

HHT SCHOOL GUIDE 2023

For a safe return to school



CONTENTS

| | |
|----|------------------------------------|
| 3 | WORD FROM THE FOUNDER |
| 4 | INSTRUCTIONS FOR USE |
| 5 | HHT A RARE DISEASE |
| 6 | MANAGEMENT OF HHT AT SCHOOL |
| 7 | ARTERIOVENOUS MALFORMATIONS (AVMS) |
| 8 | IN CASE OF EMERGENCY |
| 9 | MY CHECKLIST |
| 10 | NOTES |
| 11 | ANY QUESTIONS? |

WORD FROM THE FOUNDER



Dara Woods

FOUNDER OF HHT IRELAND

Dear Parents,

We hope you find this school guide helpful while you prepare to send your child back to school. As an advocate for your child with HHT, it is imperative that you help our teachers to understand how it may affect your child. Be assured that your child will be in safe hands knowing the teacher is aware of HHT.

Our school days should be the happiest days of our life.

Let's make this happen for our children!

INSTRUCTIONS FOR USE

How to proceed?

- 1 Please read the information form carefully and completely.
- 2 Fill in the parts related to your child's personal and clinical data on pages 4-7.
- 3 Give these pages to your child's teacher for future reference.
- 4 If you are in any doubt about filling in the form, you can ask HHT Ireland or your doctor for help.
- 5 Many schools organise meetings for children with certain 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. We encourage parents to have a conversation and help their children 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.



HHT: A RARE DISEASE

Personal information:

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 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 type 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 common.

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, and 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. Severe recurrent migraines
- b. Difficulty breathing
- c. Significant lack of concentration, fatigue and/or disorientation

Administering medication 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 AVMs becomes an EMERGENCY:

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.



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/her condition with his/her classmates through a Power Point Presentation.

Do you have any questions?

If you have any questions about HHT, contact HHT Ireland:

By phone: 083 422 2302 (Monday to Friday, 9am - 8pm)

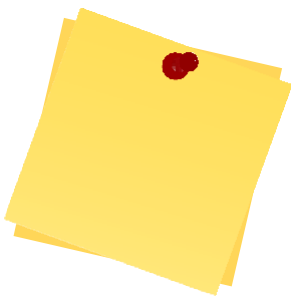
By email: info@hhtireland.org

CHECKLIST



Here is a little recap of what you need to think of:

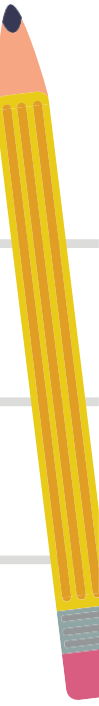
- Read carefully the school guide and complete page 4 - 7
- Give the completed pages 4-7 to your teacher
- Prepare a nosebleed kit
- Supply your child with a mask, if needed for COVID-related precautions, and a spare mask, as a replacement if the first becomes wet (e.g. from a nosebleed)
- Prepare a spare T-shirt
- Talk to your child, explaining the situation to him/her and prepare him/her for the new changes
- Talk to your child's teacher about HHT



Note for your child: Don't forget to have fun, laugh, exercise and enjoy every moment at school.

We wish you a fabulous new school year!

NOTES



Do you have any questions?

Contact our HHT team:
083 422 2302

From Monday to Friday:
9am – 8pm

Or by email:
info@hhtireland.org

Find out more about HHT on our website:
www.hhtireland.org

Guide developed from the original version created by HHT Onlus.

Content related to HHT reviewed by Dr Adrian Brady, from the National Centre of HHT, Mercy University Hospital, Cork.

Sources: HHT Onlus, HSE, Irish Government, WHO (World Health Organisation), European Centre for Disease and Control.