



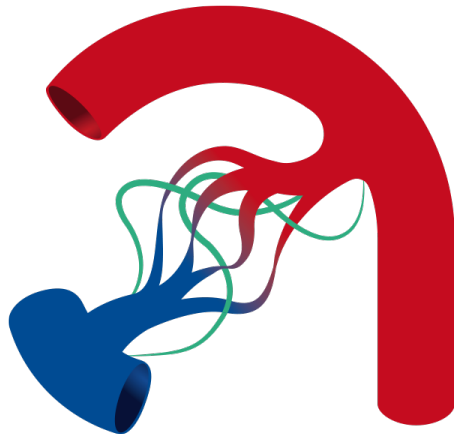
**European
Reference
Network**

for rare or low prevalence
complex diseases



Network

Vascular Diseases
(VASCERN)



Parallel Session 6

Good practice in the Pediatric and Primary Lymphedema Working Group

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Disclosure statement

We have no actual or potential conflict of interest in relation to this program/presentation

1. Activities of the PPL Group developed by patients and clinicians



1. Pills of knowledge on Lymphedema (video and other materials for patient information)
2. Do's and don'ts factsheets
3. Clinical outcome measures and Quality of Life (work on progress)
4. Patient pathways (patient journey from pre-diagnosis to follow.up): patients first draft and clinicians are validating locally, and they will be refined together
5. Revision of Orpha codes: clinicians are leading

2. Success factors and barriers for patient-clinician partnership in the PPL - WG



1. Success factors:

- Patient feedback is relevant, is being taken into account and has an impact.
- Patients are real team members (for example, they receive all the information at the same time)
- Previous working common history – pre-ERN and an identity as a group already formed
- Regular calls, usually well attended

2. Barriers:

- Use of medical jargon sometimes makes it difficult for patients to follow the discussions and transform that info into lay language
- Understanding of some complex medical topics for patients is not always easy and this might limit their contribution
- Patients and clinicians need to understand their role as representatives of the European wider patient and scientific community
- Limited representation from Eastern Europe (clinicians and patients)




3. Lessons learned

1. Be brave and build trust! It's easier than anticipated to work together – once you bring patients around the table, the collaboration gets easier. They come up with suggestions and a cooperative approach.
2. Being aware of the limitations and challenges is good because then you can address them.
3. When you go together, you go faster and further.
4. Cultural differences are important, have an impact in the work of the group and make it difficult to develop standards of care. We need to find a middle ground that is acceptable for everyone.
5. Patient and scientific community is very heterogeneous and it is still a challenge to join efforts and work together towards common goals.

4. Results



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Vascular Diseases (VASCERN)

VASCERN

The European Reference Network *ERN* on rare multisystemic vascular diseases

An overview of pediatric and primary lymphedema

www.VASCERN.eu

By the health care professionals and ePAG advocates (EURORDIS) from the Pediatric and Primary Lymphedema-Working Group

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An Overview of Pediatric and Primary Lymphedema

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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 disease (affecting aorta to small arteries), arterio-venous anomalies, venous 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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