Bridging the Gap in HHT Emergency Care

Presenting Author: Mildred Lundgren - HHT Sverige - osler@hhtsvetriag.org, tel + 46 70 212 8286
Co-authors: Aino Goustitte - AMRO France-HHT; Bienvenida Muñoz - HHT Spain; Fernando Brocca - HHT Onlus; Peta Woods - HHT Ireland; Ralf Schmiedel - HHT Germany; Claudia Cricione - HHT Europe.
ECRO 2020 - Poster #102 - Theme: Share, Care, Rare: Transforming Care for Rare Diseases by 2030

HHT Background
Hereditary Hemorrhagic Telangiectasia (HHT), also known as Rendu-Osler-Weber Syndrome is a rare genetic disorder that causes arteriovenous malformations (AVMs) in the brain, lungs, liver, and GI tract. The most commonly experienced symptom is nosebleeds. However, HHT is #MoreThanJustnosebleed. 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

1. French Guidelines - 2016
2016 HHT Emergency Guidelines published on Orphanet in French. This resource is presented to HHT Europe who opens dialogue with Orphanet to cooperate with translations into all languages.

3. National Translations - 2019
Orphanet provides the HHT PO with the original document for translation that is then endorsed by national HHT Center and submitted to Orphanet HQ for final approval and publication.

4. Patient Driven Dissemination - 2020
The project is implemented with an Italian Pilot project in cooperation with Orphanet and SIEME (Italian Society of Emergency Medicine): an emergency card with QR code leading directly to the translated text.

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.