

Edition:
Fall
2018

Cure HHT

newsletter

News & Information for the HHT Community

So Many Ways to Engage!

2018 is **The Year of Engagement** and we want to recognize your amazing support by offering more ways for you to be involved in our mission to find a cure for HHT -- for yourself, for your family and loved ones, and for future generations.

One of the most important things you can do is to **Educate** yourself, your family, and your local physicians about HHT. Our new website makes it easy with a vast online **Cure HHT Resource Library** with the latest HHT information, fact sheets, publications, videos and more. With **more than 30 Webinars** available online free of charge, CureHHT.org has become the international portal for all things HHT.

Join Us! The HHT community is welcoming and supportive. Sign up for a Cure HHT walk, attend a conference, launch a Facebook fundraiser, or become a **50 State Challenge Champion**. This issue is packed with opportunities to engage with others who are facing the same challenges as you and your family.

Help Cure HHT stay on the leading edge in the fight for our lives! See the centerfold to sign up for **Priority Notice** when our new **Cure HHT iOS App** is ready, and find out how your engagement helps us to lead the way as a **Monthly Sustainer**.

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2018

**The
Year of
Engagement**





Message from Marianne

It was my privilege to meet and Engage with so many of you in our community during the Spring Walk and Family Day Season! We were able to partner with 3 HHT Centers of Excellence in May and June. I must say I was inspired by meeting and talking with new families as well as seeing so many within our community for years.

The one resounding message I provided is one of Hope! Our families learned about new clinical trials that will be happening within the year, new centers opening so access of care is easier and ways to grow awareness.

I was thrilled to see *150 people in Chicago, 100 in NYC, and 60 in Boston!!* So many people brought extended

family and friends who love and support them on this journey. There was so much energy and networking; I wish you could have been there to experience the unity!

Our wonderful physicians, coordinators and nurses were also on hand to talk with families and answer questions. The partnership with our medical teams is strong and we appreciate all they do every day for HHT patients and families.

Since our fiscal year ended June 30, we are busy preparing for our upcoming year of webinars, conferences, walks and family days so please stay tuned. We are launching the Cure HHT App very soon - we know this will be a game changer for you and your physicians!

Join us in Stepping Up to participate!

Yours in good health,

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

**Cure HHT welcomes new Board President and members to the team!
And Special Thanks to our outgoing Board President Terry Thompson, Jr.**



Chandra McMahon,
New Board President



John Dunn
New Board Member



Marijo McCune
New Board Member



Dennis Sprecher, M.D.
New Board Member



Terry Thompson, Jr.
Outgoing Board President

Cure HHT is excited to announce that Chandra McMahon, Senior Vice President and Chief Information Security Officer for Verizon Communications Inc., assumed the role of President of the Cure HHT Board of Directors effective July 1, 2018. We heartily thank Terry Thompson, Jr. for his leadership as President for the past 3 years. Plus, we are welcoming 3 new Board members! See our website at www.CureHHT.org/BoardAnnouncements for more.



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

CURE HHT NEWSLETTER

Marianne Clancy, RDH, MPA

Editor

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Thank You for Taking Steps to Cure HHT During **HHT Awareness Month!**



This past June the global HHT community stepped up to help make incredible strides to help find a cure by spreading the word about HHT.

Facts were shared. Stories were heard. Red shoelaces were worn. Steps were taken. All with a common goal in mind, elevating Awareness around the World.

Thanks to the thousands of you who joined in, great strides were made in bringing this disease into conversations everywhere.

The amazing actions of the HHT Community helped more people get screened and treated for HHT, while also raising critical funds to advance HHT research.

We are so grateful to all who were able to make a donation during HHT Awareness Month. Every donation made during that time was matched and those dollars led to DOUBLE the impact!

All of this would not have been possible without YOU, our remarkable, resilient and strong HHT community.

Thank you to all who stepped up during HHT Awareness Month. Together with you, our global HHT Community, the commitment to fulfilling the underlying mission of all—to find, treat and cure HHT in this lifetime—is stronger than ever!

Help raise HHT awareness all year long!

There are many ways to raise awareness. So, why wait until next June?

Visit our website to find out more about how you can help us educate more people about HHT today: www.curehht.org/get-involved/raise-awareness

Back to School The Perfect Time to Educate Your Child's School About HHT

Educating your child's school nurse about HHT is important for your peace of mind, as well as for your child's psychological health and academic success. School Nurses are used to their share of nosebleeds, but they may not know the reason why your child is getting them. This is your opportunity to meet with and **educate** your child's school nurse, teacher or school administration about HHT.

The **Cure HHT Resource Library** offers several articles relating to your child and educating their school about HHT, including a **fact sheet** - *Tips to Educate Your Child's School Nurse About HHT*, and a **webinar** conducted by a school nurse. Access these resources and more at:

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

Join us at the HHT Conference in Ann Arbor, MI on October 20-21, 2018 to learn more about how HHT can affect your entire family. A special program for children and teens is planned. Grateful thanks to the dynamic HHT pediatric team at the St. Louis Children's Hospital/Washington University for leading the program.

Cure HHT Conferences – SAVE THE DATES!



Special Edition Education Conference
(Featuring an exciting pediatric program
for patients and physicians)

October 20-21, 2018

Ann Arbor, Michigan

This will be the only conference this year to highlight the pediatric component of HHT, featuring a presentation by HHT pediatrician, Dr. Andy White, a parent forum, and a Youth Program designed specifically for children (ages 6-12) and teens (ages 13-16). HHT is a family affair and this is an event that everyone should attend! Learn more at: <https://curehht.org/understanding-hht/get-support/patient-conferences/>



SAN JUAN
PUERTO RICO

13th HHT
INTERNATIONAL
SCIENTIFIC CONFERENCE

June 12-16, 2019 (Puerto Rico) - The HHT International Scientific Conference takes place every two years, rotating between Europe and North America. The program will feature several outstanding keynote speakers, multiple cross-disciplinary sessions, interdisciplinary discussions and extensive opportunities for presenting and viewing posters about HHT research. Abstract submissions will begin this fall. Learn more at: <https://curehht.org/research/tools-education/research-conferences/>.

More details about hotel reservations and conference registration will be available in the coming weeks. Be the first to be notified when conference registration is open; make sure we have your current contact information by emailing hhtinfo@curehht.org



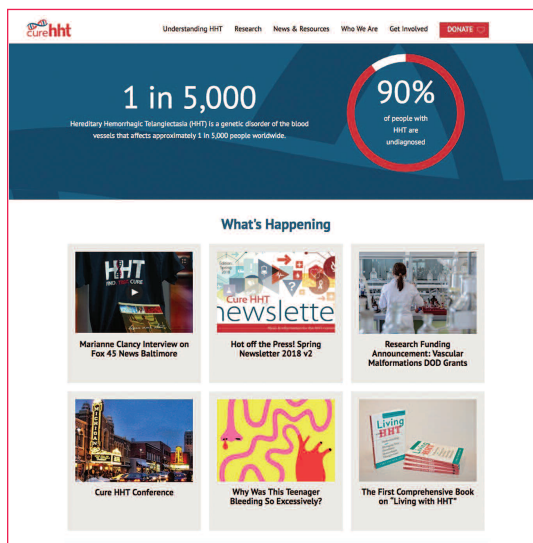
The Cornerstone of
the HHT Community

THANKS TO YOUR SUPPORT.....

CURE HHT IS ON THE LEADING EDGE

The Year of Engagement 2018 has been a year of vital advances, as **Cure HHT** continues to leverage your support to continue our mission to **Find, Treat and Cure HHT**. It is your generous, ongoing support that makes these advances possible, and we hope you share in the pride of accomplishment!

- We launched an unprecedented online resource for HHT - the new **CureHHT.org!**



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. It also reinforces our role as the only international advocacy organization for HHT and the convener of international scientific conferences to advance the study of the disease.

- Your investment in research leveraged scientific research grants totaling **\$24,000,000!**

Cure HHT has a long history of leveraging donor gifts into breakthrough research. The investment of \$50,000 seed research grants totaling \$1.4 million since 2004 has leveraged over \$24 million in large grants to scientists. 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. Now, the specific mechanisms related to development of HHT at a cellular and molecular level are falling into place for advancing a cure!

Your generous donations have put us on the leading edge of scientific research.

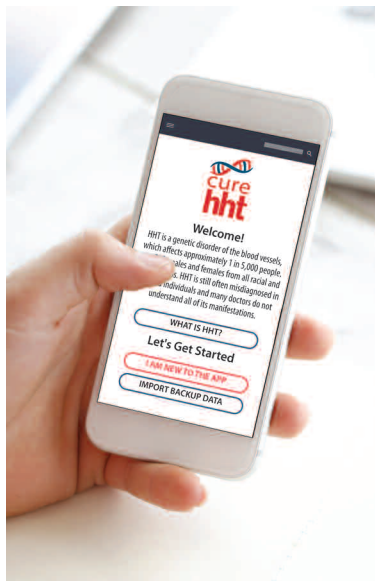


- **The future is just around the corner! We will soon launch the groundbreaking Cure HHT iOS app!**

The Cure HHT app for iPhone has been painstakingly developed at a cost of \$44,000. It has everything you need to track your nosebleeds, test results, appointments, HHT doctors and more! You can upload images, record your nosebleed frequency and severity, track iron therapy and anemia, and send critical information to your doctor direct from the app.

Best of all, because of your support, once again Cure HHT is on the leading edge **and the app will be FREE!**

To thank you, you can receive **Priority Notice** as soon as the app is approved by Apple and released. Simply register here:
<https://CureHHT.org/PriorityAppNotice>



Meet Peter Lauwers, of Arbormoon Software, Inc. in Ann Arbor, Michigan, the developer of the Cure HHT app, at the upcoming HHT Patient Conference October 20-21 in Ann Arbor Michigan. Peter will be demonstrating the new app and helping conference-goers set it up on their iPhones.
See page 5 for information on the conference.

HELP US LEAD THE WAY BECOME A MONTHLY SUSTAINER!

**We need your sustained help now more than ever before
to help us stay at the forefront of building awareness,
communications, treatment and research for a cure!**

Although as a small organization we are financially challenged, we leverage your gifts for maximum return on investment. In order for Cure HHT to continue to accomplish so much, we need the kind of sustained, reliable support that comes with monthly giving. Since we no longer ask for an annual Membership fee, it is up to you to decide how much you can comfortably give each year. Of course, your tax-deductible contribution in any amount is truly appreciated, and some people find it easier to make a monthly gift on a credit card -- \$10, \$25, \$50, \$100 or even more. Just check the box **"Make my gift monthly!"** on the enclosed donation envelope, and **thank you!**

Nosebleed Treatment Option: Geranium Oil



The essential oil of geranium has much to offer HHT patients. Geranium Oil can stop bleeding in two ways: it causes blood vessels to contract and helps stop blood flow and it speeds up coagulation or clotting of blood. According to research conducted by Dr. Douglas Reh, Otolaryngologist at the

Johns Hopkins HHT Center, “a sesame/rose geranium oil compound can significantly reduce the epistaxis severity scores of patients with hereditary hemorrhagic telangiectasia-related epistaxis”.

There are four articles in the Cure HHT resource library about Geranium Oil, including the dosage compound – learn more at:

<https://curehht.org/resource/health-benefits-geranium-essential-oil/>

Be sure to check out the Articles Most Recently Added to the Resource Library

- Vitamin D Levels are Associated with Epistaxis Severity and Bleeding Duration in HHT (*Biomarkers in Medicine*; University of Utah HHT Center)
- Applicability of the Curacao Criteria for the Diagnosis of HHT in the Pediatric Population (*The Journal of Pediatrics*; Washington University HHT Center) – Important for Children’s Diagnosis
- Prevalence and Predictors of Anemia in HHT (*American Journal of Hematology*; University of North Carolina HHT Center)
- Surgical Treatment vs. Nonsurgical Treatment for Brain Arteriovenous Malformations in Patients with HHT (*Neurosurgery*; University of California San Francisco HHT Center, et al)
- Association of common candidate variants with vascular malformations and intracranial hemorrhage in HHT (*Molecular Genetics & Genomic Medicine*; University of California San Francisco HHT Center, et al)
- Transthoracic contrast echocardiography (CT Scan) for detection of pulmonary arteriovenous malformations in HHT: How can the process be improved for patient safety? (*International Journal of Diagnostic Imaging*; University of Alberta HHT Center)
- Role of Contrast Echocardiography in Screening for Pulmonary Arteriovenous Malformation in Patients with HHT (*Chest*; Augusta University HHT Center)

The Cure HHT Resource Library is a comprehensive depository of the latest HHT information, fact sheets, publications, videos and more. When you visit the resource library at <https://curehht.org/resource-library/> you'll find our most popular resources listed first but you can use the drop-down menus to filter by audience, topic, type or keyword search. View our tutorial videos at https://curehht.org/resource-library/?_sf_s=website%20tutorial if you need help navigating the website / resource library.

The library is constantly being updated with new information. Check it out today!

What's New in HHT Research?

Three years ago with your support, Cure HHT funded the Young Scholar program. These young researchers have completed their work and continue their HHT research. This review is the second in our series focusing on the impact of this important work.

Using Gene Therapy to Reduce Severity of Brain Arteriovenous Malformations in HHT



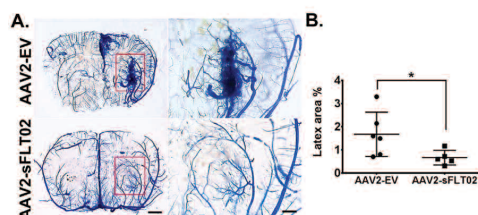
Wan Zhu, PhD, formerly at UCSF, now at Stanford University Medical Center.

Arteriovenous malformations (AVMs) that occur in the brain of HHT patients create a risk for rupture and bleeding inside the skull. If AVM rupture occurs, it can be life threatening and the treatment to stop bleeding can sometimes cause more problems. Therefore, the need to find and implement better and safer treatments is highly relevant. Dr. Wan Zhu from Dr. Hua Su's Lab at the University of California San Francisco is using gene therapy to minimize the severity and impact of brain AVMs.

When AVMs are present in the brain or other organs, a protein called vascular endothelial growth factor, or VEGF, is also present in higher than normal amounts. VEGF signals the body to stimulate blood vessel growth, and it is thought that increased VEGF plays a role in AVM formation. Blocking VEGF throughout the body in order to minimize AVMs can have negative consequences because the body needs VEGF for regular blood vessel formation. The researchers at UCSF used targeted gene therapy to block VEGF in the brains of mice and saw successful reduction in size and severity of their AVMs.

Endoglin, a gene that causes HHT, was knocked-out, or mutated, in mice, allowing the mice to have a malfunctioning endoglin protein like human HHT patients do. Endoglin is a protein involved in the formation of blood vessels, and these mice were able to develop brain AVMs that Dr. Su and her team could study.

If the endoglin knock-out mice were injected with a protein that binds to VEGF (AAV2-sFLT02) at the same time their endoglin gene was disrupted, it prevented the mice from developing brain AVMs. These mice were compared to mice with the endoglin knockout who were injected with a control substance that would not stop the formation of AVMs (AAV2-EV). In figure A, blood in the mouse brain was replaced with a colored latex that allowed researchers to see AVMs. Inside the red rectangle of the top photo, the control mouse's brain had a large AVM. However, the mouse brain treated with the VEGF inhibitor did not develop AVMs during the same timeframe. Figure B has circles and squares that represent individual mice from each of these groups. The figure is showing how much latex was in the brain of each mouse, with more latex representative of AVMs. The mice treated with the VEGF inhibitor showed significantly less latex compared to the control.



Once the researchers saw they could stop AVMs from forming, they wanted to see what the VEGF inhibitor would do to mice that already had brain AVMs. When mice were injected with the inhibitor, it greatly reduced the severity of their AVMs and that group's mice lived longer than the group that did not get the inhibitor. This important research paves the way for gene therapy in HHT patients as a way to reduce the severity of brain AVMs.

50 State Challenge: **We're Halfway There!**

Since we launched the 50 State Challenge at the start of this year, we've been inspired by all the 50 State Challengers who stepped up to join us and change the future of HHT.

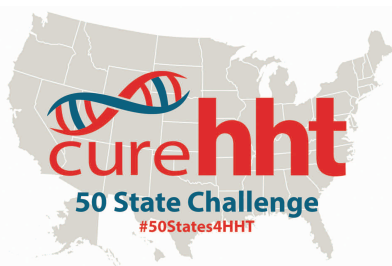
Our 50 State Challengers have hailed from places like

Arizona • California • Hawaii • Maryland • Massachusetts • North Carolina

and our 50 State Challengers have achieved their goals by doing things like

Creating a Fundraiser on Facebook • Joining a HHT Team • Organizing an Event

As we hit the halfway mark of our 50 State Challenge, we want to have every state represented, and we need YOUR help in making that happen!



Put Yourself on the Map!

*See who has joined our **50 State Challenge**.
Learn more about how to join us! Head to the Cure HHT
50 State Challenge website for news, information
and support for becoming a 50 State Challenger.
www.curehht.org/50-state-challenge*

Join us to accomplish one single goal: having at least one person in every state across the U.S.A. organizing a fundraiser for Cure HHT.

The more people who sign up, step up and raise money through our 50 State Challenge, the better chance we have to fund critical projects, get closer to a cure and change the future for tens of thousands of people who face living with HHT every day.

**You have a chance to strengthen your local HHT community,
while also meeting others who are impacted by HHT!**

Six months to go, and we want YOU to join us as a Challenger NOW!

Active & Retired Federal Employees and Military Personnel

You can make a vital donation to **Cure HHT** through the **Combined Federal Campaign** starting September 1, 2018 through January 15, 2019.

**Just designate *Cure HHT* as your
CFC Charity of Choice #10233**



Cure HHT Walks and Family Days



This June we were in three great cities for HHT Walks and Family Days, partnering with three incredible HHT Centers of Excellence. Together, we raised an amazing \$35,000 for our HHT education, research and patient support initiatives!

More than just a way to fundraise and spread awareness about HHT, our HHT Walks and Family Days allow our local HHT supporters to meet Cure HHT staff, talk with HHT experts and connect with other HHT families in their area.

Whether newly diagnosed or living with HHT for decades, these events had something for everyone.

To see where our next HHT Walks and Family Days will be, check out our website: www.curehht.org/get-involved/upcoming-events

Want to get involved helping us plan a HHT Walk and Family Day in your area?
Contact us today! events@curehht.org | (410) 357-9932

We are appreciative that the following three HHT Centers of Excellence joined us for this June's HHT Walks and Family Days:

University of Chicago Medical Center HHT Center of Excellence

Massachusetts General Hospital HHT Center of Excellence

**New York-Presbyterian Hospital/Columbia University Irving Medical Center
HHT Center of Excellence**



We are also very grateful for our Corporate Partners who joined us for this June's HHT Walks and Family Days:



HHT NYC Walk and Family Day
Regional Sponsor



HHT Boston Walk and Family Day
Community Partner



Cure HHT
PO Box 329
Monkton, MD 21111



SAVE THE DATE!
October 20-21, 2018
Ann Arbor, Michigan

This will be the only conference this year to highlight the pediatric component of HHT, featuring a presentation by HHT pediatrician, Dr. Andy White, a parent forum, and a Youth Program designed specifically for children (ages 6-12) and teens (ages 13-16). HHT is a family affair and this is an event that everyone should attend!

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