

IMAGING & HHT



COMPANION FACTSHEET TO
MY HHT CARE CHECKLISTS

UTILIZED IMAGING

MAGNETIC RESONANCE IMAGING (MRI)
CT (COMPUTED TOMOGRAPHY) SCAN
DOPPLER ULTRASOUND
CONTRAST ECHOCARDIOGRAPHY
(ECHO BUBBLE STUDY)
ECHOCARDIOGRAM
BRAIN (CEREBRAL) ANGIOGRAM
BRAIN (CEREBRAL) EMBOLIZATION
PULMONARY EMBOLIZATION

FACTSHEET
FS

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SOME IMPORTANT FACTS TO REMEMBER ABOUT HHT ARE:

Some manifestations of HHT can be asymptomatic (no visible symptoms), can occur at any age, and can result in serious and life-threatening complications.

Imaging is used to identify these manifestations and is an important part of screening and management for HHT patients.

Imaging is used to treat pulmonary AVMs and brain VMs.

Screening imaging studies are essential in the disease management and prevention of catastrophic events in HHT.



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HHT (Hereditary Hemorrhagic Telangiectasia) is a hereditary disorder (meaning it is passed down through generations) that is characterized by abnormal blood vessel formation. A person with HHT has a tendency to form blood vessels that lack normal capillaries between an artery and vein.

Some manifestations of HHT, such as **telangiectasia** and **epistaxis** (nosebleeds) present with symptoms or can be seen on physical examination. Other manifestations, like **pulmonary (lung) arteriovenous malformations (AVMs)**, **brain vascular malformations (VMs)**, and **liver VMs**, can be asymptomatic, can occur at any age, and can result in serious and life-threatening complications. **Imaging** is used to identify these manifestations and is an important part of screening and management for HHT patients. Imaging is also used to treat pulmonary AVMs and brain VMs.

Screening imaging studies are essential in the disease management and prevention of catastrophic events in HHT.

TYPES OF IMAGING UTILIZED FOR SCREENING AND TREATMENT:

- > **Magnetic Resonance Imaging (MRI):** The recommended test for identifying **brain VMs**. This may also be performed to evaluate for **liver VMs**. This test utilizes strong magnetic fields to form images of the body. No radiation is used during this study. An **IV** will need to be started for contrast (dye) to be given. The scanner resembles a large tube and the patient is required to lie still during the actual MRI scanning. If the patient has **claustrophobia**, the doctor may prescribe an oral medication to take prior to the MRI. This typically requires **sedation** or anesthesia in young children.
- > **CT (Computed Tomography) scan:** Used to evaluate for **pulmonary AVMs** if the echo bubble study is positive. This may also be performed to evaluate for **liver VMs**. This is a high-resolution X-ray. If contrast (dye) is used, an **IV** will need to be started.
- > **Doppler ultrasound:** The imaging of choice for screening for **liver VMs**. This test uses sound waves to produce a picture of the organs in the abdomen. No radiation is used during this study.

- > **Contrast echocardiography (echo bubble study):** The recommended study for initial screening for **pulmonary AVMs**. This test uses sound waves (ultrasound) to determine if injected saline bubbles can get through the lung circulation and be seen back in the heart, on the left side. This is called a **shunt**. An **IV** will need to be started for saline bubbles to be given. No radiation is used during this study.
- > **Echocardiogram:** Used to assess for cardiac effects of **liver VMs**. This test uses sound waves (ultrasound) to determine how the heart muscle and valves are working. No radiation is used during this study. It is recommended at the time of liver VM diagnosis.
- > **Brain (cerebral) angiogram:** May be recommended if a **brain VM** is identified on MRI. It is a minimally invasive procedure performed by a **neurointerventional radiologist** in an angiography suite. The patient is given **sedation** or general anesthesia for this procedure. A **catheter** (a small tube) is inserted into an **artery** in the top of the thigh and directed through the blood vessels in the body to arteries in the neck or the brain. After the procedure, the patient is observed for several hours or overnight before being discharged home.
- > **Brain (cerebral) embolization:** A procedure performed to block the blood flow to the abnormal vessels. The patient is given **sedation** or general anesthesia for this procedure. In an angiography suite, a **catheter** (a small tube) is inserted into an **artery** in the top of the thigh and directed through the blood vessels in the body to arteries in the brain. An **agent** is then inserted to block off blood flow into the VM and lessen the risk of stroke. After the procedure, the patient is observed overnight before being discharged home.
- > **Pulmonary embolization:** A procedure performed to block the blood flow to the abnormal vessels. The patient is given **sedation** or general anesthesia for this procedure. In an angiography suite, a **catheter** (small tube) is inserted into a **vein** in the top of the thigh and directed through the blood vessels in the body to the pulmonary arteries. A small **coil** or plug is then inserted to block off the artery that leads into or "feeds" the **pulmonary AVM**. This stops the blood flow to the pulmonary AVM which eliminates the occurrence of a potentially life-threatening complication. After the procedure, the patient is observed for several hours or overnight before being discharged home.



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