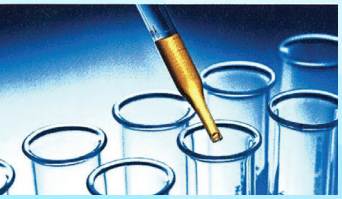
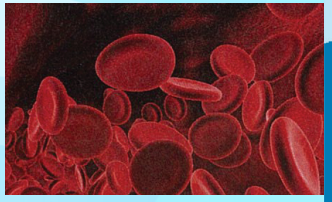
International HHT Centers of Excellence

http://curehht.org/resources/hht-treatment-centers/international-2/





Resources

http://curehht.org/resources/

- Webinars
- Epistaxis Severity Scoring Tool *(https://www2.drexelmed.edu/HHT-ESS/)*
- Clinical Guidelines *(http://curehht.org/resources/physician-resources/)*
- HHT Treatment Centers of Excellence
- Learn About HHT Brochure *(http://curehht.org/resources/physician-resources/)*
- Medical and Scientific Publications *(http://curehht.org/resources/research-publications/)*
- Physician Directory – add yourself or find a local doctor *(https://directory.curehht.org/)*

cure hht

The Cornerstone of the HHT Community

www.curehht.org

P.O. Box 329, Monkton, MD 21111 Tel: 410-357-9932
Email: hhtinfo@curehht.org

Your HHT Diagnosis Will Save A Life!

Identification of the disease is the biggest challenge faced by the HHT patient community due to lack of awareness both in the general population and among medical professionals.

The Role of a Doctor

Your Role as a Doctor

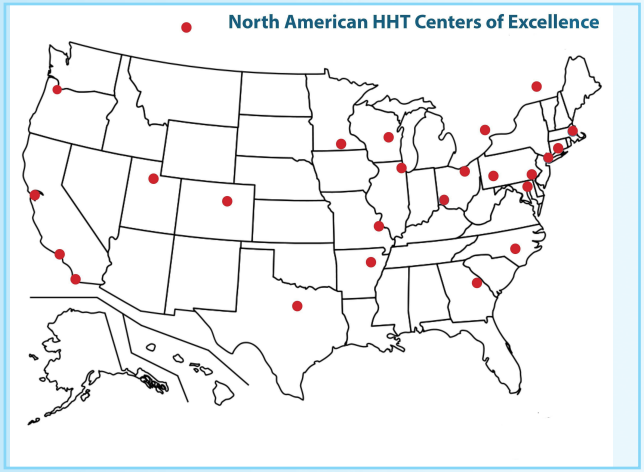
Intercede and consider an HHT diagnosis for patients with nosebleeds that run in the family!

Health Care Providers have the opportunity to recognize HHT in their patients and direct them to the care they need. Nosebleeds are a symptom in over 90% of people affected by HHT. Asking about family history and checking for the presence of telangiectases in anyone with chronic nose-bleeds could help to diagnose an entire family.

If you suspect that a patient may be affected by HHT, there are several steps that can be taken.

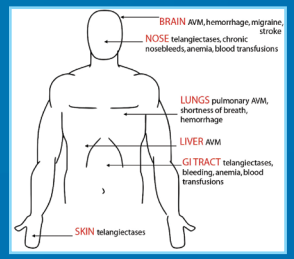
- Talk to your patient about HHT. Explain the disease, symptoms and steps toward diagnosis and treatment.
- Direct your patient to www.curehht.org where they can find information regarding diagnosis and treatment.
- Refer your patient to the nearest North American HHT Center of Excellence.

http://curehht.org/resources/hht-treatment-centers/



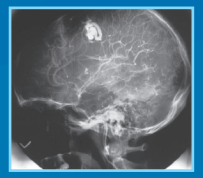
What is HHT?

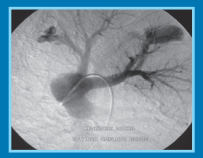
(Hereditary Hemorrhagic Telangiectasia, also known as Osler-Weber-Rendu Syndrome)



- Most common symptom of HHT is nosebleeds, caused by ruptured telangiectases in the lining of the nose.

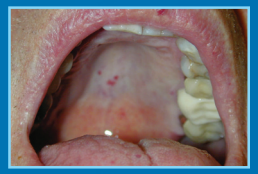
Untreated AVMs can cause strokes, seizures, brain abscesses, numbness of the arms or legs, heart failure and in the worst of cases, death.

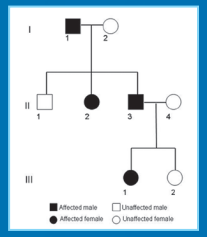




- Genetic multi-organ disorder resulting in large malformed blood vessels (arteriovenous malformations or AVMs) and smaller malformed blood vessels (telangiectases) that are prone to bleeding.
- AVMs are most commonly present in the brain, lungs, liver and spine.

- Telangiectases appear as tiny red or purple dots, typically on the hands, lips and tongue or on the skin inside the nose, mouth and GI tract.
- Each child born to a parent with HHT has a 50% chance of inheriting the disease. When diagnosed and treated correctly, HHT patients can live full and normal lives.





Diagnostic Criteria*

1. Recurrent and spontaneous nosebleeds (epistaxis), which may be mild to severe
2. Multiple telangiectasias on the skin of the hands, lips or face, or inside of the nose or mouth.
3. Arteriovenous malformations (AVMs) or telangiectasias in the internal organs including the lungs, brain, liver, intestines, stomach, and spinal cord
4. A family history (i.e., first-degree relative such as brother, sister, parent or child) who meets these same criteria for definite HHT or has been genetically diagnosed

**Definite HHT = 3+ criteria; Possible HHT = 2 criteria*

STATISTICS

- **25 years**** the average time from first symptomatic visit to a physician until diagnosis
- **9 of 10 people** with HHT are undiagnosed
- Lung and brain hemorrhage, stroke, brain abscess and death are preventable complications of AVMs if diagnosis and screening occur early
- **50% of HHT patients** suffer from anemia and iron deficiency which causes symptoms such as fatigue and migraines
- **1.4 million people** worldwide have HHT
- Sudden death or disability occurs in 20% of undiagnosed children and adults

***Donaldson, JW. 2015. Complications and mortality in hereditary hemorrhagic telangiectasia: A population-based study. Neurology. 84(18):1886-93*