




European
Reference
Network

for rare or low prevalence
complex diseases

 **Network**
Vascular Diseases
(VASCERN)

Patient involvement on vascular anomalies in the European Reference Network VASCERN

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VASCERN

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

www.VASCERN.eu

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Mandate

- EURORDIS has been the consistent partner, nurturing from the start in 2004 to the launch in 2014 of the 24 ERNs: therefore the concept it is patient centered
- Their recommendation to the European Commission was to recognize patient representatives (ePAGs) and organisations (POs) as stakeholder in the ERN structure



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Methods

- EURORDIS established 24 European Patient Advocacy Groups (ePAGs), one for each ERN
- Webex meetings:
 - Monthly with Health Care Providers and patient representative
 - Monthly with the patient representatives of all 5 Workgroups
 - Bi-monthly with the patient representatives of VASCA
- Meetings face-to-face: the VASCERN meets once a year including patient representatives



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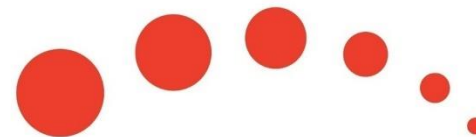
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VASCA patient group



Bundesverband Angeborene
Gefäßfehlbildungen e.V.



HEVAS


Patient Association Vascular Anomalies

More Patient Organisations were found and contacted to create a larger European Community



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Results

- A Mobile App was created with info of HCPs and POs to assist patients in finding help (abroad)
- Pills of Knowledge: sharing existing brochures and video's of Patient organisations in various languages
- Involvement of POs in development of Patient Pathways and Guidelines, and so bringing the patient perspective forward
- More Patient Organisations were found and contacted to create a larger European Community
- International collaboration between these Patient Organisations



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Conclusion

- The VASCA Patient Group focuses on patient involvement in the network groups and activities
- With this ERN structure of shared knowledge we expect more research for our rare diseases, goal of all POs
- Cooperation and communication between POs and HCPs is crucial
- We encourage Centers of Expertise to register their interest in joining the VASC ERN



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An unique step forward for strengthened cooperation



VASCA team, Paris 2017