

Edition:  
Winter  
2018

Cure HHT

# newsletter

News & Information for the HHT Community

## 2018: The Year of Engagement

Over the past 26 years, **Cure HHT** has learned that if we want progress on research, legislation, better access to care and improved treatments, we have to engage with all of our strength.

With your amazing support and involvement in our cause, each year brings us closer to fulfilling our mission to find a cure for HHT for our loved ones, for future generations and for ourselves.

That's why, as the only international advocacy organization for people with HHT, we have named 2018 **The Year of Engagement**. Central to our efforts to raise awareness, educate both the public and medical professionals, and advocate for our community, this year we are launching the **50 State Challenge**, with the goal of assisting you in creating HHT awareness opportunities and fundraisers in all 50 states. Details are inside.

We know not everyone is in a position to engage in fundraising activities, so we will also be providing opportunities for funding scientific research, taking legislative action, and so much more. **Join us in choosing the level of engagement that's right for you!**

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2018

**The  
Year of  
Engagement**



## Message from Marianne

### The Importance of the Patient Voice in HHT – *An Invitation to Engage*

**A**s your spokesperson, **Cure HHT** represents you. When we work with our partners in government, industry, medicine, press and media, we increase awareness and increase the quality of life for our HHT family. We have been driven to ensure you have access to expert care wherever you live by tripling the number of HHT Centers of Excellence since 2009. And, through continued investment in research, conferences and young scholars, we strive to bring you new tested therapies that are safe and effective.

While there is no current cure, we truly believe this is a possibility in the next decade - it is our job to make this dream into a reality!

How will we do it? By serving as a powerful organization to unite and connect our efforts across the HHT community. **We invite you to ENGAGE with us.** There are so many ways for you to participate that are meaningful for you and the HHT community. In 2018 we will continue the momentum forward as we partner to advance treatments, education and awareness! We have been at this for 26 years now - our children are now adults. I challenge all parents to bring the next generation into the HHT community and encourage them to get involved and change the face of this disease forever. Our families' health and well-being are critical for a normal life filled with joy and spontaneity. I hope you will **Answer Our Call to Engage** and do your part to make an HHT cure a reality.

IMAGINE how much impact we can accomplish by coming together in all 50 states. Personally, I, too, want to see faster progress and have signed up for the 50 State Challenge. I plan to get on my bicycle and dust off my running shoes. **What will you do to engage in the HHT community?**

With hopeful anticipation,

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

**How do you want  
to contribute toward creating  
an HHT- free future?**

Email me any time at  
[marianne.clancy@curehht.org](mailto:marianne.clancy@curehht.org)



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Stay current on HHT clinical trials, education programs and community events. Sign up to receive electronic announcements by registering at [www.curehht.org](http://www.curehht.org) or send us an email at [hhtinfo@curehht.org](mailto:hhtinfo@curehht.org)

## CURE HHT NEWSLETTER

**Marianne Clancy, RDH, MPA**

Editor

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# Introducing the New *CureHHT.org*

*An Unprecedented Online Resource for HHT*

**Cure HHT** recently celebrated 26 years of building awareness of HHT, educating the public and medical professionals, leveraging funding for research, and advocating for patients and families affected by the disease. The new website showcases our tireless work to make an impact, as well as reinforces Cure HHT's role as the only international advocacy organization for the disease.

Your complete online resource for HHT includes special sections on "Understanding HHT" and what a newly diagnosed person needs to know PLUS:

- News
- Resource Library
- HHT Treatment Centers
- Fact Sheets
- Webinars
- Scientific Research
- Find A Doctor
- Events
- Blog
- Glossary
- And More...*



**Visit the NEW WEBSITE at [www.curehht.org](http://www.curehht.org) and learn how you can get involved in our mission to find a cure!**

# Music City . . . Here We Come!



**Cure HHT** is thrilled to announce that we will be hosting a regional conference this spring in **Nashville, Tennessee**. This area is underserved, but has HHT Centers of Excellence in neighboring states. We will be bringing in conference speakers representing HHT Centers in Arkansas, Georgia, Maryland and Ohio.

## REGISTRATION

Conference registration includes priceless time to interact one-on-one with HHT specialists, along with presentation materials and meals served throughout the conference (lunch, breaks, welcome reception). We are offering a volume discount on registrations for more than two attendees.

**\$175\* / \$250 Conference Attendee (early bird\* / regular admission)**  
**\$75 Medical Student / Medical Resident**

*\*Early Bird pricing ends March 15, 2018.*

## INVITE YOUR DOCTORS AND FAMILY MEMBERS

This is a unique opportunity to learn from and speak directly with HHT specialists. Print an invitation from our website

<https://curehht.org/understanding-hht/get-support/patient-conferences/>

## BOOK YOUR HOTEL

Reserve your room at the **Hilton Garden Inn Nashville Vanderbilt** by calling 615-369-5900 (mention "HHT" for group rate). We have reserved discounted rooms starting at \$189/night plus tax.

**QUESTIONS?** Contact Nicole Schaefer at [conference@curehht.org](mailto:conference@curehht.org) or 410-357-9932.

**REGISTER and LEARN MORE** about the conference program, speakers, venue and more on the conference website at <http://www.cvent.com/d/qtqrkb>

One of the featured speakers, Sara Palmer, Ph.D., is the author of *Living with HHT: Understanding and Managing Your Hereditary Hemorrhagic Telangiectasia* and will be on hand to sign copies of her book.





# JOIN THE 50 STATE CHALLENGE . . .

## *What is the 50 State Challenge?*

To state it simply, **Cure HHT's goals are to find, treat and cure HHT.** We know this disease is complicated, hard to diagnose, difficult to treat and affects the quality of life for HHT patients and their families.

While we have made great progress for our HHT community, there is much work to be done.

**The 50 State Challenge is a national movement to engage as ONE community across the United States.** We challenge YOU to JOIN US as we change the future of HHT through this opportunity to become an advocate and fundraiser in 2018.

There is no fundraising minimum. The choice is yours for what you want to do, how much you want to raise and when you want to start.

## *How Do I Sign Up?*

1. Decide if you will participate as an individual, create a team or join an existing team.
2. Commit yourself to a fundraising goal.
3. Reach your goal through one or multiple ways!

Need help? Email Allyson Clancy at [allyson.clancy@curehht.org](mailto:allyson.clancy@curehht.org)

## *Where Can I Get More Information?*

Visit [www.curehht.org/50-state-challenge](http://www.curehht.org/50-state-challenge) and get started today!



*Take on the Town*



*Inspire a City*

**To see who is in your area and find out how to join them . . .**

# AND CHANGE THE FUTURE OF HHT

## *Why Should I Join?*

We are at a pivotal point of major breakthroughs for this disease.

This is the year where we learn about taking a pill to reduce bleeding, using an app to track HHT, updating clinical guidelines for physicians and identifying the best protocols to manage HHT.

This organization is focused on making HHT diagnosis easier by educating physicians and the public on how to recognize HHT. We are committed to ensuring consistent quality of care throughout our North American Centers of Excellence. And, we know that investing in better treatments today will yield a longer, healthier life for HHT patients for years to come.

## **We are setting our sights high, but we know we can't do this work alone.**

We are asking the entire HHT community across all 50 States in America to join us in changing the future of HHT.

By joining the 50 State Challenge, you will help us make real strides to improve the lives of those affected by HHT.

## *Can I Participate with Other People?*

Yes! While you can participate as an individual, you can also join a team or create a team based on where you live or what you want to do.

## *Who is Already Participating?*

People are already taking on the 50 State Challenge in the following states:

California ● Colorado ● Hawaii ● New York ● Maryland  
● Massachusetts ● Oregon ● Pennsylvania



*Regional Renegade*



*Statewide Strength*

visit: [www.curehht.org/50-state-challenge](http://www.curehht.org/50-state-challenge)

# HHT Treatment Centers

## *The Experts in HHT Care*

HHT Centers proactively manage the care of patients by collaborating with an integrated team of experts who are knowledgeable about the disease. HHT specialists work closely with an HHT Coordinator to ensure proper follow-up and scheduling of patient care throughout the center.

### HHT Center Updates

- New Center Director at New York Presbyterian / Columbia University Irving Medical Center – Dr. Sergei Sobolevsky, Interventional Radiology
- New Center Director at Froedtert & Medical College of Wisconsin - Dr. Jake Decker, Internal Medicine
- University of California, San Diego is growing – hematologists from the Moores Cancer Center have joined the HHT team
- Johns Hopkins Hospital – contact information updates:
  - For general appointments call 410-550-5864 and follow prompts to HHT Clinic
  - For ENT appointments contact Dr. Doug Reh at 410-821-5151
- Germany, Marburg University Hospital - Dr. Urban Geithoff has relocated and is now at this location.

VIEW all of the HHT treatment Centers around the world at <https://curehht.org/understanding-hht/get-support/hht-treatment-centers/>



#### Welcome!

HHT is a genetic disorder of the blood vessels, which affects approximately 1 in 5,000 people. It affects males and females from all racial and ethnic groups. HHT is still often misdiagnosed in affected individuals and many doctors do not understand all of its manifestations.

WHAT IS HHT?

Let's Get Started

I AM NEW TO THE APP

IMPORT BACKUP DATA

**Coming soon . . .  
an iOS app for HHT patients**

**Everything you need to track your nosebleeds, test results, appointments, HHT doctors and more!**

You'll be able to upload images, keep track of your nosebleed frequency and severity and send critical information to your doctor direct from the app. The app will be FREE and available for all Apple products.



# Advancing a Cure Through HHT Research and Young Scholars

**Cure HHT** has a long history of leveraging donor gifts, ultimately resulting in breakthrough research. The investment of \$50,000 seed research grants totaling \$1.4 Million since 2004 has led to over \$24 Million in large grants. We are now able to determine the classes of **drug therapies** that are best targeted to **reverse AVM development** and **prevent AVMs from forming** in the future. For over 26 years we have carefully invested in learning how AVMs form. The specific mechanisms related to development of HHT at a cellular and molecular level are falling into place for advancing a cure. Read the HHT Research Funding Portfolio online at:  
<https://curehht.org/research/other-funding-opportunities/funding-portfolio/>.

Cure HHT has supported senior scientists and young scholars who show exceptional ability in conducting HHT basic science, clinical science or translational science research to further our mission to find, treat and cure HHT. You can read about all HHT research grants, including Young Investigators and their publications at:  
<https://curehht.org/research/other-funding-opportunities/research-projects/>.

Together with you, Cure HHT is committed to radically changing the treatment of HHT and improving the quality of life for HHT patients and their families around the world.

## Cure HHT welcomes a new board member to the team!



"I am a retired physician who not only comes from an HHT family, but who also experienced a serious, almost fatal consequence of HHT: a ruptured cranial AVM. I appreciate Cure HHT and their mission to teach the public and medical community about this uncommon, but potentially fatal disorder, and I want to lend my many years of experience teaching medical professionals and patients."

– Charles Ingardia, MD

**We are with you ...for life!**

## ***You Pushed Us Over the Top!***

**Thank you** for supporting our Year-End Appeal! Your gifts both large and small pushed us past our goal of **\$325,000** to a grand total of **\$342,000**. The entire **\$150,000** challenge was matched by gifts from more than **600** donors. Your generosity, dedication and advocacy helps us leverage results far beyond our size. Thank you for standing with us once again!

## **Year-End Appeal Videos Sparked Our Campaign!**

This year, Cure HHT produced a series of videos featuring intimate conversations and personal stories from Terry Thompson, President of the Board of Cure HHT; Tania Competiello, HHT Patient, mother and advocate, and Chris Hughes, Ph.D., Chair of the Global Research and Medical Advisory Board (GRMAB).

These outstanding perspectives on HHT were seen by more than **20,000** people via our Facebook page, eNews announcements, and on Vimeo. Filmed by videographer Chris Bell of Boston, the conversations generated numerous gifts to our Year-End Appeal and started many discussions about the work for Cure HHT and how we can further leverage your generous donations to advance our mission to find a cure.

**Did you miss them?** Each video is only a few minutes long - watch them all starting with Chris Hughes, in sequence here: <https://vimeo.com/246533979>

Chris discussed the importance of the Cure HHT scientific conferences and the process by which scientists and researchers become engaged in studying HHT. He also explained the importance of Cure HHT's small seed grants which have been leveraged into large grants for HHT research. Cure HHT is leading the way to find, treat and cure HHT.



**Did you miss a chance to give to our Year-End Appeal?** Your tax-deductible gifts in any amount are welcome any time of year! Use the envelope in the centerfold of this newsletter to make a contribution, or give in memory or in tribute to a family member or friend. Do it today, while you are thinking about it, and ***thank you!***

# Walks and Family Days Update

Do you or your family live near:

- Boston, MA
- Chicago, IL
- New York, NY

If your answer is YES, Cure HHT will be there in spring 2018 for a HHT Walk & Family Day and we want to see YOU!

We will be partnering with our HHT Centers of Excellence in all 3 cities. This is a GREAT opportunity to join together for this cause, meet others with HHT, learn about managing HHT and have one-on-one time with the HHT Center physicians and nurses who are joining us.

For more information, including dates, locations, activities and volunteer opportunities, please contact us at [events@curehht.org](mailto:events@curehht.org).



## HHT Blog Update

Have you read our blog, *What the HHT*, lately? Here are two of our favorite posts from January 2018:

### Genetics 101! Happy New Year, HHT Community!

By Cassi Friday | January 22, 2018 | 0



I thought I would use this time and space to update you on the newest Friday family addition, our son, Theo! Theodore was born last month and came out a healthy, hefty bundle of snuggles and cuteness. Our life has been a giant blur of moving to a new duty station, having a baby, chasing a toddler, and changing a lot of diapers! In between all this, of course, have been the appointments to address the not-so-fun part of our lives... HHT.

**Genetics 101** - a newborn can bring about reminders to how HHT genetics work and what goes into genetic testing.

### I am So Lucky!!!

By MaryAnn Donnelly | January 2, 2018 | 0



A silver lining is a funny thing. You wish you could see it while you are mucking your way through a crisis, but you can't, and it often doesn't show up for a long time, if at all. My silver lining appeared in the most unexpected of ways.

**Lucky Silver Lining** - a suspicion of a cancer-related condition led to the diagnosis of HHT.

Want your story  
to be heard?

Have your own tips  
and life experiences  
to share?

Consider joining  
our blog as a writer!

To learn more, email  
[marisa.maccia@curehht.org](mailto:marisa.maccia@curehht.org)

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