

GASTROINTESTINAL (GI) BLEEDING & HHT



COMPANION FACTSHEET TO
MY HHT CARE CHECKLISTS

SIGNS AND SYMPTOMS

BLOODY STOOL OR BLACK (TARRY
LOOKING) STOOL

VOMITING BRIGHT RED OR BLACK
ANEMIA (LOW BLOOD COUNT)

IRON DEFICIENCY (LOW AMOUNTS OF
IRON IN BLOOD)

SIGNS AND SYMPTOMS OF ANEMIA AND
IRON DEFICIENCY (*SEE ANEMIA AND IRON
DEFICIENCY FACTSHEET*)

FACTSHEET
FS

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SOME IMPORTANT FACTS TO REMEMBER ABOUT HHT ARE:

Approximately 30% of people with HHT develop symptomatic GI bleeding.

GI bleeding is most common after age 40.

Bleeding telangiectasias are most common in the stomach and small bowel and are less common in the colon and esophagus.

GI bleeding should be considered if patient has chronic anemia or iron deficiency.

The SMAD4 gene causes Juvenile Polyposis Syndrome (JPS) and can also be associated with HHT.

Patients with the SMAD4 gene have an increased risk of developing non-cancerous GI polyps, as well as colorectal cancer and stomach cancer and will require additional routine screening.



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Gastrointestinal (GI) bleeding is all forms of bleeding from the gastrointestinal tract, from the mouth to the rectum. About 80% of those with **HHT (Hereditary Hemorrhagic Telangiectasia)** have **telangiectasias**, dilated small blood vessels, in their stomach or intestines. Only 30% develop obvious gastrointestinal (GI) bleeding. The bleeding can range from mild to severe.

Telangiectasias can be found anywhere in the gastrointestinal system, including the esophagus, stomach, small intestine, and colon (large intestine). Telangiectasias in the GI tract do not cause pain or discomfort. Signs of GI bleeding are black or bloody stools and/or **anemia**. Symptoms of GI bleeding are usually due to anemia and may include fatigue, shortness of breath, chest pain, light headedness, etc. Often patients do not notice any change in the stool but instead are found to be anemic through blood work.

HOW IT IS DIAGNOSED

- > **Esophagogastroduodenoscopy (EGD):** If GI bleeding is suspected. This is a procedure that examines the **esophagus, stomach**, and first portion of the **duodenum** (small intestine) using a flexible tube with a camera at the end of it. The scope is inserted into the mouth and advanced to the small intestine. The patient is given **sedation** for this procedure.
- > **Capsule endoscopy (camera pill):** If EGD does not show any significant telangiectasia. This is a procedure that uses a tiny wireless camera to take pictures of your **digestive tract**. A camera sits inside a vitamin-size capsule you swallow. As the capsule travels through your digestive tract, the camera takes thousands of pictures that are transmitted to a recorder you wear on a belt around your waist.
- > **Colonoscopy:** This is a procedure that examines the **large intestine** (colon) using a flexible tube with a camera at the end of it. The scope is inserted into the rectum and advanced to the large intestine. The patient is given **sedation** for this procedure.
- > **Blood work** to evaluate for **anemia** and **iron deficiency** (complete blood count, ferritin levels, iron panel).
- > Patients with **SMAD4-HHT** should undergo **screening colonoscopy** at age 15 AND every 3 years thereafter if no polyps are found OR every year along with EGD if colonic polyps are found.

HERE ARE SOME THINGS TO DISCUSS WITH YOUR PHYSICIAN:

- If you have been previously diagnosed with and/or treated for GI bleeding.
- If you or your family members have the SMAD4 gene and/or Juvenile Polyposis Syndrome (JPS).
- If you have any of the listed signs and symptoms.
- Blood work to evaluate for anemia and iron deficiency (complete blood count, ferritin levels, iron panel).
- Whether you are due for a colonoscopy for colon cancer screening.
- Getting screening and/or treatment at a HHT Center of Excellence.

TREATMENT

- > **Argon Plasma Coagulation (APC):** Should only be used sparingly for **bleeding lesions** and significant (1-3 mm) **non-bleeding lesions**. This procedure is done under EGD and uses a jet of argon gas and high-frequency electric current to seal the irregular or bleeding areas. The patient is given **sedation** for this procedure.
- > **Oral antifibrinolytics (tranexamic acid):** An oral medication that can be used for patients with **mild GI bleeding**.
- > **IV bevacizumab or other systemic anti-angiogenic therapy:** An IV medication used to treat a number of types of cancers. There is growing evidence of the benefits of this medication for patients with **moderate to severe GI bleeding**. This may be considered for patients who have failed other types of medical management. There are potential serious side effects which should be considered prior to treatment.
- > **Management of anemia and iron deficiency** (see *Anemia and Iron Deficiency Factsheet*).

AFFILIATED ISSUES

- > Anemia and Iron deficiency
- > Juvenile Polyposis Syndrome (JPS) if the SMAD4 gene is present



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