
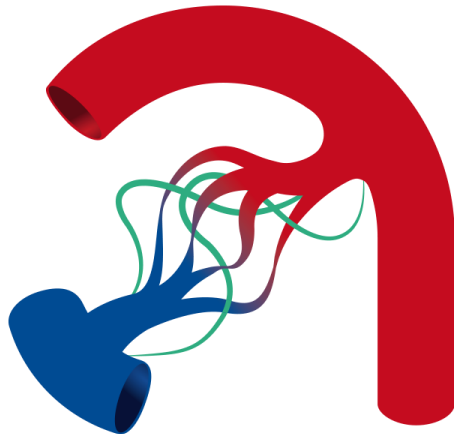




# European Reference Network

for rare or low prevalence  
complex diseases

 **Network**  
Vascular Diseases  
(VASCERN)



# VASCERN DAYS 2019

## VASCERN's enlargement & cooperation

- New Affiliated Partners 2019
- Call for new HCP Full Membership 2019
- interERN cooperation
- Brexit

# New Affiliated Partners 2019



- Designated by Member States

- **Associated National Centres** mainly healthcare providers
- **National Coordination Hub** major national HCP making links with several ERNs (small countries, e.g. Malta, Luxembourg)

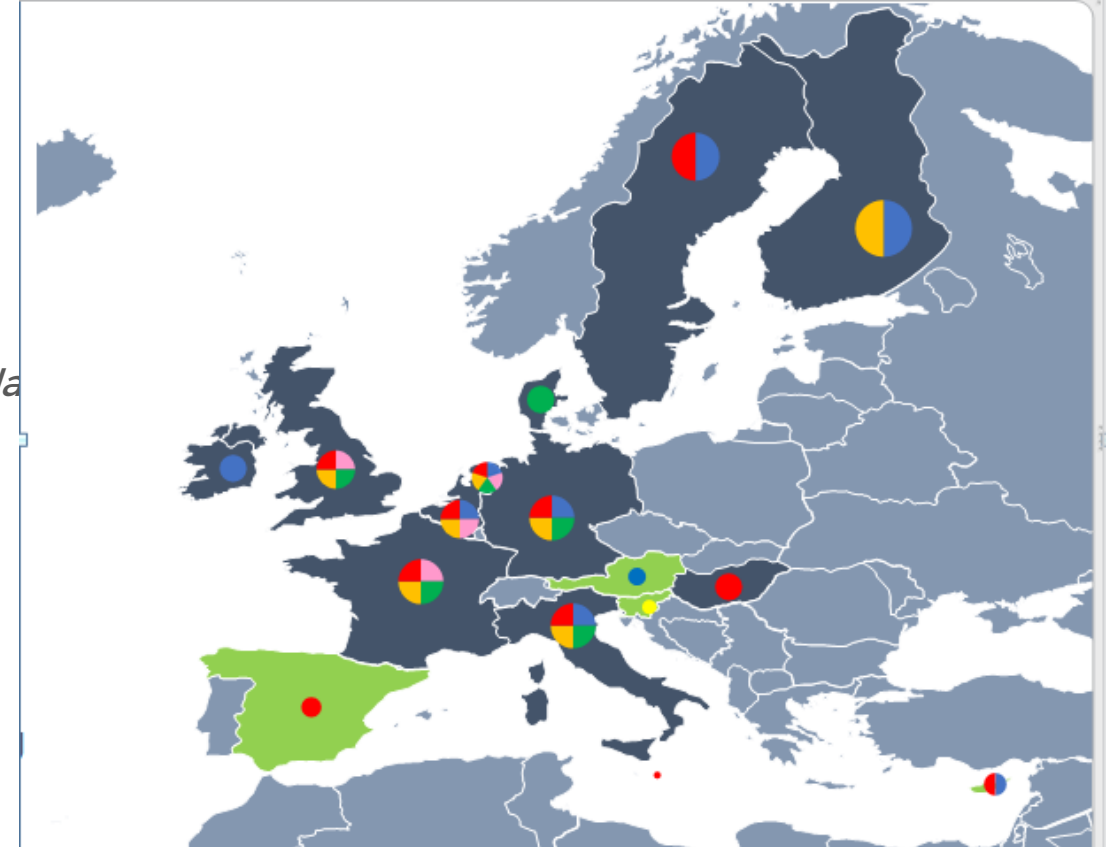
## Affiliated Partner:

- Participate to everything
    - Dataset in mobile app
    - Website
    - Monthly RDWG meetings & F2F
    - CPMS case discussions: referral of national patients, upload of cases for panel discussions
    - Registries
    - Discussion on pathways, guidelines, etc.
    - Translations
  - HCP finance participation to F2F meetings
  - No voting right in Board
  - Role to disseminate knowledge in their own country
- 
- **ERN:** integrate the Affiliated Partner to the RDWG and ERN, provide all information needed, monitor participation, provide support, ensure participation in Work Packages, add to website and mobile app

# New: Affiliated Partners 2019 (Associated National Centers and Coordination Hubs)



- **7 Associated National Centres**
  - 3 from **Austria**
    - Graz, in VASCA (Prof. Paolo Gasparella)
    - Vienna in VASCA (Dr. Katja Canigiani De Cerchi)
    - Innsbruck (HTAD, Dr. Julia Dumfarth, on hold)
  - 2 from **Spain**
    - 1 for HTAD (Prof. Arturo Evangelista, Dr. Gisela Teixido)
    - 1 on hold (VASCA, Dr Santiago Dario Rosati, neurovascula
  - 1 from **Slovenia**
    - for PPL (Dr. Tanja Planinšek Ručigaj)
  - 1 **Cyprus**
    - HTAD and MSA
- **2 National Coordination Hub**
  - **Malta**
    - HTAD (Dr. Maryanne Caruana, Prof. Kevin Kassar)
    - MSA (Prof Kevin Kassar)
  - **Luxembourg**
    - unknown RDWG





# 2019: New Call for HCP Full Membership

<https://vascern.eu/call-for-new-hcp-full-members-to-join-the-existing-24-erns-now-open/>

deadline: 30/11/2019

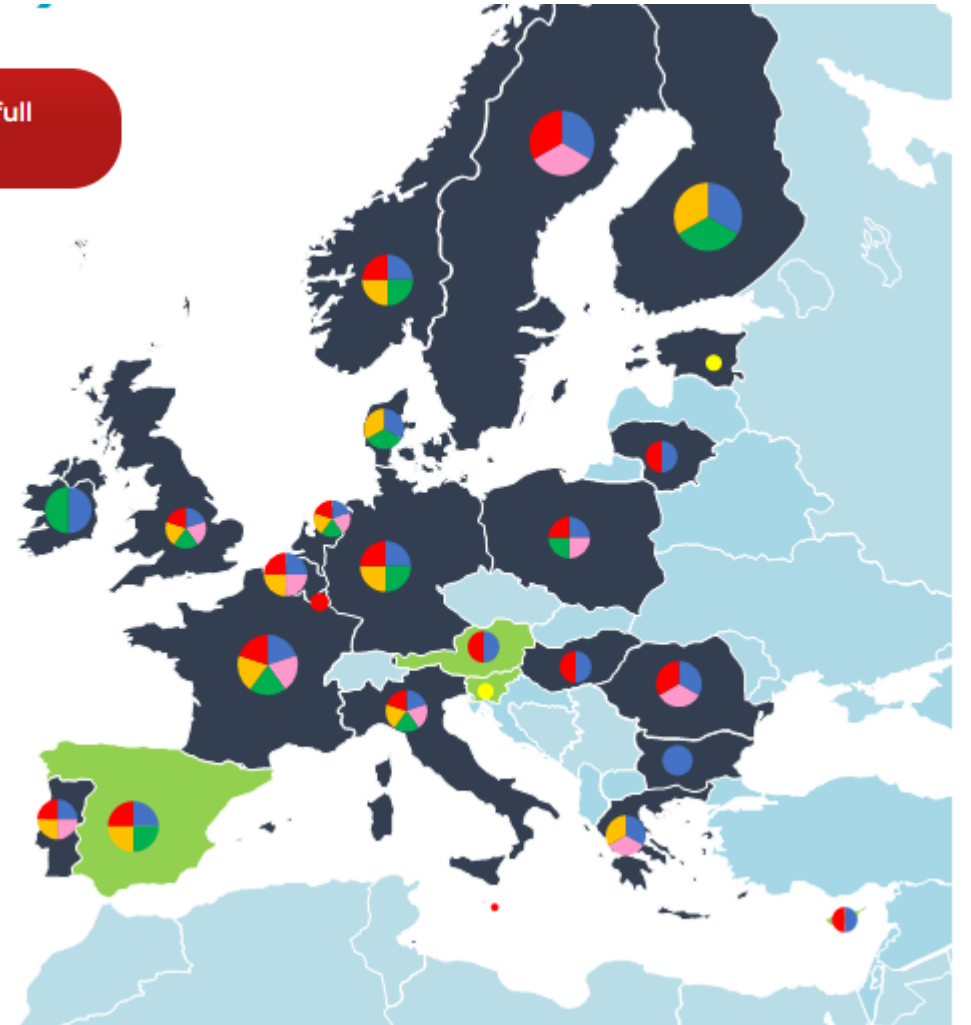
opinion of the ERN: spring 2020

Integration: end 2020/ Jan 2021



Call for new HCP full members

**HCP identified & contacted** in many New EU Member States to encourage and support applications to broaden our Geographical & diseases coverage  
(*Portugal, Norway, Lithuania, Poland, Romania, Luxembourg, Spain, Ireland, Estonia, Greece*)  
Also in countries not represented in specific RDWG (*e.g: Denmark,...*)



# 2019: New Call for HCP Full Membership Strategy

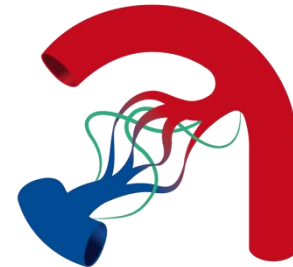


## Priority given to:

- Gaps in expertise (new rare diseases: FMD, SCAD, Moya-Moya, Cadasil)
  - New RDWG (cerebrovascular anomalies)
- New EU Member States to broaden geographical coverage:
  - Each country in each RDWG
- Number of expected centers x2, without increase of funding

## National networks :

Each HCP national relay , responsible for national network  
Specific logo available



# Brexit



- Postponed to January 2020
- European Commission: update on consequences for UK HCPs & post-Brexit situation ?



Will be further discussed at ERN CG 9th on November 14-15th

+ in the framework of interERN Registry Task Force

All ERNs:  
[https://ec.europa.eu/health/ern/networks\\_en](https://ec.europa.eu/health/ern/networks_en)

