



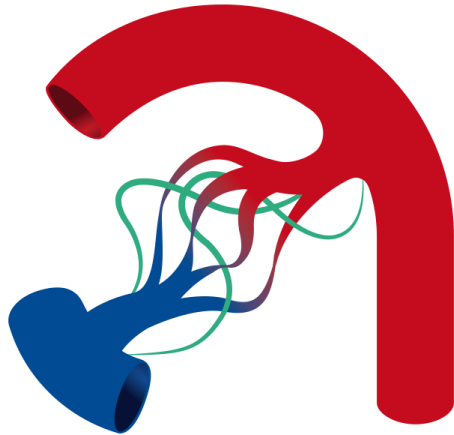
**European
Reference
Network**

for rare or low prevalence
complex diseases



Network

Vascular Diseases
(VASCERN)

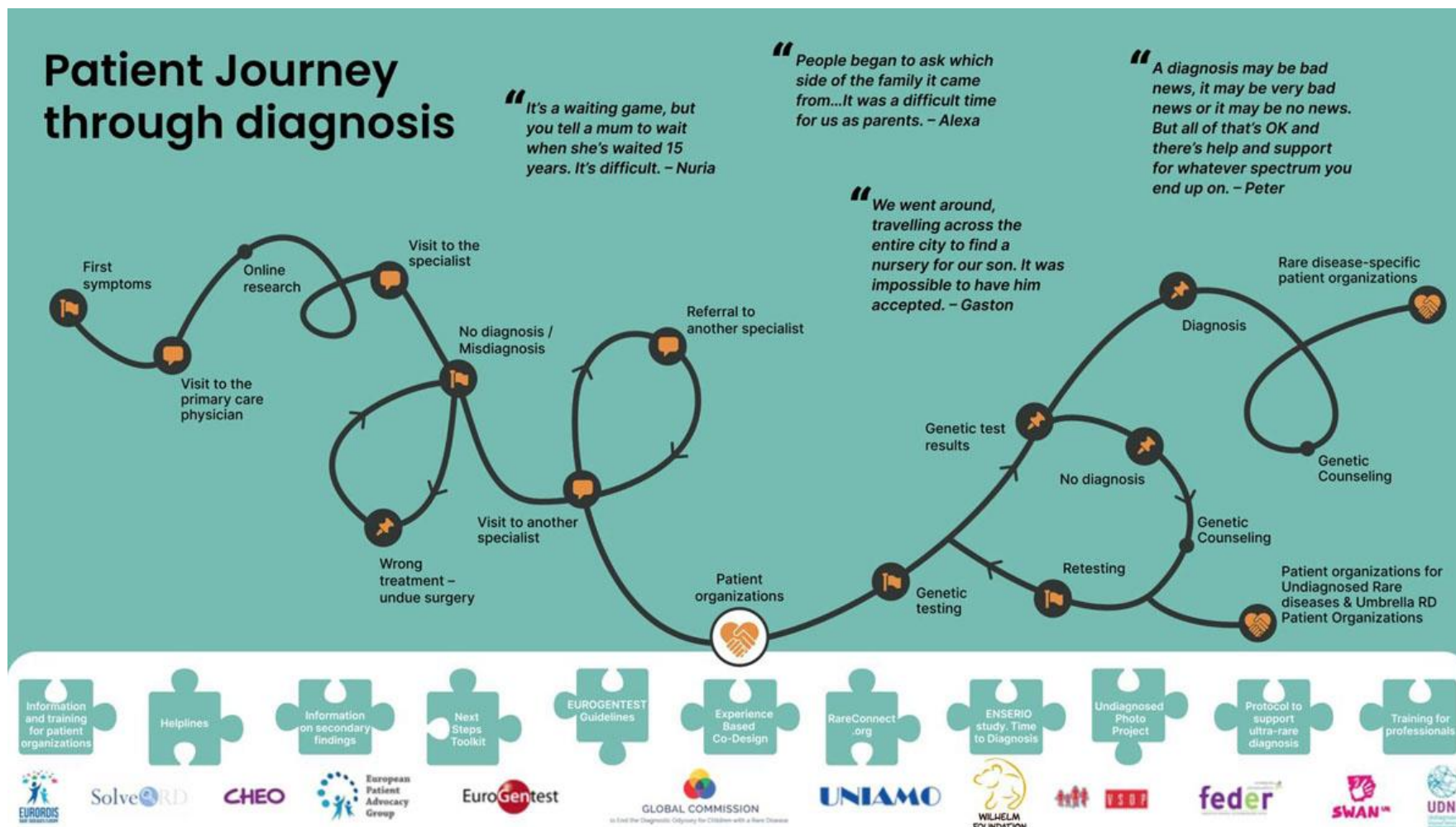


VAC 2025

Patient Role and Engagement in Vascular Anomalies

Biggest Challenges in Vascular Anomalies

- Generally rare diseases (<1/2000) or ultra rare (<1/50.000)
- Over 40 different types of vascular anomalies (VAs)
- Unique cases which can evolve over time
- Lack of specialised centres in Europe/centres for adults
- Difficult transition from pediatric to adult care
- Outside expert centres:
 - Average of five years to receive a correct diagnosis.
 - False diagnoses (often diagnosed as "hemangioma")
 - Wrong treatments for years



Beyond the Medical Aspects

- Physical
- Disfigurement
- Functional impairments
- Chronical pain
- Complications like bleeding or infections
- Drug side effects

Beyond the Medical

- Psychological challenges
- Exclusion, unwanted stares
- Bullying
- Frequent absences from school or work create additional difficulties
- Financial burdens for patients/caregivers
(giving up/reducing work, medicines)
- Mothers struggle with guilt, fearing of having done something wrong during pregnancy

The Role of Patient Organisations

- Share medical knowledge from a patient's perspective.
- Give a voice to the experiences, feelings and challenges of patients and caregivers.
- Collaborate closely with experts to improve research and treatment approaches.
- Build a strong and structured community across Europe and beyond.
- Advocate for better policies both the national and European levels.

The VASCA ePAG (European Patient Advocacy Group)



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