



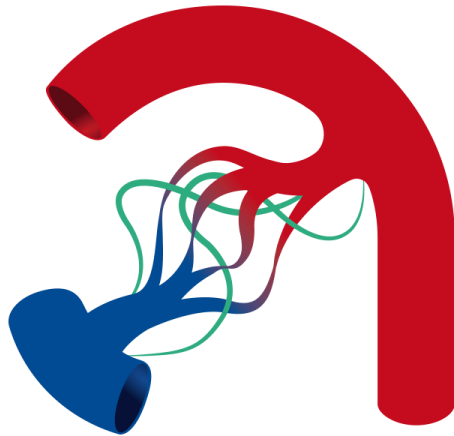
**European  
Reference  
Network**

for rare or low prevalence  
complex diseases



**Network**

Vascular Diseases  
(VASCERN)



# ePAG feedback & new developments, including Q&A

*Juergen Grunert*

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

# VASCERN ePAG Group



European  
Reference  
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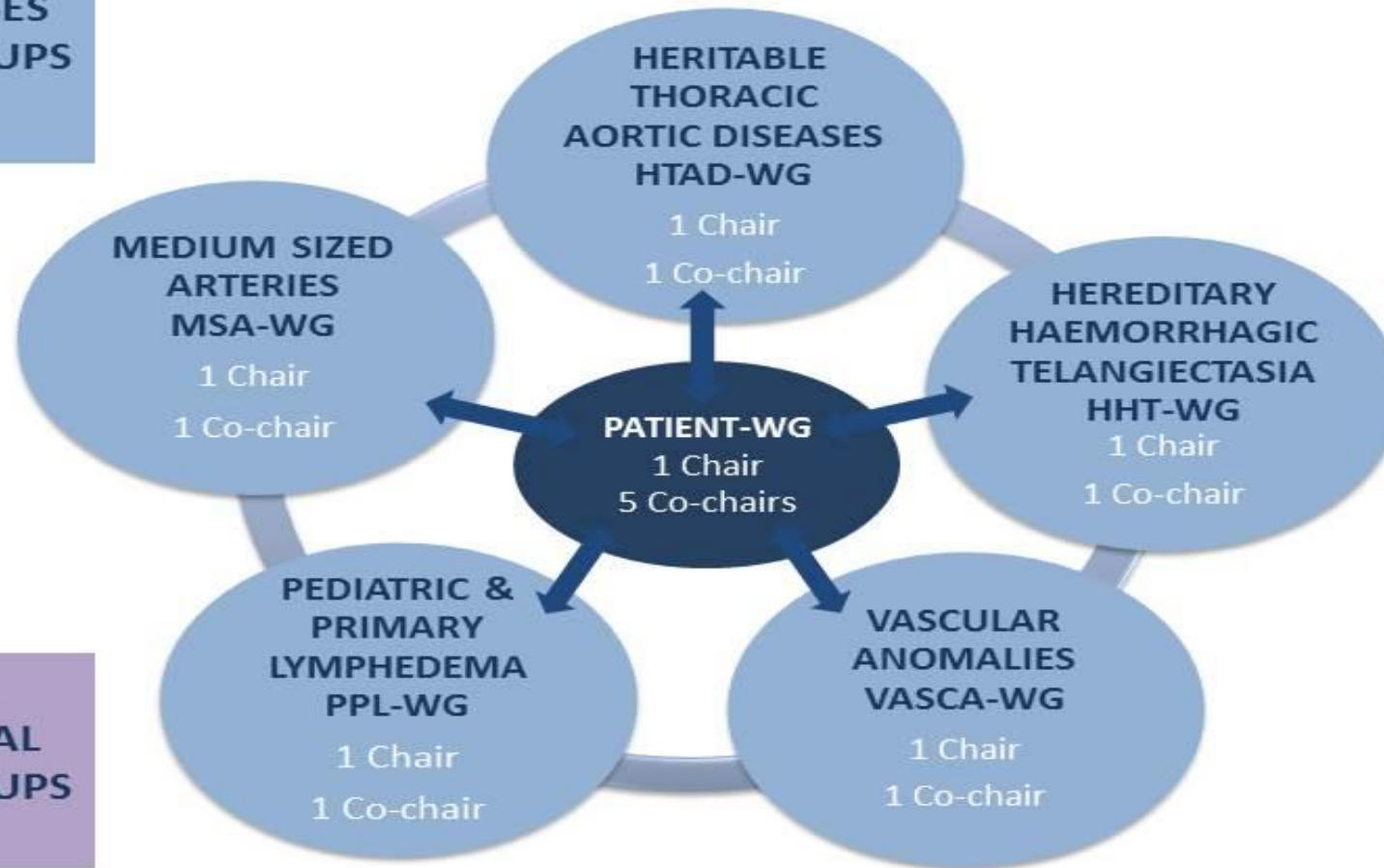
 **Network**  
Vascular Diseases  
(VASCERN)

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

**Vascular Anomalies  
(VASCA)**



**Pediatric and Primary  
Lymphedema (PPL)**



**Medium Sized  
Arteries (MSA)**



**Hereditary Haemorrhagic  
Telangiectasia (HHT)**



**Heritable Thoracic  
Aortic Diseases (HTAD)**



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

| ePAG representative                  | Patient organization     | Member State    | Rare Disease Area |
|--------------------------------------|--------------------------|-----------------|-------------------|
| Lise Murphy<br>(Co-Chair)            | Marfanforeningen         | Sweden          | HTAD              |
| Claudia CROCIONE<br>(Co-Chair)       | HHT Europe               | Italy           | HHT               |
| Juergen GRUNERT<br>(Chair)           | Ehlers-Danlos-Initiative | Germany         | MSA               |
| Caroline Van Den BOSCH<br>(Co-Chair) | HEVAS                    | The Netherlands | VASCA             |
| Pernille Henriksen<br>(Co-Chair)     | DALYFO                   | Denmark         | PPL               |

# *Terms & Definitions*

## **European Patient Advocacy Group (ePAG):**

A patient group, specific to each ERN,

composed by patient advocates

established by EURORDIS

to optimise patient involvement

in the ERNs' decisions and activities.

Some ERNs have formally recognised these

groups as part of their governance structure.

## **ePAG Patient Advocates:**

ePAG Advocates represent the interests of the wider patient community to ensure that the needs of people living with a rare disease are included in the strategic and operational delivery of the Networks.



# ePAG involvement in VASCERN:

- Building a larger network within the patient community for the various diseases covered in VASCERN
- Integration into the National Healthcare Systems, connecting and networking between research, expert centers and patient organisations on a national level
- Development of patient pathways
- Development of Do's and Don'ts together
- Participation in the making of PoKs
- Participation in the transversal WGs
- Regular online meetings of the RDWG, the Co-Chairs and the ePAG Group
- Translating the VASCERN APP; feeding with datasets

- The ePAG group in VASCERN is generally considered as well developed and sometimes used as reference by EURORDIS
- We are a very strong team and in more than two years the relations - /cooperation and friendship have reached high levels
- VASCERN ePAGs have already established Terms of Reference and are working in a structured environment.
- The CoChairs are participating in the „New Leadership Training“ by Eurordis

# Our Role

- Per definition it is „bringing the patient perspective to the table“

but

- We see different approaches in the different working groups regarding the acknowledgement of expert patients
- Our main goal is to raise awareness for the impact of living with a rare disease in daily life and to improve diagnosis, treatment and quality of live for patients with a rare disorder

# Achievements

- Being a valued and recognised part of the ERN structure, the different working groups and participating in nearly every WP

## Deliverables

- Best practice – learning from each other
- Having a structured and common approach

# Achievements

- Raising Awareness
  - For the ERN at all
  - For the Rare Disease
  - In the country
  - Amongst the HCPs
  - For the patient community

# Achievements

## How to?

- Presenting on conferences
- Presenting with national umbrella organisations
- Using social media
- Networking, networking, networking 😊

# Achievements

- The password is playing an active role in setting up national networks
- i.e. the Netherlands

# Our expectations

- We have to deliver something at the end
- For that we need knowledge
- Outcome measures for the ePAG work , for the patient advocates
- Deliverables from a patient perspective
- To Take back into the PO and disseminate
- Dos and donts
- Patient pathways for patients
- Fact sheets
- PoK's
- More collaboration between HCPs on grants and not competition



## Future:

Integration of  
ERN's into NHS  
&  
Expanding the  
network and the  
collaboration

## Ambition:

Sustainability

## Challenges:

We are all  
volunteer  
patients  
>20h per Month