



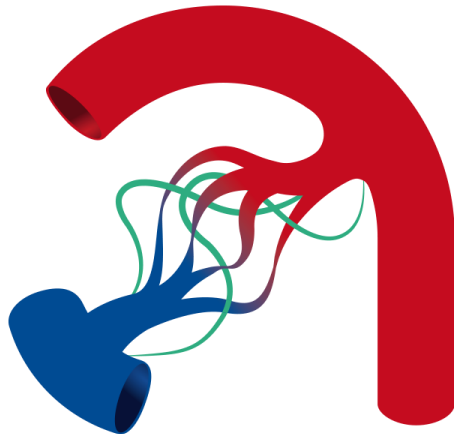
**European  
Reference  
Network**

for rare or low prevalence  
complex diseases



**Network**

Vascular Diseases  
(VASCERN)



# General Patient Pathway for Pediatric and Primary Lymphedema

Final Approved Patient Pathway by the Pediatric and  
Primary Lymphedema (PPL) Working Group – Version 1  
- 08/11/2019

VASCERN PPL working group Members:

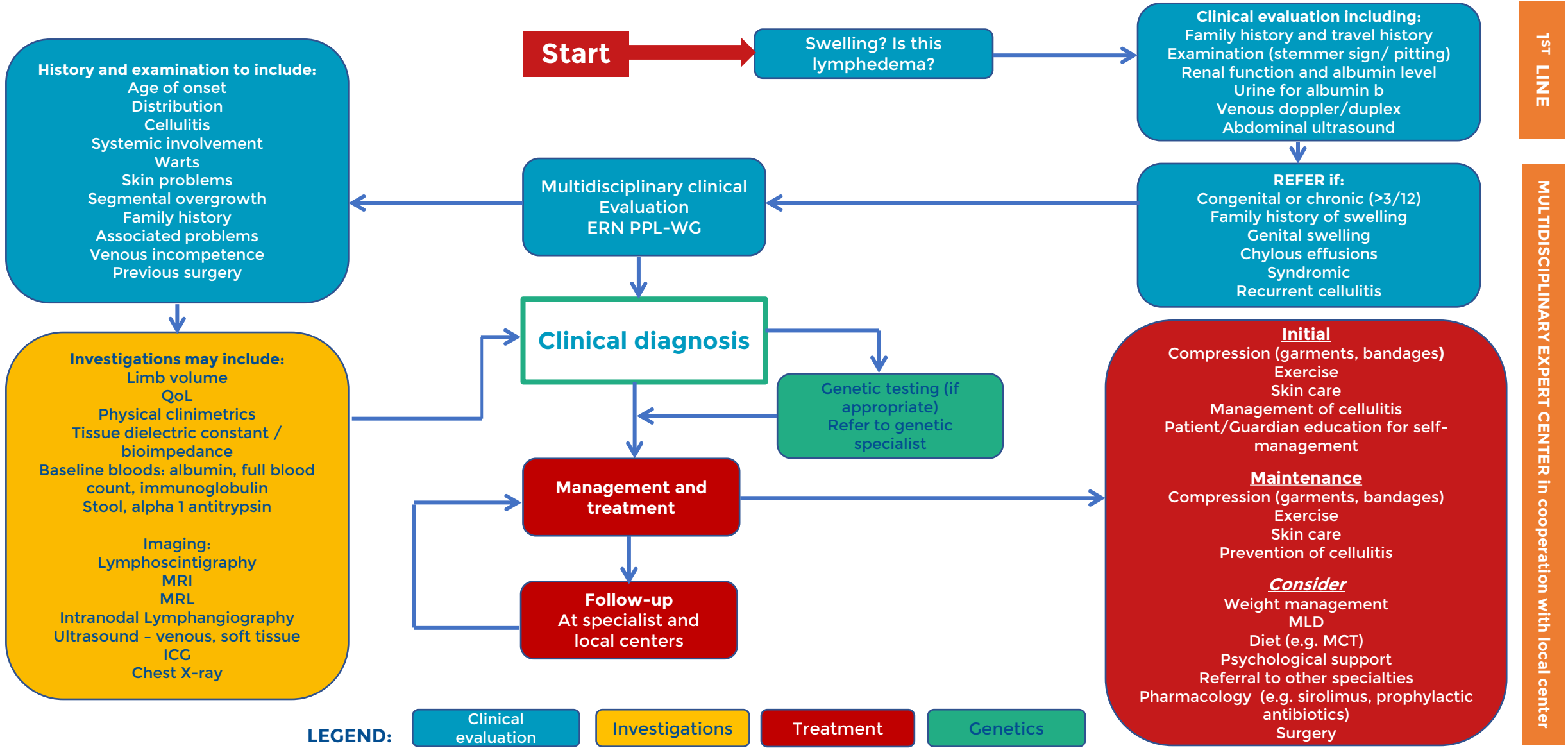
Robert Damstra, Florence Belva, Nele Devoogdt, Janine Dickinson,  
Guido Giacalone, Kristiana Gordon, Peter Hall, Pernille Henriksen, Heli  
Kavola, Vaughan Keeley, Manuela Lourenço Marques, Michael  
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# Disclaimer

- This document is an opinion statement reflecting strategies put forward by experts and patient representatives involved in the Pediatric and Primary Lymphedema (PPL) Rare Disease Working Group of VASCERN.
- This pathway is issued on 08/11/2019 and will be further validated and adjusted as needed.
- Responsibility for care of individual patients remains with the treating physician.



# General Patient Pathway for Pediatric and Primary Lymphedema (V1 - 08/11/2019)





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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