

CURE HHT ANNOUNCES NATIONAL PATIENT & PHYSICIAN CONFERENCE TO HELP FURTHER AWARENESS, EDUCATION AND RESEARCH

National Conference for HHT, a Rare Disease and the Second Most Common Genetic Bleeding Disorder, affecting 1 in 5,000 people, with 90% unaware they have it.

SEATTLE, WASHINGTON, USA, April 18, 2023 /EINPresswire.com/ -- [Cure HHT](#), the only patient advocacy organization in the world funding research, awareness and education for HHT ([Hereditary Hemorrhagic Telangiectasia](#)) patients, their families and the medical/scientific community, is pleased to announce that it 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. June is HHT Global Awareness Month, giving the Seattle conference even more significance. For details visit <https://hhtconference.org>



Cure HHT's National Patient & Physician Conference in June HHT Global Awareness Month

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HHT is a rare disease and the second most common genetic disease that causes bleeding, affecting an estimated 1.4 million people of all races and backgrounds. HHT affects 1 in 5,000 people.”

Marianne S. Clancy, Executive Director of Cure HHT

HHT is a rare disease and the second most common genetic disease that causes bleeding, 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, but receives far less funding and attention than other rare diseases. Importantly, as many as 90% of those with HHT are unaware that they have the disease, which can have dire, even fatal consequences. Learn more at www.curehht.org

Cure HHT's National Patient & Physician Conference offers an opportunity for patients and families to get their

questions answered by the world's leading HHT experts. Living with a rare disease like HHT can

be difficult and isolating. The conference provides a venue for families to meet and share information, while learning about the revolutionary treatments and research that are taking place today.

One of the main goals of the organization is to drive physician education, as HHT is often misdiagnosed. Thus, the conference also seeks to educate medical professionals, many of whom are unfamiliar with HHT diagnosis and care, and offers CME/CEU credits for professionals for participating. The conference also serves as invaluable forum for the world's leading experts in this disease, as it offers the ability for researchers and clinicians to collaborate and accelerate the pace of scientific advancements.

"We're thrilled to once again be hosting in-person conferences, the impact of which truly cannot be overstated," said Cure HHT Executive Director Marianne Clancy. "Over the years, countless patients have come up to me and said attending these meetings has quite literally saved their lives. HHT is a complex, multi-organ disease and it's so important for patients to be educated on latest in treatment guidelines and care standards so they can advocate for themselves and their families."

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. The most common symptom of HHT is frequent and severe nosebleeds, often dismissed, especially in children. 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.

Cure HHT, which is headquartered in Maryland, 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) 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.

“Since its inception in 1991, Cure HHT has grown from a handful of committed families and volunteers to become the cornerstone of a global movement to find a cure for this rare genetic disease,” comments Marianne S. Clancy, Executive Director of Cure HHT. “June is HHT Global Awareness Month, so it is especially thrilling for us to return to holding in-person conferences after so many years.”

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Editor’s Notes:

- Interviews can be arranged with Executive Director Marianne S. Clancy, and physicians and patients at the Seattle conference. Media coverage is encouraged.
- Interviews are available throughout the United States with patients and medical professionals at the HHT Centers of Excellence:

Ann Arbor, Michigan
Augusta, Georgia
Aurora, Colorado
Baltimore, Maryland
Boston, Massachusetts
Chapel Hill, North Carolina
Chicago, Illinois
Cincinnati, Ohio
Cleveland, Ohio
Dallas, Texas
Gainesville, Florida
Indianapolis, Indiana
Little Rock, Arkansas
Los Angeles, California
Milwaukee, Wisconsin
New Haven, Connecticut
New York, New York
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