NEWS RELEASE

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CURE HHT PROMOTES JUNE AWARENESS MONTH

Baltimore, MD – Ninety percent of people with the rare disease Hereditary Hemorrhagic Telangiectasia (HHT), also known as Osler-Weber-Rendu Syndrome, are undiagnosed. The genetic disorder of the blood vessels affects 1 in 5,000 people worldwide and a diagnosis means there is a whole family of potentially affected people.

Cure HHT invites you to learn more about this disease during **HHT June Awareness Month**. We have dramatically increased the visibility of HHT through our outreach, international conferences, legislative efforts, training of health care professionals and research grants, but we still have much more to do.

Raising awareness is key to increasing diagnosis and treatment. Cure HHT is the only international patient advocacy organization focused solely on HHT patients and their families. In the past year, the visibility of HHT has been raised with international conferences, legislative efforts, training of health care professionals and more.

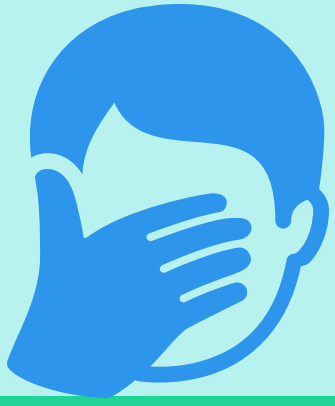
Hereditary Hemorrhagic Telangiectasia (HHT) is a cruel and unrelenting disease, affecting families for generations. While it can have seemingly mild symptoms like frequent nosebleeds, or no symptoms at all, it can result in disabling and catastrophic events. It is often a severe event that leads to a diagnosis and HHT can affect members of the same family differently. Knowing the signs and symptoms can help lead to a faster diagnosis.

This hereditary disorder creates abnormalities in the blood vessels; they are fragile and thus susceptible to rupture and bleeding, which can result in lung and brain hemorrhage, stroke, and death. HHT, like ALS, is a rare disease, but it receives far less research grants and is often misdiagnosed. Cure HHT is building awareness, unifying the HHT community, educating the public, and advocating for patients and families all around the world.

This year, Cure HHT will host an international scientific conference in Rio Grande, Puerto Rico, June 13-16, 2019. The scientific conference will serve over 200 medical professionals in the clinician and research fields from 6 continents. Every two years scientists from around the world gather to discuss the latest advances in HHT research. These meetings lead to international scientific collaboration that accelerates progress in HHT research, treatment, and extending patient access to expert care. The Patient and Physician Conference will be held September 2019 in Pompano Beach, FL.

Since 2003, Cure HHT has leveraged $24 million in research grants from the DOD, National Institute of Health, the FDA, and the CDC. Cure HHT is also excited to promote our brand, new app, the HHT Tracker. This new IOS app allows patients to track nosebleeds, appointments, test results, confer with HHT Doctors and more.

In celebration of Awareness Month, Cure HHT invites you to learn more at www.curehht.org.



What is HHT? When a nosebleed isn't just a nosebleed...

1.4 Million People are estimated to have HHT. Only 1 in 10 have been successfully diagnosed.

Hereditary Hemorrhagic Telangiectasia (HHT) is a rare, genetic disease that causes malformed blood vessels, leading to sudden and extreme bleeding throughout the body. The most obvious symptoms are chronic nosebleeds and red spotting on the skin. It can result in brain hemorrhage, stroke and heart failure. There is no cure.

cure hht
www.curehht.org

HHT by the Numbers

1

50%:
The chance of passing HHT on to your child.

2

27 Years:
The average time it takes to be diagnosed with HHT.

3

90%:
The chance symptoms will begin by the teen years.

4

One in every 5,000 people:
70,000 people in the USA and 1.4 million world wide have HHT, but only 10% have been diagnosed.

HHT Daily Facts
HHT Awareness Month

June 2019

1. HHT, or Hereditary Hemorrhagic Telangiectasia, is a genetic disease that causes malformed blood vessels leading to sudden and extreme bleeding throughout the body. It can result in brain hemorrhage, stroke and heart failure. There is currently no cure.

2. One in every 5,000 people has HHT (that translates to 70,000 people in the USA and 1.4 million people worldwide), but only 10% have been diagnosed. Saving lives means sharing information about HHT with your medical professionals. Education is bringing HHT awareness to your community.

3. HHT symptoms tend to start around 12 years old. Nosebleeds are usually the first sign, but they can begin as early as infancy or as late as adulthood. If you and your family have a history of chronic nosebleeds, you should learn more about this disease! Visit www.curehht.org.

4. In addition to nosebleeds, other common Hereditary Hemorrhagic Telangiectasia symptoms include shortness of breath, exercise intolerance, fatigue, migraine headaches, seizures, abdominal pain, leg swelling and intestinal bleeding. Knowing the signs and symptoms of HHT can help lead to a faster diagnosis. Learn more at www.curehht.org.

5. Telangiectasias in the skin of the hands, face and mouth are found in about 95% of all people with HHT. They appear as small red to purplish spots that disappear and turn white when pushed on.

6. Every child born to a HHT parent has a 50% chance of inheriting the HHT gene. To learn more, visit https://curehht.org/resource/child-hht-screening-guidelines/.

7. The HHT gene does not skip a generation. HHT has variable expressivity, meaning each member of an HHT family may have completely different manifestation of HHT and these will vary from mild to severe.

8. There are several tests that everyone who is known or suspected to have HHT should have. These are called screening tests. HHT screening at a HHT Center of Excellence involves a physical examination, a thorough family history review, MRI of the brain and an echo bubble cardiogram of the lungs. HHT Centers have an experienced multi-disciplined team to address the variety of symptoms seen and manifestations that are internal and not seen. Learn more about Screening Guidelines here: https://curehht.org/understanding-hht/diagnosis-treatment/screening-guidelines/.

9. The four diagnostic criteria that HHT physicians use to determine if a person has HHT are known as **the Curaçao Criteria**. If a doctor determines that at least three of these criteria are met, it is considered to be DEFINITE HHT. If two of the criteria are met, it is considered POSSIBLE HHT. If less than two of these criteria apply, it is unlikely to be HHT. (FOR ADULTS ONLY) Learn more about the four criteria here: https://curehht.org/understanding-hht/diagnosis-treatment/diagnostic-criteria-hht/.

10. Genetic testing is the only way to diagnose HHT for a person who is at risk for HHT but who does not meet the clinical diagnostic (aka the Curaçao) criteria. Genetic testing for HHT consists of analyzing DNA of the HHT-associated genes in a laboratory. Genetic testing is usually done on a small sample of blood, but can be done on a sample of saliva. In a given family, genetic testing should start with someone who clearly has HHT. Learn more about Genetic Testing for HHT here: https://curehht.org/understanding-hht/diagnosis-treatment/genetic-testing-hht/.

11. Brain AVMs are found in 5% to 20% of people with HHT, but often do not cause warning symptoms prior to bleeding. Screening is the best precautionary measure. Review the Brain AVM checklist with your physician to make sure your HHT is being managed properly here: https://curehht.org/resource/brain-avm-clinical-guidelines-checklist/.

12. At least 40% of people with HHT have lung AVMs. HHT patients are often unaware that they have lung AVMs until they develop a life-threatening complication, such as stroke, brain abscess or lung hemorrhage. With proper screening and treatment, these life-threatening complications can be prevented. Review the Lung AVM checklist with your physician to make sure your HHT is being managed properly here: https://curehht.org/resource/pulmonary-avm-clinical-guidelines-checklist/.

13. HHT is often misdiagnosed as other disorders. If nosebleeds run in your family or you know a family where it does, have them visit www.curehht.org to learn more about this disease. Find out more about diagnosis/misdiagnosis (and check out our Misdiagnosis man), here: https://curehht.org/wp-content/uploads/2017/11/FACT-SHEET-HHT-the-Masquerader.pdf.

14. People with HHT who suffer from bleeding should be routinely screened for iron deficiency. Appropriate blood tests for the physician to order are: CBC, reticulocyte count and an iron panel.

15. There are several HHT-related clinical trials and research studies currently taking place to improve the lives and well-being of those who have HHT. Want to learn more about the current clinical trials and see if there is anyone you know who qualifies for one of the studies? More information can be found here: https://curehht.org/research/participate-in-research/clinical-trials/.

16. Iron deficiency is common among HHT patients and is primarily a consequence of bleeding from telangiectasias in the lining of the nose and intestinal tract. Iron deficiency tends to be both under-diagnosed and under-treated in HHT patients and can lead to decreased exercise tolerance, chronic fatigue, and poor quality of life.

17. Iron deficiency can be corrected by taking iron supplements, having iron transfusions or by adding more iron to your diet. For more information about pertinent topics related to iron, visit: https://curehht.org/resource/pumping-iron-hht/.

18. HHT patients with treated and untreated lung AVMs should take antibiotics before any “dirty procedure” such as dental work/cleaning, tattoo or surgery. Bacteria from these procedures can travel in the blood, through the lung AVM and lodge in the brain. Those with HHT should also inform their dentists and dermatologists, in addition to physicians, about their diagnosis. We created a handout for HHT families and patients to give to medical professionals that is easy to print – check out it here: https://curehht.org/resource/hht-facts-glance/.

19. HHT patients with lower iron levels are at a higher risk of blood clots than HHT patients with normal iron levels. Despite having a bleeding disorder, normal clot prevention measures, including low dose blood thinning agents, should be used at appropriate times. To learn more about low iron levels and blood clots in HHT, visit: https://curehht.org/resource/low-iron-levels-blood-clots-hht/.

20. 90% of individuals affected by HHT will develop chronic nosebleeds. In some people nosebleeds may be an uncommon occurrence and one that is easily managed, while others may have multiple nosebleeds every day. The Epistaxis Severity Score (ESS) is a useful tool for tracking nosebleeds to help determine whether treatment is necessary. Check out the tool and your score here: https://curehht.org/understanding-hht/diagnosis-treatment/nosebleed-severity-score/.

21. Most major manifestations of HHT, including AVMs and ruptured telangiectasias, are very treatable. They cannot yet be prevented and HHT cannot yet be cured, but the options for treatment allow HHT patients to live normal lives. It can take some time to find the right treatment for you, but don’t give up! HHT is indeed very treatable and there are experts who want to help you develop a treatment plan specific to your HHT. To learn more about treatment options, visit: https://curehht.org/understanding-hht/diagnosis-treatment/treatment-of-hht/.

22. According to a 2012 medical survey, most HHT patients experience an average of 25.7 years of misdiagnosis by Emergency Room physicians and Otolaryngologists (ENT) because of general lack of knowledge about the disease.

23. Today is HHT Global Awareness Day! Share how you are spreading awareness about HHT by commenting below with your stories, photos and videos!

24. Liver AVMs are common but typically do not require treatment. If treatment is required, it is essential that an HHT Center physician is consulted regarding the best option. Procedures to treat Liver AVMs can be very invasive and have the potential to worsen the condition of the patient if an HHT specialist is not involved. More resources about HHT in the liver can be found here: https://curehht.org/resource-library/?_sf_s=liver.

25. AVMs in the lung have a risk to rupture, particularly during pregnancy, when blood pressure and blood volume tend to increase. This can be life threatening. Consult your HHT Center for advice. Resources about HHT and pregnancy can be found here: https://curehht.org/resource-library/?_sf_s=pregnancy.

26. Mutations in the ACVRL1 (formerly known as ALK1), Endoglin (ENG), and SMAD4 genes cause HHT. HHT type 1 is caused by mutations in the gene ENG. Type 2 is caused by mutations in the gene ACVRL1. Juvenile polyposis/HHT syndrome is caused by mutations in the gene SMAD4. Watch our recorded webinar to learn more about the genetics of HHT: https://curehht.org/resource/genetics-unraveling-dna-recorded-webinar/.

27. Genetic testing detects a mutation in about 80% of people with clear-cut HHT. At-risk relatives can be screened against a confirmed HHT gene mutation to determine whether or not they are affected this disease.

28. 15% to 20% of people with HHT have at least mildly elevated pulmonary artery pressures, which means they either have or are developing Pulmonary Hypertension (PH). More resources about PH and HHT can be found here: https://curehht.org/resource-library/?_sf_s=pulmonary%20hypertension.

29. Common treatments for bleeding due to HHT include embolization, surgery, laser therapy, Young's procedure, sclerotherapy and coblation. More information about HHT treatment options can be found here: https://curehht.org/understanding-hht/diagnosis-treatment/treatment-of-hht/.

30. Everyone who is known or suspected to have HHT should be screened at an HHT Treatment Center at least once as early in life as possible. There are 26 HHT Centers of Excellence in North America and 19 International HHT Treatment Centers. To see a list of all the HHT Centers, visit: https://curehht.org/understanding-hht/get-support/hht-treatment-centers/.