

I HAVE HHT: FOR KIDS



IN COLLABORATION WITH
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HHT is a genetic disease. That means you inherited it from your mom or dad and you've had it since you were born. HHT can cause nosebleeds, red spots on your skin, or problems with the blood vessels in your lungs, brain, liver and intestines. Most kids with HHT have nosebleeds, but some don't.

FACTSHEET
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SOME IMPORTANT FACTS TO REMEMBER ABOUT HHT ARE:

With the help of family and friends, most kids with HHT grow up to live pretty normal lives.

Kids living with HHT can sometimes feel sick, tired, or scared, but these feelings are normal.

Most kids learn to cope with HHT. Coping means finding ways to get through a rough time and feel good about life.



The Cornerstone of
the HHT Community

HHT Foundation International Inc.
P.O. Box 329 / Monkton / MD 21111



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Lots of kids with HHT sometimes feel scared, embarrassed, sad, grumpy, frustrated, worried, or angry. These feelings are normal and usually get better after a while.

Nosebleeds can be embarrassing and get other people upset. Some things you can do to deal with nosebleeds are:

- › Tell your friends, family, teachers and coaches about your nosebleeds, so they won't be shocked or surprised when you get one. Let them know if you usually need help, or if you can stop a nosebleed yourself.
- › Always have tissues in your pocket.
- › Keep hydrogen peroxide handy for getting blood stains out of clothing, sheets or carpet (bring some when you go to a sleep-over at a friend's house).

When you have HHT, it might be hard to breathe, or you may feel **tired or weak**. These problems can make it hard to concentrate; run or play sports; do things with your friends; or get your homework done. Some things you can do to deal with being tired are:

- › Ask friends to do easier activities with you, like watch a movie or play a video game. **DON'T** stop seeing your friends!
- › Decide what things are most important to get done. Put less important things aside until you feel better.
- › If you need more time for school work, or a break from gym class, discuss this with your teachers (your parents can help you with this).

Some kids with HHT need a medical procedure or surgery to fix the blood vessels in their lungs or brain. These treatments are usually not painful, but they can be scary. Lots of kids with HHT sometimes feel scared, embarrassed, sad, grumpy, frustrated, worried, or angry. These feelings are normal and usually get better after awhile.

Most kids learn to **cope** with HHT. **Coping** means finding ways to get through a rough time and feel good about life. Some things that you can do to cope are:

- › Talk about your feelings to your mom or dad, or other family members who have HHT
- › Spend time with your friends
- › Do something fun that takes your mind off your problems
- › Learn more about HHT from your parents or doctors
- › Do something to relax
- › Exercise or take a walk
- › If you can't stop feeling bad, talk to a school counselor or psychologist. They can get you more help if you need it.

When you cope with HHT, you'll probably have some good feelings. You'll feel self-confident, secure and proud of yourself. You'll be able to enjoy life, even though you have HHT.



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