## VASCERN

The European Reference Network on Rare Multisystemic Vascular Diseases

"VASCERN aims to facilitate and improve diagnosis, treatment and care for ALL patients suffering from Rare Multisystemic Vascular Diseases, thus enhancing access to care, and improving quantity and quality of life. Networking, sharing and spreading our expertise, promoting best practices, guidelines and clinical outcomes, patient-empowerment, improving knowledge through clinical and basic research are among our objectives."

Prof. **Guillaume Jondeau**, Network Coordinator, Center of Reference Marfan Syndrome and related disorders, AP-HP Hôpital Bichat, Paris, France

Vascular Diseases including rare, low prevalence and complex disorders that affect different types and sizes of vessels:

- Aorta
- Medium Sized Arteries
- Small Arteries / Veins / Capillaries / AV fistulaes
  - HHT
  - Out of HHT
- Lymphatic vessels
- and involving Multisystemic consequences and external signs

## **5** Rare Diseases **5** Transversal Working Groups (RDWG) **Working Groups Communication** Heritable 1 Chair / 1 Co-chair **Thoracic Aortic Diseases HTAD-WG eHealth** 1 Chair / 1 Co-chair 1 Chair / 1 Co-chair **Hereditary Medium Sized** Haemorrhagic **Telangiectasia Arteries Patient Group Ethics HHT-WG MSA-WG** (ePAG) 1 Chair / 1 Co-chair 1 Chair / 1 Co-chair 1 Chair / 1 Co-chair 1 Chair / 5 Co-chairs **Patient Registry Pediatric** 1 Chair / 1 Co-chair Vascular & Primary **Anomalies** Lymphedema **VASCA-WG PPL-WG Training & Education** 1 Chair / 1 Co-chair 1 Chair / 1 Co-chair 1 Chair / 1 Co-chair

## **Our Members**

31 European highly specialized Healthcare Providers (HCPs) from 11 EU Member States

Many Patient Organisations in the Patient Group in development

## HCPs Belgium Denmark Finland France Germany Hungary Ireland Italy Netherlands Sweden United Kingdom