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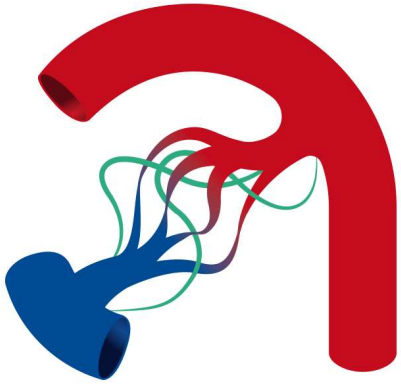
for rare or low prevalence complex diseases

Network Vascular Diseases (VASCERN)



Capillary Malformation

Final Approved Patient Pathway by the Vascular Anomalies (VASCA) Working Group – 29/04/2020

VASCERN VASCA working group Members:
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Cooperating Guests:
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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.
- It is preferable that patients be evaluated in a multidisciplinary center specialising in the diagnosis and management of vascular anomalies.
- This pathway is issued on 29/04/2020 and will be further validated and adjusted as needed.
- Responsibility for care of individual patients remains with the treating physician.

Dieses Dokument wurde am 05.12.2022 von Dr. Friedrich Kapp für das Zentrum für Gefäßfehlbildungen (Uniklinik Freiburg) für das FZSE Freiburg geprüft und kommentitiert. Eine gemeinsame Überprüfung und Diskussion wird unabhängig hiervon in VASCA-WG erfolgen.

Dieses Dokument wurde am 15.11.2023 von Dr. Friedrich Kapp für das Zentrum für Gefäßfhelbildungen (Uniklinik Freiburg) für das FZSE Freiburg geprüft, es war keine Kommentierung notwendig. Eine gemeinsame Überprüfung und Diskussion wir unabhängig hiervon in der VASCA-WG erfolgen.

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Dieses Dokument wurde am 10.09.2025 von PD Dr. Friedrich Kapp für das Zentrum für Gefäßfhelbildungen (Uniklinik Freiburg) für das FZSE Freiburg geprüft, es war keine Kommentierung notwendig. Eine gemeinsame Überprüfung und Diskussion wir unabhängig hiervon in der VASCA-WG erfolgen

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

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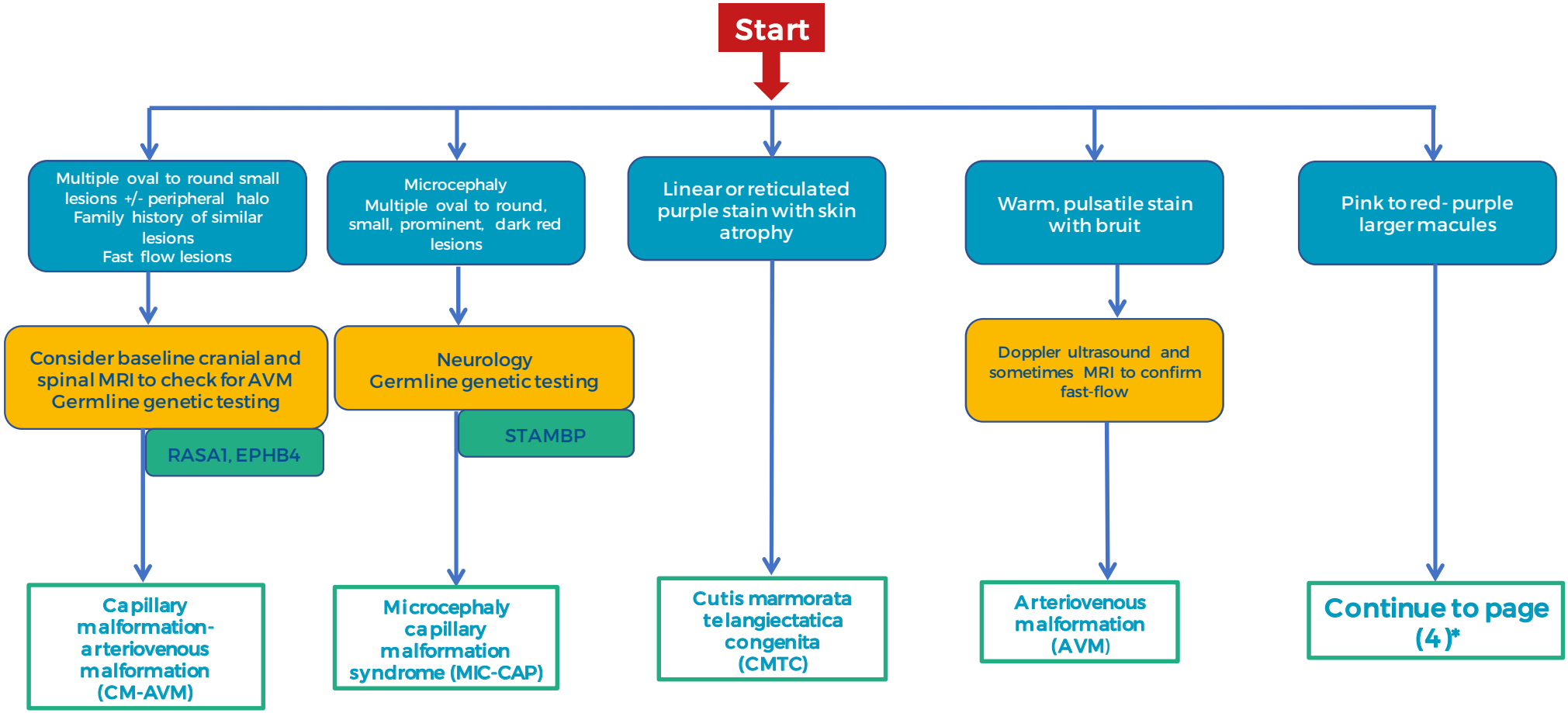
Capillary malformation (Vascular stain) Diagnostic Work-Up



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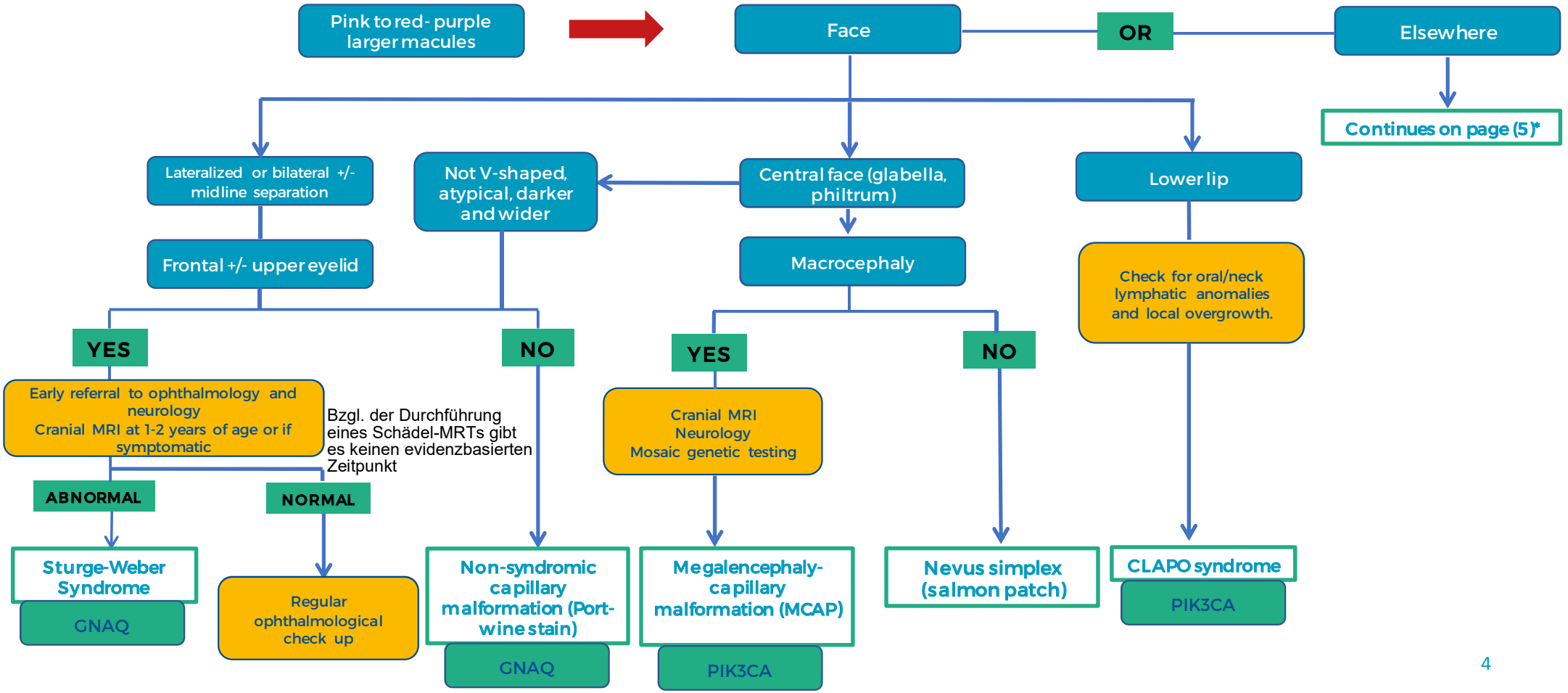
Capillary malformation (Vascular stain) Diagnostic work up continued



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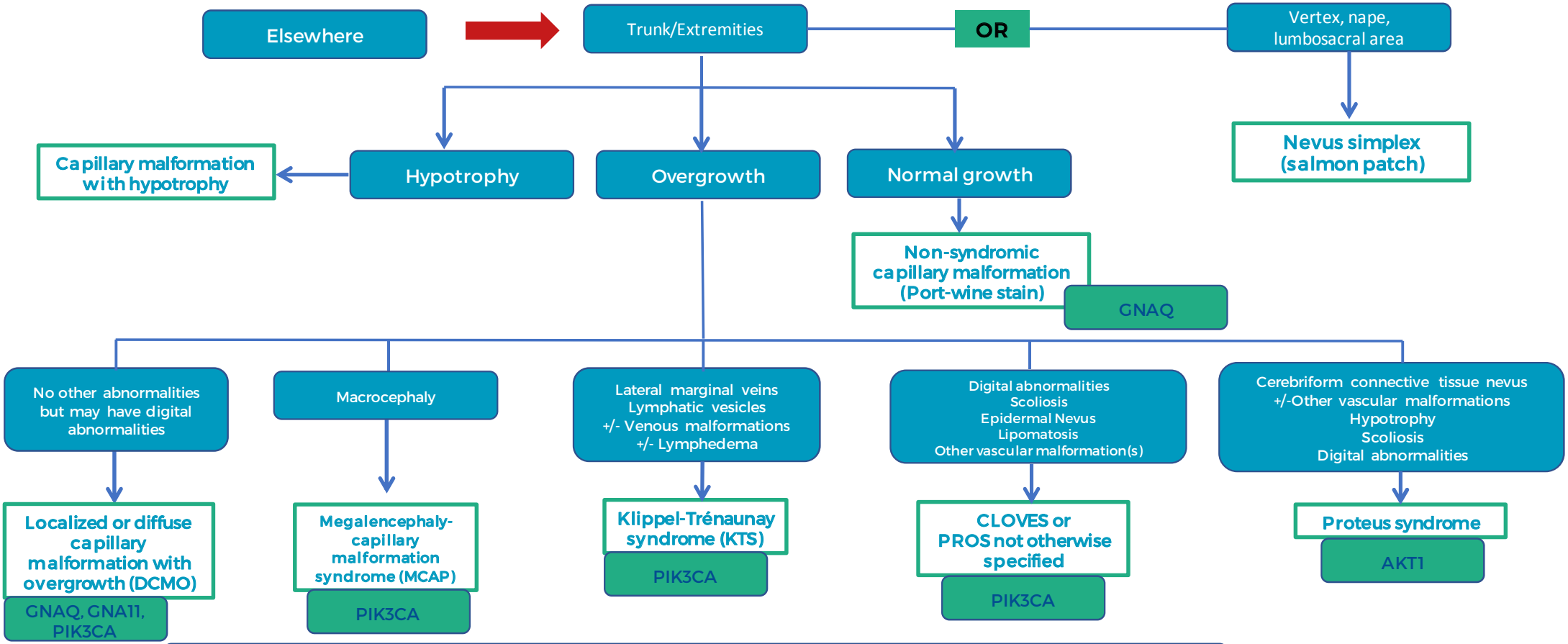
Capillary malformation (Vascular stain) Diagnostic work up continued



Go to next page: Management/Treatment of Capillary malformation (Vascular stain)

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Management/Treatment of Capillary malformation (Vascular stain)

Capillary malformation-arteriovenous malformation (CM-AVM) → Doppler ultrasound and/or MRI of any suspected AVM → Consider repeated cranial and spinal MRI at puberty → Germline genetic testing → Response to and safety of laser not known → Treatment of AVM (refer to AVM pathway)

Sturge-Weber Syndrome → Ophthalmology at regular intervals → Annual neurology and repeat cranial MRI if symptomatic → Consider early laser → Consider acetylsalicylic acid or prophylactic antiepileptic drugs if severe leptomeningeal involvement

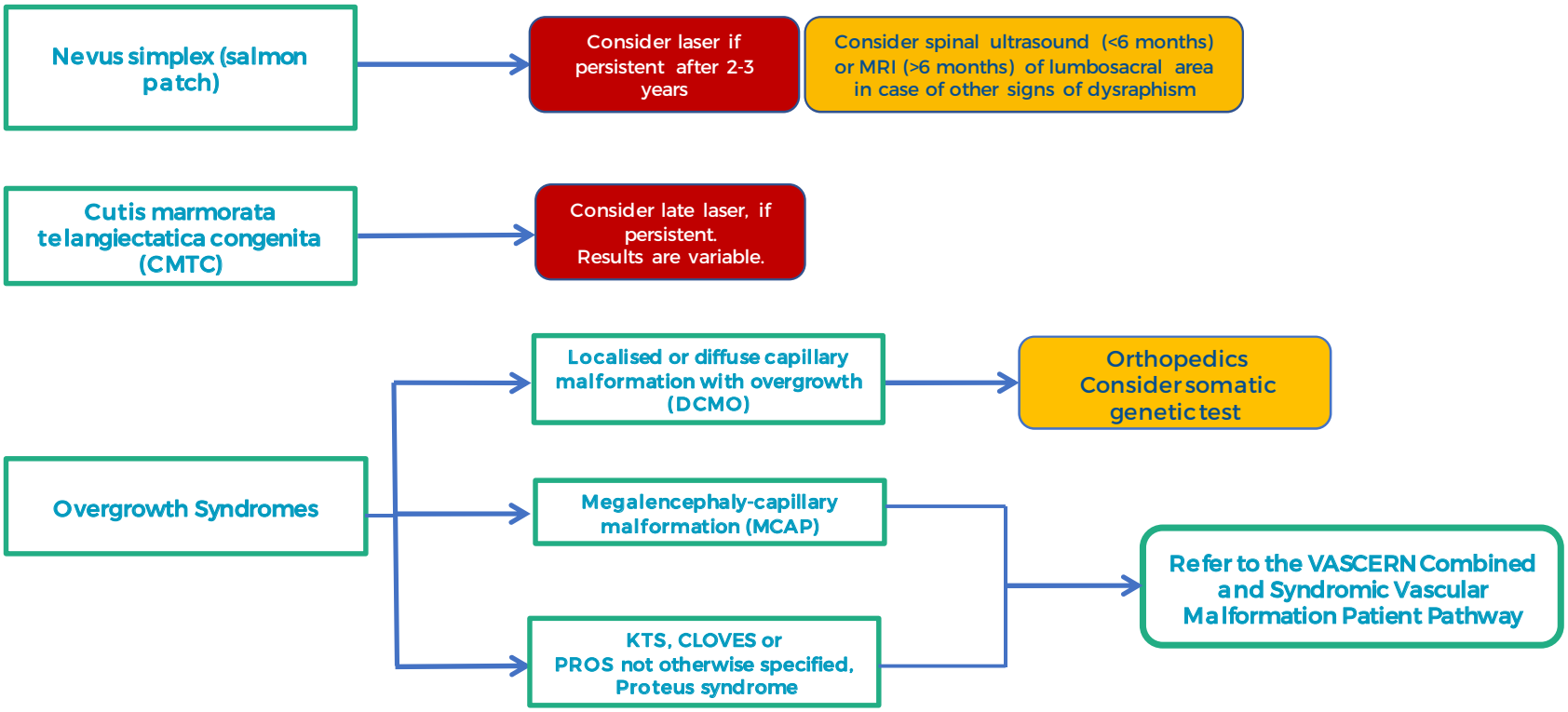
Facial capillary malformation (Port-wine stain) w/o Sturge-Weber Syndrome → Consider early laser

Kommentar FK 12/2022
Bzgl. der Durchführung einer Lasertherapie gibt es keinen evidenzbasierten Zeitpunkt

CLAPO syndrome → Check for oral or neck lymphatic anomalies and facial overgrowth. Consider somatic Genetic test → Consider early laser

Microcephaly capillary malformation syndrome (MIC-CAP) → Refer to neurologist

Management/Treatment of Capillary malformation (Vascular stain) continued



LEGEND: Clinical evaluation | Investigations | Treatment | Genes

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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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