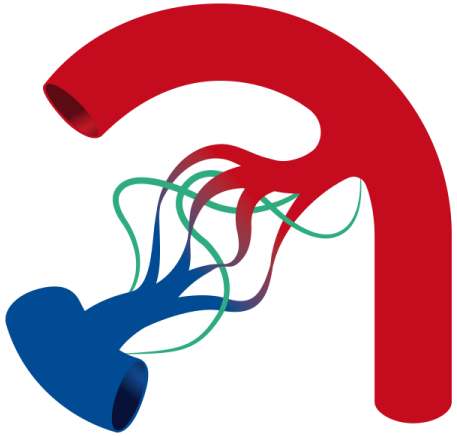
European Reference Network

for rare or low prevalence complex diseases

Network Vascular Diseases (VASCERN)



Hereditary Haemorrhagic Telangiectasia

Final Approved Patient Pathway by the HHT Working Group – 11/07/2017

VASCERN HHT working group Members:

Claire Shovlin, Elisabetta Buscarini, Claudia Crocione, Urban Geisthoff, Anette Kjeldsen, Hans-Jurgen Mager, Carlo Sabba, and Sophie Dupuis-Girod

Disclaimer

- This document is an opinion statement reflecting strategies put forward by experts and patient representatives involved in the Hereditary Haemorrhagic Telangiectasia (HHT) Rare Disease Working Group of VASCERN.
- This pathway is issued on 11/07/2017 and will be further validated and adjusted as needed.
- Responsibility for care of individual patients remains with the treating physician.

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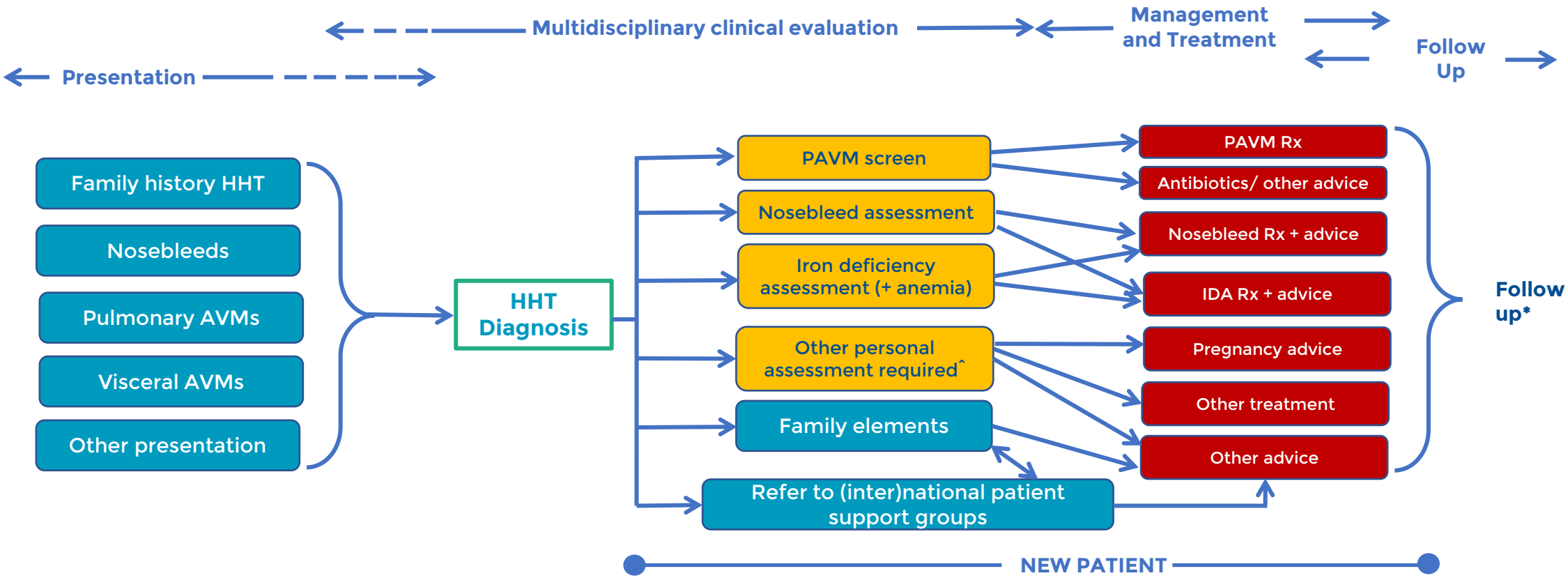
Gathering the best expertise in Europe to provide accessible cross-border healthcare to patients with rare vascular diseases

https://vascern.eu

Hereditary Haemorrhagic Telangiectasia Patient Pathway (v2 - 11/07/2017)



*In accordance with clinical need and geographical location. Should include:
1) Ongoing access to services on demand
2) Ongoing support of local medical teams
3) Individual follow up as required for new clinical indications such as pregnancy, new symptoms assessment, and ~6 months post PAVM embolisation.
^ As formalised through HHT WG Programmes

LEGEND: Clinical evaluation | Investigations | Treatment

European Reference Network

VASCERN

Gathering the best expertise in Europe
to provide accessible cross-border healthcare
to patients with rare vascular diseases

VASCERN, the European Reference Network on Rare Multisystemic Vascular Diseases, is dedicated to gathering the best expertise in Europe in order to provide accessible cross-border healthcare to patients with rare vascular diseases (an estimated 1.3 million concerned). These include arterial diseases (affecting aorta to small arteries), arterio-venous anomalies, vascular malformations, and lymphatic diseases.

VASCERN currently consists of 30 highly specialised multidisciplinary Healthcare Providers (HCPs) from 11 EU Member States and of various European Patient Organisations and is coordinated in Paris, France.

Through our 5 Rare Disease Working Groups (RDWGs) as well as several thematic WGs and the ePAG – European Patient Advocacy Group, we aim to improve care, promote best practices and guidelines, reinforce research, empower patients, provide training for healthcare professionals and realise the full potential of European cooperation for specialised healthcare by exploiting the latest innovations in medical science and health technologies.

More information available at: https://vascern.eu

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