



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.



HHT by the Numbers

1

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

2

25 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.

Top 20 HHT Facts

HHT Awareness Month

June 2020



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, although some patients report no nosebleeds at all. Nosebleeds 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. These tend to appear more frequently with age.
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 echocardiogram 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. 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>.
10. 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>.

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11. 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>.
12. 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.
13. 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, restless legs, poor sleep and an overall poor quality of life.
14. Iron deficiency should be addressed in HHT patients. While a proper diet is advisable, diet alone does not correct the anemia in many patients. Oral supplements can be helpful. If oral iron does not correct the deficiency, IV infusions may be needed. For more information about pertinent topics related to iron, visit: <https://curehht.org/resource/pumping-iron-hht>.
15. 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>.
16. 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 most 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>.
17. Liver AVMs are common but typically do not require treatment. Liver AVMs rarely damage the liver itself but can affect the heart by shunting blood back to the heart and causing it to work harder. 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/patient-topic/liver>.
18. 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/patient-topic/pregnancy-and-womens-issues>.
19. 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/patient-topic/lungs>.
20. 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>.