VASCERN
THE EUROPEAN REFERENCE NETWORK ON RARE MULTISYSTEMIC VASCULAR DISEASES

- Hereditary Haemorrhagic Telangiectasia (HHT)
- Heritable Thoracic Aortic Disease (HTAD)
- Medium Sized Arteries (MSA)
- Pediatric and Primary Lymphedema (PPL)
- Vascular Anomalies (VASCA)

www.vascern.eu
The European Reference Networks (ERNs) gather highly-specialized expert centers across Europe to improve the management of all patients with rare diseases by providing accessible cross-border healthcare. VASCERN is the European Reference Network on Rare Multisystemic Vascular Diseases.

### ABOUT US

- **30** Member States of the European Union
- **11** Member States of the European Union work with their national networks of expert centers
- **30** Associated National Centers in other EU Member States are already working with VASCERN (Spain, Slovenia, Austria...) and our network will expand in the upcoming years.

### HOW ARE PATIENTS INVOLVED IN VASCERN?

The patient's needs are a priority for VASCERN and the patient advocates work hand in hand with VASCERN’s medical professionals.

### RARE DISEASES:

- **80%** are of genetic origin
- Affect **< 1 in 2000 people**
- **> 7000 rare diseases**

### How are patients involved in VASCERN?

The patient's needs are a priority for VASCERN and the patient advocates work hand in hand with VASCERN's medical professionals.

**1.3 MILLION PATIENTS** concerned by over 80 rare vascular diseases covered by our 5 rare disease working groups.

Your condition might fall into one of these rare disease working groups, check here: www.vascern.eu/expertise/
We offer cross-border virtual consultations using the **Clinical Patient Management System** (CPMS), where complex cases can be discussed with the experts of our Network.

**VASCERN produces and translates valuable documents and media for both patients and healthcare professionals**

- Guidelines and expert consensus statements for the medical community
- Patient pathways used to define the best patient care
- Do’s and Don’ts factsheets that alert medical professionals to the unique needs of rare disease patients in frequent situations
- Clinical outcome measures used to identify healthcare providers of good care and to encourage care improvement
- Pills of Knowledge / short educational videos
- Encourages collaborative research
- Develops registries

**VASCERN App** allows patients to reach the closest ERN and non ERN expert centers and patient organisations in Europe.
Gathering the best expertise in Europe to provide accessible cross-border healthcare to patients with rare vascular diseases.

Check out [www.vascern.eu](http://www.vascern.eu) for more information and to access our educational material.

**CONTACT US**

- If interested in joining the network
- For more information
- For expertise
- For referral of patients

contact@vascern.eu

**VASCERN Coordination**

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