



Edition:  
Winter  
2019

# Cure HHT newsletter

News & Information for the HHT Community

## With Great Success Comes Greater Need

**Thank you!** Our 2018 Year End Appeal was our most successful fundraising campaign to date! You have been the driving force behind our accomplishments, and you are the driving force for our future, making possible so many significant advances in innovative scientific research, advocacy, and awareness campaigns.

To date, Cure HHT has created **27 Centers of Excellence** in North America, with four more in the pipeline. A pilot program is actively underway that could enable patient access to HHT care through the existing network of federally funded **Hemophilia and Thrombosis Centers across the country.**

**We are on the leading edge of scientific research** throughout the HHT Community worldwide. To date we have leveraged **\$30 million for scientists** working on HHT. Research, drug trials and scientific exchanges are the path to better treatments and a cure, and would not be possible without your commitment to YOUR HHT Community. Together we are creating a world where HHT is commonly recognized, treated and cured ... **In Our Lifetime!**

As we continue to **expand and accelerate** our efforts, we need your support and involvement **more than ever before.** **With great success comes greater need!** In this newsletter you will find many opportunities to become involved, advance our work, build awareness, **and support YOUR cause!**

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## Message from Marianne

### *A Look at the Year Ahead*

The start of a new year provides us an opportunity to reflect on last year's accomplishments while looking ahead to fresh new opportunities and prioritizing key initiatives.

The pace of research and advances in therapies present unprecedented opportunities. I have been astonished at the pace of change in research and advancements all while recognizing the importance of the patient voice. Cure HHT represents your voice and with the volume on high we work to ensure

those making decisions about drug trials truly understand the challenges faced by our families. Listening to you, we are able to help guide study design, motivate researchers and connect industry with patients.

Your voice is important in fostering the My HHT Tracker App, which enables you to track your nosebleeds, iron levels, tests and, most importantly, the ability to share your collected data with your doctors to ensure you are receiving the most effective treatment.

Your voice will again be critical as we invite you to join us for a meeting with the FDA. Patient Listening Sessions, designed by the FDA, are a way for medical product centers to engage with patients and advocates. As we advance new clinical trials, your experiences in living with HHT daily will play a crucial part in promoting an understanding of your critical unmet needs.

By uniting our efforts, our voices will resonate and bring about the advances you so deserve.

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](mailto:marianne.clancy@curehht.org)

### **Cure HHT** welcomes new board member **Mark Topaz**

"I've seen HHT affect four generations of my family and I want to do everything I can to make sure the detrimental impact stops there. Cure HHT has done so much to help so many people with HHT by increasing awareness, provoking the interest of the medical community, helping to promote ways to treat HHT, improving patient lives and to ultimately find a cure. I'm very happy and proud to be a part of Cure HHT" **–Mark Topaz**





## CONNECT WITH US



[facebook.com/hht.org](https://facebook.com/hht.org)



[@curehht](https://twitter.com/curehht)



[youtube.com/HHTFoundation](https://youtube.com/HHTFoundation)



[instagram.com/cure\\_hht/](https://instagram.com/cure_hht/)



<https://curehht.org/blog/>

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

### CURE HHT NEWSLETTER

**Marianne Clancy, RDH, MPA**

*Editor*

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## A Year in the Making: One Mother's Challenge to reach a National Audience and Beyond

Every day we continue the journey of working alongside our HHT Community to build Awareness around the world. This past November, with the tireless work of Zina Martinez, an HHT patient herself, her physician, Dr. Justin McWilliams, Director UCLA HHT Center of Excellence and Cure HHT, Zina's harrowing story was able to reach not only a national audience, but a global audience in the acclaimed *Washington Post*.

Since 1877, *The Washington Post*, a leading American newspaper and recipient of forty-seven *Pulitzer Prizes*, prides itself on bringing the most trusted and informative news to its readership. Since its simple past as a local D.C. newspaper to its now bi-continental and international audience of over a million readers, thanks to a daily circulation and online presence, WaPo (its favored abbreviation) was a dream publication for Zina's story.

Now, that dream has become a reality. With WaPo's award-winning reputation, it was only fitting that Zina's HHT battle be featured in their highly recognized Health & Science section as a featured article.



After her long journey of going undiagnosed, Zina just wanted answers. HHT was now, not only affecting her life, but the lives of her three young children. Zina's journey led her to Cure HHT and to Dr. Justin McWilliams at the UCLA HHT Center of Excellence. Together—patient, doctor and Cure HHT, fought for Awareness on a grand scale. "Having my story hit the newsstands made me feel like I had finally accomplished my mission", states Martinez. My children and I need to live our lives and my best advice is to be educated about HHT so that you can share what you know with your doctors and others."

Educating the public about "medical mystery diagnoses" is exactly what WaPo medical reporter, Sandra G. Boodman, is fostering in her column. Sandra's column, which focuses on a different unusual medical illness each month, is generating a buzz in the medical community and to everyday folks with unusual and undiagnosed symptoms, just like Zina and the rest of the HHT population of patients. This featured article gave Zina and the entire HHT Community a voice that once was silent among the non-HHT world. While Zina's story resonates with so many other HHT sufferers, it was Sandra's first look into the complicated world of HHT. Having Sandra bring HHT directly into the homes and offices of so many unknowing HHT sufferers and physicians, with little or no knowledge about the disease, is a ground-breaking journalistic feat for Awareness in the HHT Community around the world. Photo: Cameron Cottrill for *The Washington Post*

**The Washington Post** To read *The Washington Post's* full story about Zina Martinez and her incredible HHT journey catch it here at <https://curehht.org/zina-martinez-washington-post/>

## Eating for Health: Dietary Choices that Impact HHT

Did you know over 180 foods and dietary supplements have evidence to suggest they may promote bleeding? If you have a tendency to bleed easily, foods that may thin your blood or reduce your ability to clot can be harmful. For this reason, it is important to know what dietary choices may increase bleeding.

Cure HHT recently invited Lisa Mannik, a registered dietitian with the Toronto HHT Centre to speak on this popular topic. Over 350 people registered for our latest webinar and hundreds have visited our website to watch the recorded webinar.

Many that watched the webinar were surprised to hear that oily fish, such as salmon and trout contain Omega-3 Fatty acids which may promote bleeding because of its anti-platelet effect. Many spices and seasonings such as raw garlic and ginger, ginkgo biloba extract and ginseng, commonly found in some teas and energy drinks, may also increase bleeding in some. It is also important to note that alcohol and foods high in salicylates such as berries, pineapple, cherries and dried fruits, as well as some vegetables may promote bleeding, again due to the anti-platelet effects.

It is important for HHT patients to determine their triggers. What triggers bleeding for one person, may not affect another. Lisa Mannik suggests keeping a “food and symptom” record to help identify foods that may be problematic for you.

Other topics in this webinar include sources of dietary iron and dietary factors that affect its absorption. HHT patients that are anemic will want to check out the information on how to eat a high iron diet.

To watch the recorded webinar and view related resources, go to <https://curehht.org/resource/eating-for-health-dietary-choices-the-impact-bleeding/>

### Eating for Health: Dietary Choices that Impact HHT



January 16, 2019

Lisa Mannik, RD, MSc, CDE  
Registered Dietitian, Toronto HHT Centre  
St. Michael's Hospital

### Have You Attended Our Webinars Yet?

You might be missing out on some valuable information. REGISTER NOW!  
(<https://curehht.org/understanding-hht/get-support/webinars/>)

#### UPCOMING LIVE WEBINARS

**March 25 (7-8pm EST)**

Screening & Treatment of Brain AVMs in HHT

**May 15 (7-8pm EST)**

Iron Deficiency & Anemia

Did you know we post all of our past webinars online? Check them out in our Resource Library at [https://curehht.org/resource-library/?\\_sft\\_type=webinar](https://curehht.org/resource-library/?_sft_type=webinar)

#### SOME PAST WEBINARS

- Eating for Health: Dietary Choices That Impact HHT
  - Genetics: Unraveling Your DNA
  - My HHT Tracker (App)
  - Nosebleed Management in HHT
  - Iron Deficiency and Anemia in HHT
  - Caring for the Younger Generation
  - Pulmonary Hypertension and HHT
  - Psychological and Social Aspects of HHT
- And much more ...*

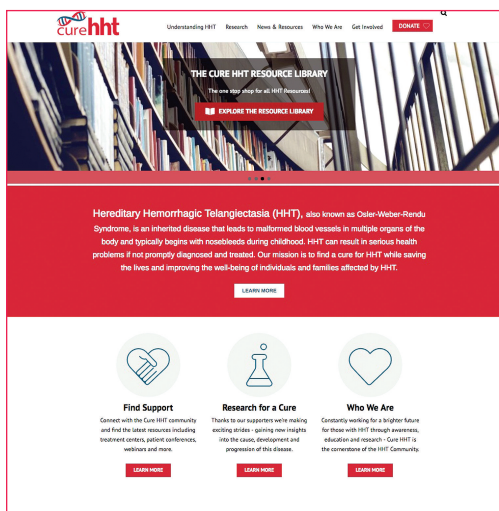


The Cornerstone of the HHT Community

## YOUR PERSONAL HHT TOOL KIT

Cure HHT fiercely pursues one mission that drives everything that we do: to find a cure for HHT or Hereditary Hemorrhagic Telangiectasia. We simply don't take "No" for an answer! While we are working towards that goal every day, we also want to ensure that you have the resources you need to take charge of your disease -- we call it Your Personal HHT Tool Kit!

## CureHHT.org - A Vast Online Source of Information



Our website is an unprecedented online resource for you, and access is Free.

- The Resource Library has vital fact sheets, nutrition information, helpful tips for parents, scientific articles and more!
- Our archive of more than 30 webinars can be viewed upon demand.
- There are now more than 700 doctors in our "Find A Doctor" Directory, and so much more!
- Last year we had more than 30,000 repeat visitors, who accessed more than 100,000 pages.
- Have a question about HHT? Go to [www.CureHHT.org](http://www.CureHHT.org)

## Living With HHT - The First Comprehensive Book!

Now in Paperback or Kindle Formats!

- 200 pages of information on diagnosis, screening and treatment of HHT, personal stories, illustrations, a glossary, and contact information for Cure HHT Centers of Excellence.
- Addresses the effects of HHT on emotions, quality of life, and relationships, with tips on how to live life as fully as possible.
- Author Sara Palmer is an HHT patient, board member and clinical psychologist, and she donates all book royalties to Cure HHT.

For details visit:  
<http://tinyurl.com/curehhtbook>



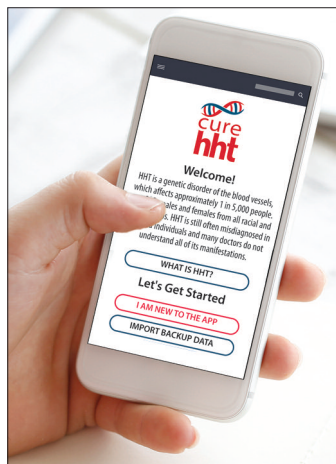
## “My HHT Tracker” App Now Available for Free Download Globally

Hundreds of people have already downloaded Cure HHT's FREE “My HHT Tracker” App for iOS! While keeping your private information totally confidential to you, it has everything you need to track your nosebleeds, test results, appointments, and more! Upload images, record your nosebleed frequency and severity and, if you choose, send critical information to your doctor direct from the app. Learn more: <https://tinyurl.com/HHTTrackerInfo>

**PRIVACY NOTICE** - Did you know that everything on My HHT Tracker is completely private? The App lets you manage your health, track nosebleeds, and more without auto-uploading your data to Apple when you backup your device.

*“Downloaded this in November. Have only been tracking my nosebleeds so far, but has worked really well and for the first time I can see what is happening with them. Seeing ENT and Hematologist next month so will start using more features then. Well worth getting it!” - Daniel*

**If You Use Android:** Cure HHT developed the iOS App at a cost of \$44,000, and we launched the App in October 2018 in the U.S. and about a month later globally. Making the App on one platform initially helps us track feedback and response for an Android version in the future. We are asking iOS users to download the App and provide us feedback, <https://www.surveymonkey.com/r/HHTTracker>, so we know it is useful to the HHT community. The App upgrade and investment to meet privacy standards on Android will require a future investment. Thanks!



## YOU ARE ONE OF THE 10%!

While HHT is a “rare disease”, we estimate that 1 in 5,000 people have it. That’s approximately 1.4 million people worldwide.  
**But, 90% of those with HHT are still undiagnosed.**

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, some people find it easier to make a monthly gift of any amount on a credit card -- \$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!**



SAN JUAN  
PUERTO RICO

# 13<sup>th</sup> HHT INTERNATIONAL SCIENTIFIC CONFERENCE

## North America Hosts Scientific Conference

Rio Mar, Puerto Rico June 13-16, 2019

The world's leading HHT research and clinical specialists are coming together for the 13th HHT International Scientific Conference.

Our goal is to accelerate progress toward a cure for HHT by strengthening collaborations between clinicians, scientists and industry to encourage more investigation into drug therapy and treatment research.

The biennial meeting sponsored by **Cure HHT** is considered a "must attend event" for both established and early-stage researchers, as well as clinicians experienced in treating HHT and those just entering the field.

Visit <http://science.hhtconference.org> for more information or to register. Early Bird rates end on April 30.

### INVITED SPEAKERS INCLUDE:

- Denise Adams, M.D., *Boston Children's Hospital*
- Holger Gerhardt, Ph.D., *Max Delbruck Center for Molecular Medicine*
- Christopher Gibson, Ph.D., *Recursion Pharmaceuticals, Inc.*
- Mark Kahn, M.D., *University of Pennsylvania Perelman School of Medicine*
- Andrei Kindzelski, M.D., Ph.D., *NHLBI, National Institutes of Health*
- Justin McWilliams, M.D., *University of California Los Angeles*
- Michael Ohliger, M.D., Ph.D., *University of California San Francisco*
- Ivan Radovanovic, M.D., Ph.D., *FMH, Toronto Western Research Institute*
- Ellie Tzima, Ph.D., *University of Oxford*

## RESOURCE LIBRARY



Did you know that **Cure HHT** has a comprehensive library full of resources for patients, physicians and scientists? You can search by topic or key words. *Give it a try!*

- Cure HHT Fact Sheet - [https://curehht.org/resource-library/?\\_sft\\_type=fact-sheet](https://curehht.org/resource-library/?_sft_type=fact-sheet)
- Information on Nutrition - [https://curehht.org/resource-library/?\\_sft\\_topic=nutrition](https://curehht.org/resource-library/?_sft_topic=nutrition)
- Information for Parents - [https://curehht.org/resource-library/?\\_sft\\_classification=parent](https://curehht.org/resource-library/?_sft_classification=parent)
- Articles and Tools for Nosebleed Management - [https://curehht.org/resource-library/?\\_sft\\_topic=nosebleed-mgmt](https://curehht.org/resource-library/?_sft_topic=nosebleed-mgmt)

*And much more ...*

Need help navigating the Resource Library? Watch a tutorial video at: [https://curehht.org/resource-library/?\\_sf\\_s=tutorial](https://curehht.org/resource-library/?_sf_s=tutorial)



## Our Newest CURE HHT Champion

Cure HHT is pleased to announce the most recent recipient of the Cure HHT Champion Award—Dr. Jeffrey Terrell. Dr. Terrell, Professor of Medicine, Division of Otolaryngology, University of Michigan, has devoted much of his practice to the treatment of HHT patients and over the last two years, was the mastermind behind the My HHT Tracker App.

It was Dr. Terrell, who had the vision for an App that would be instrumental in helping HHT patients track their nosebleeds as well as other features associated with the



**Dr. Jeffrey Terrell, Professor of Medicine, Division of Otolaryngology, University of Michigan**

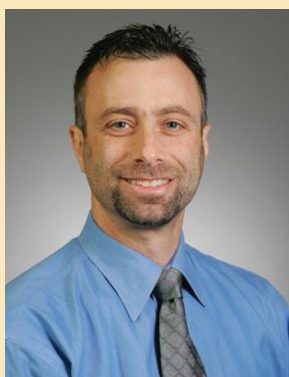
disease. When asked about the origin of the My HHT App, Dr. Terrell states, “I came up with the idea of the App about two years ago... I pitched it, along with a medical student, to the Cure HHT organization. I did a lot of research trying to figure out the best way to design this... working very closely with Cure HHT and Arbormoon Software.”

Cure HHT recognized Dr. Terrell and his two years of dedication to this project with the Cure HHT Champion Award at the Patient & Physician Conference this past Fall in Ann Arbor, MI.

Our heartfelt thanks to Dr. Terrell and his outstanding contributions to the HHT Community, patients and Cure HHT.

## Our New Chief Medical Officer

We are thrilled to announce that **Scott E. Olitsky, M.D., MBA** has been named **Chief Medical Officer for Cure HHT**. Dr. Olitsky obtained his medical degree from Jefferson Medical College in Philadelphia. He then completed a residency in ophthalmology followed by a fellowship in pediatric ophthalmology and later obtained an MBA from



**Scott E. Olitsky, M.D., MBA**

The Bloch School of Business. He recently retired from clinical practice where he was Chief of Pediatric Ophthalmology at Children’s Mercy Hospital and Professor of Ophthalmology at The University of Missouri - Kansas City School of Medicine. He has been an established member of the Cure HHT Board of Directors for the past 10 years.

When asked about his new and exciting role with Cure HHT, Dr. Olitsky states, “I am proud to be the first CMO of Cure HHT. Part of my decision to retire from clinical practice was my interest and passion to be more involved in helping Cure HHT during this promising and exciting time of opportunity to find better treatments and, one day

hopefully soon, a cure. I am a member of a family with 5 generations of people known to have HHT. Some have benefited greatly from the work the foundation has done. I hope to use my past clinical and research experience to continue to improve the lives of families with HHT, including mine. I look forward to working with the talented and dedicated physicians and scientists who will make this happen”.

# Sharing to Make a Difference

By Lindsey Conger



Recently I had an amazing opportunity to share my HHT story with a group of researchers from Recursion Pharmaceuticals, Inc. as well as local medical professionals in the Salt Lake City area. It all started by saying yes to a Facebook invitation. I saw on Facebook that Cure HHT was looking for a patient to volunteer to share a few experiences with researchers who are working on an HHT project. I thought that sounded like a cool opportunity as I always enjoy sharing with people how HHT has made me who I am today and raise awareness to help others to have success stories as well. Little did I know what an experience I was going to have.



I arrived at the event and I learned that Recursion Pharmaceuticals, Inc. is working on something truly amazing. They are repurposing medications that are already FDA approved to help HHT patients. This amazed me because it is much cheaper and faster than developing new drugs. I found that this truly is the future for HHT patients as well as so many others who suffer from rare diseases that are not adequately funded.

My parents and grandparents attended the event as well and following the presentation by Cure HHT Grant Recipient, Dr. Paul Oh, Professor of Neurobiology at the Barrow Neurological Institute, I shared about a ten minute version of our family's history with HHT. I absolutely loved the opportunity because I was able to thank each of them personally for their efforts to help progress the medical technology that blesses each of our lives every day. My family has had many tragedies over the years as we have lost multiple family members to HHT, but because ... (To read the rest of Lindsey's blog and other blogs from the HHT Community, go to <https://curehht.org/blog/>)

**"What the HHT" – A Blog for the HHT Community"**

Cure HHT  
**BLOG**

Like to blog yourself and want to get involved?  
Contact [Cathleen.kinnear@curehht.org](mailto:Cathleen.kinnear@curehht.org) for more information.

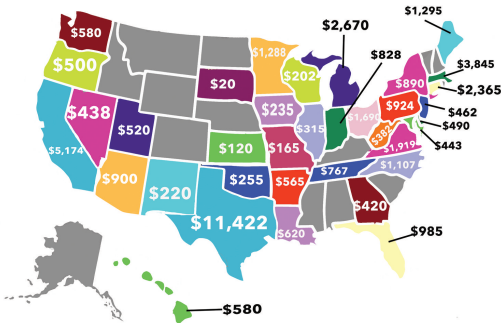
# And the Winner of the 50 State Challenge is...

2018 was the year of the 50 State Challenge and our HHT Community didn't disappoint! The challenge was launched across our great Nation, all with the purpose of creating awareness about this disease. Halfway through the year we introduced a

NEW challenge and any state that raised over \$10,000 would be entered to win a special event with our Executive Director, Marianne Clancy.

**We are thrilled to announce that TEXAS has won our 50 State Challenge!**

The Lone Star state raised over \$11K for HHT research, education and outreach, which will be used this year to help our HHT families.



While Texas was our winner, this challenge was truly about our great States coming together for one cause...HHT! There were over 100 participants in 36 states working together to take on our challenge and united, they created a movement to change the future of this disease.

**Even though the challenge is over, there are still plenty of ways to get involved and help us move closer to a cure for HHT!**

To learn about different ways you can join us, please visit our website:  
<https://curehht.org/get-involved/>

## Your Involvement Makes a Difference Get Involved with an Event

Thanks to our HHT Centers of Excellence and volunteers all over the country, Cure HHT boasts countless education, networking and fundraising events throughout the year. Your engagement makes all of this possible!



### MARCH 16

Plymouth, MI – 7th Annual Night of Hope Gala

### MARCH 25

Live Webinar – Screening & Treatment of Brain AVMs in HHT (7:00pm-8:00pm EST)

**Coming Spring 2019** Classic Car Raffle

### APRIL 27

Portland, OR - Family Day and Walk

### MAY 4

Salt Lake City, UT - Family Day and Walk

### MAY 15

Live Webinar – Iron Deficiency & Anemia in HHT (7:00pm-8:00pm EST)

### MAY 19

San Francisco, CA - Bay to Breakers 12K

### MAY 19-20

Denver, CO – Colfax Races

### JUNE 2

St. Louis, MO – Family Day and Walk

**JUNE Awareness MONTH** Stay tuned...

### JULY 12

Kresgeville, PA - 10th Annual Stoner Golf Open

### August 25

Denver, CO – Family Day and Walk

### SEPTEMBER (Date TBD)

Miami Area – Patient & Physician Conference

**Don't see an event in your area?**

Contact us at [events@curehht.org](mailto:events@curehht.org) or visit <https://curehht.org/get-involved/> to learn how to get started.



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



 **Start a Facebook fundraiser  
in honor of your birthday!**

Cure HHT would like to thank the over 160 members of the HHT community around the world who have already raised over \$46,000 to benefit Cure HHT!! It's easy to get started. Learn more at:

<http://bit.ly/FBFundraiser>

If you no longer wish to receive this newsletter please contact [hhtinfo@curehht.org](mailto:hhtinfo@curehht.org) or 410-357-9932.