

MOBILE APPLICATION FOR PATIENTS WITH HEREDITARY HEMORRHAGIC TELANGIECTASIA (HHT)

A research group from CIBER, CSIC and Asociación HHT España have developed an app for patients with Hereditary Hemorrhagic Telangiectasia (HHT) to improve their follow-up.

The Need

HHT is a rare vascular disorder characterized by telangiectases and arteriovenous malformations that may affect the skin and mucous membranes, as well as different organs such as brain, liver and gastro intestinal tract . Recurrent epistaxis is the most common clinical manifestation and can lead to iron deficiency and anemia, significantly affecting patients' quality of life. **HHT's management requires specialized knowledge**; consequently, patients presenting to non-specialized emergency services may be treated by healthcare professionals who are unfamiliar with the disease. This may hinder **appropriate and timely management**, particularly in **emergency situations**.

The Solution

A **mobile application specifically designed for patients with HHT**, providing access via a QR code to essential and up-to-date clinical information to facilitate appropriate medical care, particularly in emergency situations.

Innovative Aspects

- **Immediate access to relevant clinical information:** the QR code will allow healthcare professionals to rapidly access essential patient information, even when care is provided outside the patient's usual specialist team.
- **Support for clinical decision-making in emergencies:** the application will provide disease-specific information and recommendations, reducing the risk of inappropriate interventions.
- **Digital monitoring of epistaxis:** patients will be able to continuously record the frequency and severity of nosebleeds, facilitating assessment of disease progression and treatment response.
- **Personalization and continuity of care:** the application will integrate clinical data, symptoms, treatments, comorbidities, and, where appropriate, genetic information, providing a comprehensive overview of the patient.
- **Research potential:** longitudinal collection of epistaxis data may enable analysis of bleeding patterns in relation to treatments, age, comorbidities, and genetic characteristics, generating valuable real-world data to improve the understanding and management of HHT.

Intellectual Property / Stage of development:

- Software registered: March 2025

App HHT

Patients

Aims

Looking for a partner interested in a license and/or a collaboration agreement to develop and exploit this asset.

Contact details