HEREDITARY HEMORRHAGIC TELANGIECTASIA (HHT)

IS IT MORE THAN A NOSEBLEED?

Hereditary Hemorrhagic Telangiectasia (HHT) is an autosomal dominant genetic disorder that causes abnormal blood vessel formation, including:

- **Telangiectasias** – Small dilated vessels on the skin and mucosa
- **Arteriovenous malformations (AVMs)** – In the lungs, brain, liver, and other organs

HHT is frequently underdiagnosed. Many patients first present to primary care with recurrent nosebleeds.

CLINICAL CLUES FOR PRIMARY CARE

Recurrent Epistaxis

- **Spontaneous nosebleeds**
- **No minimum frequency required**
- **Increased suspicion if:**
  - > Occurring weekly or monthly
  - > Positive family history

Auto-Referral Red Flags

- **Family history of HHT**
- **Mucocutaneous telangiectasias – located on the lips, tongue, nose, fingertips**
- **Shortness of breath**
  - > Possibly pulmonary AVM
  - > Pulmonary, cerebral, hepatic

LUNG AVMS AND HHT – WHY IT MATTERS

- **Approximately 80% of patients with pulmonary AVMs have underlying HHT**
- **30% risk of paradoxical embolization (stroke or brain abscess) every 10 years**
- **Approximately 50% lifetime risk if untreated**

CONTACT US

If you are treating a patient with HHT, we urge you to use a low threshold to contact our program with questions and referrals.

To refer a patient to the HHT Center of Excellence, part of the UPMC Comprehensive Lung Center, email **PittHHT@upmc.edu** or **contact Dr. Quyen Nguyen at 412-451-1874**.

For direct pulmonary AVM scheduling, **contact Dr. Adam Fish at 412-647-5050** or **Fishag@upmc.edu**. Since early recognition prevents stroke and improves patient outcomes, it is critical to contact our team if you have detected or are suspicious of lung AVM. Waiting to schedule with the general HHT program may delay lifesaving care.

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