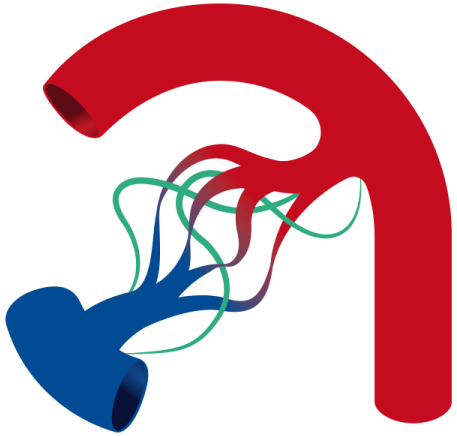
European Reference Network

for rare or low prevalence complex diseases

Network Vascular Diseases (VASCERN)



Severe/Rare Infantile Hemangioma

Final Approved Patient Pathway by the Vascular Anomalies (VASCA) Working Group - 20/03/2019

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Disclaimer

- This document is an opinion statement reflecting strategies put forward by experts and patient representatives involved in the Vascular Anomalies (VASCA) Rare Disease Working Group of VASCERN.
- This pathway is issued on 20/03/2019 and will be further validated and adjusted as needed.
- Responsibility for care of individual patients remains with the treating physician.

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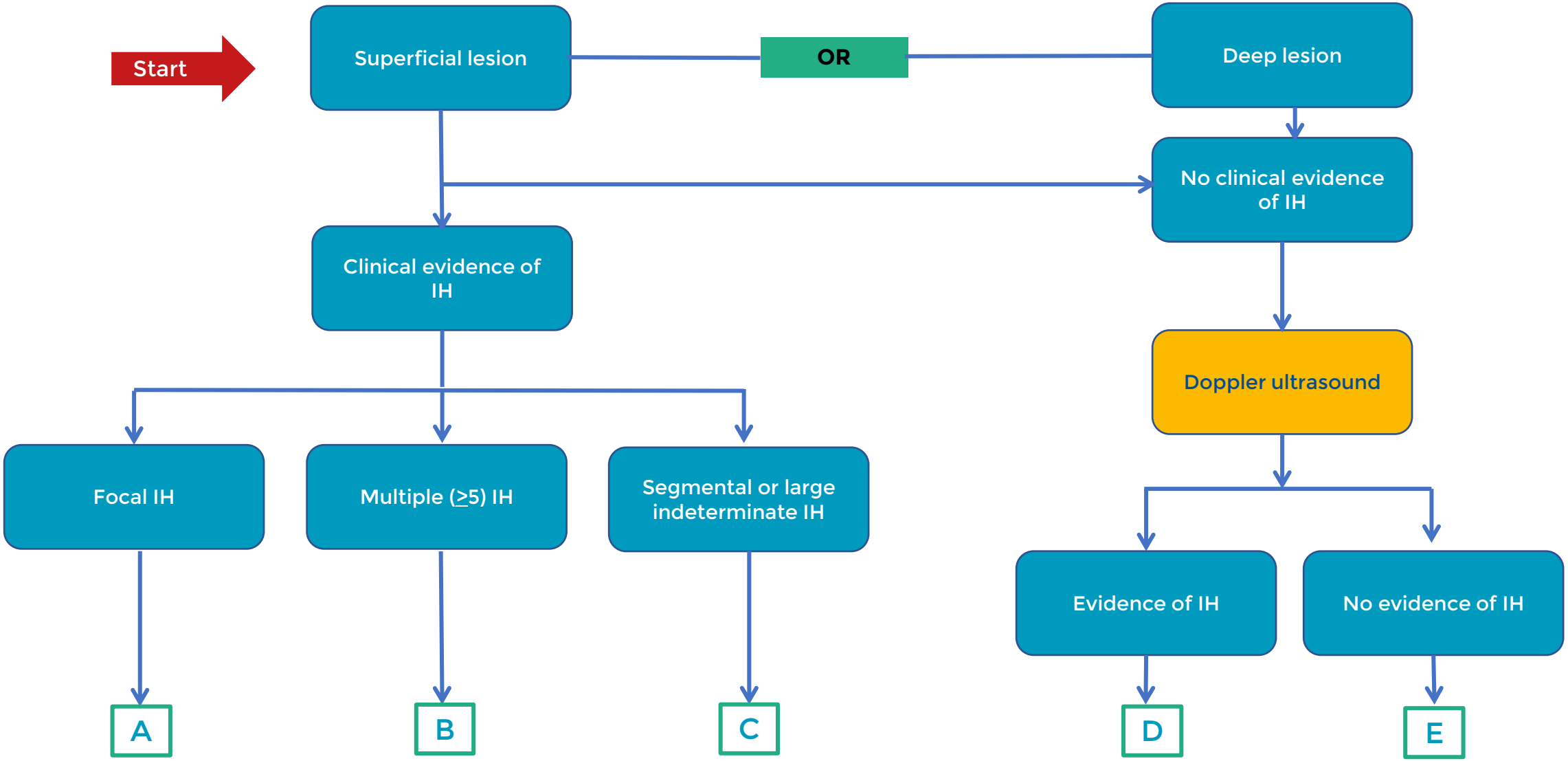
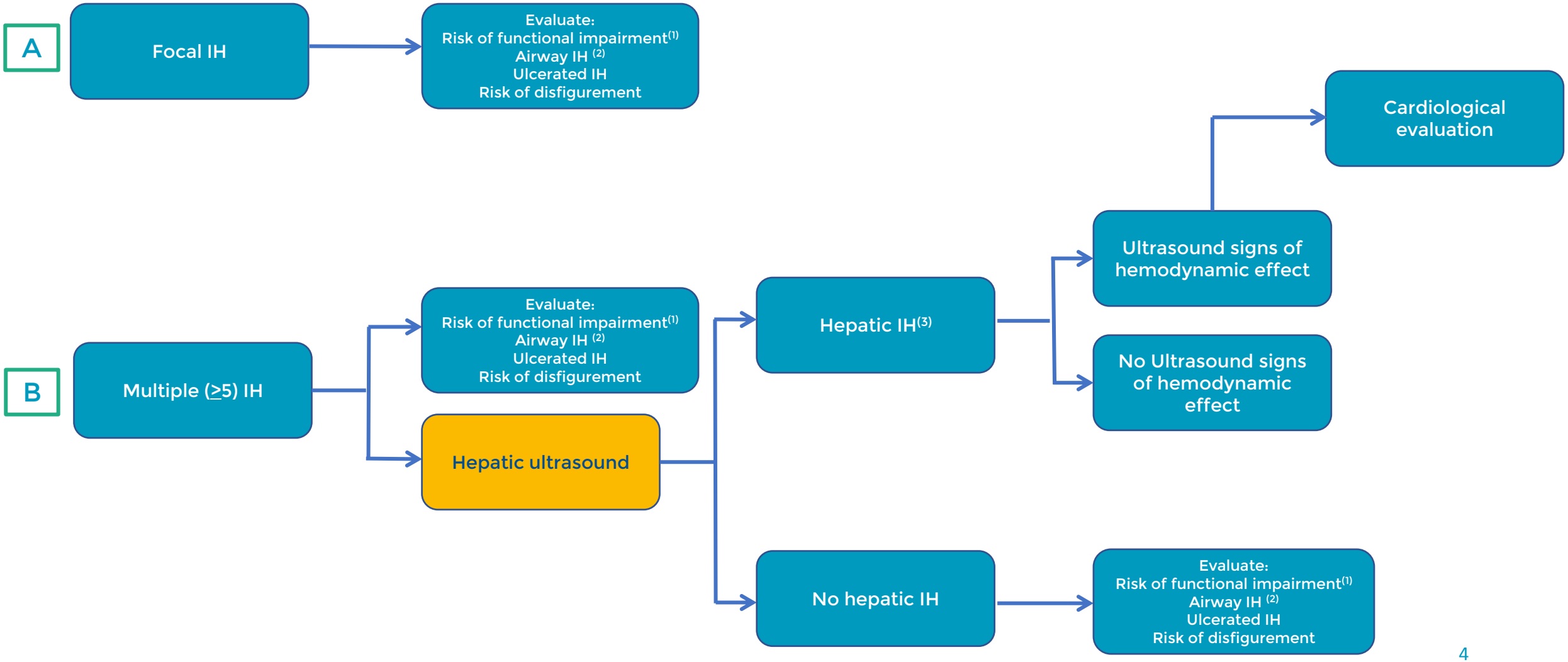
Gathering the best expertise in Europe
to provide accessible cross-border healthcare
to patients with rare vascular diseases

https://vascern.eu

Patient with Suspected Severe/Rare Infantile Hemangioma (IH)



Patient with Suspected Severe/Rare Infantile Hemangioma (IH) continued



C

Segmental or large indeterminate IH

→ PHACES criteria (refer to experienced centres): MRI, MRA, ophthalmological consultation, and consider laryngoscopy if beard distribution and upper respiratory symptoms.

→ Evaluate:
Risk of functional impairment[1]
Airway IH [2]
Ulcerated IH
Risk of disfigurement

If lumbosacral/genital IH perform ultrasound and/or MRI to search for other associated anomalies (PELVIS/LUMBAR/SACRAL)

D

Evidence of IH

→ Evaluate:
Risk of functional impairment[1]
Airway IH [2]
Ulcerated IH
Risk of disfigurement

E

No Evidence of IH

→ Search for new diagnosis. Consider MRI and/or biopsy if uncertain diagnosis

(1) Risk of functional impairment
- Orbital or auricular IH
- IH of the lip or hand

In some cases MRI is necessary to evaluate the relation between the IH and other structures

(2) Airway IH
-Suspect when beard distribution or upper respiratory symptoms
- Consider diagnostic and follow-up laryngoscopy

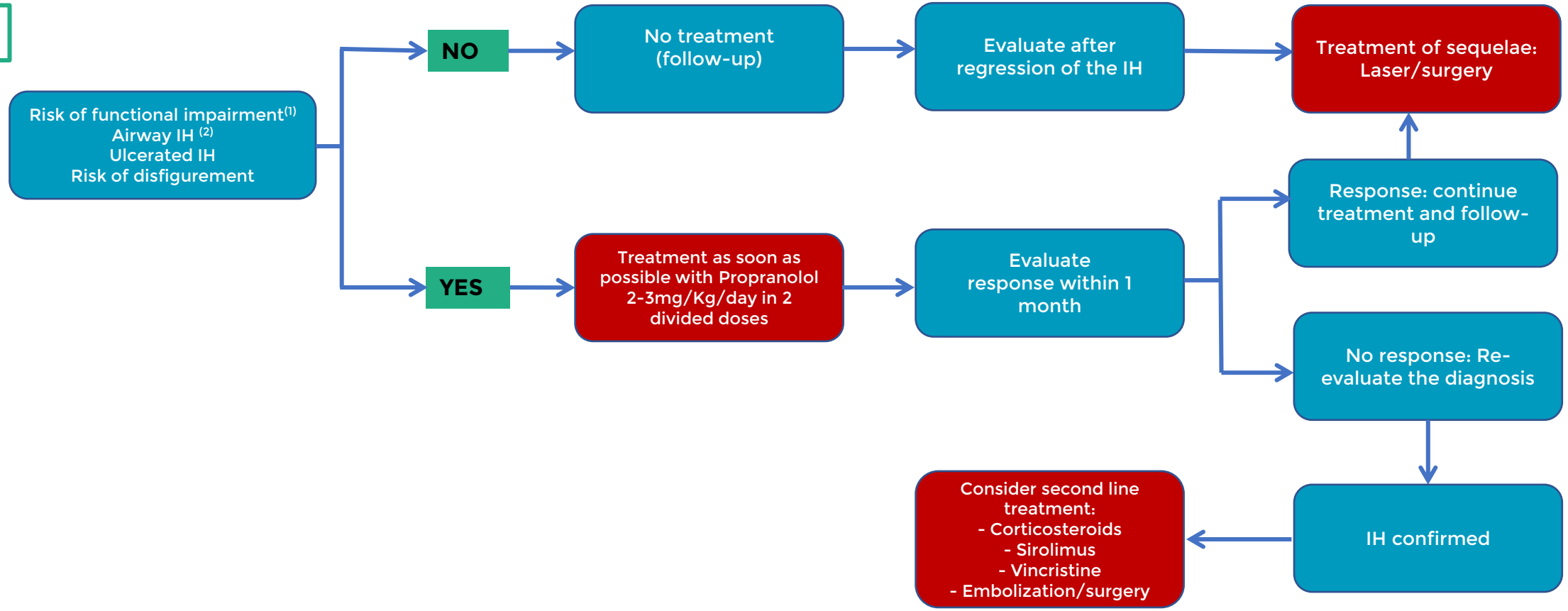
(3) Hepatic IH
-Test thyroid function

Voluminous IH
- Cardiological evaluation
- Test thyroid function

Go to next page: Treatment of Severe/Rare Infantile Hemangioma (IH)

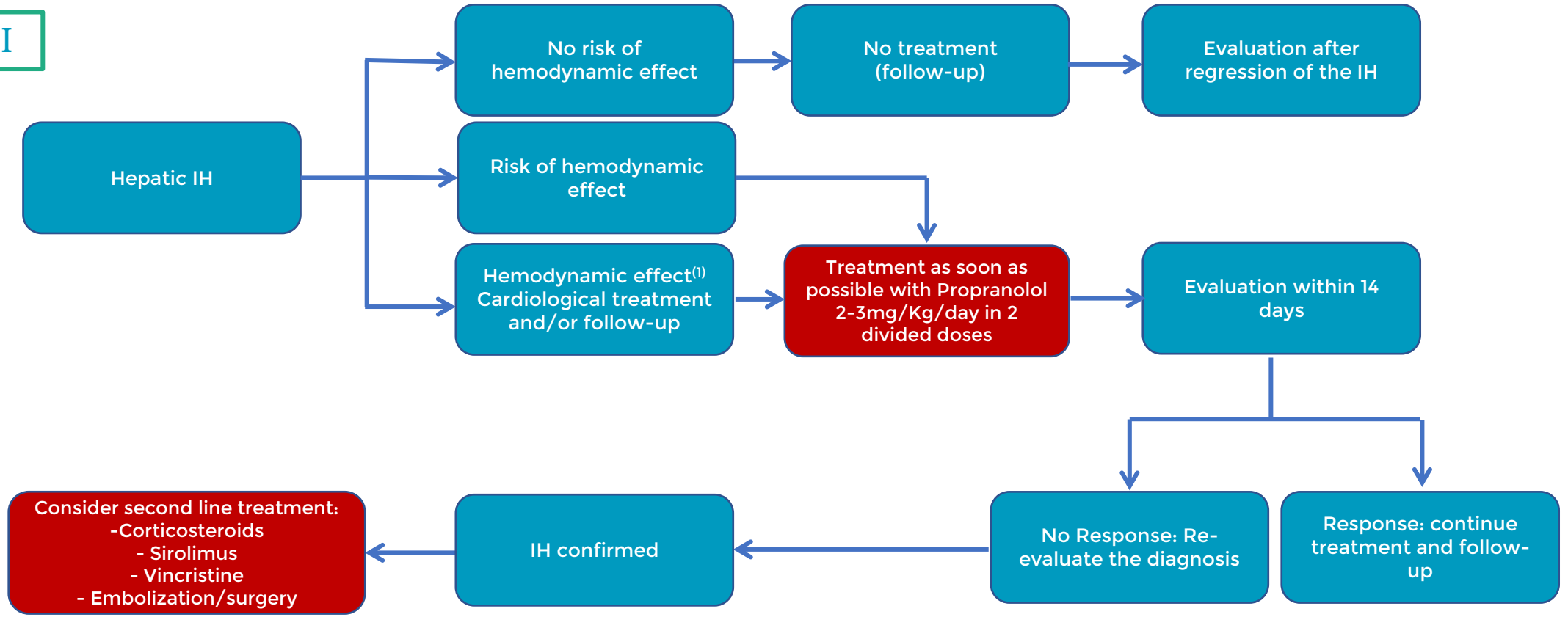
Treatment of Severe/Rare Infantile Hemangioma (IH)

I



Treatment of Severe/Rare Infantile Hemangioma (IH) continued

II



(1) In case of cardiac failure consider embolization prior to propranolol treatment

Treatment of Severe/Rare Infantile Hemangioma (IH) continued

III

PHACES syndrome with abnormal cerebral arteries → Treatment as soon as possible with low dose Propranolol (start with 0,5mg/kg/day) in 3 divided doses → And treatment according to other specific abnormalities → Consider repeating MRI depending on risk of stroke

IV

PHACES syndrome with no abnormal cerebral arteries/PELVIS/LUMBAR/ SACRAL syndrome → Treatment as soon as possible with Propranolol 2-3mg/Kg/day in 2 divided doses → And treatment according to other specific abnormalities

V

Low weight
Premature
Comorbidity
Low compliance → Treatment as inpatient as soon as possible Start with low dose Propranolol (start with 0,5mg/kg/day) in 3 or more divided doses

In case of ulceration during propanolol treatment consider lowering the dosage.

LEGEND: Clinical evaluation | Investigations | Treatment | Particular cases

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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 31 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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