



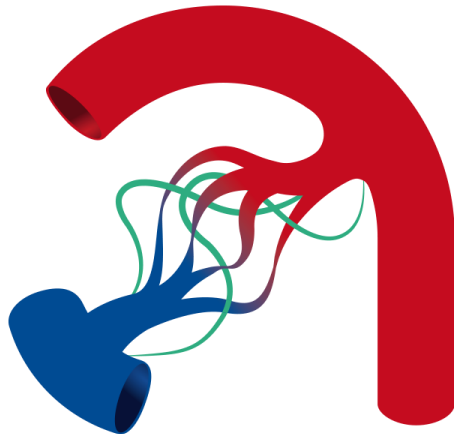
**European  
Reference  
Network**

for rare or low prevalence  
complex diseases



**Network**

Vascular Diseases  
(VASCERN)



# VASCERN DAYS 2018 PLENARY SESSION

10:15-10:35: **European Patient  
Advocacy Group developments**  
Juergen Grunert, ePAG Chair


<https://vascern.eu/expertise/epag/>

# VASCERN ePAG Group



European  
Reference  
Network

for rare or low prevalence  
complex diseases

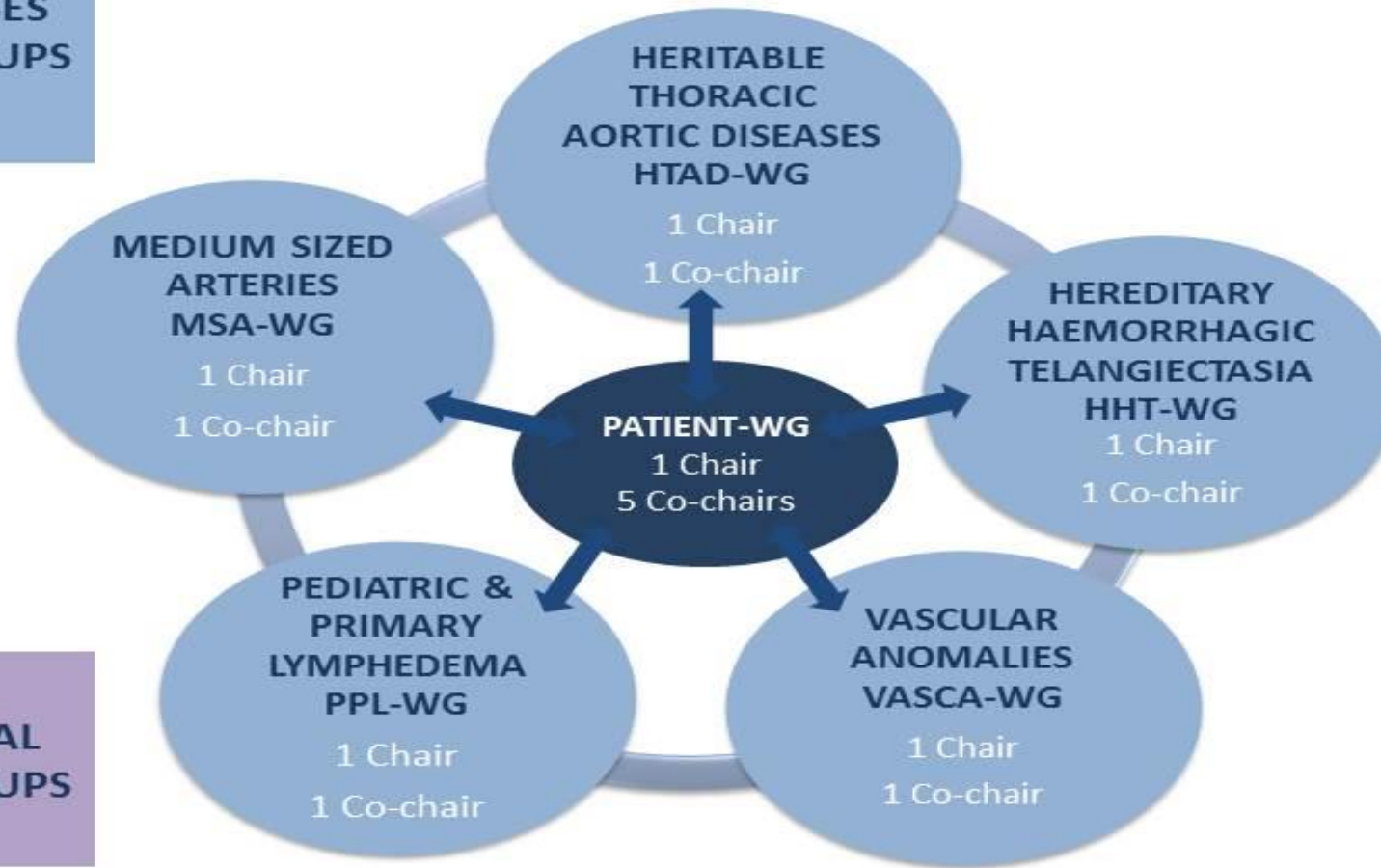
 **Network**  
Vascular Diseases  
(VASCERN)

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

**Share. Care. Cure.**



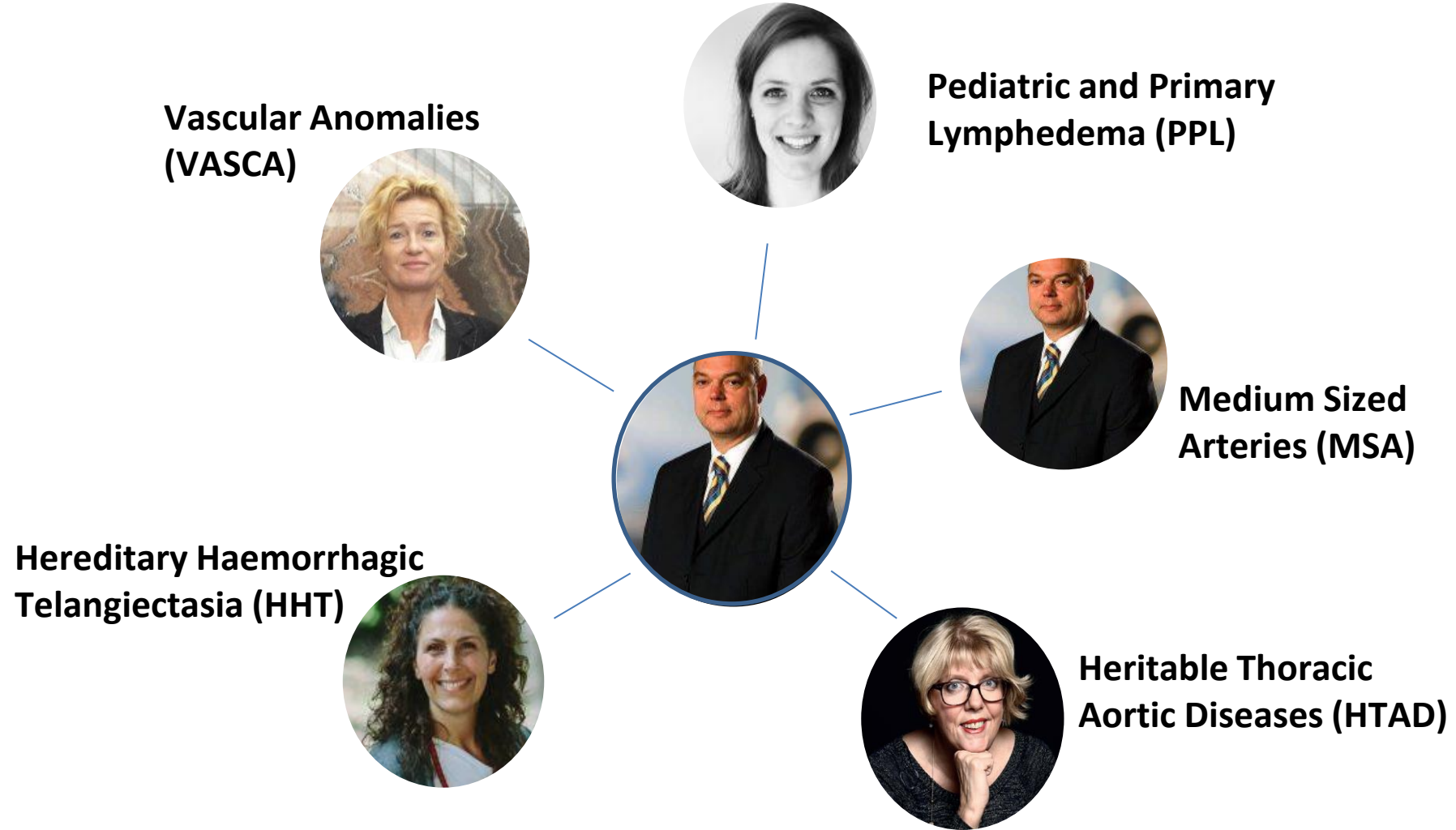
**5 RARE DISEASES  
WORKING GROUPS  
(RDWG)**



**5 TRANSVERSAL  
WORKING GROUPS**



# VASCERN European Patient Advocacy Group



# VASCERN Patient Group (ePAG) Chair & Co-Chairs

ePAG representative	Patient organization	Member State	Rare Disease Area
Lise Murphy (Co-Chair)	Marfanforeningen	Sweden	HTAD
Claudia CROCIONE (Co-Chair)	HHT Europe	Italy	HHT
Juergen GRUNERT (Chair)	Ehlers-Danlos-Initiative	Germany	MSA
Caroline Van Den BOSCH (Co-Chair)	HEVAS	The Netherlands	VASCA
Natascha ASSIES (Co-Chair)	NLNet	The Netherlands	PPL

**Our Achievements  
in the first 18 Months at  
VASCERN**

# External Activities – supporting the ERNs:

- Advocacy Work for the ERN / on National and European Level, for example integration into NHS
- Our presence in Eurordis WGs such as training, ethics, guidelines and in ePAG Steering Committee, which are influential roles for a developing reality

# General ERN Work:

- General Advocacy
- Building a larger network under the new concept of the ERN within the patient community for the various diseases covered in VASCERN



# EURORDIS

## Rare Diseases Europe

### providing framework and direction

- Evaluating new POs
- Constitution and Terms of Reference (VASCERN now updating ToR)
- More than 1000 Patient Organisations and 300 ePAG advocates in all 24 ERNs
- 2 x training so far, one more in 2018
- Steering Committee, to mirror the BoMS and Coordination Group

# Activity in VASCERN:

- Building a larger network under the new concept of the ERN within the patient community for the various diseases covered in VASCERN
- Developing the VASCERN APP and in Beta Testing
- Development of patient pathways
- Development of do's and don'ts together with the clinicians
- Participation in the making of PoKs
- Participation in the transversal WGs
- Regular online meetings of the Co-Chairs and the ePAG Group
- Adapting the Terms of Reference for the VASCERN ePAG Group

- The ePAG group in VASCERN is generally considered as well developed and used as reference by EURORDIS
- We are a very strong team and in one year the relations - cooperation and friendship have reached high levels
- VASCERN ePAGs have already established Terms of Reference and are working in a structured environment.

## Future:

Integration of  
ERN's

## Ambition:

Sustainability

## Challenges:

We are all  
volunteers  
>20h per Month