TALKING TO YOUR PHYSICIAN ABOUT HHT

Genetic testing is the most reliable way to assess which type of HHT is inherited and where the specific change occurs on the gene. Other members within the family can then all be tested against this genetic change to determine if he or she has also inherited HHT.

FACTSHEET **FS**

SOME IMPORTANT FACTS TO REMEMBER ABOUT HHT ARE:

The worst medical consequences of HHT are mostly preventable, once you know you have it.

Living with HHT can be stressful, at times, but most people can manage it.

Most people who take good care of their HHT can have pretty normal lives.

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cure hht
The Cornerstone of the HHT Community

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TALKING TO YOUR PHYSICIAN ABOUT HHT:

HHT is an uncommon disease; do not be surprised if medical professionals are not familiar with HHT. Cure HHT seeks to provide you with the resources you need to advocate for yourself, educate your physician, and ultimately receive the best medical care.

A physician is able to make a diagnosis of HHT if a patient has the following criteria:

- Recurrent and spontaneous nosebleeds, which may be mild to severe.
- Multiple telangiectasias on the skin of the hands, lips or face, or inside of the nose or mouth. Telangiectasias appear as small red or purple spots.
- Arteriovenous Malformations (AVMs) or telangiectasias in an organ, most commonly the lungs, brain, liver, intestines, stomach, and spinal cord.
- A first-degree relative (brother, sister, parent or child) who meets these same criteria for definite HHT or has been diagnosed through genetic testing.

A **definite** HHT diagnosis has at least three of the four criteria.

A **possible** HHT diagnosis meets two of the four criteria.

Genetic testing is the most reliable way to assess which type of HHT is inherited and where the mutation occurs on the gene. Specific information about genetic testing can be found on the Cure HHT website at http://www.curehht.org/living-with-hht/genetic-testing.

When talking with your physician about HHT for the first time, plan to be prepared with the following:

- Results from any genetic testing or screening.
- Your medical history, including any relatives that have HHT.
- The "HHT Quick Facts for Healthcare Professionals" factsheet found on the Cure HHT website http://www.curehht.org/resources/physician-resources
- Complete a family health portrait online at https://familyhistory.hhs.gov/FHH/html/index.html
- Resources specific for medical professionals found at http://www.curehht.org/resources/physician-resources
- Contact the Cure HHT office at 410-357-9932 or visit www.curehht.org to find an HHT Center of Excellence closest to you.

POTENTIAL HEALTH RISKS & TREATMENTS TO DISCUSS:

Iron Deficiency

- Iron deficiency is not uncommon among HHT patients. It is easy to diagnose and a variety of treatments are available. Your doctor should be made aware of this manifestation of HHT.

Management of Nosebleeds

- Chronic nosebleeds, also known as epistaxis, occur in 90% of HHT patients. A wide variety of therapeutic and surgical treatments are available for HHT-related epistaxis, and different treatments are more effective for different people. Consult with your physician to determine which is best for you.

Lung AVMs

If you have a known PAVM or if you have not been screened to determine if you have a PAVM, you should take the following precautions:

- Take antibiotics before any invasive procedures like a dental cleaning, surgical procedure, or colonoscopy.
- A .22 micron IV filter is recommended to keep air out of the IV line (does not apply to blood transfusions).
- Avoid blood thinners or nonsteroidal anti-inflammatory medicines.