

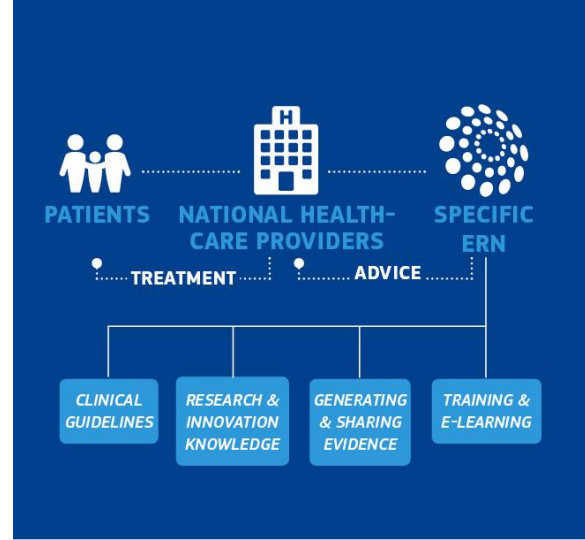


# European Reference Network

for rare or low prevalence complex diseases

**Network**  
Vascular Diseases (VASCERN)

  
Follow and tweet with us using:  
**#VASCERNdays2017**



EUROPEAN REFERENCE NETWORKS  
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

## Share. Care. Cure.



European Reference Networks



European Commission | Health

EUROPEAN COOPERATION

# VASCERN

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

## 1st Annual Seminar

[www.VASCERN.eu](http://www.VASCERN.eu)



European Reference Network

Supported by the




VASCERN 1st Annual Seminar, 13-14 October, 2017





European  
Reference  
Network

for rare or low prevalence  
complex diseases

 **Network**  
Vascular Diseases  
(VASCERN)

## 8.30-12.15: PLENARY SESSION

**8.30-9.00: Welcome by Prof. Guillaume Jondeau and brief introduction by all participants (30')**

9.00-9.45: **VASCERN Structure & Organisation: state of play 1 (45')**

Presentation of VASCERN & Functioning since March (20') (Guillaume Jondeau, Marine Hurard)

Feedback, Q&A and discussion (25')

9.45-10.05: **VASCERN Patient Group (ePAG) (20')** including Q&A

ePAG involvement within VASCERN, co-presentation by the Patient Group Chair & EURORDIS (Paolo Federici, Matt Bolz-Johnson)

Q&A

*10.05: coffee break*

*Photo booth*

10.20-11:20: **VASCERN 1<sup>st</sup> year Action Plan: State of play 2 (60')**

Objectives & state of play of Work packages (Marine Hurard) & Feedback from the Council (Guillaume Jondeau and WGs Chairs: Julie de Backer, Claire Shovlin, Leema Robert, Miikka Vikkula, Sahar Mansour, Alessandro Pini, Leo Schultze Kool, Paolo Federici) (40')

Q&A and discussion (20')

11.20-12.15: **Achievements, Challenges & Opportunities for ERNs (55')**

The ERN Policy (Anna Carta, ERN Team, DG SANTE, European Commission) (10')

The ERN Collaborative platform and the Clinical Patient Management System (Jean-Marie Misztela)(10')

ERN Board of Member States views (Muriel Eliazewicz, French representative at the ERN Board of Member States) (10')

European Joint Programme on Rare Diseases Research: opportunities for ERNs (Daria Julkowska) (10')

Q&A (15')



# European Reference Network

for rare or low prevalence complex diseases

**Network**  
Vascular Diseases  
(VASCERN)

## March 2017: ERNs Launch in Vilnius



ERN BOND	European Reference Network on bone disorders ( <a href="#">Factsheet</a> - Website)
ERN CRANIO	European Reference Network on craniofacial anomalies and ear, nose and throat (ENT) disorders ( <a href="#">Factsheet</a> - Website)
Endo-ERN	European Reference Network on endocrine conditions ( <a href="#">Factsheet</a> - Website)
ERN EpiCARE	European Reference Network on epilepsies ( <a href="#">Factsheet</a> - Website)
ERKNet	European Reference Network on kidney diseases ( <a href="#">Factsheet</a> - Website)
ERN-RND	European Reference Network on neurological diseases ( <a href="#">Factsheet</a> - Website)
ERNICA	European Reference Network on inherited and congenital anomalies ( <a href="#">Factsheet</a> - Website)
ERN LUNG	European Reference Network on respiratory diseases ( <a href="#">Factsheet</a> - Website)
ERN Skin	European Reference Network on skin disorders ( <a href="#">Factsheet</a> - Website)
ERN EURACAN	European Reference Network on adult cancers (solid tumours) ( <a href="#">Factsheet</a> - Website)
ERN EuroBloodNet	European Reference Network on haematological diseases ( <a href="#">Factsheet</a> - Website)
ERN eUROGEN	European Reference Network on urogenital diseases and conditions ( <a href="#">Factsheet</a> - Website)
ERN EURO-NMD	European Reference Network on neuromuscular diseases ( <a href="#">Factsheet</a> - Website)
ERN EYE	European Reference Network on eye diseases ( <a href="#">Factsheet</a> - Website)
ERN GENTURIS	European Reference Network on genetic tumour risk syndromes ( <a href="#">Factsheet</a> - Website)
ERN GUARD-HEART	European Reference Network on diseases of the heart ( <a href="#">Factsheet</a> - Website)
ERN ITHACA	European Reference Network on congenital malformations and rare intellectual disability ( <a href="#">Factsheet</a> - Website)
MetabERN	European Reference Network on hereditary metabolic disorders ( <a href="#">Factsheet</a> - Website)
ERN PaedCan	European Reference Network on paediatric cancer (haemato-oncology) ( <a href="#">Factsheet</a> - Website)
ERN RARE-LIVER	European Reference Network on hepatological diseases ( <a href="#">Factsheet</a> - Website)
ERN ReCONNET	European Reference Network on connective tissue and musculoskeletal diseases ( <a href="#">Factsheet</a> - Website)
ERN RITA	European Reference Network on immunodeficiency, autoinflammatory and autoimmune diseases ( <a href="#">Factsheet</a> - Website)
ERN TRANSPLANT-CHILD	European Reference Network on Transplantation in Children ( <a href="#">Factsheet</a> - Website)
VASCERN	European Reference Network on Rare Multisystemic Vascular Diseases ( <a href="#">Factsheet</a> - Website)



European  
Reference  
Network

for rare or low prevalence  
complex diseases

Network  
Vascular Diseases  
(VASCERN)

## What are the aims of an ERN?

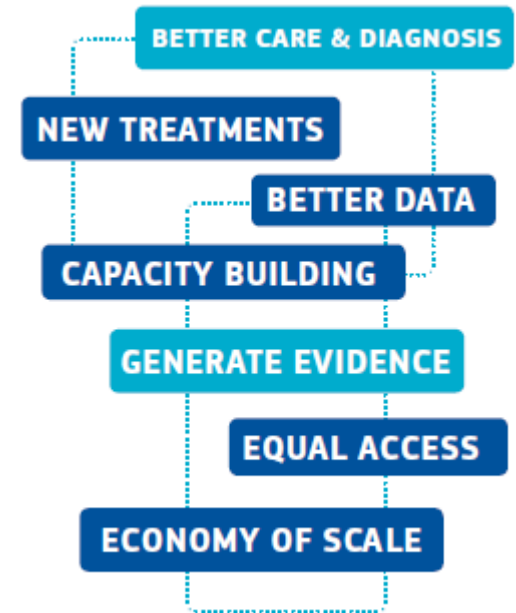
- Priority: **care** of the patient
- Research: registry, clinical trials
- Knowledge generation: guidelines, training

## Our 3 main objectives

- To help to realise the **potential of European cooperation** regarding **highly specialised healthcare** for patients and for healthcare systems by exploiting **innovations** in medical science and health technologies
- To reinforce **research**, epidemiological surveillance like **registries** and provide **training** for health professionals
- To encourage the **development of quality and safety benchmarks** and to help develop and spread **best practice** within and outside the network

All info on:

[www.vascern.eu](http://www.vascern.eu)




## What is VASCERN?

- **Vessels:** different diseases, different specialities
- **Multidisciplinary**



European  
Reference  
Network

for rare or low prevalence  
complex diseases

 Network  
Vascular Diseases  
(VASCERN)

## 8.30-12.15: PLENARY SESSION

### Introduction of Attendees

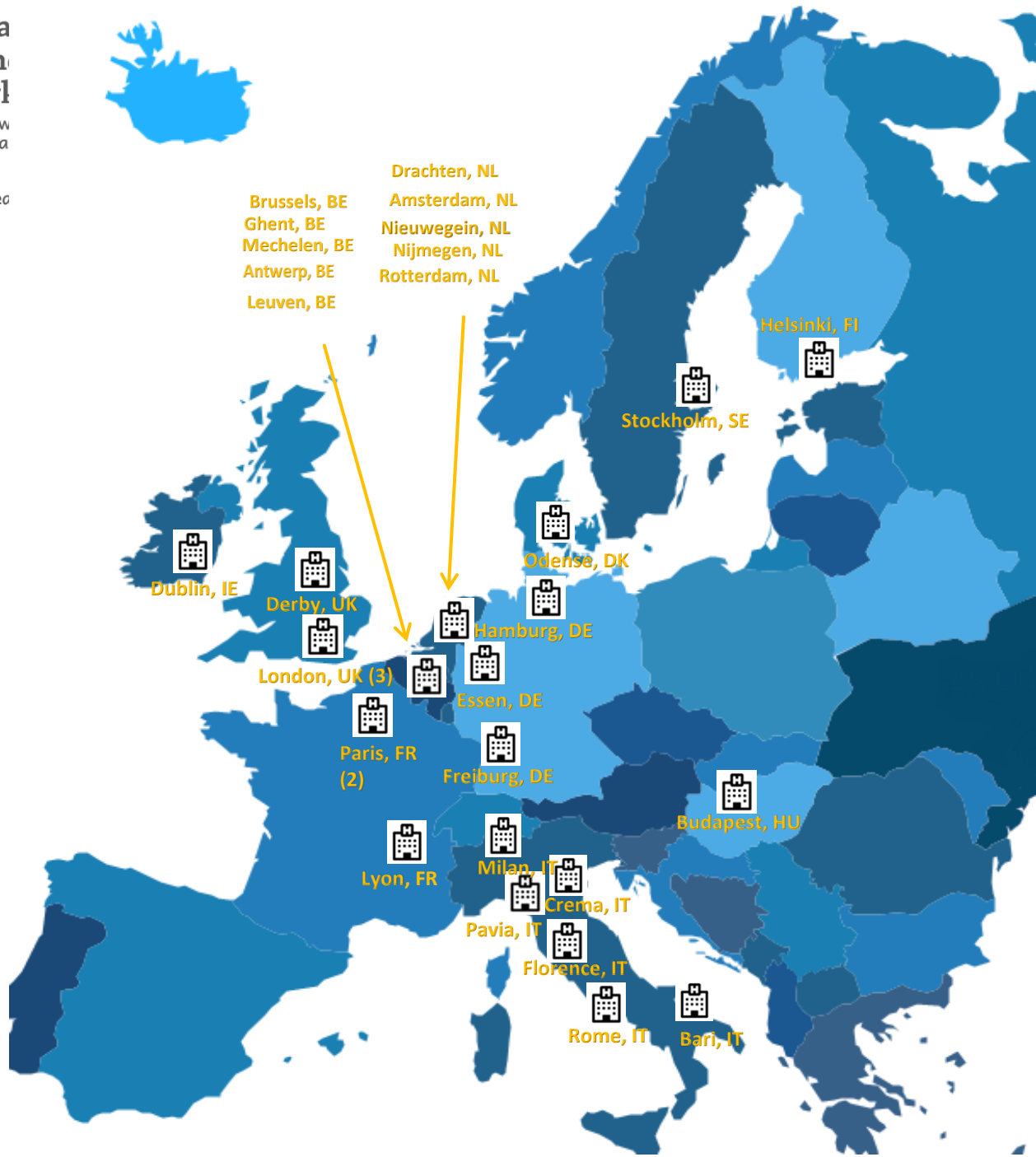
- 31 HCPs Members' Representatives
- 12 ePAG Patient Organisations' Representatives
- VASCERN Coordination team
- Other stakeholders



# Europea Referen Network

for rare or low complex disea

**Network**  
Vascular Disea  
(VASCERN)

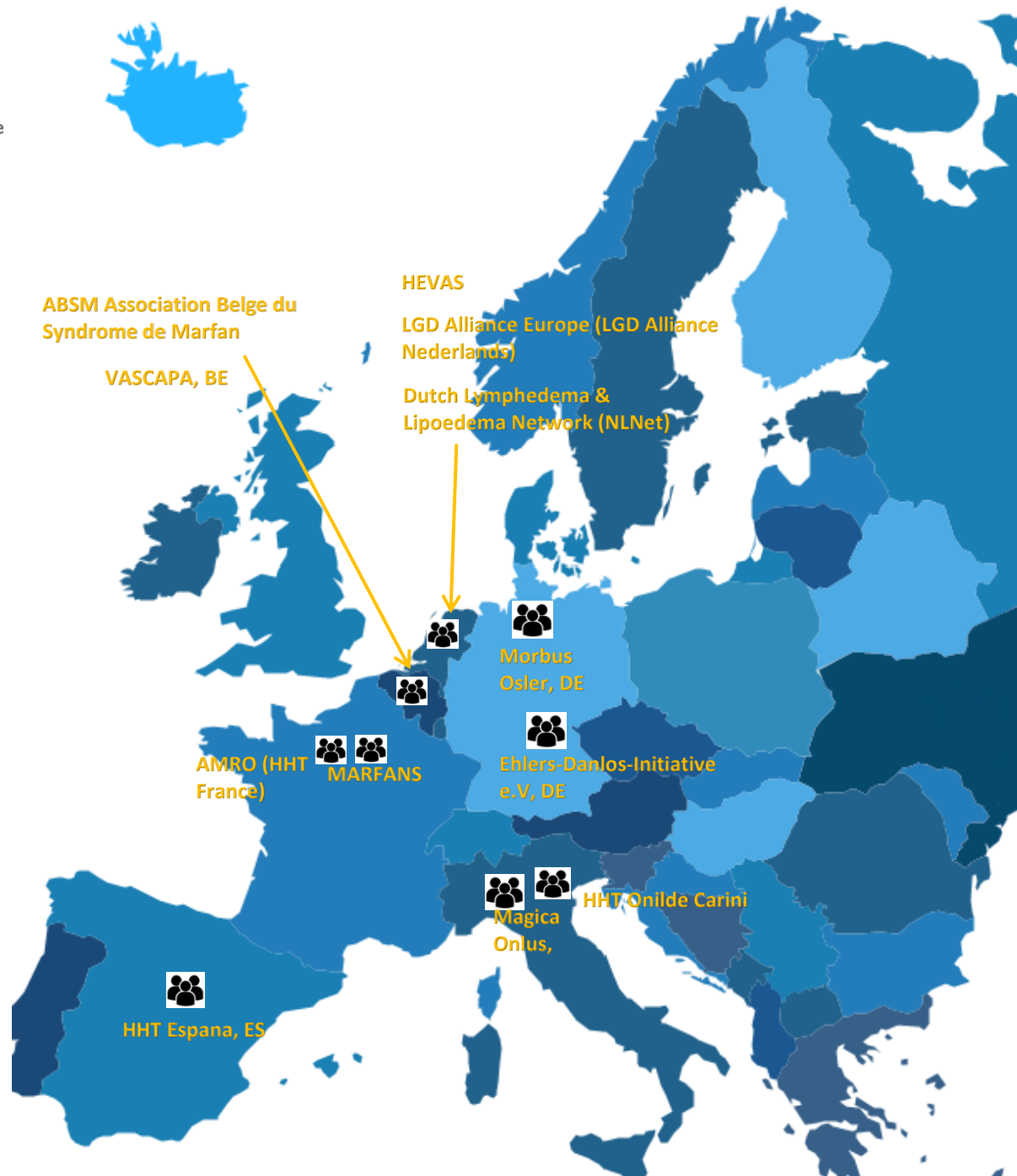




# European Reference Network

for rare or low prevalence complex diseases

**Network**  
Vascular Diseases  
(VASCERN)



ABSM Association Belge du Syndrome de Marfan

VASCAPA, BE

HEVAS

LGD Alliance Europe (LGD Alliance Netherlands)

Dutch Lymphedema & Lipoedema Network (NLNet)



Morbus Osler, DE



Ehlers-Danlos-Initiative e.V., DE



AMRO (HHT France)



MAFANS



Magica Onlus,



HHT, Onilde Carini



HHT Espana, ES



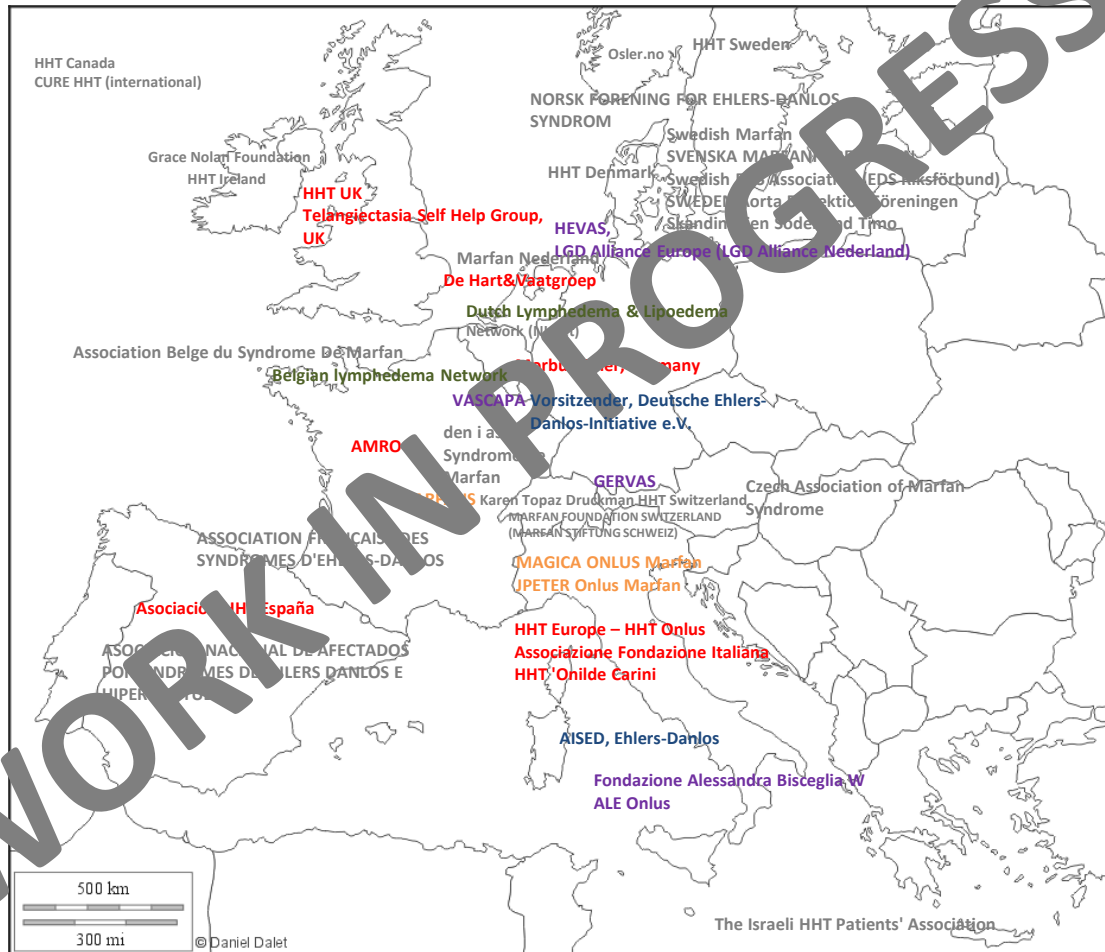


# OTHER PATIENT ASSOCIATIONS INVOLVED



Patient Group

**HHT**  
**HTAD**  
**MSA**  
**PPL**  
**VASCA**



- ePAG Chair
- Co-chairs
- Representatives
- Members





**European  
Reference  
Network**

for rare or low prevalence  
complex diseases

**Network**  
Vascular Diseases  
(VASCERN)

# VASCERN

## Coordination Team, based in Paris



**European  
Reference  
Network**  
for rare or low prevalence  
complex diseases

- Network**  
Vascular Diseases  
(VASCERN)
- Coordinator**  
Assistance Publique-  
Hôpitaux de Paris, Hôpital  
Bichat – France



**Prof Guillaume Jondeau**  
VASCERN Coordinator  
Tel: +33 1 40 25 74 60  
Email: [guillaume.jondeau@aphp.fr](mailto:guillaume.jondeau@aphp.fr)

**2 new Coordination team members  
since September 2017!**



**Marine HURARD**  
VASCERN Project Manager  
Tel: [+33 \(0\)1 40 25 80 66](tel:+330140258066)  
Email: [marine.hurard@aphp.fr](mailto:marine.hurard@aphp.fr)



**Natasha BARR**  
VASCERN Project Officer  
Tel: [+33 \(0\)1 40 25 70 76](tel:+330140257076)  
Email: [natasha.barr@aphp.fr](mailto:natasha.barr@aphp.fr)



**Hélène DEPARIS**  
VASCERN Administrative Assistant  
Tel: [+33 \(0\)1 40 25 70 77](tel:+330140257077)  
Email: [helene.deparis@aphp.fr](mailto:helene.deparis@aphp.fr)

[www.VASCERN.eu](http://www.VASCERN.eu)

 Follow us [@vascern](https://twitter.com/vascern)

<http://vascern.eu/contact/>



European  
Reference  
Network

for rare or low prevalence  
complex diseases

 Network

Vascular Diseases  
(VASCERN)

# Stakeholders

- **Speakers' organisations:**

- European Commission
- EURORDIS
- DGOS, French Ministry of Health, Representative in the Board of Member States
- European Joint Programme on Rare Diseases
- RD-Action
- FAIR (Leiden University Medical Centre )

- **Other stakeholders:**

- HCP Coordinating - Director representative
- APHP Europe Department
- French Filière FAVA Multi
- ORPHANET
- RaDiCO