



HHT Guide for School

Dear Parents,

Our children spend most of their days at school and it can be helpful to inform school staff adequately about the health of your HHT child. This small guide will help you to present all the necessary information to your school.

The English version of this Guide is brought to you by HHT Ireland and reviewed Dr. Adrian Brady at the HHT Center at Mercy University Hospital – Cork, Ireland.

How to proceed:

1. Please read the information form carefully in all its parts.
2. Fill in the parts relating to your child's personal and clinical data (deleting the statements that don't apply, where multiple options are provided).
3. If you are in any doubt about filling in the form, you can ask HHT Ireland or your Doctor for help.
4. Many schools organize events for children with special needs. If this is not the case in your school, ask the Secretary of the school for a meeting and specify that the teachers and the safety officer should be present.

Further useful tips:

1. Make sure that your child always has a kit to manage nosebleeds in his/her backpack or to give to the teacher. It can contain everything you are used to using for managing nosebleeds - handkerchiefs, dry ice, ointments and any medications provided in any treatment plan. It will make it easier for everyone to know that what's required is always available.
2. Make sure your child always has a spare T-shirt in school to allow them to change and continue their school day without the signs of nosebleeds on their clothes.
3. It is useful for your child to be aware of his/her condition. HHT Onlus organizes a Youth Program to help young people understand HHT in a language suitable for their age group.
4. If your child already has a good awareness of HHT, make them aware of the information which you will give to the school. This is something that concerns them closely and it is right that they should be involved and agree to it.

For further information or help, please contact HHT Ireland email at info@hhtireland.org



HHT GUIDE FOR SCHOOL

Personal information document of:

Pupil: _____ Class: _____ School year: _____

Preamble:

The main purpose of this guide is to raise awareness of children's health issues without creating undue concerns among teachers.

The aim is to raise your awareness of HHT and provide you with all the precautionary guidelines to handle any (very rare) emergency situations.

We would like to point out that the HHT patient can participate without limitations and/or risks in all school activities, including physical and leisure activities.

We do not want to exaggerate fear of the HHT disorder in the school or student, nor do we want to treat the student in a more protective way which could marginalize him/her from some school activities, making him/her sicker than he/she is and exaggerating the restrictions which HHT already imposes on him/her.

What is HHT?

HHT (Hereditary Haemorrhagic Telangiectasia) is a rare hereditary genetic disorder (also known as Osler Weber Rendu Syndrome). The most common symptoms in childhood are nosebleeds (epistaxis).

In addition to epistaxis, children may have vascular malformations called AVMs (arterio-venous malformations) that can be present in some internal organs (lungs, liver, brain).

Such AVMs sometimes require surgical or interventional radiological treatments; many do not need any specific intervention, and only in rare cases can they cause serious complications.

HHT is **not** a clotting disease.

HHT is **not** an infectious disease and is therefore **not** transmitted by contact. No other individual can contract HHT as a result of interacting with an affected person.

Management of HHT events at school

NOSEBLEEDS:

HHT commonly manifests itself in nosebleeds (epistaxis) that are usually controllable in childhood.

The school staff are informed that the pupil:

- Is able* to manage the ordinary nosebleed on his/her own.
- Is not able* to manage the ordinary nosebleed on his/her own.

Ordinary epistaxis management in a patient with HHT:

In case of epistaxis, the child must bend his/her head forward and press the bridge of the nose with thumb and forefinger, closing the nostrils. In this way, a sort of "buffering" by compression from the outside of the bleeding point is achieved, stopping the nosebleed. This position must be maintained for at least 5-10 minutes without loosening the grip.

The duration and effectiveness of this "Pinching of the Nose" may vary depending on the size of the nosebleed.

If the family has indicated that the child is capable of handling nosebleeds on his/her own, it is advisable to leave him/her to do so independently, even if his/her method is different from that indicated here (provided it is effective). Self-management may include techniques that are different from those recommended, but equally valid.

Administering medication at school:

Some children may need medication to stop or control their epistaxis as part of their treatment plan. It will be the family's responsibility to indicate this on the special forms provided by the school.

The use of topical ointments to humidify the nasal walls is also very frequent.

When epistaxis becomes an EMERGENCY:

If the nosebleed is very heavy, is difficult to manage, and goes on for more than 30 minutes, it is considered an extraordinary nosebleed and the family should be contacted. In the event of illness or fainting, call 999.

Arteriovenous Malformations (AVMs)

A pupil affected by HHT may have Arteriovenous Malformations (AVMs) in the liver, lungs, brain, or, rarely, in other organs.

The school staff are informed that the pupil:

- has undergone surgical/radiological treatment of Pulmonary/Cerebral AVM
- is in preventative therapy because he/she has Pulmonary/Cerebral AVM
- was negative during screening for Pulmonary/Cerebral AVM (screening carried out on
- not yet been screened for Pulmonary/Cerebral AVMs.

The family must be informed if the pupil has the following symptoms

- a. strong recurrent migraines
- b. difficulty breathing
- c. significant lack of concentration, fatigue and/or disorientation

Administration of medication for AVMs at school:

Some patients undergoing (or who have undergone) embolization of cerebral AVMs may need anti-epileptic drugs that will be reported by the family in the appropriate school form.

When an AVM becomes EMERGENCY at school:

Although very rarely, AVMs can be responsible for sudden serious events such as STROKE or BRAIN ABSCESS.

Relevant symptoms (loss of consciousness, seizures, severe and persistent headache sometimes associated with vomiting, visual disorders) may occur without much notice. Patients with a diagnosis of HHT are screened to avoid these complications. But if the pupil has a severe illness at school, it cannot be ignored. It could be as a result of HHT.

Therefore, in this case, the Emergency services should be contacted and a copy of this form should be provided promptly, containing the student's past history and the contact details of the specialist(s) in charge of the minor.



NUMBERS to be contacted in case of EMERGENCY

Mother of the Pupil:

Father of the Pupil:

Other Contacts:

Primary Care Doctor (GP)

Specialist Doctor

Awareness and Acceptance:

Living with a rare disease also requires emotional and psychological attention for the family affected by HHT. It seems right to us to inform the school staff of the level of awareness & acceptance that the pupil has developed with regard to HHT.

The school is therefore informed that the pupil :

- does not know he/she has HHT
- knows he/she has HHT but does not want to share this information with others.
- knows he/she has HHT and has a good level of awareness & acceptance that allows him/her to talk openly with others if he/she feels the need.

Sharing:

School staff are informed that HHT is a disorder with a very low level of diagnosis (10% of the affected population). Raising awareness of the disorder means increasing the level of diagnosis and hence the safety and health of patients.

For this reason, the pupil's family informs the school management

- would be willing, with the help of HHT Ireland to make a small presentation on HHT for school staff
- would like to share some information about his condition with his classmates through a Power Point Presentation.

The English version of this guide is brought to you by:

HHT Ireland - www.hhtireland.org- info@hhtireland.org

All Scientific Content was reviewed by: Dr. Adrian Brady Consultant Radiologist – HHT Center Mercy University Hospital – Cork, Ireland - Tel: 353-21-2305040

Guide Originally by

HHT Onlus Italy – Associazione Italiana Telenagectasia Emorragica Ereditaria. + 39.333.6159012| info@hhtonlus.org www.hhtonlus.org

Scientific Consultant Dr. Patrizia Suppressa – Centro HHT Policlinico di Bari – centromalattierare@gmail.com

Scientific Consultant Prof. Dottor Fabio Pagella – Centro HHT Policlinico San Matteo di Pavia – hht@sanmatteo.pv.it