

# MY HHT CARE CHECKLIST

USING THE HHT GUIDELINES

HHT=hereditary hemorrhagic telangiectasia

Date: \_\_\_\_\_

Name: \_\_\_\_\_

*Please check all that apply*

**I HAVE HHT OR I SUSPECT THAT I MIGHT HAVE IT.**

Review the HHT Diagnosis Care Checklist with my doctor, to confirm or rule out my HHT diagnosis and to determine if I need genetic testing.

**I AM AN ADULT WITH HHT OR POSSIBLE HHT.**

Review the HHT Epistaxis Care Checklist with my doctor, because I have nosebleeds.

Review the HHT Brain VM Care Checklist with my doctor, even if I am not sure if I have brain VMs.

Review the HHT Pulmonary AVM Care Checklist with my doctor, even if I am not sure if I have lung AVMs.

Review the HHT Liver VM Care Checklist with my doctor, even if I am not sure if I have liver VMs.

Review the HHT GI Bleeding Care Checklist with my doctor, even if I am not sure if I have bleeding from the stomach or bowels.

Review the HHT Anemia and Iron Deficiency Care Checklist with my doctor, even if I am not aware of any bleeding symptoms.

**I AM PREGNANT OR PLANNING A PREGNANCY, AND I MIGHT HAVE HHT.**

Review the HHT Pregnancy and Delivery Care Checklist.

**I AM A TEEN AND I MIGHT HAVE HHT.**

Review the HHT Teen Years Pediatric Care Checklist.

**I HAVE CHILDREN AND THEY MIGHT HAVE HHT.**

Review the HHT Pediatric Care Checklist.



## WHAT ARE THE HHT GUIDELINES AND WHY ARE THEY IMPORTANT?

- The HHT Guidelines are recommendations for care based on evidence and expertise from HHT experts from around the world.
- The HHT Guidelines help ensure that people living with HHT get the best care possible.

## WHAT IS MY ROLE AS SOMEONE LIVING WITH HHT?

- Be aware of the Guidelines. Share them with your care team. Ideally you should be seen at an HHT Center of Excellence or your care team may want to consult with one.
- Read up on your condition and know what care is available for HHT.
- **Prepare ahead of time for your appointments:** Bring your HHT Care Checklists and a family member or friend. They can help you communicate your questions and priorities, as well as act as a second set of ears. Share your experiences, worries and priorities to help your care team better understand your needs and provide individualized care.

