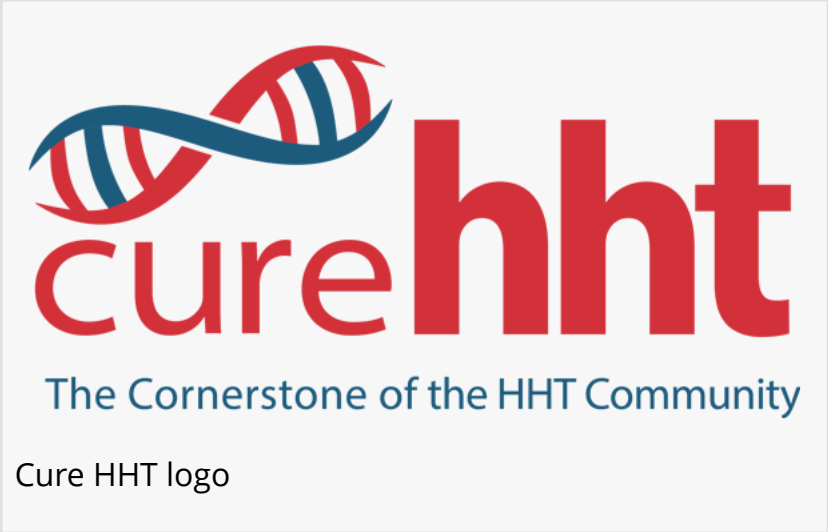
National CHORUS Study Brings New Visibility to the Full Impact of HHT, Urgency of HHT Diagnosis

New CHORUS data published in Blood show HHT is a serious multisystem bleeding disorder requiring earlier diagnosis, expert care, and research.



Cure HHT logo

MONKTON, MD, UNITED STATES, March 25, 2026 /EINPresswire.com/ -- Cure HHT proudly announces the publication of "Clinical Spectrum of Hereditary Hemorrhagic Telangiectasia: Data from the Comprehensive HHT Outcomes Registry of the US (CHORUS)" in Blood, the flagship journal of the American Society of Hematology (ASH). The study reports early findings from CHORUS, the first national U.S. registry designed to capture the real-world clinical impact of hereditary hemorrhagic telangiectasia (HHT).

> This publication gives the HHT community stronger national evidence for what patients and families have experienced all along."
>
> *Marianne Clancy, MPA*

HHT is a genetic blood vessel disorder that causes abnormal connections between arteries and veins, known as arteriovenous malformations (AVMs), in organs including the lungs, brain, liver, and gastrointestinal tract. It is the second most common inherited bleeding disorder in the U.S. and worldwide, resulting in frequent and severe nosebleeds, chronic gastrointestinal bleeding, iron deficiency anemia, and other serious complications. Because HHT often goes unrecognized for years, delayed diagnosis can lead to preventable, life-threatening outcomes, including brain and lung hemorrhage.

This publication marks a major milestone for the HHT community. By documenting the clinical spectrum of HHT using data from patients receiving care across U.S. HHT Centers of Excellence, the CHORUS study helps strengthen medical understanding of the disease, elevates awareness

among clinicians, and reinforces the urgent need for earlier diagnosis, expert care, and continued research investment.

“This publication gives the HHT community something incredibly important: stronger national evidence for what patients and families have been experiencing all along,” said Marianne Clancy, MPA, Chief Executive Officer of Cure HHT. “It shows that HHT is a serious, multisystem inherited bleeding disorder that demands earlier recognition, expert care, and continued investment in research. We hope this publication helps drive greater awareness, better care, and better outcomes for every family affected by HHT.”

Key Takeaways from the Publication

- Patients with HHT experience a substantial burden from chronic bleeding, iron deficiency, anemia, and organ involvement.
- Delayed or missed diagnosis can leave serious complications undetected and untreated.
- Researchers found that intracranial hemorrhage occurred in 3% of those studied, with most first brain bleeds happening by age 25. This rate is very high among bleeding disorders.
- Genetic testing was performed in only 60% of patients in the study’s cohort, highlighting ongoing gaps in diagnosis and management.
- 76% of patients with HHT develop moderate-to-severe nose bleeding and/or gastrointestinal bleeding requiring treatment.
- One-sixth of patients develop serious abnormal blood clots like strokes or pulmonary emboli.
- The incidence of potentially life-threatening brain bleeding is similar to that of hemophilia in the 1990s, before those patients received long-term treatment to prevent bleeding.

“CHORUS is helping us better understand the true burden of HHT,” said Hanny Al-Samkari, MD, the study’s first author who is a classical hematologist, The Peggy S. Blitz Endowed Chair of Hematology/Oncology, and Co-Director of the HHT Center of Excellence at Massachusetts General Hospital and an Associate Professor of Medicine at Harvard Medical School. “These findings underscore in dramatic fashion the serious unmet need in HHT, and therefore the urgency of developing new medications to treat this disease that currently has no FDA-approved therapies.”

CHORUS was launched through federal funding secured after years of advocacy by Cure HHT and the broader HHT community. The registry was created to generate a stronger evidence base for HHT, improve care delivery, and accelerate progress toward better treatments. This publication represents an important step forward in that work and a powerful example of what is possible when patient advocacy, expert clinical care, and research infrastructure come together.

Valaree Machen
Cure HHT
+1 410-357-9932 ext. 116

valaree.machen@curehht.org
Visit us on social media:
LinkedIn
Instagram
Facebook
YouTube
Other
