

Edition:  
Fall  
2017

# Cure HHT newsletter

News & Information for the HHT Community

## HHT Conference goes Global

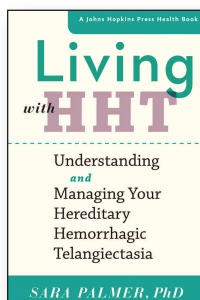
For the first time at an HHT Conference, 200 voices were heard from six continents (23 countries), motivating interest for those new to the field, and encouraging young researchers and clinicians to continue to build a career surrounding HHT. The attendance of young scientists was at an all-time high and the conference was buzzing with the excitement of knowledge and opportunity.

It was truly amazing to see the array of information presented at this meeting that all function to develop a greater global understanding of HHT. As always, this event continued to foster the opportunity for scientific collaboration, welcome young scholars to the community, and rekindle old friendships.

Oral Presentation Abstracts, Poster Presentation Abstracts and an Executive Summary of the talks and workshops will be published in the Fall issue of *Angiogenesis*.

Cure HHT will also host a webinar this fall to review the highlights of the conference, with hopes that the knowledge gained from this meeting will spread and reach all corners of the HHT community. In the meantime, check out:

<https://curehht.org/2017/07/recap-12th-hht-international-scientific-conference/>



**Announcing the first comprehensive book on Living with HHT!**

**See page 8 & 9 to find out how you can reserve an advance copy, signed by the author, while also supporting our mission to cure HHT !**





## Message from Marianne

### ***Our Future is Full of Possibilities***

**C**hange is happening faster than I could have imagined!

Breakthroughs for HHT are within reach and **Cure HHT** is proud to be able to bring our community members together to make possibilities a reality! You will read several stories in this issue describing this dynamic that brings us hope.

When I attended the 12th International Scientific Conference in Croatia this summer, I saw firsthand how collaborations continue to lead to faster progress in HHT research, treatment, and access to care. It was a privilege to once again host this important event, where critical knowledge and advances are shared and new partnerships are formed.

You will be excited to hear that there are several potential new therapies for HHT treatment. New drug therapies are focused on shrinking and eliminating telangiectasia and AVMs, while gene therapy studies may make it possible to target AVMs in specific organs.

Many exciting new possibilities surrounding access to HHT care are also in the works. I am very proud to announce **Cure HHT's** investment in legislative advocacy has resulted in receipt of federal funding to explore a potential new way to increase access to care for patients by joining forces with Hemophilia Treatment Centers and giving them the knowledge and tools needed to begin to evaluate and treat HHT. In addition to that, we have also recently opened an online portal to accept applications for new HHT Centers in North America!

We are constantly working to accelerate progress towards better treatments and a cure.

**You can help us grow the momentum we are building together.**

In partnership,

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

Sponsorship and/or advertisement in the Cure HHT newsletter does not constitute endorsement of any treatment or product by Cure HHT.

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# HHT Awareness Month

This past June, our community came together across oceans to unite as one. Through HHT events, daily HHT facts, stories about HHT and a special candle lighting campaign for HHT patients and families, thousands acted to enlighten the world about this disease.

**WALKS:** We had three HHT Walks and Family Days this month with over 150 participants, and raised over \$10,000 for HHT research and education programs!



**JUNE 23rd:** This year's **HHT Global Awareness Day** had over 200 people across 66 cities and 8 countries lighting candles and sharing their stories to **#LigHHTUp the World** for this disease.



**MARSHA HANSEN:** A concert vocalist and author, collaborated with artists to produce the song, *This Little Light of Mine*, for HHT Global Awareness Day. The song is available on iTunes and proceeds from each download go to **Cure HHT** in order to help educate the public about this disease.

## BY THE NUMBERS

### This June:

- 3 HHT Walks raising over **\$10,000** for HHT
- HHT Golf Tournament raising over **\$15,000** for HHT
- **66 cities** and **8 countries** participating in **HHT Global Awareness Day**
- **600 people** watched Marsha Hansen's tribute to HHT
- Over **5,000** likes on Facebook during **HHT Awareness Month**

*Through awareness efforts, we are making it possible for HHT patients to receive an accurate diagnosis, doctors to receive accurate education about managing HHT and researchers to receive funding to improve treatment options.*

**Thank you for making this HHT Awareness Month the best one yet!**



# Cure HHT Welcomes New Board Members

Join us in welcoming Christopher Gibson, Ben Holt and Kelsey Hall to the Cure HHT Board of Directors, a role dedicated to guiding the HHT community toward new levels of awareness and a cure.



"I joined **Cure HHT** for a number of reasons. First, in my role in the BioPharma Industry I think it is important to stay connected to patients and patient needs. Second, as our company begins to move into the clinic with a number of programs across multiple rare diseases, familiarity with Cure HHT will help me engage with patient groups. Lastly, as our company works on many diverse genetic diseases, why did I pick the HHT group over others? Simply put, I studied with Dean Li and Kevin Whitehead, two pioneers in the HHT field, and

was introduced to the disease and nominated for the Board by them. Altogether, I'm excited to be a part of this group, and hope that I can provide some useful contributions to help advance the study of the disease." – **Christopher Gibson, Ph.D., Founder & CEO, Recursion Pharmaceuticals (Park City, UT)**



"I got involved with **Cure HHT** because I was looking for a way to make a difference. While talking with a friend in California, she told me about the disease and how it affected her family. She also indicated a need for an attorney to help out with contracts and legal risk analysis. As I began helping **Cure HHT**, I discovered a network of caring individuals dedicated to making life better for others. I joined the board because I believe in the cause and the people. While I am fortunate to not be directly affected by the disease, those that I

count as friends are." – **Ben Holt, Attorney, Stoel Rives LLP (Sandy, UT)**



"My family learned about HHT when I was about 5 years old. My family members have been impacted in different ways with varying levels of severity. So like for many others involved with the organization, for me it's personal. I always knew I wanted to be involved with the **Cure HHT** foundation. But when I envisioned it, it was always sometime in the future. When the HHT Center opened in New York and I met the team up close and in person, I felt an immediate connection with those in the community - the doctors, other patients, board members, Marianne and


the team. It quickly became clear that there were needs that I could help realize now. No need to wait. I was thrilled to be asked to join the board. I am excited to do my part in helping the team tackle key challenges around awareness, communication and furthering the mission to find better treatments and a cure." – **Kelsey Hall, HHT patient (New York, NY)**

## Growing the HHT Research Community



*Our conference in Dubrovnik drew 195 HHT scientists, and with attendees from 6 continents, 8 invited speakers, 58 oral presentations and 117 poster presentations!*

**The Young Scholar Research Program**, launched by **Cure HHT** in 2015, was designed to attract new researchers into the field of HHT. The program was carried over into the HHT International Scientific Conference by funding travel awards that allowed a group of 18 young scientists / fellows to attend the event in Croatia. In addition, eight young scholars received recognition, along with a monetary award, for their outstanding presentations at the conference. This year, Cure HHT is proud to support Young Scholars from Belgium, Canada, France, Germany, Italy, The Netherlands, Scotland, Spain, United Kingdom and the United States.

A group of 18 young scientists and fellows, including both men and women of various ethnicities, are posing for a group photo outdoors. They are standing on a stone wall or ledge, with a body of water and hills in the background. The group is diverse in age and appearance, and many are wearing lanyards with identification badges. The setting appears to be a scenic outdoor location, likely in Croatia as mentioned in the text.

**Thank You!** We'd like to give an enthusiastic thank you to everyone who contributed to this conference both scientifically and financially. Your dedication to this community had a direct impact on Cure HHT's ability to provide attendees with a rich and fulfilling experience. Your contributions are deeply appreciated by all!

- ◆ 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



## Executive Committee

*"Thanks again to you and the amazing team at Cure HHT for supporting my science and for putting on a truly fantastic conference."*

- Dr. Melissa Hector-Greene, Duke University



***"It was one of the best and most interactive conferences I've attended and was very proud to be part of it."***

**- Dr. Charles Theuer, TRACON Pharmaceutical (Invited Speaker)**

## **Up Close and Personal in Dubrovnik**

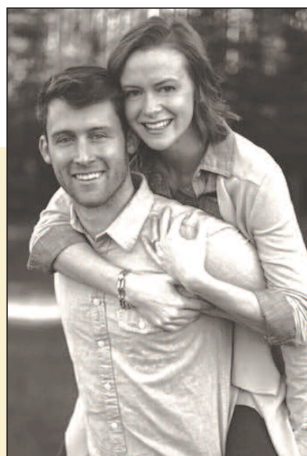
**By Anthony Anzell, PhD Candidate, Wayne State University School of Medicine and HHT Patient**

My wife Emily and I had the pleasure this year of attending the scientific conference in Dubrovnik, Croatia. Aside from being surrounded by HHT doctors and scientists from around the world who have centered their career around our disease, it was amazing to have the opportunity to meet patients from around the world who know all too well the struggles of HHT.

As a patient and an aspiring scientist, it's inspiring to see the work scientists and doctors are doing to understand this disease. To experience the discussions, debates, and collaborations that were made at the conference gave my wife and I such confidence that an HHT cure is not just a distant fantasy anymore, but soon a reality! And it certainly is an honor to potentially be a part of that.

My wife, a nurse and HHT caregiver, found the clinical portion of the conference invaluable. "Just being able to understand more about the preferred screening processes and the different available options for clinically viable therapies for HHT nosebleeds/AVMs was incredibly useful. Not only for my husband and I to help him fight this disease, but also for the patients I see daily that I suspect may have HHT."

Beyond all the exciting findings and encouraging information, I think what amazed Emily and me the most was the outstanding community the HHT foundation has created. To see all different kinds of people (doctors, scientists, patients, family) being unified through one common cause was remarkable. To all the HHT patients/doctors/scientists out there, we truly have something special that not very many other foundations possess and we are so blessed not only to have the opportunity to experience that community, but to be a part of it.

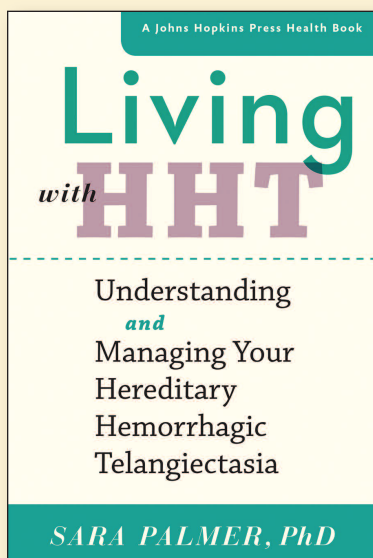


**Read the scientific conference recap at:**

**<https://curehht.org/2017/07/recap-12th-hht-international-scientific-conference/>.**

You will find conference summaries and photos, all of the details on our Young Investigator Travel Award Recipients, our Young Scholar Presentation Award Recipients, and much more!

# The First Comprehensive Book on HHT



## *Living With HHT*

### Understanding and Managing Your Hereditary Hemorrhagic Telangiectasia

Paperback, 200 pages

Sara Palmer, PhD and Johns Hopkins University Press announce the first ever book on HHT, due out in December 2017.

A Cure HHT Board Member, Sara has HHT herself. As a Psychologist, she is an expert in helping people cope with health conditions. She draws on current research as she thoroughly describes the symptoms of HHT, explains how the diagnosis is made (and often missed), and details treatment options.

Sara also addresses how HHT patients can maintain their own emotional health, help other family members including children, partners and parents, and live life as fully as possible. Enriched with illustrations, personal stories of people living with HHT, a glossary, and contact information for the HHT Centers of Excellence, this is a complete resource for individuals with HHT and their families.

Sara is an assistant professor in the Department of Physical Medicine and Rehabilitation at Johns Hopkins University School of Medicine. She is the co-author of *Spinal Cord Injury: A Guide for Living*, as well as other books.

Generously, Sara has pledged all of her royalties from this book to Cure HHT. See the next page on how you can support Cure HHT and be one of the first to receive an advance copy of this ground-breaking book, signed by Sara!



## Upcoming LIVE Webinar with Sara Palmer, PhD and James Gossage, MD

**Tuesday, October 24, 2017 from 7:00pm - 8:00pm (EDT)**

Join Drs. Gossage and Palmer for an in-depth discussion on how to advocate for your health. This webinar is for young adults living on their own or newly diagnosed patients needing to navigate the HHT healthcare system. Gain an understanding of general HHT screenings and follow-up schedules, know your insurance benefits, learn how to find a doctor and prepare for long-term relationships that may include planning a family. James Gossage, MD, is the Cure HHT Medical Director.

**Find out about all of our webinars here:**

**<https://curehht.org/resources/webinars/>**

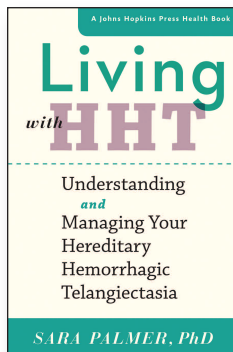


# Thank You! We Could Not Do This Without You

*We have one mission that drives everything we do: to find a cure for HHT disease ...and your continuing support is vital!*

**Cure HHT** is the *only* patient advocacy organization focused solely on HHT patients and their families. We will always stand with you, and we thank you for standing with us.

**Special Offer!** [Click here](#) to reserve an advance copy, signed by the author, while also supporting our mission to cure HHT!

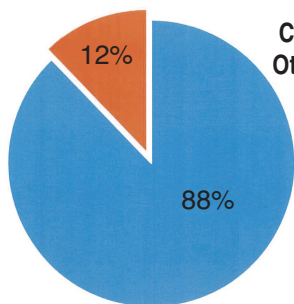


**Make a tax-deductible contribution of \$100 or more before November 1st**, and you'll receive a complimentary advance copy of *Living With HHT* personally signed by the author and Cure HHT Board Member, Sara Palmer, PhD.

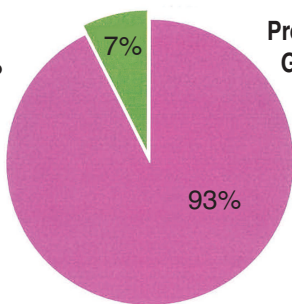
This is an exclusive offer to the Cure HHT community, and you will be among the first to receive an advance copy of this groundbreaking book before the release date. ([Read about the book on the previous page](#))

Your generous gift in any amount is always appreciated, and really does make a difference for **Cure HHT**:

- **93 cents of every dollar** you can afford to give goes directly into research and programs.
- **Your gift is vital!** Individual donations and family foundations account for 88% of our budget.



Revenues for FY 2016



Expenses for FY 2016

## Active & Retired Federal Employees and Military Personnel

You can make a vital donation to **Cure HHT** through the *Combined Federal Campaign* starting October 2, 2017 through January 12, 2018.

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



# Clinical Science Summary

**By Urban Geisthoff, MD, HHT Center Director, Cologne and Homburg, Germany**



**12<sup>th</sup>** HHT  
INTERNATIONAL  
SCIENTIFIC CONFERENCE

The 12th HHT International Scientific Conference provided an abundance of clinical research on current treatments as well as promising new therapies.

- The data from one of the presented studies showed that screening for pulmonary arteriovenous malformations (PAVMs) together with treatment can increase and even normalize life expectancy for HHT patients.
- It was noted that screening by CT scan alone might miss PAVMs which can be detected by echocardiography.
- During a workshop on hepatic vascular malformations (HVMs) a long discussion on the appropriate treatment took place. Most participants were of the opinion that Bevacizumab is a valid option to try before liver transplantation.
- Management of cerebral vascular malformations and screening children were other important topics of discussions.
- Promising results for new drugs for nosebleeds were reported including the beta blocker propranolol and the tyrosine kinase inhibitor Pazopanib. Multiple other novel findings on various aspects of HHT were presented, however, data is often not sufficient yet for a clinical application.

*The full Clinical Science Summary Presentation can be viewed on the scientific conference website at <http://science.hhtconference.org/welcome/> and will be presented as a Cure HHT webinar this fall.*

## HHT Center Application Portal is NOW OPEN!

We are excited to announce that after eighteen months of intense review and improvement the Cure HHT Center of Excellence Committee, led by Marianne Clancy, *Executive Director*, and Dr. James Gossage, *Medical Director*, has re-developed a process to evaluate the medical expertise and viability of an HHT Center.

Increasing access to knowledgeable HHT professionals has always been a priority for the Cure HHT Board of Directors but since 2008 Cure HHT has been committed to adding two new North American centers per year. By increasing the number of Cure HHT Centers of Excellence, diagnosis and treatment becomes more affordable for HHT patients by decreasing travel costs and increasing the likelihood of insurance coverage.

# Basic Science Summary

*By Carmelo Bernabeu, PhD, Centro de Investigaciones Biologicas (CSIC), Spain*



**12<sup>th</sup>** HHT  
INTERNATIONAL  
SCIENTIFIC CONFERENCE

Novel and interesting findings were reported at the 12th HHT International Scientific Conference.

- Elucidation of the three dimensional structure of human endoglin in complex with the physiological ligand BMP9.
- New genetic, antibody-induced and virally-induced animal models for HHT, including Smad4 heterozygous mice.
- Studies on putative therapeutic targets, such as PI3K and tyrosine-kinase inhibitors, TEK/Angiopietin2, and CXCR4/CXCL12.
- Functions of endoglin in blood flow, in macrophages/bacterial infections, and in platelet adhesion to endothelium/hemostasis.
- Results with the anti-angiogenic drug bevacizumab, which targets VEGF.
- Remarkable findings in cancer therapy with three anti-angiogenic drugs that target HHT proteins (TRC105, Dalantercept and PF03446962), which reproduce HHT symptoms (epistaxis, telangiectasias, gingival bleeding).
- In vitro results using induced pluripotent stem cells (iPSCs) from HHT patients.
- Preliminary gene therapy studies with adenovirus associated virus (strain AAV-1) to correct haploinsufficiency of HHT genes.
- Repurposing of existing drugs as the immunosuppressor Tacrolimus, the beta-blocker propranolol, or the aminoglycoside Ataluren, which allows reading through stop codons mutations.

*The full Basic Science Summary Presentation can be viewed on the scientific conference website at <http://science.hhtconference.org/welcome/> and will be presented as a Cure HHT webinar this fall.*

Now that our network of HHT Centers has grown from eleven (2008) to twenty-five (2016) it was time to revisit the Center of Excellence certification process. Currently, twenty hospitals throughout the United States have expressed an interest in becoming an HHT Center of Excellence and the Criteria for North American Cure HHT Centers of Excellence is now available for their review.

*For specific questions relating to the center criteria, application process, or becoming an HHT Center of Excellence, please contact Nicole Schaefer at [HHTcenter@curehht.org](mailto:HHTcenter@curehht.org).*

# Fundraising Highlights



## Spotlight on our August Fundraisers!

On August 19th **Anthony Anzell** and **Jordan Campbell** swam 19 miles across Torch Lake in Michigan to spread HHT awareness and raise funds for better access to care. With the support of our HHT community, they raised over \$9,000 for this cause. ***Awesome job guys!***



On August 26th over 170 people participated in a **5K Run/Walk in Ridge, NY for HHT!** Event organizers **Jenn Bannon** and **Liz Montelione** organized this incredible race for HHT, and raised over \$8,000! A huge thank you to Jenn, Liz and all the participants, sponsors and donors who made this event possible.

## Ready for a Challenge? HHT in all 50 States!

We want **YOU** to join us in a movement to spread HHT awareness across all corners of the United States. **Our goal? 50 HHT events in 50 States!**

**Our HHT community may be small, but we are everywhere!**

**Help Cure HHT** by educating your community about HHT and raising funds for HHT research and education programs. Events can range from a dinner party to a kickball tournament and everything in between. The possibilities are endless!

**Have an idea? Want to learn more? Contact us at [events@curehht.org](mailto:events@curehht.org)**

## Call For Walk Captains!

**Cure HHT is heading to the following cities for HHT Walks and Family Days:**

- **San Francisco, CA**
- **New York, NY**
- **Chicago, IL**
- **Boston, MA**

*If you want to help us plan an amazing day for HHT families and friends, join us at one of these Walks as a Walk Captain! This is a great volunteer opportunity to support those who have the disease and have fun meeting others with HHT. To learn more, contact us at [events@curehht.org](mailto:events@curehht.org)*



# Volunteer Spotlight

In January 2018, two Australians will embark on a one-of-a-kind adventure for HHT: to travel 3,000 km/1,800 miles in India in nothing but a rickshaw, a three-wheeled vehicle with very little horsepower and a questionable braking system.



**Grant Maw**, a software developer from Queensland and **Simon Sawyer**, a lawyer from Brisbane, will spend two weeks riding such a vehicle to promote HHT awareness with Cure HHT as one of the selected charities for this team.

We sat down (virtually, of course) with Grant and Simon to understand more about this unique trip:

**Cure HHT:** Why the Rickshaw Run?

**Simon:** *The point of this trip, from a fundraising point of view, is to get people's attention and get them to engage. We think we've picked the right event because the Rickshaw Run is off-the-wall INSANE! It is totally unsupported – we have no backup, no check-points, no set route (and, according to our wives – no brains!). We both love the unpredictable nature of the Run, and that we will be interacting with locals on a personal level in order to make it through the two weeks. If that doesn't grab people's attention, nothing will!*

**Cure HHT:** Why did you pick **Cure HHT** as your charity?

**Grant:** *I have HHT, and have dealt with nosebleeds and other symptoms for the past 40 years. The level of ignorance about the condition amongst the medical community is astounding, and I want to raise awareness by doing something so completely off-the-wall that people would notice. Raising a few dollars along the way to help with research is a bonus as well.*

**Cure HHT:** Anything you want the HHT community to know about this adventure?

**Grant:** *We want to raise awareness and raise money, but also want others to know that HHT doesn't have to be a life sentence. You can enjoy life, do crazy things... there is always hope!*

To learn more about Grant and Simon and this incredible journey, check out their website: <http://www.curryontukkin.com/>

And, stay tuned for announcements this fall to find out how you can support these volunteers as they prepare for the Rickshaw Run.

# Awards

## Dr. Steve Hetts Receives The Robert I. White, MD Young Clinician Award



*"Dr. Hetts brings a dedicated passion to his treatment of HHT patients and participation in the Cure HHT mission. He is always invigorating peers and mentees in various projects, championing ideas and following through. We are lucky to have him on our team!"*

- Marianne Clancy, Cure HHT Executive Director

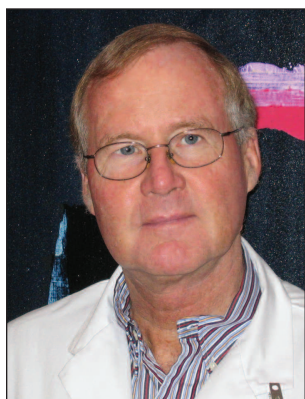
**Cure HHT** is honored to present the **Robert I. White, MD Young Clinician Award** to Dr. Steve Hetts, a driven, intelligent asset to the HHT medical team. Not only was he instrumental in starting the HHT Center of Excellence at UCSF, he has continued to educate the HHT community as a whole at

family conferences as well as the medical community at HHT related seminars.

*"The care I provide for patients with HHT is inspiring to me and a highlight of my career. An award associated with a true pioneer in the field of HHT is humbling and deeply meaningful to me."* – Dr. Hetts

The RIW Award was established in 2004, in recognition of Dr. Robert I. White Jr's outstanding contribution to HHT care and 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.

## Dr. Karel terBrugge Receives The Lifetime Scientific Leadership Award



*"Dr. terBrugge is truly world-renowned, having led the development of minimally invasive therapies for some of the most feared brain diseases and complications, including brain AVMs. He has taught countless doctors all over the world about brain AVMs and HHT. I have always admired his leadership of the medical and scientific community."*

- Marie Faughnan, MD, MSc, Cure HHT Scientific Research Director

**Cure HHT** is honored to present the **Lifetime Scientific Leadership Award** to Dr. Karel terBrugge, who has dedicated his career to neurointerventional radiology, brain AVMs and HHT. Dr. ter Brugge has been a leader, teacher, innovator, scientist, doctor and mentor in his field and in

the HHT community for the past forty-seven years.

*"I am proud to have built a multidisciplinary team in Toronto, bringing people together to provide expert care to HHT patients while serving on the HHT foundation medical board and promoting brain vascular malformation research worldwide. It has been my privilege to be part of the HHT community."* – Dr. terBrugge

The Scientific Leadership Award was established in 2010 to recognize a researcher who has committed their career to the study of HHT and has made great strides in scientific research.

## Hemophilia Treatment Centers – A potential way to increase access to HHT care



*Thanks to  
Congressman David E. Price (D-NC)  
and the constituents of North  
Carolina who let their voices be heard,  
federal funding for a two year pilot  
study involving the “co-location”  
of HHT Centers with existing  
Hemophilia Treatment Centers (HTCs)  
has been secured!*

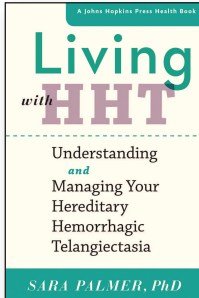
On August 24, 2017, Cure HHT, in conjunction with the Cure HHT Center of Excellence at UNC Chapel Hill, honored Congressman Price with the **Cure HHT Champion Award**. Congressman Price made securing federal funding for the new HHT pilot initiative one of his top three legislative priorities. The presentation and reception were held at the Carolina Club at UNC Chapel Hill, after a tour of the Chapel Hill HHT Center with Center Director Dr. Raj Kasthuri and Cure HHT Executive Director Marianne Clancy.



While there has been significant progress towards increasing the number of HHT Centers of Excellence over the last decade, we are far from the goal of an HHT Center in every state. There are 147 Hemophilia Treatment Centers in the US that are regulated and funded through the Centers for Disease Control and Prevention (CDC) to provide patients access to multidisciplinary health care professionals. One approach to quickly address the current needs of HHT care is to have existing HTCs serve as specialty centers for the evaluation and management of HHT, as much of the necessary infrastructure for an HHT Center already exists in an HTC.



**Cure HHT**  
PO Box 329  
Monkton, MD 21111



***Announcing the first comprehensive book  
on Living with HHT!***

**See page 8 & 9 to find out how you can reserve  
an advance copy, signed by the author,  
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