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This pamphlet was developed to assist children who may be uncertain or anxious about the symptoms of HHT experienced by themselves and/or their parents. To learn more about HHT, please contact:

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MY FAMILY HAS HHT

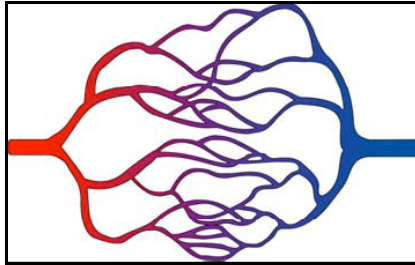


WHAT IS HHT?

You and your family members that have HHT were born with it. In your family, your mom or dad, grandma or grandpa or other family members are likely to have HHT. You inherited HHT, just like you inherited blue or brown eyes or brown or blond hair. People with HHT have blood vessels that developed abnormally and are called telangiectases and arteriovenous malformations (AVMs).

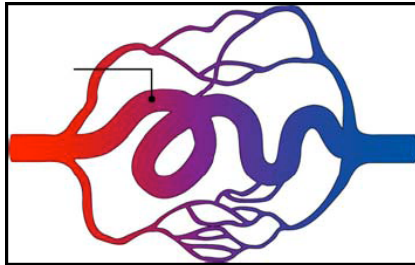
WHAT IS DIFFERENT ABOUT MY BLOOD VESSELS?

Everyone has blood vessels or tubes that carry blood to different parts of the body. These tubes are called arteries and the heart pumps fresh oxygenated blood into them and they carry the blood to your lungs, kidneys, liver, brain and other places in your body. Oxygen and nutrients are given to your body through small tubes called capillaries. Once the oxygen is gone, the blood returns to the heart in vessels called veins. Your blood continues this cycle all the time without you even realizing it!



Normal Lung Circulation

If you have HHT, some of your blood vessels are not normal and cause problems. In most people, arteries are connected to capillaries and then to veins and blood circulates throughout the body through these blood vessels or tubes. In the abnormal blood vessels or arteriovenous malformations (AVMs), the arteries are directly connected to the veins, making the vessels weak and sometimes they break and bleed. When these vessels break and bleed, they cause nose bleeds, red spots on your skin, problems with your lungs and sometimes your brain. The abnormal vessels that cause your nose to bleed and the red spots are called telangiectases (tel-AN-jee-eck-TAZE-eez). You may not have any red spots or nosebleeds now, but most likely you will sometime in your life. Almost everyone with HHT has nosebleeds and red spots on their skin. In addition to these two symptoms, abnormal vessels may develop in your lungs, liver and brain.



Arteriovenous Malformation (AVM)

HOW DOES HHT AFFECT MY LUNGS?

You breathe air into your body through your nose and mouth. The air goes down an air pipe in your throat to your lungs. Lungs work like big balloons. When you breathe in, your lungs expand and when you breathe out they get smaller. Your lungs put oxygen into your blood so your heart can pump it into your arteries. Arteries take fresh blood from your heart to your other organs and your veins carry the used blood back to your heart. For this to happen, you need capillaries to connect the arteries and veins. In HHT, the capillaries are missing or are not working properly in your lungs, which means your lungs can't get as much oxygen as other people's lungs. To get more oxygen, your lungs keep trying to get more air which makes you feel like you can't catch your breath.



WHY DOES HHT MAKE ME FEEL SO TIRED?

Your body needs blood to do all of the things you like to do. Your body makes new blood all of the time but if you have lost some blood, through frequent nosebleeds for instance, you will feel weak until you have made enough new blood to replace the blood you lost. Sometimes people with HHT have to get extra blood from other people to help them feel stronger quickly.

WHAT WILL HELP ME?

One of the most important things that you can do is to see your doctor every year for a physical examination or check-up. If problems are identified, then recommendations can be made to see your HHT doctor. When you visit your HHT doctor, you may have some tests. These tests include a bubble echocardiogram (picture of your heart), Chest CT scan (computerized tomography of chest), pulse oximetry and MRI of your brain (magnetic imaging of the brain). These tests help the doctors know and learn about your body and the blood vessels. They must know the size and location of the AVMs in order to make a decision about treatment. Doctors can treat these abnormal blood vessels in your nose, lungs and brain with a medicine, procedure or surgery. You will need to go to the hospital for treatment, but most of the time you won't have to stay at the hospital. You and your family are not the only ones that have HHT. Thousands of people have this condition. Many doctors and scientists are working hard to try to find medical treatments that make it easier for you to live with your HHT.