

## Bridging the Gap in HHT Emergency Care

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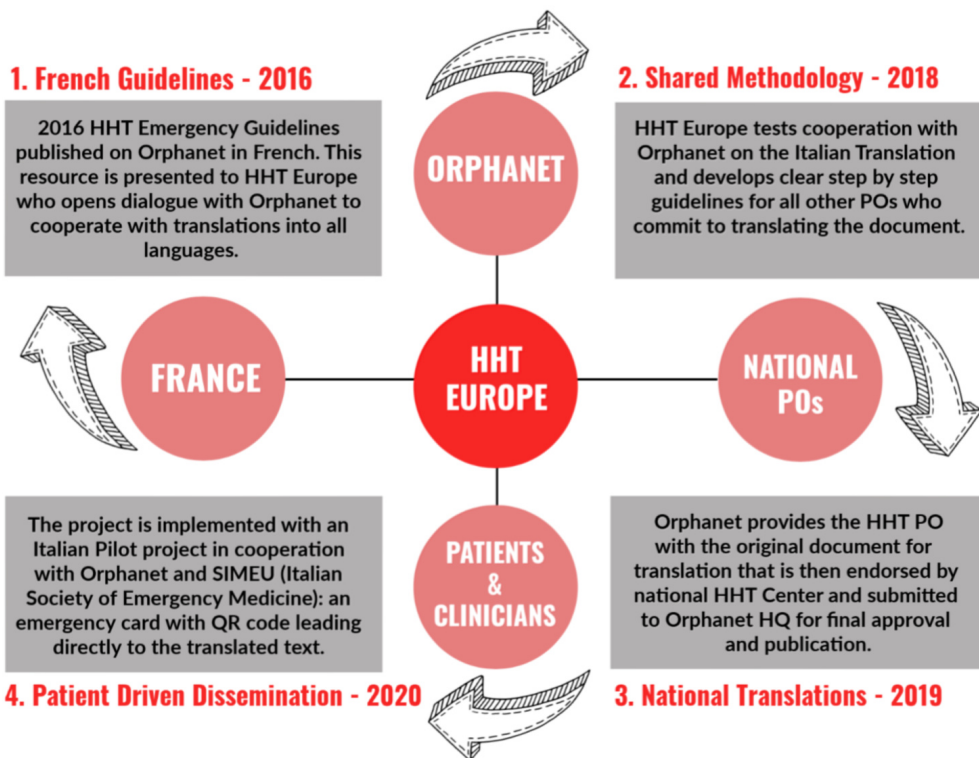
### HHT Background

Hereditary Hemorrhagic Telangiectasia (HHT), also known as Rendu Osler Weber Syndrome is a rare genetic disorder that causes arteriovenous malformations (AVMs) the brain, lungs, liver and GI tract. The most commonly experienced symptom is nosebleeds. However, HHT is #MoreThanANosebleed. AVMs in the lungs and brain can lead to severe consequences such as strokes, aneurysms and brain abscesses.

### Project Background

HHT symptoms are misleading often causing misdiagnosis. Even when diagnosed, emergency management of HHT can be challenging without necessary expertise creating great concern for all European patients. HHT Europe cooperatively addressed this request helping bridge the expertise gap in HHT emergency care through the Orphanet Emergency Guidelines.

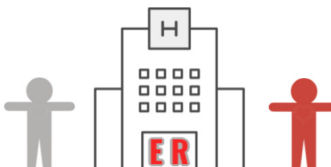
## EFFICIENT DEVELOPMENT OF ACCESSIBLE HHT EMERGENCY GUIDELINES



Emergency Healthcare professionals are able to access the guidelines in French, Italian and Spanish while Swedish, English and German translations are in the pipeline. Patients can access, print and carry the guidelines with them. A practical QR code card is currently being trialled in Italy. This project supports better access to information for emergency management in HHT patients and bridges the expertise gap throughout Europe.

### before

Doctor, I have a rare disease called HHT, it causes vascular malformations, please keep in mind that ....



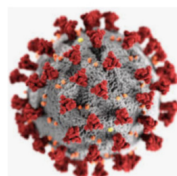
### after

Doctor, here are the Emergency Guidelines for HHT.

## PROJECT IMPACT DURING COVID 19 PANDEMIC

### Importance of guidelines

During the COVID-19 outbreak these guidelines are paramount as many HHT patients who present the need for emergency care are unable to reach their expert centers. This crisis has highlighted the importance of translating these guidelines into as many languages as possible.



### Impact of experience

Due to the experience developed in the guideline project, HHT Europe was able to draft and validate a HHT & COVID 19 statement at the very early hour of the pandemic. This was published and disseminated contemporarily in eight different languages thanks to the teams who had worked on the Emergency Guidelines.