

Edition:
Fall
2020

Cure HHT newsletter

News & Information for the HHT Community

Turning Turmoil to Triumph for HHT Awareness Month!



In June, with a global “pandemic” on the minds of the world that played havoc on everything we had come to know, we gingerly stepped into our annual June Awareness Month with hope and determination, venturing into uncharted territory. Recognizing that the vast community of HHT patients needed us NOW more than ever gave rise to the spirit of our #YouLiftMeUp campaign. We were determined to spread Awareness that would catapult us past all of the uncertainty of the spring and lead us to the success we so passionately wanted for HHT patients and their families. With steadfast determination and the unwavering support of a community that rises to every challenge put in its path, we accomplished more than we ever could have imagined!

Beginning with Dr. Anthony Anzell’s full-circle story that reached thousands of mailboxes, to the excitement on our social media platforms, to fun Facebook live broadcasts and heartfelt email blasts featuring

#YouLiftMeUp tributes, it all combined to create our most stellar Awareness campaign to date. Let’s not forget the GIANT billboard soaring high in the sky over one of the busiest highways, sending the important message “*Sometimes It’s More than a Nosebleed*” to thousands who are unaware of the perils of HHT. All this created record-breaking new engagements and re-engagements of patients, family members and physicians, fueling the educational message that is so vital to our mission. ***Venture back to June Awareness Month 2020 with us on our centerfold and see why our HHT Community is like no other!***

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Message from Marianne

During this unprecedented time, I want to assure you that Cure HHT continues to be strong and united in our support for you and your families. While we were disappointed to postpone our regional conference and our Walk and Talk Days, our Awareness Month activities and first global *Strides for Strength* virtual event brought our community together like never before!

Thank you for participating and donating! The funds raised will be used to provide critical education to medical providers about HHT. Our staff and volunteers continue to bring you the information you need regarding COVID-19 and, of course, HHT. They stand ready to answer your questions, connect you with referrals, and steer you to critical resources for your family. Our physicians also continue to offer

important medical advice (featured on our website) to keep you well-informed and safe. I thank them sincerely for their tireless work on our behalf.

These are exciting times for HHT research and our work to develop new therapies for reducing bleeding and AVMs. We are also working hard to develop the website and resources for the updated standards of care developed at the recent Christopher McMahon Memorial International HHT Guidelines Conference. We can't wait to share them and will alert you when they are published online in early Fall. Exciting news to follow soon! Congratulations to Drs. Marie Faughnan, Hans-Jurgen Mager and Steve Hetts along with all of the participating physicians and patients who are bringing the guidelines to publication in record time. None of this would be possible without the generosity of the McMahon Family in sponsoring this scholarship. We are so grateful!

Stay connected, informed and safe. Rest assured we are here to support you in your journey.

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



Welcome!

We are thrilled to announce **Ann Trussell** as our newest Board Member. Being an HHT patient and having two daughters with the disease, Ann is committed to helping advance a cure so that HHT patients can live their best life. Ann brings a wealth of knowledge to the organization and is looking forward to attacking multiple initiatives.

To learn more about Ann and the rest of our Board of Directors, log on to www.curehht.org/who-we-are/leadership-board



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

CURE HHT NEWSLETTER

Marianne Clancy, RDH, MPA

Editor

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Marianne Clancy, RDH, MPA

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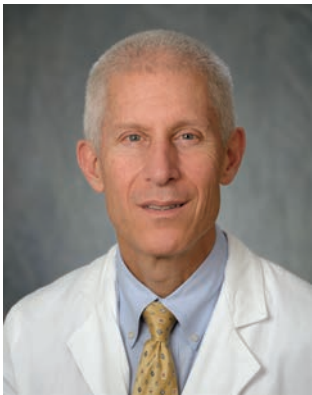
Top Geneticist and HHT CoE Co-Director Announces Retirement



We are at once happy and sad to announce the retirement of **Reed Pyeritz, M.D., Ph.D.**, Co-Director of the University of Pennsylvania School of Medicine (“UPenn”) HHT Center of Excellence. Dr. Pyeritz has been an integral part of our organization since 2003 when UPenn became Cure HHT’s 7th HHT Center of Excellence. The knowledge and commitment to the HHT Community that Dr. Pyeritz has contributed over a stellar forty-five-year career as one of this country’s leading geneticists is immeasurable.

From his early years at Johns Hopkins Hospital where he screened his first HHT patient in 1979 to his twenty-year tenure at the University of Pennsylvania, Dr. Pyeritz has made invaluable contributions to the HHT Community. Particularly, his most notable contribution to HHT, among many, was creating access for patients and their family members to genetic testing, a pivotal turning point in screening, diagnosing and treating HHT. His years of commitment to HHT and the steadfast dedication he parlayed into a career focused on a rare disease that many said was “unimportant,” is worthy of our admiration. We wish Dr. Pyeritz a long and happy retirement.

To read the full article about Dr. Pyeritz’s career, his many contributions to HHT, and his future plans, log on to www.curehht.org/newsletter



With the announcement of Dr. Reed Pyeritz’s retirement as Center Director for the UPenn HHT Center of Excellence, we are thrilled that **Scott Trerotola, M.D.**, Interventional Radiologist, will step smoothly into the role of Center Director. Many of you have had the pleasure of meeting Dr. Trerotola over the years while he was the acting Co-Director alongside Dr. Pyeritz. Dr. Trerotola will continue to evaluate new patients, manage care for necessary referrals, and treat existing patients in the area of interventional radiology. For genetic testing and counseling, Dr. Trerotola is excited to

work with Theodore Drivas, M.D., Ph.D. in the Division of Human Genetics. Drs. Trerotola and Drivas will be tag-teaming to ensure HHT patients are seen quickly and are methodically managed to ensure the best course of treatment.

To reach out to this outstanding team for all your HHT needs, please contact Mary O’Dea, Coordinator at 215-615-3540.



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders



With our goal of always making HHT education a top priority, we were once again honored that **Raj Kasthuri, M.D.**, our **HHT Center of Excellence Director from the University of North Carolina Chapel Hill**, gave an exceptional HHT presentation (the best attended presentation of the day) at last month's **National Hemophilia Foundation's Bleeding Disorder Conference: Future Therapies and Surveillance for Blood Disorders**.

With this year's conference fully virtual, *Dr. Kasthuri was able to reach a global audience of fellow hematologists, medical students, researchers and patients to educate on the manifestations of HHT.*

Dr. Kasthuri's participation in the conference was instrumental in introducing HHT to his Hematology peers who are unfamiliar with HHT. This type of education will open doors for patient access to care from hematologists who now have a basic understanding of HHT, which is vitally important to patients in areas without access to an HHT Center of Excellence.

In addition to presenting HHT information, Dr. Kasthuri shared the promising results of a current pilot program of multidisciplinary care through two of the National Hemophilia Treatment Centers (HTC's), which was initiated by the Centers for Disease Control and Prevention (CDC), the American Thrombosis and Hemostasis Network (ATHN), and Cure HHT. Under Dr. Kasthuri's leadership, this program could potentially assist in extending treatment to patients with HHT at nationwide HTC's.

Dr. Kasthuri's full presentation is available on the National Hemophilia Foundation's website. Hats off to Dr. Kasthuri for being one of our top HHT champions!

Thank you and Farewell!



Alyson Conger



Christopher Gibson, Ph.D.



Cheryl Wilson

As we move into our new fiscal year, we note changes to our Board of Directors. At this time, we would like to thank Board Members, Ali Conger, Christopher Gibson, Ph.D., and Cheryl Wilson for their dedication and commitment to Cure HHT over the years. Each served our organization in many ways and left behind numerous important contributions. We wish them well in their future endeavors both professionally and personally!



June HHT Awareness Month

#YouLiftMeUp

Awareness Campaign Makes a BIG Impact

We were moved by the Awareness Campaign this year! We are proud of each and every one of you, and particularly those who shared your personal stories, participated in an awareness event, made a donation, or distributed our new Physician Fact Sheet to your doctors and family. You were shouting to the world that HHT needs to be recognized, treated and cured!



Thank you to General Mechanical Services, LLC & Greg Lilly

One of the highlights of the month included the reveal of our "More Than Just a Nosebleed" Cure HHT billboard! Perched on Route 50 in Maryland, approximately 30,000 cars passed this sign every day! The social media post celebrating this momentous occasion then reached over 28,000 people with 289 shares!

Virtual Outreach Engages Audiences Both Young & Old

Our social media platforms provide a fast and effective means of communication not only to members of our HHT Community, but also the general public. In a world where technology rules, remaining active on these platforms enables us to provide real time information on resources, educational materials, fundraising opportunities and more. Take a look at the range of connections we had with you so far this year —

VIRTUAL INITIATIVES

Facebook Live

Reach 17.3k

Facebook Frames

Reach 1,972

Awareness Posts



Reach 142,357
1,902 "Shares"

1,148 "Likes"

Average individual post reach of 778 people

194% increase in page views with 131% increase in unique visitors

Friday Facts



Reach 50,000
618 "Shares"

108 "Likes"

Reach 5,600

Reach 400

*You can find the Friday Fact Sheets on our Cure HHT Facebook page at [Facebook.com/hht.org](https://www.facebook.com/hht.org)



8,062 Followers



1,469 Followers



1,285 Followers



207 Followers



#YouLiftMeUp Spotlights

»Dustin, his daughter Avery & Dr. Conrad, Director of the UCSF Center of Excellence, who helped Dustin and his family see that they weren't alone in this fight. **#HeLiftsUsUp**

»Sienna & her great grandmother, who helped Sienna receive an early HHT diagnosis. **#SheLiftsUsUp**

Awareness Month is about continuing to educate ourselves, our families and communities, and most critically, the medical community. Cure HHT, together with the HHT community, has increased awareness of HHT with healthcare professionals by leaps and bounds. Many of you know the frustration of receiving treatment from someone with no knowledge of HHT, let alone proper procedures and treatment protocol. This is simply unacceptable, and it drives us to deliver vital HHT education in the most targeted, impactful ways.

Cure HHT is transforming the future of this disease through the expansion of our educational initiatives, including participation in medical conferences where we can reach hematologists, ENTs, and other specialists. We are also connecting with organizations in the areas of school nursing and dentistry.

Now we need to build on the success of Awareness Month and keep the momentum going. You are invited to continue on this journey to educate! Please consider supporting Cure HHT with a donation today, and help make three tiny letters—HHT—a powerful lesson!

Your tax-deductible contribution in any amount is greatly appreciated. To help us create even more Awareness-building opportunities, make a monthly gift of any amount - \$10, \$25, \$50, \$100 or more. Simply check the box "Make my gift monthly!" on the enclosed donation envelope or donate online at: www.curehht.org/ways-to-give. Thank you!

Together, let's educate those who don't know!

HEREDITARY HEMORRHAGIC TELANGIECTASIA (HHT)

Osler-Weber-Rendu Syndrome

HHT is an inherited, genetic disorder that causes malformed blood vessels in multiple organs of the body, and typically begins with nosebleeds during childhood.

Approximately 1 in 5,000 people are affected by HHT, totaling 1.4 million worldwide. However, HHT is often misdiagnosed and its symptoms are often mistaken for other conditions. The disease affects men, women and children at any age, as well as all ethnicities and races.

DIAGNOSIS

It's important to recognize that HHT does not affect every individual in the same way. Some people have symptoms in several different parts of the body (detailed below), while some may show hardly any symptoms at all.

AFFECTED ORGANS



COMMON MISDIAGNOSES

SKIN: Birthmarks or cherry angioma
NOSE: Allergies, drug addiction, hemophilia, or Von Willebrand Disease
BRAIN: Aneurysm, cerebral hemorrhage, epilepsy, abscess, migraine, or stroke
LUNGS: Asthma, Alzheimer's disease, lung disease, tumor, stroke, Polycythemia, Patent Foramen Ovale (PFO)
SPINE: Scoliosis or stroke
LIVER: Cirrhosis, heart failure, shortness of breath
GITRACT: Angiodysplasia, anemia, black stool or cancer

visit www.curehht.org for more info.

Cure HHT, P.O. Box 329, Monkton, MD 21111 | (410) 357-0922

PHYSICIAN FACT SHEET

VIRTUAL INITIATIVES

Cure HHT Website 61,000 total page views in June
1,300 Awareness Page views
27,000 new users

NEW! Virtual Meet-Ups 953 Registrants

Strides for Strength Event 14,028 people reached through FB

Webinars 568 Registrants

Up Close and Personal with Christopher Hughes, Ph.D.



Cure HHT's 2020 Robert E. Berkman Leadership Award Recipient

by Phyllis Loveland

Have you ever spoken to someone who is just so darn brilliant that you stand in awe, hanging on their every word? If not, then you need to meet Dr. Christopher Hughes, Chair of the Cure HHT North American Scientific and Medical Advisory Council, Lead Researcher for the Rare as One, Chan Zuckerberg Initiative, and, most spectacularly this year's recipient of the Robert E. Berkman Leadership Award ("REBLA"). Dr. Hughes is one of those people who is connected to HHT with a passion and drive that stands out among not only his peers but also the entire HHT Community. "He was a unanimous and natural choice for this Award," states Bob Berkman, named Award Honoree.

I had the opportunity to chat personally with Dr. Hughes about new advancements in the HHT research world and, of course, the excitement of being the newest REBLA recipient. When he told me that it was "such an honor to be part of the same group of people that have received the award over the past 10 years," I couldn't help but be struck by the humility in his voice. "I know all the former winners personally, worked with them, and feel incredibly proud to be part of this impressive group," says Dr. Hughes in his melodic and sincerest English accent.

Read the full article containing Dr. Hughes' input on Cure HHT's research path at www.curehht.org/newsletter



Robert E. Berkman Leadership Award Recipients

In recognition of Robert E. Berkman's exemplary leadership, we honor his legacy through the creation of the Robert E. Berkman Leadership Award, to recognize those members of the Cure HHT Community who exhibit the qualities that have made Bob such a valued part of our organization's mission.

- 2012 – Marie Faughnan, M.D.
- 2014 – Michael Lewis
- 2016 – Dennis Sprecher, M.D.
- 2018 – James R. Gossage, M.D.
- 2020 – Christopher C. Hughes, Ph.D.

HHT Clinical Guidelines Publication Around the Corner

Since the **Christopher McMahon Memorial International HHT Guidelines Conference** was held last November, our team of top HHT physicians and selected patients from around the world have been actively working on publication of the updated guidelines. We are counting the days to the release of these game-changing guidelines that will soon be ready for publication. These new HHT Clinical Guidelines, featuring the most up-to-date information and standards of care, will include significant changes and new topics in the areas of Anemia, Epistaxis (Nosebleeds), Gastrointestinal, Liver, HHT in Children, and Pregnancy and Women.

Cure HHT's website will host all of the conference overview and highlights, the guidelines publications, and specially designed patient Fact Sheets on each of the guideline topics (easily understandable and print-ready for you to share with your healthcare providers).

Check your mailboxes and inboxes for the announcements and stay tuned to our social media channels for news and information about this impactful educational component for both physicians and patients.

Clinical Trial Now Open at Several CoEs!

Clinical research is essential in our fight to cure HHT.

We are recruiting adult HHT patients with moderate to severe nosebleeds who require iron infusions or blood transfusions to participate in PATH*, a research study exploring the use of an oral medication called pomalidomide**.

Your participation has a huge impact on the diagnosis and treatment of HHT. Diseases can only be cured when scientists understand them. This understanding, which comes from basic research, leads to new drugs and treatments.

Without you, the advancement of a cure for HHT is impossible!

Learn more, check eligibility, and view list of centers currently recruiting as well as future recruitment sites at:

www.curehht.org/research/participate-in-research/clinical-trials

Site Name	Phone Number
Cleveland Clinic	216-445-2246
Massachusetts General Hospital	617-726-8033
UNC HHT Center of Excellence	919-966-2790
UT Southwestern Medical Center	214-645-6493
Johns Hopkins Medicine	410-502-3628
University of California San Francisco Medical Center	415-514-8995
University of Pennsylvania Perelman School of Medicine	
Medical College of Wisconsin	414-805-7291
University of Utah	801-213-3417
Mayo Clinic	507-284-9259
University of California Los Angeles	310-794-9202

*PATH is funded by a grant from the National Heart, Lung and Blood Institute (NHBI), and is led by researchers at the Cleveland Clinic and RTI International.

**Pomalidomide is an FDA-approved drug for the treatment of some cancers and is manufactured by Celgene.

Resource Library Holds Your HHT Answers

After months of collaboration between physicians and specialists, patient feedback, and the vetting of an entire inventory of new and updated HHT resources, Cure HHT was able to launch our beautifully redesigned and informative free online **HHT RESOURCE LIBRARY**.

This user friendly and intuitive library hosts thousands of HHT materials including published medical articles, recorded educational webinars, fact sheets, physician interviews, and a whole lot more. Since its launch in May, the Resource Library has expanded even more. It will soon be home to newly designed patient **FACT SHEETS** that cover all of the new diagnosis and treatment protocols from the new HHT Clinical Guidelines.

Key Features:

Two main audience categories: “**Patient Resources**” and “**Physician Resources**,” each with unique articles and resources designed with the reader in mind.

The **Patient Resources** aid the newly diagnosed, the knowledgeable patient or those in between. Whereas the **Physician Resources** help medical professionals navigate an HHT diagnosis for their patients with peer-reviewed and published articles, as well as simple facts to break through to diagnosis.

With **fifteen common HHT topic areas** including Anemia, Drug Therapy, Insurance and Mental Health to name just a few, each category has its own section of resources to help guide you in finding the answers you need. For those looking for very specific articles and resources, the Resource Library also hosts an **Advanced Search** feature to dive deeper into a given topic area.



Explore these areas and more in the Cure HHT Resource Library by visiting www.curehht.org/resource-library



Strides for Strength, Cure HHT’s first EVER virtual event was beyond successful. With attendees, including our canine friends, from around the world, we hit goals that blew us away! It was a fun-filled two weeks of community bonding, competitive excitement, and an opportunity for Global Awareness around HHT. Take a look at the incredible participation and see why we have the best HHT Community ever!

**Strides for Strength – Virtual Walk by the Numbers –
TOTAL RAISED: \$42,033.85**

Individual Registrations: 347

Top 5 Individual Fundraisers:

- James Gossage, M.D. - \$3,122.00
- Marijo McCune - \$1,227.00
- Nicole Bixler - \$1,090.00
- Audrey Bellis - \$918.00
- Julie Bolton - \$840.00

- Top Adult Walker** – Robert Schmidt
- Top Child Walker** – Landon W.
- Top Dog Walker** – Hudson (from Italy)

US Representation: 38 states

Most Registrants per State (Top 5):

- Arkansas
- Florida
- Maryland
- New York
- Pennsylvania

Team Registrations: 38

Top 5 Teams:

- Buckeye - \$4,005.00
- Devlin - \$3,145.00
- Cornale - \$2,036.00
- Rare Be the Robbs - \$1,775.00
- Meek But Not Mild - \$1,643.00

International Representation: 9 Countries

- Australia
- Canada
- China
- Germany
- Ireland
- Italy
- New Zealand
- Puerto Rico
- South Korea

THANKS TO EVERYONE THAT HELPED MAKE STRIDES FOR STRENGTH A GREAT SUCCESS!

Host a Virtual Event for the Fun of It!

In June, we held our first virtual event, *Strides for Strength—A Virtual Walk*. Thanks to you, our HHT community, this inaugural virtual event was a huge success – with participation throughout and beyond the United States! Virtual events can be just as fun and exciting as in-person events. If you were thinking about hosting an event for Cure HHT, consider gathering your friends and family for a virtual event!

To those who are considering it and just can’t figure out what to do, we have lots of ideas that you can simply do from the comfort and safety of your home, all while having fun, connecting with friends and family, and raising funds to help fight HHT. Help us keep the momentum going and continue to build on the success of *Strides for Strength*.

Please email me at Tracy.kelly@curehht.org with ideas or questions. I’m here for you!



Tracy Kelly, Cure HHT Events Coordinator



Cure HHT

PO Box 329
Monkton, MD 21111



DAYS AWAY! The Christopher McMahon Memorial International HHT Guidelines are headed to publication. See Page 9 for more details.

Not on our email list? Receive up-to-the-minute news: Register your email TODAY at www.curehht.org/joinus

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

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