HHT FACTS

Affects 1 in 4,000 worldwide

HEREDITARY HEMORRHAGIC TELANGIECTASIA

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.

2 1 in every 4,000 people has HHT (that translates to 83,000 people in the USA & 2.075 million people worldwide), but only a fraction 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 in childhood with nosebleeds as the most common 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!

4 In addition to nosebleeds, other common hereditary hemorrhagic telangiectasia symptoms include shortness of breath, exercise intolerance, fatigue, migraine or headaches, intestinal bleeding, heavy menstrual bleeding, and tingling or numbness in extremities.

5 Telangiectasias on 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.

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HHT FACTS

Most people with HHT are undiagnosed

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6 At least 40% of people with HHT have lung AVMs. People with HHT are often unaware that they have lung AVMs until they develop a life-threatening complication, such as stroke, brain abscess or lung hemorrhage. Review the Lung AVM checklist with your physician.

7 Every child born to a parent with HHT has a 50% chance of inheriting the HHT gene.

8 Everyone who is known or suspected to have HHT should have certain screening tests performed at a CoE: liver ultrasound, physical examination, family history review, MRI (brain), and echo bubble echocardiogram (lungs).

9 The HHT gene does not skip a generation, and each member of an HHT family may have completely different symptoms of HHT that can vary from mild to severe. If space allows that HHT has to start somewhere - it is possible to be the first person in a family with HHT.

10 Brain AVMs are found in up to 25% of people with HHT, but often do not cause symptoms prior to bleeding. Screening is the best precautionary measure. Review the Brain AVM checklist with your physician.

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HHT FACTS

11 HHT is often misdiagnosed as other disorders. If nosebleeds run in your family or you know a family where it does, visit curehht.org to learn more about this disease. Find out more about diagnosis/ misdiagnosis with our 2020 Physician Fact Sheet.

12 People with HHT who suffer from bleeding should be routinely screened for iron deficiency. Appropriate blood tests include: 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 can lead to decreased exercise tolerance, chronic fatigue, restless legs, poor sleep and an overall poor quality of life.

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40% of people with HHT have lung AVMs

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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. For more advise on iron deficiency please review Cure HHT's IV iron guide or consult your physician.

15 HHT patients with treated & untreated lung AVM 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 causing a brain abscess.

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HHT FACTS

There is no cure for HHT

HEREDITARY HEMORRHAGIC TELANGIECTASIA

16 Most major manifestations of HHT, including AVMs and ruptured telangiectasias, are very treatable. They cannot yet be prevented. There is currently no cure for HHT, but the options for treatment allow most HHT patients to live length lives.

17 Liver AVMs are common but typically do not become symptomatic. When they do, liver AVMs rarely damage the liver itself but can affect the heart by shunting blood back to the heart, causing it to work harder. Treatments are still being explored for symptomatic liver vascular malformations, but continuing care at your HHT CoE to screen for liver AVMs and heart health is important.

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 CoE for advice.

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).

20 Everyone who is known or suspected to have HHT should be screened at an HHT Center of Excellence at least once as early in life as possible. There are 33 HHT CoEs in North America & 29 internationally.

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