

Patient involvement on vascular anomalies in the European Reference Network VASCERN

AUTHORS

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AFFILIATIONS

- 1) HEVAS, Patient Organisation for Vascular Anomalies, the Netherlands
- 2) EURORDIS, Rare diseases Europe, France
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- 9) Dept. of Pediatric Surgery, Karolinska University Hospital, Stockholm, Sweden
- 10) Paediatric Dermatology, Our Lady's Children's Hospital Crumlin; National Children's Research Centre; Clinical Medicine, Trinity College Dublin
- 11) Helsinki University Hospital, Helsinki, Finland
- 12) VASCAPA, Vascular Anomaly Patient Association, Belgium
- 13) LGD Alliance Europe (Lymphangiomas and Gorham's Disease), the Netherlands
- 14) The Federal Association of Congenital Vascular Malformations (FACVM), Germany

PURPOSE OF ERNS

European Reference Networks (ERNs) for Rare Diseases were established March 2017, based on:

- patient empowerment
- participation
- patient-centricity

GOALS

To improve:

- access
- safety
- quality of diagnosis
- care
- treatment

for people living with a rare or complex condition.

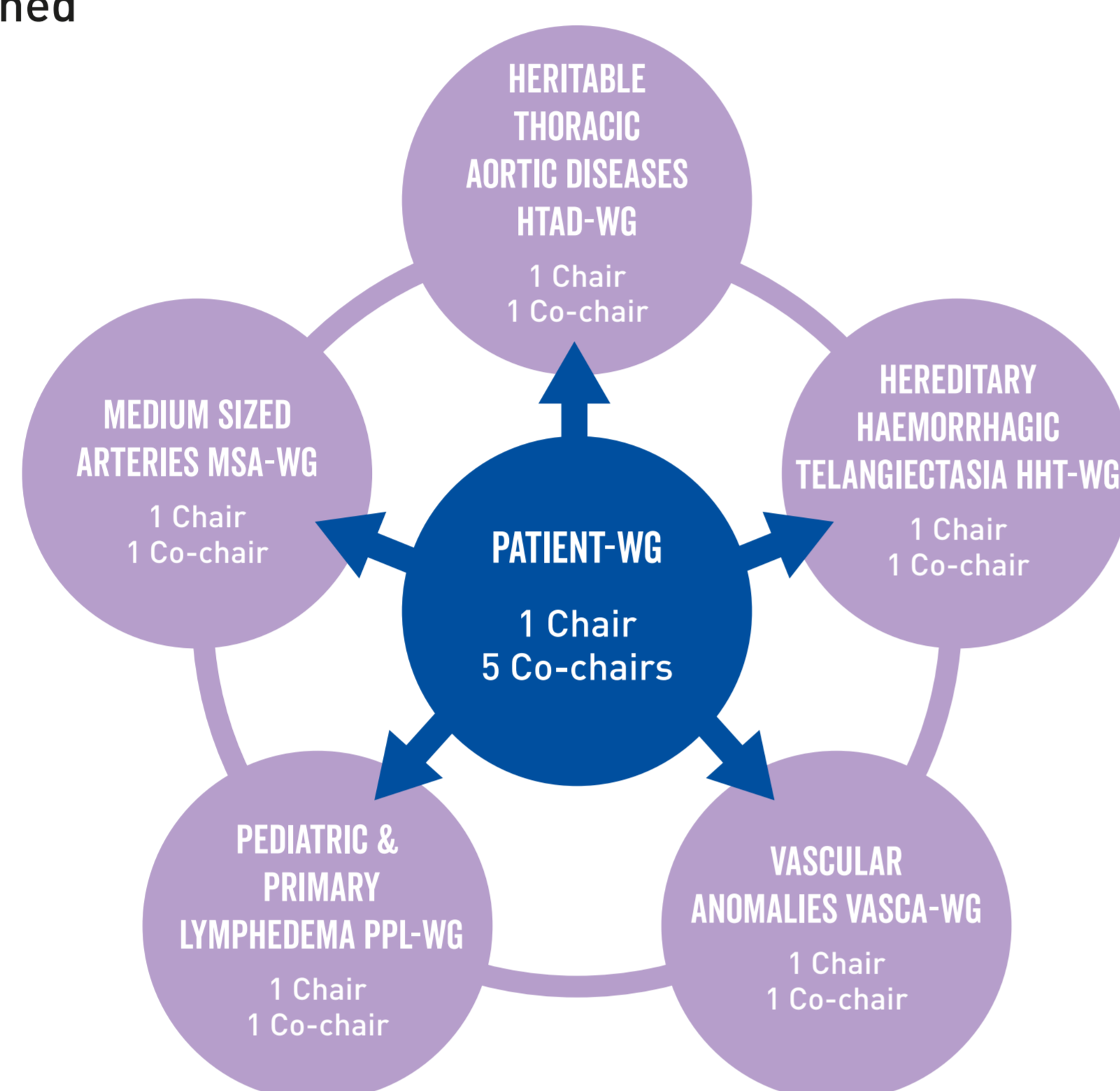
MANDATE

Patient representatives and organisations (POs) are recognized by the European Commission as integral to the strategic and operational delivery of ERNs, and play an active role in network decisions and opinion-making structures.

METHODS

EURORDIS established 24 European Patient Advocacy Groups (ePAGs), one for each ERN. The Multisystemic Vascular Diseases ERN (VASCERN) has 5 disease-oriented working groups

5 RARE DISEASES WORKING GROUPS (RDWG)



European Reference Network

for rare or low prevalence complex diseases

Network
Vascular Diseases
(VASCERN)

www.vascern.eu

VASCERN PATIENT WORKGROUP

PEDIATRIC AND PRIMARY LYMPHEDEMA (PPL)

Natascha Assies



VASCULAR ANOMALIES (VASCA)

Caroline van den Bosch



ePAG CHAIR

Paolo Federici



MEDIUM SIZED ARTERIES (MSA)

Jürgen Grunert



HEREDITARY HAEMORRHAGIC TELANGIECTASIA (HHT)

Claudia Crocione



HERITABLE THORACIC AORTIC DISEASES (HTAD)

Lise Murphy

- Meetings virtually: 5 Patient co chairs + other ePAG representatives and members each month
- Meetings face-to-face: the VASCERN meets once a year including ePAG

GOALS FOR THE VASCULAR ANOMALIES (VASCA) PATIENT GROUP:

- improve treatment options and clinical research (biobanks, registries, classification) for patients with vascular anomalies
- promote cooperation between Healthcare Providers (HCPs)
- find more Patient Organisations (POs) on vascular anomalies

RESULTS

4 POs are involved in VASCA Work Group:

- HEVAS
- LGD
- VASCAPA
- FACVM

21 more POs were found and contacted to create a larger European community.

- A Mobile App was created with info of HCPs and POs to assist patients in finding help (abroad)
- Involvement of POs in development of Patient Pathways
- Pills of Knowledge: sharing video's on vascular anomalies via YouTube in various languages
- Involvement of POs in development of Guidelines



VASCA team

CONCLUSIONS

- The VASCA Patient Group focuses on operationalising patient involvement in the network groups and activities
- cooperation on communication between POs and HCPs is crucial
- POs will meet and participate at the world conference ISSVA 2018

AN UNIQUE STEP FORWARD FOR STRENGTHENED COOPERATION!



www.hevas.eu



LGD Alliance Europe

Lymphangiomas & Gorham's Disease



Bundesverband Angeborene Gefäßfehlbildungen e.V.