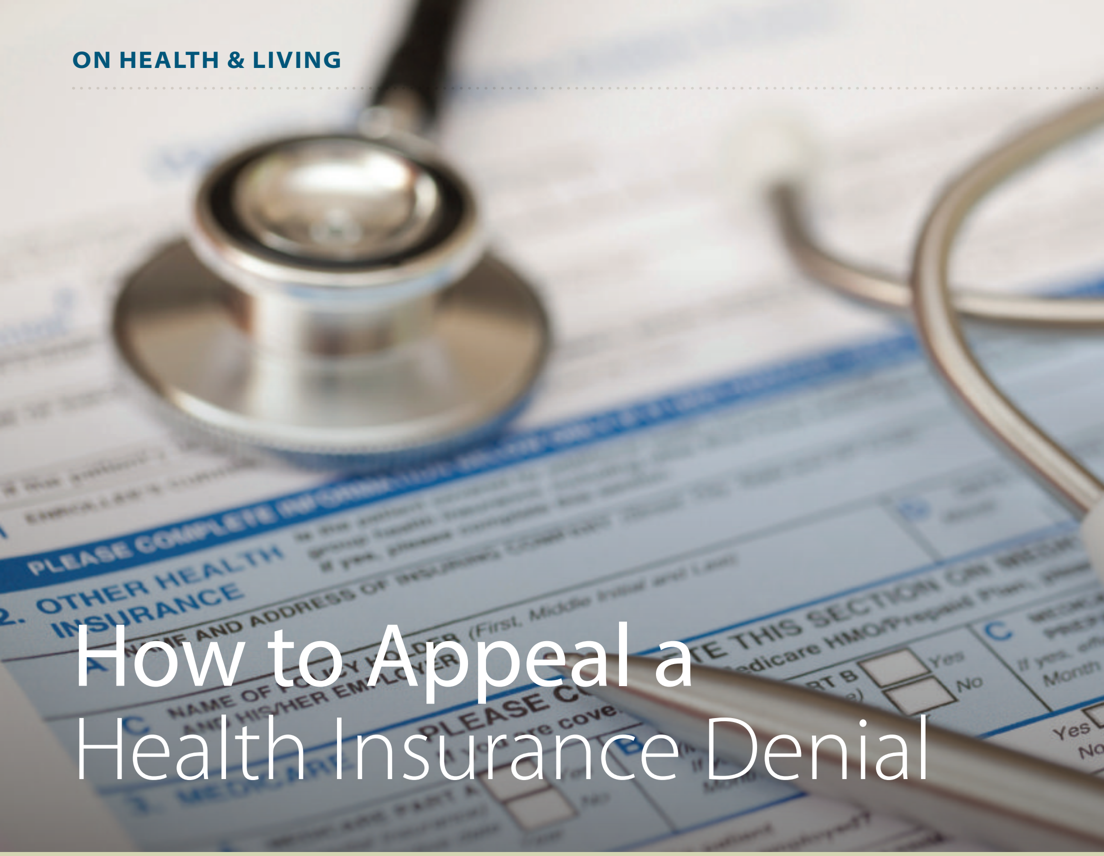

How to Appeal a Health Insurance Denial

There are processes in place to help those who receive denials from a health insurance provider.

Start by reviewing the denial letter to determine why the request was denied, what manners of appeals are available, and if there are time lines in which the appeal must be received.

MOST HEALTH PLANS REQUIRE THAT YOU COMPLETE THEIR INTERNAL APPEALS PROCESS PRIOR TO REQUESTING ASSISTANCE FROM A REGULATORY AGENCY.

Step 1: file an appeal with your health plan

- Generally health insurance appeals can be submitted over the phone by contacting your health plan's member/customer service department, in writing by mail or by submitting your appeal online at your health plan's website.
- Your appeal should be concise and include the reasons why you believe you need the requested service and your desired outcome. If your condition is serious, request the health plan review your appeal on an urgent/expedited basis.
- If applicable, include any relevant supporting documentation. This may include a copy of the denial letter, medical records and physician letters of support. Send copies of your documentation, not the originals, as these are not likely to be returned.
- Keep copies/records of your appeal documentation and any health plan correspondence, including letters, phone calls, dates and names.

- If you mail your appeal you may want to consider sending it by certified mail return receipt requested. If you submit your appeal online, print a confirmation of your submission.

Step 2: file an appeal with the health insurance regulator

If your health plan denies your appeal you should contact the applicable regulatory agency for assistance. Most health plans are regulated by a federal and/or state agency. These regulatory agencies accept complaints, appeals, and external/independent medical review requests and objectively review health care disputes between a consumer and their health plan. These agencies are in place to ensure health plans follow applicable state and/or federal law and provide enrollee's the health care treatment or services to which they are entitled to through their health plan contract.

It should be noted that each state regulatory agency has different mechanisms and time lines for filing an appeal. For specific information contact your states regulatory agency. A list of these agencies is provided on the HHT insurance resources page at bit.ly/hhtresources.

Sample Physician of Support Letter to Insurance Companies

RE: XXX
Birth date: XXX
To Whom it May Concern,

I am writing this letter in reference to the above patient, who has been referred to our HHT (Hereditary Hemorrhagic Telangiectasia) Center for evaluation. Insurance companies often question the need to refer a patient out of network or out of state for consultation regarding HHT. HHT is a hereditary disease that results in the gradual development of blood vessel malformations (arteriovenous malformations or AVMs). The absolute seriousness of this disease is due to the brain and lung AVMs, which can result in life-threatening complications such as stroke, lung hemorrhage, and death - without warning - even in asymptomatic patients. Review of a recent CT scan of the chest shows at least 1 pulmonary AVM in this patient.

There are currently 17 HHT centers in the U.S. and less than 40 in the entire world! Each of these centers has considerable experience in the management of HHT and the AVMs that complicate it. While many good-intentioned but inexperienced physicians have taken on the "challenge" of managing these patients, some of these cases have had unnecessarily tragic outcomes. As center director, I coordinate the care of 60-80 new HHT patients each year. Our HHT interventional radiologist embolizes 80-100 pulmonary AVM each year. While you may have in-network physicians who are willing to see HHT patients, it is unlikely that any of them sees more than one or two a year - and most have never seen one! Center referral may be a bit more costly to your company up front, but there are many tangible benefits, including a thorough and coordinated evaluation of the patient's HHT, avoidance of unnecessary tests, greater certainty of fixing AVMs the first time, and lower morbidity and mortality. In fact, the current Clinical Guidelines for HHT (published in the *Journal of Medical Genetics*) recommend initial referral to an HHT Center. If you are still uncertain as to the benefits of referral to an HHT center, please feel free to give me a call or visit the Cure HHT website at www.CureHHT.org. Thank you.

Sincerely,

Dr.___________

The New HHT Center of Excellence is Northern California's Leading Academic Medical Center

The University of California, San Francisco (UCSF) Medical Center is the only facility in northern California that specializes in the diagnosis and treatment of HHT disease. The UCSF Medical Center is among the nation's premier hospitals for 13 consecutive years in the America's Best Hospitals survey from *U.S. News & World Report*.

The **UCSF HHT Center of Excellence** provides a coordinated team of nationally recognized and specially trained physicians across multiple subspecialties. Physicians have extensive knowledge and provide patients with comprehensive and proactive approach to screening, diagnosis management and treatments.

Specialized resources include:

- World-renowned interventional and neurointerventional radiology treatment facilities.
- Access to the Center for Cerebrovascular Research (CCR) with a focus on vascular malformations of the brain.
- The USCF Pediatric Brain Center will be part of the UCSF Benioff Children's Hospital in early 2015.

Physician specialists include:

- Interventional Radiology
- Neurointerventional Radiology
- Pulmonology
- Cardiology
- Pediatrics
- Gastroenterology
- Genetics
- Otolaryngology/Head & Neck Surgery
- Neurology
- Dermatology

UCSF HHT Center of Excellence Co-Directors:

Miles Conrad, M.D., M.P.H.

Dr. Conrad is an Associate Clinical Professor in the Department of Radiology at UCSF. A member of UCSF's staff for six years, he specializes in minimally-invasive treatment for pulmonary AVMs.

Steven Hetts, M.D.

Dr. Hetts is an Associate Professor in the Department of Radiology at UCSF and Chief of Interventional Neuroradiology at SFGH and SFVAMC. He provides minimally-invasive endovascular treatment of brain AVMs.

UCSF HHT Center of Excellence
Website: bit.ly/ucsfHHTcenter

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Social Security Income (SSI) & Social Security Disability Insurance (SSDI)

WHAT IS THE DIFFERENCE?

by Andrea Olitsky, JD, MBA

A time may come when a person with HHT finds themselves in need of government assistance due to their disability.

With initials so similar, it's easy to confuse the two programs. The following discusses the options available and the differences between them.

Supplemental Security Income (SSI)

This federal income supplement program helps aged, blind and disabled people, who have little to no income, with cash assistance to help meet basic needs for food, clothing and shelter.

In order to qualify for SSI, an individual's monthy earnings (Substantial Gainful Activity (SGA)) must be less than $12,840 a year or up to $1,070 a month. Spousal income and any assets, owned individually or jointly, can also be counted to determine eligibility.

SSI is also available for children who are disabled and meet the financial requirements of the program which is based upon income and resources of the child's family. Disability determination is based on a different standard than adults. A child who is determined disabled can receive benefits through age 18; and is then eligible for future benefits, if they meet the adult criteria.

Social Security Disability Insurance (SSDI)

This federal insurance program is not a welfare program because individuals pay into the system through taxes that are withheld from their paycheck. SSDI provides cash benefits to replace some of the income that someone living with HHT may no longer earn due to their disability.

The Social Security Administration (SSA) determines if you qualify for the benefit if you:

1. Worked and paid enough in social security taxes.
2. Have a disability that is caused by disease or injury severe enough to prevent you from working at any job.
3. Have a disability that is expected to result in death or has lasted or is expected to last at least 12 months.

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Have you worked enough?

Your insured status is based on "work credits" or quarters of coverage." Work credits are earned by working in a Social Security-covered job and paying Social Security taxes: FICA or if self-employed SECA taxes. The number of work credits you need depends on your age and when you became disabled.

You can earn up to four credits each year. The amount needed for a credit changes from year to year. In 2014, you earned one credit for each $1,200 of wages or self-employment income. When you've earned $4,800, you have earned your four credits for the year.

If you worked enough: do you meet the medical eligibility?

The SSA recognizes HHT as a genetic disease leading to excess and abnormal blood vessel formation. The excess blood vessels may be formed in the skin or mucous membranes as well as in body organs.

Common organs affected include: brain, liver and lungs. For the full definition visit, bit.ly/HHTdefinition.

HHT is found in Section 7.07 of the Blue Book, the SSA's official listing of potential qualifying conditions. In order to meet the listing requirements for Social Security disability benefits based on HHT you must: hemorrhage requiring transfusion at least three (3) times during the 5 months prior to adjudication.

What if you don't meet the criteria?

If you do not meet the criteria set forth in the official SSA's listing, you may still qualify as a result of what your condition has on affected organs. Your claim can be evaluated in relation to any and all major organs affected. If it is, the particular requirements for qualifying for disability benefits are found in the sections pertaining to those organs.

Most commonly these will be:

- **Section 11.00** for telangiectasia affecting the brain;
- **Section 3.0** for telangiectasia affecting the lungs.
- **Section 5.00** for telangiectasia affecting the liver.
- **Section 1.00 and/or 11.00** for telangiectasia affecting the spinal cord.

What about private disability insurance?

SSI and SSDI are federal government programs and differ from private disability, a type of insurance which is often provided as a benefit of employment or purchased individually by self-employed people or those who want additional coverage (not offered through their employer).

Private disability insurance policies can vary significantly from carrier to carrier and not all employers offer it as a benefit. It's important that an individual with HHT obtain a copy of the policy to determine the procedure of applying for benefits, how much the benefit will be, how long the benefits will last, and if there are work incentives. Usually these benefits, when first offered by an employer do not require disclosure of a disease to qualify.

Ways to Apply for SSDI:

Apply in person at a Social Security office. A list of SSA offices is available at https://secure.ssa.gov/ICON/main.jsp.

Apply by phone, call (800) 772-1213 to schedule an appointment.

Apply online at www.socialsecurity.gov/applyfordisability.

Download the SSA Disability Starter Kit at www.socialsecurity.gov/disability/disability_starter_kits.htm or call (800) 772-1213.

Imagine what $25 million of federal funding over the next 5 years could produce in research breakthroughs.

Make Your Voice Heard!

Did you know that HHT has never received any federal funding?

HHT is a long neglected national health problem that affects approximately 1 in 5,000 Americans. On May 8, 2013 U.S. Rep. Tim Johnson of South Dakota introduced the HHT Diagnosis and Treatment Act S.908 in the Senate. This legislation would authorize $5 million a year for the next five years to improve early detection, screening, diagnosis and treatment of HHT. A similar bill HR 4592 receiving bipartisan support, was introduced in the House by U.S. Rep. Jim Gerlach of Pennsylvania and U.S. Rep. Jim Himes of Connecticut.

Your voice can be heard in less than two minutes!!!

It's easy!!! Enter the following URL address into your web browser or click on the link: http://cqrcengage.com/hht/home. Once the website opens, click the "Write Congress Now" button, enter your contact information and then click the submit button.

It's all about the numbers

Each legislator's office counts how many emails they receive. Make sure to send the link to friends, family, neighbors, associates, etc. and ask them to support you by emailing their legislators – you don't have to have HHT to speak up and support it.

Join the Cure HHT legislative movement

You can find more information on the specifics of The HHT DATA Act, current co-sponsors and how you can help at www.CureHHT.org/get-involved/legislative-advocacy/ or contact Sharon Williams at Sharon.Williams@curehht.org.

"This bill will help fill a gap in care for thousands of patients suffering from HHT and provide patients and physicians with the resources necessary to educate, screen for, treat and better understand this sometimes deadly disease. Continuing to disregard the need for simple screenings and broader education for treatable diseases, like HHT, that could help save lives and reduce costs is unacceptable. As our nation's health care system transitions toward a focus on keeping people healthy, this bill provides important tools to detect and treat HHT and improve outcomes for those living with this disorder."

– U.S. Rep. Tim Johnson
of South Dakota

THE CLOCK IS TICKING!

We need your help, email your legislators ASAP! Congress has to act by the end of the year.

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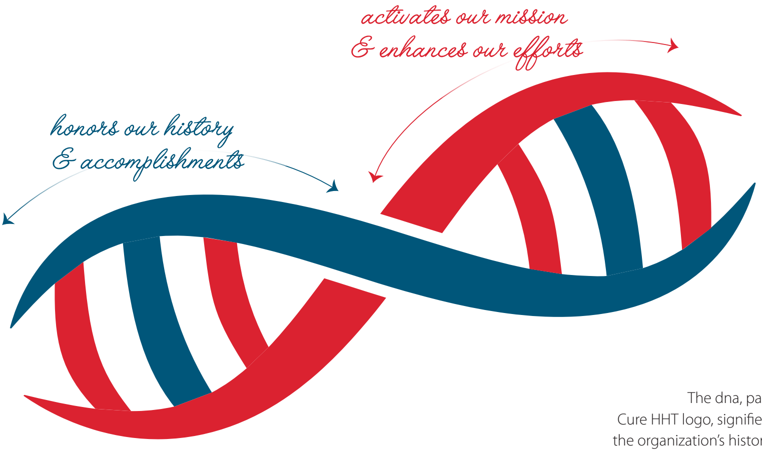
The perfect union of past and future



The dna, part of the new Cure HHT logo, signifies the unify of the organization's history and future.

What does this change mean for the HHT community?

The future has never looked brighter, Cure HHT signifies a new hope for better treatments today and an accelerated pace to finding a cure for HHT.

Our efforts continue to help:

- Fund the latest research;
- Provide patient and families with education materials and information;
- Educate physicians to recognize the signs of HHT;
- Improve access to specialists and standards of patient care and;
- Raise awareness and elevate patient voices to the national stage.

90% of people that have HHT, don't even know it.

HHT affects 1 in 5,000, almost 1.4 million people worldwide (63,000 in the US), which means that 1.2 million people don't even know they have this genetic disease. In order to transform treatments and change perceptions, we need to shed light on the serious implications that can result if HHT is left undiagnosed.

With lack of HHT awareness even among the medical community means that it can take an average of 30 years to receive a correct diagnosis. Through proper diagnosis and treatment, life-threatening complications from HHT can be prevented. It is critical for the public and medical professionals to be aware of the signs of HHT as it is often misdiagnosed. Treatments and research on HHT have not kept pace with other diseases. Cystic Fibrosis and ALS, both as common as HHT, take less time to diagnose. Today, our efforts are funding the best HHT research, educating patients and physicians and improving access to qualified HHT physicians.

> *It is time to shed light on the serious nature of HHT and the devastating impact that can occur if HHT is left undiagnosed and untreated.*
>
> ***Marianne Clancy, Cure HHT Executive Director***

Work is already underway to:

- Build a robust research grant funding program
- Grow partnerships with Bio/Pharma
- Develop specialized communications and tools for patients and caregivers
- Provide online physician education
- Launch the Cure HHT Physician Directory **(UPDATE: The directory now online at Directory.HHT.org)**

Did You Know? In 2015, Cure HHT is are hosting the 11th International Scientific Conference!

To hear about other upcoming Cure HHT Team challenges, just follow us on Facebook!

SPECIAL THANKS TO TRISH LINKE AND RYAN HARRINGTON FOR BOTH RAISING OVER $1,000 IN SUPPORT OF CURE HHT.

WAY TO GO!!!

AWARENESS MONTH:

30 Days for 30 Years

June Cure HHT Team Challenge

This year for HHT Awareness month we shined a spotlight on the lost years spent suffering, needlessly, and the tragic deaths that could have been prevented with screening and available treatments.

Awareness is change. During June, over 20 individuals in the HHT community accepted our **Nationwide Cure HHT Team Challenge** and helped spread the word and raise funds for HHT disease.

Team members created online fundraising pages and shared their stories with friends and family through emails and social media. **Kudos to those individuals who helped to raise over $6,300 in 30 days.**

We would also like to thank those of you that coordinated community blood drives, contacted local media and shared our posts via social media in an effort to raise awareness.

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

Community **Events**

> *It is my sincere hope that even just one person who experienced the 'Night of Hope' engages their own family and friends and plans their own fundraising event because we really can make a difference.*
>
> **Jody N.**

> *It was truly easy and meaningful to organize this event. Everyone was more generous and supportive than we could have imagined.*
>
> **Sophia H.**

Join us in thanking the individuals whose actions will help us to reach the day when HHT no longer threatens the lives of those we love.

2nd Annual Night of Hope

Jody Nissan

March 22, 2014
RAISED $45,000

Thanks to Jody Nissan and the HopeCrew for raising over $45,000 at the 2nd Annual Night of Hope Charity Ball & Silent Auction held on March 22 in Dearborn, MI. Guests had the opportunity to bid on such items as spa packages, sports memorabilia, jewelry and vacation getaways, to name a few.

Spin for HHT

Sophia Hershman

March 23, 2014
RAISED $7,250

Kudos to Sophia Hershman who took her passion to a new level on March 23. Using her love of spin classes, Sophia organized the first-ever Spin for HHT at the New York Sports Club in Dobbs Ferry, NY. Thanks to Sophia, her generous friends and family who raised over $7,250.

Kalb Kid's Soup Fundraiser

Austin & Madison Kalb

March 23, 2014
RAISED $1,216

Thanks to Austin Kalb and his sister, Madison who came up with the clever idea for a "Soup Fundraiser" in their community of Dubois, IN. With help of family members, they were able to raise $1,216 to help fund a cure for HHT.

Actions of passionate individuals accelerate our journey to the finish line!

> *The golfers who participated praised both the event and the cause, and many were heard vowing to return again next year.*
>
> ***Steven S.***

Email Events@CureHHT.org
for ideas to kickstart your event.

Diagnosed with HHT last summer, Austin and his family hope the money they raised will help find a cure so Austin and others can live a long, healthy life.

Future Aviation Golf Day

Adele & Frik Vandenberg

May 10, 2014
RAISED $2,000

Many thanks to Adele and Frik Vandenberg, who helped organize the Annual Future Aviation Golf Day in Ft. Meyers, FL. as well as the many sponsors and participants who helped raise $2,000 for Cure HHT. To top off the day, Team Vandenberg took home the first place trophy.

5th Annual Stoner Open

Steven Stoner

May 18, 2014
RAISED $13,000

The Fifth Annual Stoner Open was held at Hideaway Hills Golf Club in Kresgeville, PA. Thanks to the tireless efforts of Steven Stoner, the Stoner Family, and friends, 114 golfers enjoyed an afternoon of golf, food and prizes. This year's event raised more than $13,000.

It's All About Teamwork

cure hht team

Cure HHT Team Walk Cleveland, Ohio

📅 May 4, 2014
RAISED $7,600

Way to go guys! First time Cure HHT Team Captains, Denise Sherman and Marijo McCune organized a Cure HHT Walk in Fairview Park, OH. Over 65 participants showed their support to find a cure for HHT – and together raised more than $7,600. Special thanks to Jennifer Sherman and Keith Scouten for helping to make this event possible.

Cure HHT Team 5k Walk/Run Chapel Hill, NC

📅 May 18, 2014
RAISED $3,200

The first Annual Walk to Cure HHT 5K Run/Walk hosted by The University of North Carolina, UNC Healthcare, and the UNC HHT Center of Excellence was a roaring success. Special thanks to Cure HHT Team Captain, Dr. Charles Burke who organized this event along with Dr. Raj Kasthuri, Laurie Birdsong, Laura Melega and Karen Smith. Together over 80 participants helped to raise over $3,200.

Cure HHT Team Run San Francisco Bay, CA

📅 May 18, 2014
RAISED $2,600

Thanks to Angela Carlisle-Brown and her husband Greg, who together with a team from Angela's law firm, Kilpatrick Townsend, ran the Bay to Breakers Race on May 18 to raise money and spread awareness about HHT and raised nearly $2,600.

> *Organizing a Cure HHT Team event helped me meet amazing people with such positive energy. Working together towards a goal that will make a difference is very rewarding. Our community is full of warm, caring, kind individuals!!!*
>
> ***Denise S.***

Cure HHT Team Walk Michigan City, IL

June 7, 2014
RAISED $1,500

Thanks to Stephanie Lee for organizing a Cure HHT Walk in Michigan City, IN. A special thanks to those who participated and helped to raise over $1,500.

Cure HHT Team Walk St. Paul, MN

May 31, 2014
RAISED $14,000

Hats off to Colleen Libhardt and Kathryn Green for organizing the Cure HHT Team Walk in St. Paul, MN. Over 140 adults and teens raised more than $14,000 and helped to energize the Cure HHT Team movement and turn this into an annual event.

Cure HHT Team Walk Washington, DC

June 22, 2014
RAISED $11,500

The 2nd Annual Cure HHT Walk was held in Washington, D.C. Over 80 walkers from cities up and down the east coast came to our nation's capital to raise awareness for HHT. Cure HHT Team Captain, Roy Forey found that one of the great benefits of the walk was the comradery that developed amongst everyone. Thanks! Roy Forey for helping to organize this successful event that raised over $11,500.

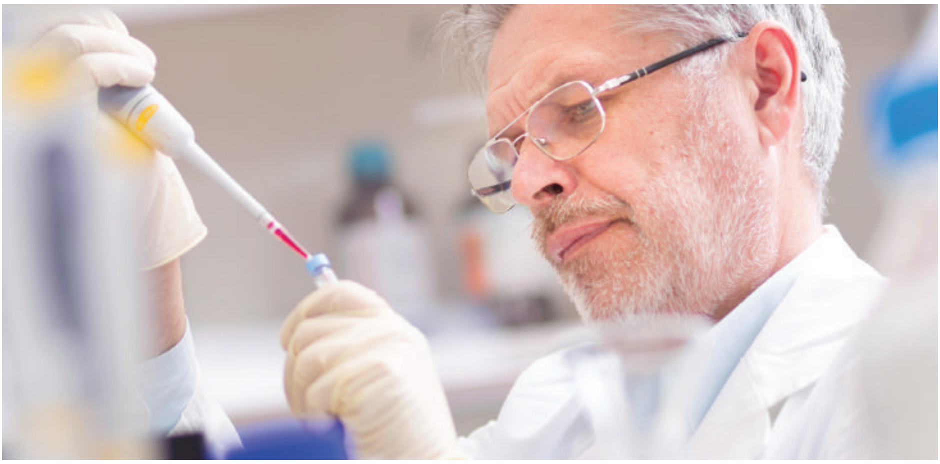
Cure HHT Team Mermaids Make Miracles

June 22, 2014
RAISED $8,700

This year the Salty Sea Sisterhood joined the Cure HHT Team in an effort to raise money and awareness for HHT. Luci Janssen and seven of her dearest friends came together for a special weekend to celebrate their many years of friendship and raise money for a cause near and dear to all of them. The sisterhood raised over $8,700 to date to help find a cure for HHT, a disease that affects Lucille and many of her family members.

Thanks to Trina Estes for educating the Midlothian Kiwanis Club about HHT during June Awareness Month. As a result, she was presented a check to the HHT Foundation for $1000 on June 26.

> *I am the first in my family to be diagnosed and we are all in the process of being tested. It is so important that we get the word out and support research to cure this potentially deadly disease if not treated.*
>
> *Sarah D.*



Scientific Research will Transform How HHT is Diagnosed and Treated

Many scientists believe that the cure for HHT will come from a deeper understanding of what causes the disease. Answers to important disease-related questions can only be found by collecting data from a large number of people over time, analyzing patterns and the results of treatment.

This fall, the HHT Foundation will pilot test the newly developed **Outcomes Registry for HHT**, a critical tool in gathering natural history, treatment outcomes and quality of life issues from HHT patients.

Bio/Pharma companies have indicated that access to this anonymous data determines whether or not they decide to invest financial resources in drug development for HHT. This de-identified data will be available to scientists and physicians to assist in targeting clinical research studies of novel new therapies that will provide important breakthroughs for HHT disease.

Other important research news:

- We have received an **additional five years of funding from the National Institutes of Health (NIH) for the Brain AVM Study** to determine what genetic and clinical factors signal high risk for bleeding from brain AVMs. Based on the preliminary results, articles have been published showing that the risk of hemorrhage appears to be related to the clinical features of the brain AVM more than the underlying diagnosis of HHT.
- We are sponsoring a special symposia entitled, ***Molecular Mechanisms Underlying the Vascular Disorder HHT*** **on Oct. 21 at this year's North American Vascular Biology Organization Conference** which will be held in Monterey, CA.
- Preliminary results of the largest, multi-center **North American Study of Epistaxis (NOSE Study) are currently under review.** Thanks to 121 patients and six HHT Centers who participated in this research, we are learning the benefits and side effects of three nasal sprays, other lifestyle factors that affect nosebleed severity and the impact of genetics on response to therapy. Results will be shared as soon as they become available.
- Is HHT research important enough to you and your family to become engaged and step forward to transform this disease? You can start by participating in our **Brain AVM webinar on September 24th at 5pm EST.**

Be informed. Check our website frequently, follow us on Facebook and Twitter or contact our office at (410) 357-9932.

17th National Patient & Family Conference

AN OVERWHELMING SUCCESS!

This year's conference was designed to offer something for everyone – the newly diagnosed, the veteran patient, siblings, caregivers and medical professionals. With 225 attendees, including 50 medical professionals, no one left on Sunday without learning something new about HHT.

HHT medical professionals from all over the country shared new research findings and participated in panel discussions with patients. Panels, workshops and Q & A sessions allowed attendees to ask questions that went unanswered by their physicians at home.

> *Interacting on a personal level with these brilliant doctors with questions that we had about the disease was invaluable. It gave us vital information to know the importance of curing and managing HHT.*
>
> ***Luci J.***

Attendees had a choice of two tracks: Family Planning and Pediatrics or Advanced Stages of HHT, which included a presentation on HHT manifestations of the heart and liver and discussed the various ways that the heart can be affected in HHT. Two top workshops, *Navigating the Insurance Maze* and *Social Security Income and Disability*, are included in this newsletter on pages 4-8.

Friday evening, attendees mingled by the pool, at the Welcome Reception, listening to live music by *Gary Stanionis and the Grand Slam Band*. It was an honor for Gary, a world class percussionist, who was diagnosed with HHT at age 27 and has two children who suffer with this disease to be able to give back to the HHT community. Research posters provided attendees an opportunity to view the cutting edge research being conducted by scientists and clinicians supported by Cure HHT.

The weekend was packed with educational sessions and fun-filled activities. A traveling exhibit hosted by the hotel gave our Youth

Program a unique opportunity to experience one of the 5-foot by 5-foot prison cells from Alcatraz, San Francisco's most notorious prison. The Youth program also took a field trip to the *Tech Museum of Innovation*.

Saturday night showcased a special performance by the *McBride Irish Dancers*, as well as a lively auction run by our very own Past President, Chuck Abbott. After dinner, individuals were recognized for their outstanding achievements, incredible efforts and continuing influence in the HHT community:

- **Michael Lewis** received the *Robert E. Berkman Leadership Award;*
- **Angela Carlisle-Brown** received the *Trish Linke Award;*
- **Jim and Michelle Lapides** received the *Compassionate Champion Award;* and;
- **David and Laura Rinn** were recognized as Cure HHT's newest Founders.

For those that weren't able to attend, we hope you will join us in 2016.

> *I'm really excited about what's happening, the changes that are taking place and the promises we have for the future of HHT patients. Sometimes there's a line in the sand and you step over and you are in a whole new place. This is what this year's conference seems to be.*
>
> ***Bob Berkman, Board Member Emeritus***

We would like to thank our volunteers, sponsors, conference speakers, exhibitors, those who provided auction and scholarship donations, ambassadors and our board of directors. You helped us set the bar very high for years to come!

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