PREGNANCY & HHT

COMPANION FACTSHEET TO
MY HHT CARE CHECKLISTS

FACTSHEET **FS**

SOME IMPORTANT FACTS TO REMEMBER ABOUT HHT ARE:

Nosebleeds commonly worsen during pregnancy.

Pulmonary AVMs can grow during pregnancy.

Your pregnancy may be considered high-risk.

During pregnancy pulmonary AVMs can be especially dangerous as the volume of blood flowing through the body significantly increases and make complications more likely.

Any HHT patient with lung AVMs (treated or untreated) should follow pulmonary AVM precautions, including antibiotics before any procedures that can cause bacteria in the blood. This is also true for HHT patients that have not yet been screened for lung AVMs.

Each child born to an HHT parent has a 50% chance of inheriting the HHT gene mutation. Genetic testing can be done on the child at birth if the familial mutation is known.

cure hht
The Cornerstone of the HHT Community

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A **pregnant woman** with HHT should be assessed for their risk of pregnancy and delivery-related complications and have access to, as needed, a multidisciplinary maternal-fetal medicine team that includes HHT experts. Screening for **pulmonary (lung) arteriovenous malformations (AVMs)** and **brain vascular malformations (VMs)** should be considered, and unscreened patients may need to be considered high-risk. In addition, since offspring are at 50% risk of inheriting the pathogenic mutation, pre-pregnancy consultation with an **obstetrician** is recommended, for consideration of options for genetic diagnosis. Some families have pursued **pre-implantation genetic testing** which involves screening cells from embryos for HHT and is performed with **in-vitro fertilization (IVF)** prior to embryo transfer, before a pregnancy is established.

HERE ARE SOME THINGS TO DISCUSS WITH YOUR PHYSICIAN:

If you have HHT or a family history of HHT and are planning a pregnancy.

Options for pre-implantation genetic testing (PGT).

Genetic testing for you and your child.

If you have pulmonary AVMs and are pregnant.

If you have brain VMs or a prior brain hemorrhage and are pregnant.

Referral to a center with high-risk pregnancy care and HHT expertise.

RECOMMENDATIONS

- Discuss **diagnostic options** including genetic testing for HHT during **pregnancy planning**. Once the causative familial mutation is identified in an affected parent, then it can be used to screen future off-spring.
- **Magnetic Resonance Imaging (MRI),** without gadolinium, should be planned in **second trimester,** for symptomatic patients including patients with previous **cerebral (brain) hemorrhage**. Asymptomatic patients do not require routine screening for brain VMs during pregnancy.
- Pregnant women with HHT who have not been recently screened and/or treated for **pulmonary AVMs** should be screened using either **contrast echocardiography (echo bubble study)** or low-dose non-contrast **chest CT**, depending on local expertise. Chest CT, when performed, should be done early in the **second trimester**.
- In patients with symptoms suggestive of **pulmonary AVMs**, diagnostic testing should be performed using low-dose non-contrast **chest CT**. This testing can be performed at **any gestational age**, as clinically indicated.
- **Pulmonary AVMs** should be treated starting in the **second trimester** unless otherwise clinically indicated.
- Pregnant women with untreated **pulmonary AVMs** or **brain VMs**, and those who have not been screened, should be considered high risk for **hemorrhagic and neurologic complications**, and should be managed accordingly by a high-risk team with HHT expertise.
- Patients with HHT may get an **epidural** and screening for **spinal VMs** is not required.
- Patients without **high-risk brain VMs** can labor and proceed with **vaginal delivery**.
- Patients with **brain VMs** should be considered for **Cesarean Section** and talk to an expert multidisciplinary neurovascular team about the brain VMs and risk of bleeding, to decide if they can proceed with vaginal delivery.