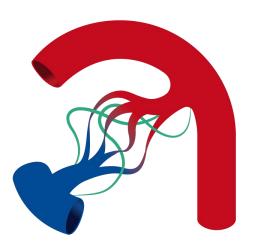


European Reference Network

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 4 - 06/10/2023 by VASCERN PPL working group Members:

Robert Damstra, Nele Devoogdt, Janine Dickinson, Guido Giacalone, Tonny Karlsmark, Manuela Lourenço Marques, Christoffer Nissen, Susan Norregaard, Michael Oberlin, Alain Pradel, Tanja RuČigaj, Sinikka Suominen, Stéphane Vignes, Kirsten van Duinen, Sarah Thomis

Updated from: Patient Pathway by the Pediatric and Primary Lymphedema (PPL) Working Group – Version 3-13/04/2023 by Robert Damstra, Florence Belva, Nele Devoogdt, Janine Dickinson, Guido Giacalone, Manuela Lourenço Marques, Michael Oberlin, Tanja RuČigaj, Sinikka Suominen, Stéphane Vignes, Kirsten van Duinen, Sarah Thomis.



- 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 06/10/2023 and will be further validated and adjusted as needed.
- Responsibility for care of individual patients remains with the treating physician.



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

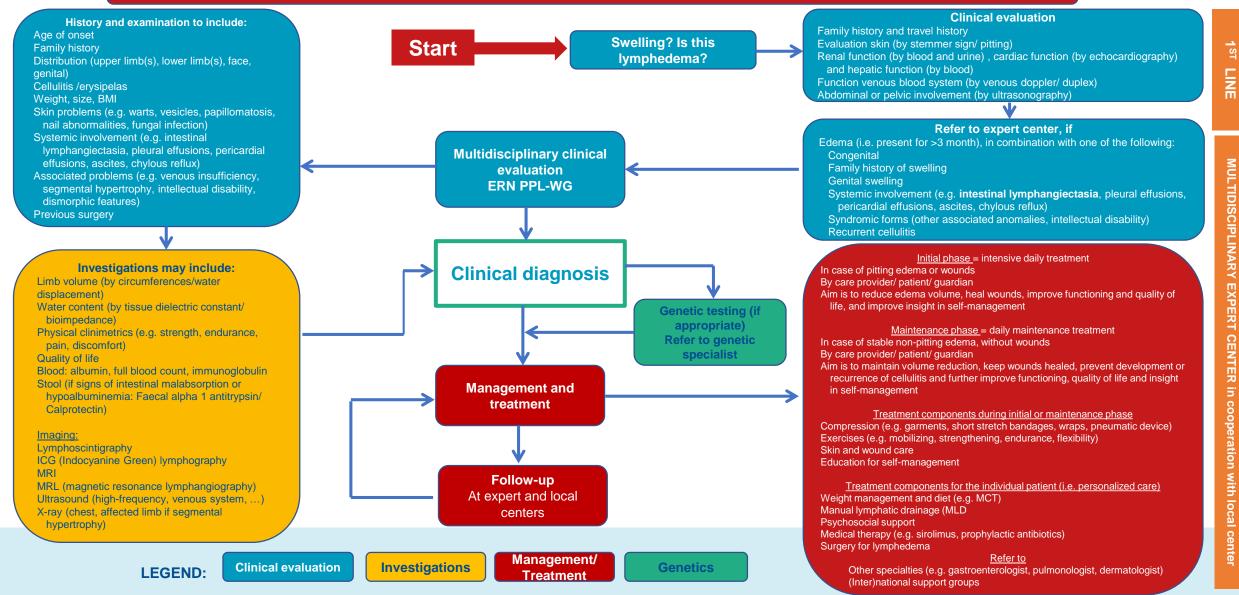


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General Patient Pathway for Pediatric and Primary Lymphedema (V4-06/10/2023)





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 gathers 48 expert teams from 39 highly specialized multidisciplinary HCPs, plus 6 additional Affiliated Partner centers, coming from 19 EU Member States, as well as various European Patient Organisations, and is coordinated in Paris, France.

Through our 6 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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