Your Story is Our Story.
Your Future is Our Future!

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 make your voices heard! HHT strives for attention among nearly 7,000 diseases that are considered "rare." 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!

On the Cover: Susan & John Wallace with their son John Patrick and their daughter Haley Morris (pictured), who died from complications of undiagnosed HHT on February 14, 2019.

"We had a beautiful, perfectly healthy, normal 20-year-old. She was driven. She was in school to become a homicide detective. One minute she was there and the next, she was gone. With no warning. This disease can change your life in a matter of minutes. I will never be the same person that I was. But I will make something beautiful out of this tragedy. It is my goal, my mission. Maybe the reason this happened to us is so that we could do something about it. So we can make sure people know about this disease, to inspire more people to get tested and to get diagnosed for HHT. This doesn't have to happen to another family." - Susan Wallace

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Right to Left: New York Presbyterian/Columbia University HHT Center of Excellence: Dr. Sergei Sobolevsky, Director, Interventional Radiology; Helen Pena-Chacon, Coordinator; and Dr. David Mobley, Interventional Radiology.

"I want to maintain an easily approachable clinic to provide comprehensive guidance to patients who are often confused by the complexity of HHT." - Dr. Sergei Sobolevsky

"HHT patients come to us often after a lot of misdiagnosis and confusion about their disease. We do what we can to educate and reassure them. We make sure they know from the start that we are part of the HHT family. We are connected at the hip: we will never leave you in the dark and we are only one call away." - Helen Pena-Chacon

"Many people in medicine get involved because they want to make a difference. When unfortunate tragedy happens, we find that people deepen their engagement not only within their own family but their communities as well. That, in turn, encourages the healthcare practitioner to continue to be engaged and involved." - Dr. David Mobley
At age 13, Danielle, now 16, suffered a ruptured brain aneurysm. Knowing about HHT, Danielle's grandmother, Paula Roberts, was able to inform the doctor, which saved her life.

"With help and therapy, I started getting back to normal, to do all the things grant my agenda: I can have friends over, and I'm looking forward to going to concerts. I'm going to start riding a bike again! I have limitations: I'm pretty afraid of hitting my head and injuring myself. I mean, I won't be playing basketball any time soon." - Danielle Seymour, Patient

Cure HHT Executive Director Marianne Clancy met the Bannon family last year's Awareness Walk and Family Day in New York. They believed their father, John Bannon, had only weeks to live. Cure HHT immediately stepped in and referred John to the Cleveland Clinic where new treatment has led to an incredible recovery and new hope. John's situation also led to the testing and diagnosis of the rest of the Bannon family.

"I'm still learning ways to cope as my three children are only recently diagnosed. It wasn't easy but I'm hopeful for the future.

Receiving medical advice andaugmenting with funding for Cure HHT has helped me cope. Luckily only my husband and eldest daughter show any symptoms of HHT. I am surprised at how little some doctors know about HHT. It's frustrating to me to have to explain things to the pediatrician or orthopedist. 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." - Jenn Bannon, Caregiver

"Knowing that I have HHT has changed my life. As I get older, I'm getting more nosebleeds, I have a great primary, ENT and hematologist who keep me healthy and make sure my family's aware of events, meetings and new research. My grandmother, my mother, my aunt, my sister, my brother all have this disease. But, we don't have to continue to suffer from it anymore." - Karen Gustas, Patient

WAYS TO TAKE ACTION DURING JUNE AWARENESS MONTH!

• Download a press kit to send to your local newspaper: www.cureHHT.org/localnewskit. Let them know if you are willing to be interviewed about your experience with HHT!

• Talk to your healthcare providers about HHT. Here's a brochure to download and print out to give them on your next visit: www.cureHHT.org/HKPhole.pdf

• Test your knowledge – Take the HHT IQ Quiz! www.cureHHT.org/HHTQuiz

• Watch our website and Facebook page for news and updates from our 13th Annual Conference in Puerto Rico June 13-15.

• Mark your calendar for Global HHT Awareness Day, June 23!

• Check out all that we have planned for Awareness Month at www.cureHHT.org/Awareness

YES! I/we are itsThisTogether! Enclosed is:

$ 25 $ 100 $ 500 $ 2,500 + Other $

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Caregiver Name

Signature

I would like to be a monthly donor at $_______ per month, for ______ months.

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