

Edition:
Fall
2019

Cure HHT newsletter

News & Information for the HHT Community

Global Scientific Collaboration Is Key to Finding a Cure!



Our 13th HHT Scientific Conference in Puerto Rico during June Awareness Month was an outstanding success, with more than 200 scientists, medical professionals and patients attending, and one of the most important exchanges of scientific and treatment information we have ever had -- furthering our mission to find a cure for HHT for you and your family. **We are recruiting the best scientific minds globally to make this a reality.**

We are also proud to be launching **Backpack Health** - a comprehensive health data management tool for iOS, Android and web, specifically for patients and families with HHT. You can input and translate your medical information in six languages! A powerful tool in an emergency when traveling. Backpack Health is **sponsored by Cure HHT, so it is free to you!** Check out the details on the centerfold.

Your support helps Cure HHT stay on the cutting edge in the fight for our lives!

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Message from Marianne

With fall arriving and as I reflect on our summer of awareness theme, #InThisTogether, I am continually inspired by you and our community of families who are working alongside Cure HHT to engage and do everything it takes to continue forward momentum in advancing our knowledge and treatments as we work toward a cure.

One of the most important initiatives we sponsor is the HHT International Scientific Conference. In this issue, read about new collaborations and possibilities for advancing treatments that are safe and effective for all aspects of HHT. We are proud to have sponsored Travel Awards for 21 young researchers who contributed to the vibrant and hopeful atmosphere of this important conference. Stay-tuned for future webinars to learn about new therapies on the horizon.

We are very excited to launch the new Backpack Health app! You are now able to store your family's health information safely and securely right in the palm of your hand. Read on in this issue to find out all you need to know about this great new tool offered to you FREE by Cure HHT!

Since 2010, we have tripled the number of HHT Centers of Excellence. We are excited to announce two new HHT Centers in 2019. Access to expert HHT care is a priority for Cure HHT and we will continue to vet and work with teams throughout North America to bring you the care you need.

During the Fall of 2019, there will be announcements about upcoming clinical trials you will not want to miss. **Stay engaged with us as we truly are #InThisTogether.**

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

HHT Center of Excellence Announcements THANK YOU AND FAREWELL!



We would like to take this opportunity to thank our former Co-Director of the University of Colorado School of Medicine HHT Center of Excellence, **Dr. Brian Graham**, for his tremendous service and dedication to our HHT patient community in Denver for the past six years. We wish Dr. Graham much success in his new role as Chief of Pulmonary and Critical Care Medicine at the Zuckerberg San Francisco General Hospital and Trauma Center.



It is with sincere appreciation that we congratulate **Dr. Thomas Kinney**, former Director of the HHT Center of Excellence at the University of California San Diego, and his long-time Clinic Coordinator, **Julie Fisher** (not pictured), on their retirement. In their combined twenty-seven year career as COE Director and Clinic Coordinator, Dr. Kinney and Ms. Fisher worked tirelessly to improve the lives of so many HHT patients and for that, we are eternally grateful. May they both have a long and enjoyable retirement!



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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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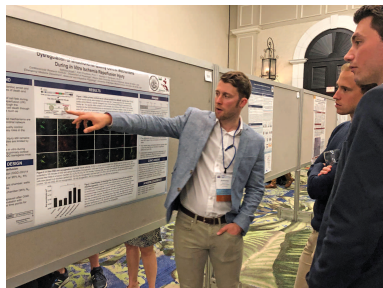


SAN JUAN
PUERTO RICO

13th HHT INTERNATIONAL SCIENTIFIC CONFERENCE

Rio Mar, Puerto Rico June 13-16, 2019

The 2019 meeting brought together the world's leading HHT experts in both basic research and clinical practice with a focus on translating findings between these fields. Over 200 voices were heard from six continents (21 countries), motivating interest for those new to the field, and encouraging young researchers and clinicians to continue to build a career surrounding HHT. It was truly amazing to see the array of information presented at this meeting in the form of 10 invited speakers, 56 oral presentations, and 72 poster presentations, that all function to develop a greater global understanding of HHT.



SCIENTIFIC CONFERENCE REVEALS EXCITING NEW HHT RESEARCH

With the 13th HHT International Scientific Conference behind us, the latest advances and research reported are providing HOPE for our HHT Community.

Here's what we are **EXCITED** about...

- **New MRI imaging techniques** of the liver could help detect changes in blood flow that could be useful in determining who could be at risk for high output heart failure as well as responses to treatment.
- **Nosebleed and anemia treatment and management** were at the top of discussions, which included iron level maintenance, doxycycline, tranexamic acid, bevacizumab, pazopanib, and thalidomide.
- **Pomalidomide is a potential new drug treatment for HHT.** A new study (PATH) looking into the use of Pomalidomide will be the first ever NIH sponsored clinical trial in HHT patients.
- **Various research was presented regarding pulmonary (lung) AVMs** including the challenges of re-treating re-canalized PAVMs, possible brain complications of PAVM embolization, impact on patients and their results were all discussed.
- **It is recommended that HHT patients with SMAD4 mutations** need head to pelvis imaging every 2 years.
- **Precision or personalized medical therapy will be the future** of HHT treatment and genetic testing will be important to achieve optimal results.
- **Pazopanib** is a medication that is delivered in pill form. A recent pilot study showed positive results on patient outcomes and quality of life; Cure HHT is working with the FDA to conduct the first multi-center clinical trial that could lead to its approved use in HHT.

Read the scientific conference recap at https://curehht.org/SciCon19_recap

Young Scholars – The Future of HHT

Cure HHT was proud to present, through The Young Scholar Research Program, travel awards that allowed twenty-one young scientists / fellows to attend the event in Puerto Rico. Eight young scholars received recognition and a monetary award for their outstanding conference presentations.



Thank You!

Hat's off to this year's Conference Program Executive Committee led by Beth Roman, Ph.D., Miles Conrad, M.D., Paul Oh, Ph.D. and Andy White, M.D. Without the committee's hard work and dedication, this year's event would not have been possible!

An enthusiastic thank you to everyone who contributed to this conference both scientifically and financially. Your commitment to this community directly impacted Cure HHT's ability to provide attendees with a rich and fulfilling experience.

- Conference Program Executive Committee and Members Invited Speakers
- Judges and Session Chairs
- Patients and Volunteers
- Sponsors and Exhibitors
- Donors who support Cure HHT and all of our research and education activities



Anonymous HHT Families

"These researchers are in the labs with mice and zebrafish trying everything to come up with cures and meds to help us. The 10 min presentations of lab and human studies showed their passion and asking questions revealed their dedication. To all presenters, thank you!" - Alexia D., patient

"This was without a doubt the most stimulating and meaningful conference I have ever attended." - Paul Freinkel, M.D., Ph.D., South Africa



+



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Carry Your Health Information With You!



Now Available!

A comprehensive health data management app designed specifically for patients and families with HHT!

- All your family's health information in one place.
- **For iOS, Android and Web!**
Access wherever you are.
- Enter or share your information in multiple languages.
- **Sponsored by Cure HHT – Free to you!**

HHT is a complex disorder often requiring management from multiple medical specialties. As a rare disease, many physicians have little experience with HHT. You and your family may need to seek care in an emergency, or when far from home. Lack of information about HHT or about your health history could have life-threatening consequences. That's where Backpack Health comes in!

Backpack Health makes it easy to have your entire family's health information at your fingertips wherever you go. This unique tool helps you track all of your vital health information so that it's portable, manageable, shareable, and translatable into six languages when you need them!



Portable - Manageable - Shareable - Translatable

Get started today! Learn more, get more details, and watch videos about Backpack Health! **This is an important development for you and your family and a groundbreaking moment for Cure HHT!**

www.CureHHT.org/backpack-health



Spring Awareness Campaign Sets New Records for Outreach

Make no mistake, building Awareness of HHT is key to increasing diagnosis, developing new treatments and ultimately finding a cure! We are all **#InThisTogether** – so thank you for making your voices heard for June Awareness Month.

For this year's Awareness Month Campaign, we:

- **Mailed a record 8,000** #InThisTogether brochures to our mailing list. Did you see it? Would you like another copy for a friend? Email us at hhtinfo@curehht.org
- **Reached over 107,500** HHT patients and families with our online social media campaign – in **45 countries around the world!**
- **Had more than 1,350 people** share our campaign news and announcements to their family and friends via Facebook.



"I'm still learning ways to cope as my three children were only recently diagnosed. Becoming involved with fundraising for Cure HHT has helped me cope. Luckily for now only my husband and oldest daughter show any symptoms. I am surprised at how little some doctors actually know about HHT. I feel lucky to know about the disease because we are able to get properly screened and monitored. It also makes me want to do whatever I can to help with future medical advances and treatments."

- Jen Bannon, Caregiver.

Photo by David Zimand.

Your support for **Cure HHT**, and taking action to increase awareness significantly raises the visibility of HHT and has a great impact on scientific research, improved and, expanded treatment, legislative efforts, training of health care professionals, and so much more!

YOU ARE OUR INSPIRATION!

Your stories, your struggles, and your hope keep us going against all odds to find a cure!

Because of you, we fight to make the impossible, possible!

We need your support today more than ever before to keep going.

As hundreds more patients and their families come to Cure HHT each month for help with their disease, we want to continue to provide them with the resources they need to understand and manage their disease, and to lead fuller lives. As we continue to expand and accelerate our efforts, we need your support and involvement more than ever before.

Your contribution, in any amount, is gratefully accepted! To help even more, make a monthly gift of any amount -- \$10, \$25, \$50, \$100 or even more. Just check the box **"Make my gift monthly!"** on the enclosed donation envelope, or donate online at <https://tinyurl.com/CureHHTDonations> **Thank you!**

Raising HHT Awareness in Puerto Rico

An underlying mission of the HHT International Scientific Conference is to choose a venue that raises awareness in an underserved area of the world. Prior to choosing Puerto Rico to host the 2019 SciCon, Cure HHT was not aware of any doctors treating HHT or HHT patients on this Caribbean island. But, thanks to Dr. Miles Conrad, Conference Executive Committee Co-Chair and one of his Residents, the foundation was able to connect with a doctor from the University of Puerto Rico Medical Campus treating four pediatric HHT patients.

Dr. Wilfredo DeJesus Rojas became our “feet on the ground”; and through his efforts, we were able to present HHT Grand Rounds to over thirty health care professionals. A representative from *Revista Medicina y Salud Publica*, a local medical publication, attended the Scientific Conference and published an article about the event while Mayra Acevedo, a local journalist, interviewed medical expert conference attendees through live streaming.

Outcome: Since the conference, Dr. DeJesus’ HHT practice has grown significantly. In fact, he was contacted by several new patients during the Facebook Live broadcast. Cure HHT connected Dr. DeJesus with Dr. Marcelo Serra, HHT Center Director in Argentina, to provide advice for organizing an HHT Center in Puerto Rico and to share Spanish resources for patients. Dr. DeJesus and his team are fully committed to treating HHT.

“This meeting was an amazing experience. I was able to meet HHT experts around the world that now will be my contacts for any questions about HHT. But more importantly, I have a new family and new friends.” - Wilfredo DeJesus Rojas, MD



New friends Dr. Wilfredo DeJesus and Dr. Miles Conrad enjoying Puerto Rican cuisine. (Wilfredo DeJesus Rojas, MD, Puerto Rico)

Live filming.



The Grand Rounds held at the University of Puerto Rico Medical Campus could not have been possible without the generous support of our Sponsor, Gerber Medical

Our Newest HHT Center of Excellence Opens in Winnipeg, Manitoba Canada

Cure HHT continues its mission to make HHT care accessible to as many patients as possible by growing our bank of HHT Centers of Excellence in North America. The new HHT Center located at Grace Hospital AMC in Winnipeg, Canada does just that for our Canadian HHT patients. The Winnipeg HHT Center specializes in the diagnosis, evaluation and treatment of HHT. This new HHT Center of Excellence features a multi-disciplinary team, led by Dr. Els de Gussem, coordinating care for both adult and pediatric patients. We are pleased to have Dr. de Gussem and her team as part of the Cure HHT community.

"It is important to have an HHT Centre of Excellence in Winnipeg, Manitoba to be able to provide care for persons with HHT closer to where they live. The closest other centre is a fifteen-hour drive from Winnipeg! It is also important to have an HHT Centre of Excellence in Winnipeg to improve awareness about HHT among physicians and hopefully find persons affected by HHT earlier in life before they suffer from complications. Over the past 15 years I have built experience in caring for persons with HHT and I am very passionate that they are able to get the care needed. I am grateful for all the physicians in Winnipeg who have joined the team and have shown interest in caring for persons with HHT." – Els de Gussem, MD, Director, Winnipeg Center of Excellence



From left to right: Dr. Siuchan Sookhoo (IR), Dr. Els de Gussem (Respirologist), Dr. Kristine Smith (ENT), Dr. Richard Gall (ENT).



Welcome Dr. Houndras, University of Colorado School of Medicine

It is with great pleasure that we announce Dr. Peter Houndras as our new Director of the HHT Center of Excellence at the University of Colorado Hospital. Dr. Houndras, with a comprehensive background in Pulmonary Sciences and Critical Care, treating HHT and PH patients, is an exceptional new addition to the existing excellent HHT team in Denver.

Did you know if you are 70 ½ years old, you can make a tax-free contribution to **Cure HHT of up to \$100,000 from your Individual Retirement Account?**

For more information on how simple the process is, check out our website at curehht.org/ways-to-give or call our office at (410-357-9932)

Robert I. White, Jr. Young Clinician Award Presented in Puerto Rico



"Dr. Iyer mentors residents, fellows and junior staff. Like Dr. Bob White, Dr. Iyer has demonstrated leadership, scholarship, dedication, collaboration and is a compassionate Champion for HHT. We are grateful for all that he does for the HHT community."

- Marianne Clancy, Cure HHT Executive Director

Cure HHT was honored to present the **Robert I. White Jr. Young Clinician Award** to **Dr. Vivek Iyer**, a compassionate and dedicated clinician devoted to improving HHT care and quality of life for his patients, at the SciCon in Puerto Rico. In addition to providing stellar leadership at the Mayo Clinic HHT Center of Excellence for the past five years, Dr. Iyer has collaborated on various research projects, presented at Cure HHT conferences, and his clinical treatment of bleeding for HHT patients has not only been effective but his publications have also provided much needed clinical evidence of experience on which other HHT Centers can rely.

The RIW Award was established in 2004, in recognition of Dr. Robert I. White Jr.'s outstanding contribution to HHT care, to the mentoring of other clinicians in HHT development and research. This award is given annually to a clinician who embodies Dr. White's qualities as a compassionate and dedicated clinician, devoted to improving HHT care.

Exciting News from our Research Team

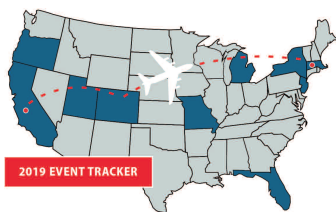
Cure HHT has once again, with your supportive donations and our legislative advocacy, opened the door for our research partners and scientific teams to apply for new and promising research grants through the Department of Defense's Congressionally Directed Medical Research Programs.

We are thrilled that Edda Spiekerkoetter, M.D. at Stanford University has been awarded 1.8 million to conduct her research titled "Understanding and Targeting Pulmonary Arteriovenous Malformations Using Repurposed Drugs" over the next three years.

These exciting developments are key in our mission to
Find, Treat and Cure HHT.

Making Coast to Coast Connections

with Our HHT Community



These past few months, we have travelled from New York to San Francisco, and places in between, spreading Awareness, introducing patients to one another, connecting those with HHT to quality healthcare, and creating life-long relationships within our HHT community. By way of our regional Walks, conferences and all of the amazing people who hosted their own special HHT Awareness events, our message to **Find, Treat and Cure HHT** was heard!

While we are so grateful to those that came out by the hundreds to support these events, meet us and most importantly, meet others affected by HHT, we couldn't have done it without all the incredible event organizers who took their precious time to help us make these valuable connections in our HHT Community. For that, we **THANK YOU** from the bottom of our hearts!

Event Name	Date	Organizer	Event City/State
7th Annual Night of Hope	March 16, 2019	Clay & Jody Nissan	Plymouth, MI
Sophia's Fly for HHT	May 1, 2019	Sophia Hershman	Scarsdale, NY
Denver Colfax Marathon	May 19, 2019	Jessica Hammer	Denver, CO
Bay to Breakers	May 20, 2019	Angela Carlisle-Brown	San Francisco, CA
Ride for HHT	June 2, 2019	Erin & James Denovan	Denver, CO
Strike for a Cure	June 30, 2019	Tania Competiello	Foxborough, MA
10th Annual Stoner Open	July 12, 2019	Steve Stoner	Lafayette, NJ
2nd Fun Run for HHT	July 20, 2019	Jennifer Bannon	Ridge, NY





Cure HHT
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Monkton, MD 21111

#GIVING
TUESDAY

**This December 3, 2019, consider joining
the #GivingTuesday movement,
a day of charitable giving at the beginning
of the holiday season, and help us
FIND, TREAT and CURE HHT
with your personal donation!**