



Cure HHT
P.O. Box 329, Monkton, MD 21111

**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 keep 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



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/HCProle.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 Scientific 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



At age 13, Daniella, now 16, suffered a ruptured brain AVM. Knowing about HHT, Daniella's grandmother, Paula Roberts, was able to inform the doctors, which saved her life.

"With help and therapy, I've started getting back to normal, to do the other things girls my age do. I can have friends over, and I'm looking forward to going to concerts. I'm going to start riding a bike again. I do have limitations. I'm pretty afraid of hitting my head and injuring myself. I mean, I won't be playing basketball any time soon."

- Daniella Seymour, Patient



Cure HHT Executive Director Marianne Clancy met the Bannon family at 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 were only recently diagnosed. It hasn't been easy, but I'm hopeful for the future. Becoming involved with fundraising for Cure HHT has helped me cope. Luckily only my husband and oldest 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 others. 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



"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 conferences, events 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 Gustus, Patient

"Both of my beautiful daughters have been diagnosed with HHT. As a photographer, I wanted to pay tribute to them and to people from so many walks of life who have been impacted by HHT: patients, medical professionals, caregivers, families. That's why I volunteered for the #InThisTogether project. I hope you will join me in doing everything you can to help spread awareness of HHT."

- David Zimand



YES! I/We are #InThisTogether! Enclosed is:

\$25 \$100 \$500 \$2,500 Other \$ _____

NAME _____
 ADDRESS _____
 CITY _____
 STATE, POSTAL CODE _____
 PHONE _____ EMAIL _____

PAYMENT METHOD

- Check (made payable to Cure HHT)
 VISA MasterCard Discover American Express

CARD NUMBER _____ EXPIRATION DATE _____
 VERIFICATION CODE _____ ZIP CODE _____

Cardholder Name _____ Signature _____
 I would like to be a monthly donor at \$ _____ per month,
 for _____ months.

Cure HHT | P.O. Box 329, Monkton, MD 21111 t: 410-357-9932 f: 410-472-5559 curehht.org/awareness2019

The HHT Foundation International Inc. is a 501(c)(3) non-profit organization. Donations are tax deductible as allowed by law: Tax ID: 22-3115041.

Your gift to Cure HHT is very much appreciated and fully deductible as a charitable contribution. A copy of our latest financial report may be obtained by writing to: Cure HHT, P.O. Box 329, Monkton, MD 21111 USA 410-357-9932. If you are a resident of one of these states, you may obtain financial information directly from the state agency: FLORIDA - A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL FREE, 1-800-435-7352 (800-HELP-FLA) WITHIN THE STATE. REGISTRATION DOES NOT IMPLY ENDORSEMENT, APPROVAL OR RECOMMENDATION BY THE STATE. Florida Registration #CH21738. GEORGIA - A full and fair description of the programs of HHT Foundation and our financial statement summary is available upon request at the office and phone number indicated above. MARYLAND - For the cost of copies and postage, Office of the Secretary of State, State House, Annapolis, MD 21401. MISSISSIPPI - The official registration and financial information of HHT Foundation may be obtained from the Mississippi Secretary of State's office by calling 1-888-236-6167. Registration by the Secretary of State does not imply endorsement. NEW JERSEY - INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION AND THE PERCENTAGE OF CONTRIBUTIONS RECEIVED BY THE CHARITY DURING THE LAST REPORTING PERIOD THAT WERE DEDICATED TO THE CHARITABLE PURPOSE MAY BE OBTAINED FROM THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING (973) 504-6215 AND IS AVAILABLE ON THE INTERNET AT <http://www.state.nj.us/ps/ca/sharfrom.htm>. REGISTRATION WITH THE ATTORNEY GENERAL DOES NOT IMPLY ENDORSEMENT. NEW YORK - Office of the Attorney General, Department of Law, Charities Bureau, 120 Broadway, New York, NY 10271. NORTH CAROLINA - FINANCIAL INFORMATION ABOUT THIS ORGANIZATION AND A COPY OF ITS LICENSE ARE AVAILABLE FROM THE STATE SOLICITATION LICENSING BRANCH AT 1-888-830-4989. THE LICENSE IS NOT AN ENDORSEMENT BY THE STATE. PENNSYLVANIA - The official registration and financial information of the HHT Foundation may be obtained directly from the Pennsylvania Department of State by calling toll-free, within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement. VIRGINIA - Virginia State Office of Consumer Affairs, Department of Agriculture and Consumer Services, PO Box 1163, Richmond, VA 23218. WASHINGTON - Charities Division, Office of the Secretary of State, State of Washington, Olympia, WA 98504-0422, 1-800-332-4483. WEST VIRGINIA - Residents may obtain a summary of the registration and financial documents from the Secretary of State, State Capitol, Charleston, WV 25305. Registration with any of these state agencies does not imply endorsement, approval or recommendation by any state.