

KNOW THE SIGNS & SYMPTOMS



Iron deficiency is very common among people with HHT, and is first and foremost a result of bleeding from telangiectasias in the nose and intestines. When left undiagnosed and untreated, iron deficiency can significantly reduce quality of life. Fortunately it is relatively easy to both identify and manage.

FACTSHEET
FS

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SOME IMPORTANT FACTS TO REMEMBER ABOUT HHT ARE:

It is important to be able to recognize symptoms of HHT for what they are. Many signs of the disease can masquerade as other, unrelated issues and sometimes it feels easier to ignore that it could be HHT. Cure HHT, in cooperation with HHT Centers of Excellence all over the country, can help you identify the disease and provide you with all the resources, education, and treatments you need to advocate for your family and improve quality of life.



The Cornerstone of
the HHT Community

HHT Foundation International Inc.
P.O. Box 329 / Monkton / MD 21111



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Roughly 95% of people who carry the gene for HHT will develop symptoms of the disease, generally by the age of 40. A person who is asymptomatic after this time is not necessarily unaffected by the disease.

EPISTAXIS

Epistaxis, or nosebleeds, is the most common symptom of HHT and occurs in 90-95% of affected individuals by the time they reach adulthood. Generally nosebleeds begin in adolescence and severity can range from infrequent and minor to daily and severe.

TELANGIECTASIAS

Telangiectasias are small, dilated blood vessels that appear as red or purple spots on the skin. 90-95% of affected individuals develop at least a few telangiectasias by middle age, generally on the lips, tongue, face, or hands.

AVMs

Arteriovenous malformations may be present in several different organs in the body.

- › 40% of patients have lung AVMs, which can pose a significant risk if not treated
- › 5-20% of patients have at least one brain AVM. These can be present at any age and have the potential to cause serious complications. Routine screening at a Center of Excellence is recommended
- › Liver AVMs are common, but only 10% cause symptoms
- › Less than 1% of patients develop spinal AVMs, which are treatable but can cause back pain and loss of feeling or function in an arm or leg

BLEEDING

About 80% of HHT patients develop telangiectasias in the stomach or intestines, and about 20% of those lead to obvious gastrointestinal bleeding. This rarely occurs before the age of 50 unless the individual is affected with juvenile polyposis in conjunction with HHT.

IRON DEFICIENCY

Iron deficiency is very common among people with HHT, and is first and foremost a result of bleeding from telangiectasias in the nose and intestines. When left undiagnosed and untreated, iron deficiency can significantly reduce quality of life. Fortunately it is relatively easy to both identify and manage. Get screened for brain AVMs. If you have one, discuss treatment options with an expert.



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