

Cure HHT Mobilizing Its Community To Heighten Awareness During HHT Global Awareness Month in June

Highlights the Importance of Family Ambassadors in Pursuit of a Cure for Rare Genetic Disease

MONKTON, MD, UNITED STATES, May 25, 2023 /EINPresswire.com/ -- June is nationally



Our 14th HHT International Scientific Conference last year brought together a record-breaking 300+ global experts, amplifying our voice internationally with our most important influencers. "

*Cure HHT Executive Director
Marianne S. Clancy*

recognized as HHT Global Awareness Month, and [Cure HHT](#) – the only patient advocacy organization in the world funding research, awareness, and education for HHT patients and the medical/scientific community – is announcing its annual campaign to heighten awareness to help prevent unnecessary suffering and loss that is still far too common with this disease.

HHT (Hereditary Hemorrhagic Telangiectasia) is the second most common bleeding disorder, affecting an estimated 1.4 million people of all races and backgrounds globally. HHT affects 1 in 5,000 people, and is as common as Cystic Fibrosis, yet it is far less known and receives less funding

for research. Importantly, as many as 90% of those with HHT are unaware that they have the disease, which can have serious, even fatal, consequences. The most common symptom of HHT is frequent and severe nosebleeds, often dismissed, especially in children.

HHT creates two types of vascular abnormalities, telangiectasias and/or arteriovenous malformations (AVMs), which are fragile and susceptible to rupture and bleeding, and untreated may result in lung and brain hemorrhage, stroke, heart failure and death. One HHT diagnosis means there is a whole family of potentially affected people spanning generations. There is, as yet, no cure, but existing treatments can be effective if HHT is diagnosed early. Learn more at www.curehht.org.

To this day, the average delay in diagnosis is 27 years. The Maryland-headquartered Cure HHT aims to reduce that number and bring timelier, life-saving treatment to thousands of patients by calling on its community of patients, caregivers, and medical professionals to both donate and leverage social media during [June Awareness Month](#) to spread the word about HHT.

This year's theme is "Root Your Family in Awareness", and Cure HHT will be sharing resources and patient stories to highlight the importance of having entire families genetically tested. Because HHT can go for years or even decades without being diagnosed, genetic testing is the only way to ensure family members get the care they need before potentially catastrophic events arise. As part of the month, Cure HHT is also organizing family "teams" who will compete in raising both funds and awareness.

As part of the continuing effort to build awareness of the disease, Cure HHT will host its first National Patient & Physician Conference since the Pandemic on June 3-4 at the Hyatt Regency in Bellevue, Washington, just outside of Seattle. For details visit <https://hhtconference.org>

In 2009, Cure HHT secured the passage of a resolution in the United States Congress declaring June as National HHT Awareness Month. Throughout the month of June, and especially on Global Awareness Day June 23rd, Cure HHT encourages wider awareness of the disease so that more people will be diagnosed in a timely way and receive treatment before their situation becomes dire.

Cure HHT has established more than 50 HHT Centers of Excellence worldwide that include interventional radiologists, cardiologists, pulmonologists, pediatricians, neurosurgeons, gastroenterologists, ENTs, and many other medical disciplines. It has helped HHT researchers gain more than \$51.3 million in government funding through the National Institutes of Health (NIH), the Department of Defense (DOD), Food & Drug Administration (FDA) and after many years of advocacy, direct federal government appropriations.

The Cure HHT website is a portal for HHT patients and families worldwide seeking information, webinars, and knowledgeable doctors through its online Physician Directory. Cure HHT recently sponsored and hosted a record-setting 14th HHT International Scientific Conference in Portugal, bringing together hundreds of the best minds in the field.

Cure HHT's most recent accomplishments include being selected as 1 of only 30 organizations to participate in the Chan Zuckerberg Initiative's (CZI) Rare As One Network, providing funding, tools, expansion support, and training to create a larger, more integrated HHT community. Cure HHT also recently launched the Cure HHT Research Network, an HHT patient-led research network that encourages the sharing of ideas among patients, scientists, and physicians.

"Everything starts with awareness," comments Cure HHT Executive Director Marianne S. Clancy. "Not just with the public, but with physicians worldwide. Our 14th HHT International Scientific Conference last year brought together a record-breaking 300+ global experts, amplifying our voice internationally with our most important influencers. The more awareness of HHT we can build, the more people are diagnosed, better treatments are developed, and more funding is forthcoming for research in finding a cure. That has always been our ultimate goal."

###

Editor's Notes:

- Interviews are available throughout the United States and Canada with patients and medical professionals at the HHT Centers of Excellence - See a list of locations, here:

<https://directory.curehht.org/hht-centers>

- Learn more at www.curehht.org/awareness

- Interviews can be arranged with Executive Director Marianne S. Clancy

Anthony Fusco

Fusco & Four

+ +1 617-363-0405

[email us here](#)

Visit us on social media:

[Facebook](#)

[Twitter](#)

[LinkedIn](#)

[Other](#)

This press release can be viewed online at: <https://www.einpresswire.com/article/635849801>

EIN Presswire's priority is source transparency. We do not allow opaque clients, and our editors try to be careful about weeding out false and misleading content. As a user, if you see something we have missed, please do bring it to our attention. Your help is welcome. EIN Presswire, Everyone's Internet News Presswire™, tries to define some of the boundaries that are reasonable in today's world. Please see our Editorial Guidelines for more information.

© 1995-2023 Newsmatics Inc. All Right Reserved.