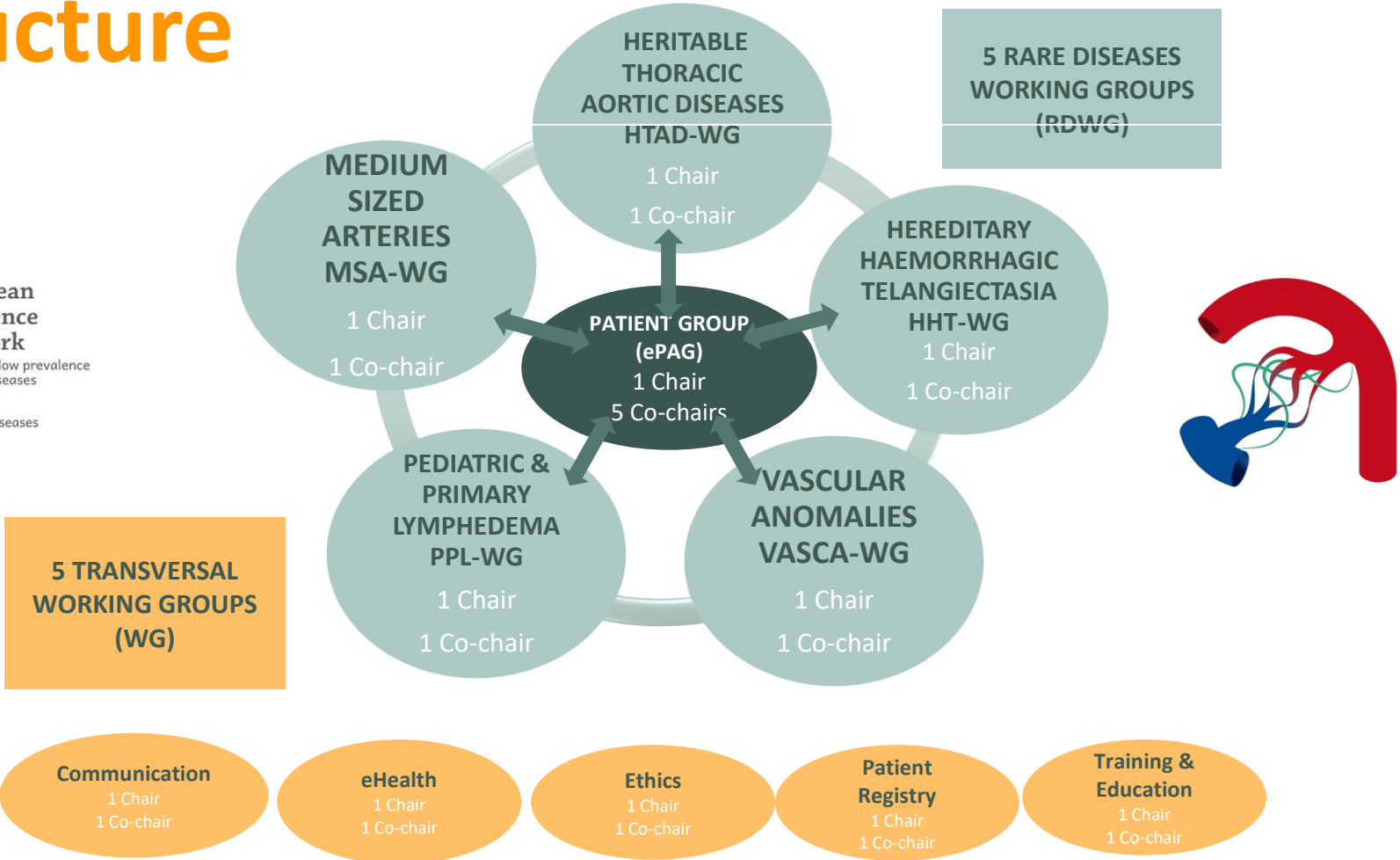


Perspectives Européennes: les ERNs

- ✓ Perspective Européenne :
- ✓ la bonne perspective : maladies rares
- ✓ European Reference network : apporter un soin de qualité, identique, à tous les patients porteurs de maladies rares en Europe

Structure

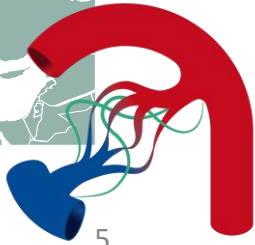
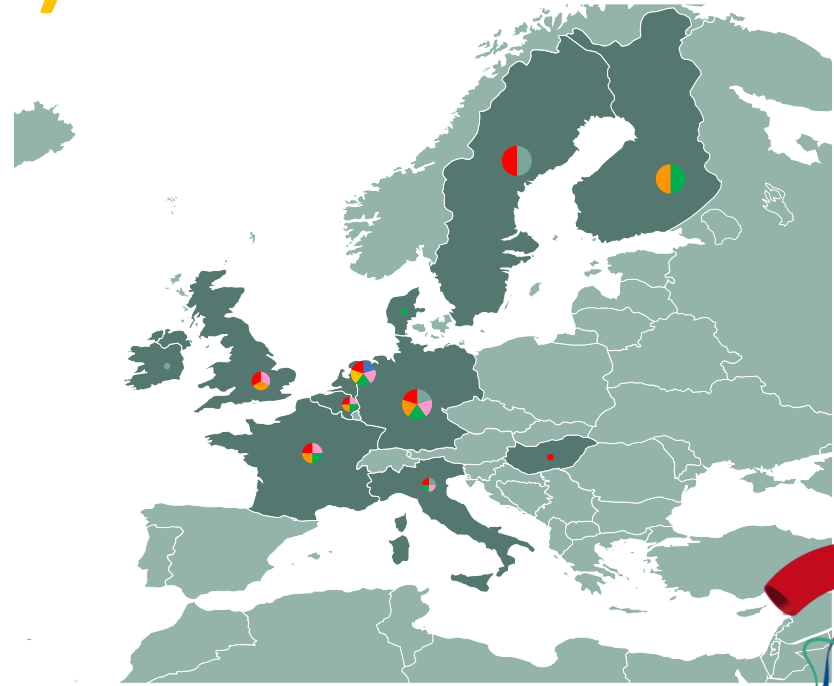
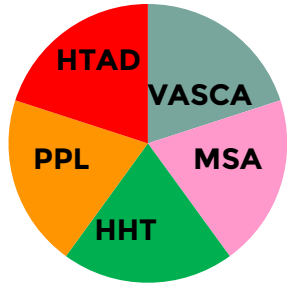


15 Patient Advocates

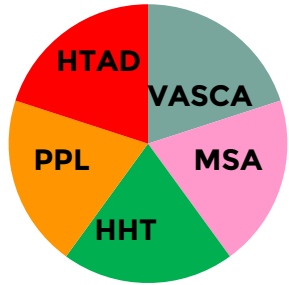
- members of our European Patient Advocacy Group



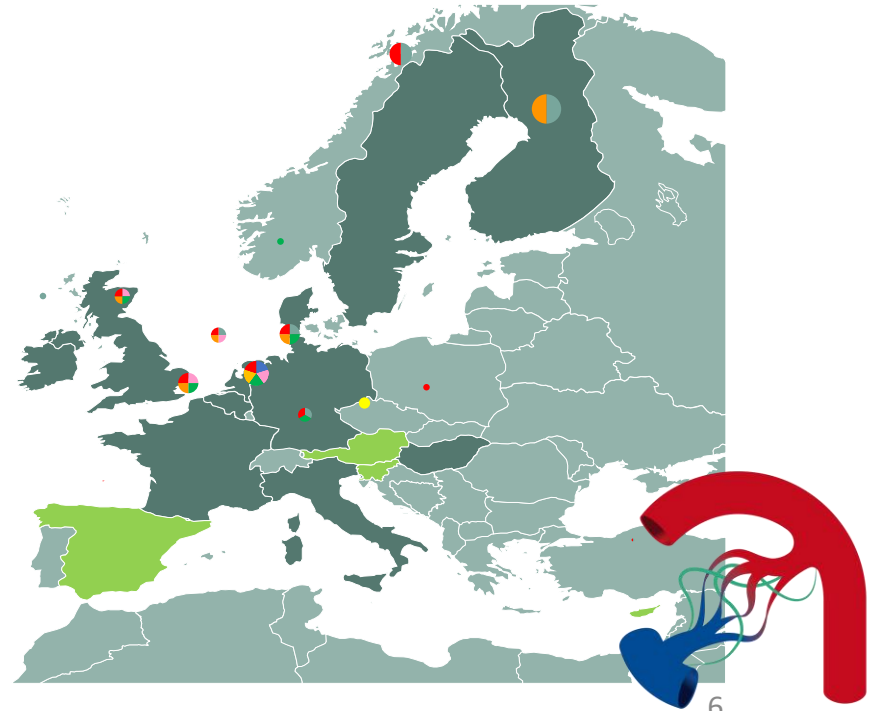
VASCERN HCPs in 2019 (before Affiliated Partners)



VASCERN HCPs in 2019 including the Affiliated Partners(in green)



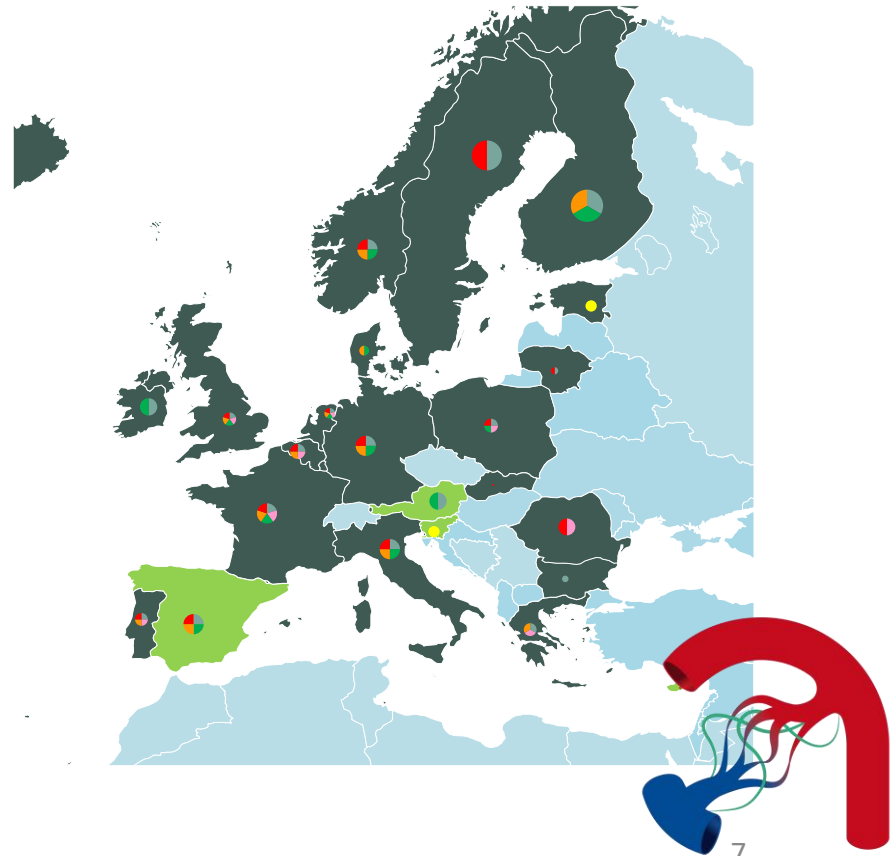
Spain
Slovenia
Malta
Austria
Cyprus
Luxembourg



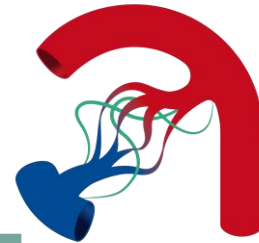
VASCERN HCPs- tentative projection 2021

- Estonia (PPL)
- Lithuania (VASCA and HTAD)
- Luxemburg (HTAD)
- Norway(HTAD, HHT, PPL, VASCA)
- Poland (VASCA, MSA, HHT, HTAD)
- Romania (MSA, HTAD)
- Bulgaria (VASCA)
- Portugal (HTAD, MSA, PPL, VASCA)
- Greece (VASCA, PPL, MSA)
- Spain (HTAD, HHT, VASCA, PPL)
- Countries already represented in VASCERN

by HCP Full Members: in new RDWGs
(ex: Denmark or Sweden).



VASCERN ACTION PLAN



	Actions / Work Packages
WP 1	Sharing of experience: discussion of difficult clinical cases
WP2	Definition of patients pathways
WP3	Cross-border pathways Mobile Application
WP4	Pills of knowledge
WP5	Registries – Safety standards collection & reporting
WP6	Clinical trials
WP7	Availability of conferences on YouTube
WP8	Definition of clinical outcomes
WP9	Writing recommendations (J1, J2) + transition Child/Adult
WP10	Communication (+cooperation with all for dissemination)



VASCERN

Gathering the best expertise in Europe to provide accessible cross-border healthcare to patients with rare vascular diseases



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Rare Diseases WGs Transversal WGs ePAG (Patient Advocacy)

Newsletters

What we do CPMS: discussion of complex clinical cases

Clinical Patient Management System (CPMS)

For Healthcare Professionals, Members of VASCERN

If you would like to join the CPMS and you belong to one of VASCERN's 31 HCPs then please contact the lead HCP representative at your HCP. If your HCP is not a member of VASCERN please contact the coordination team.

Registration to the CPMS

In order to access the CPMS you must have an EU login and request authorisation to use CPMS.



Call for new HCP full members



EU languages

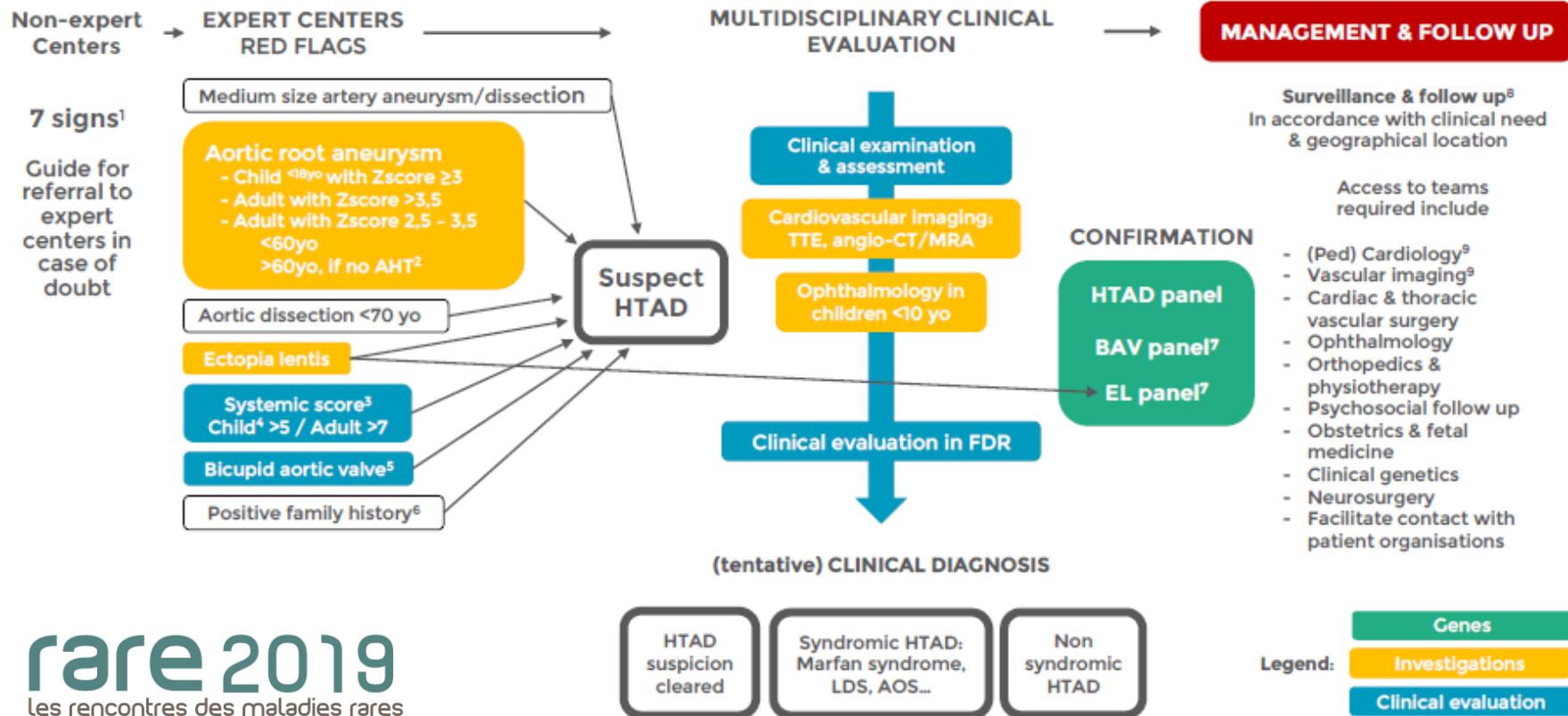


Do's & Don'ts Factsheets for rare vascular disease patients

Les rencontres des maladies rares



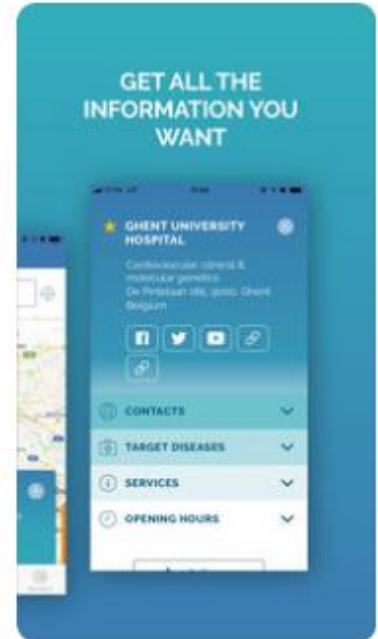
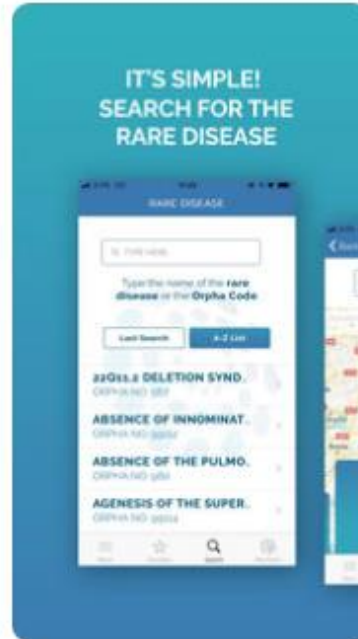
HTAD Diagnostic Work-Up





VASCERN App

Forme et santé



Do and Don't

Vascular Ehlers-Danlos syndrome



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rare 2019

29/11/2019
les rencontres des maladies rares

Pills of Knowledge

Medium sized Arteries (MSA-WG)

^ Pediatric and Primary Lymphedema (PPL-WG)

PPL-WG Pills of Knowledge videos playlist

An Overview of Pediatric and Primary Lymphedema

- Pitting test
- Stemmer Sign
- Lymphoscintigraphy
- Magnetic Resonance Imaging



THU 07 NOV 2019

FRI 08 NOV 2019

VASCERN Days 2019

THU 07 NOV 2019

EJP RD Information day & Brokerage Event
8:45 am to 4:30pm

All

Upcoming events

EU calls

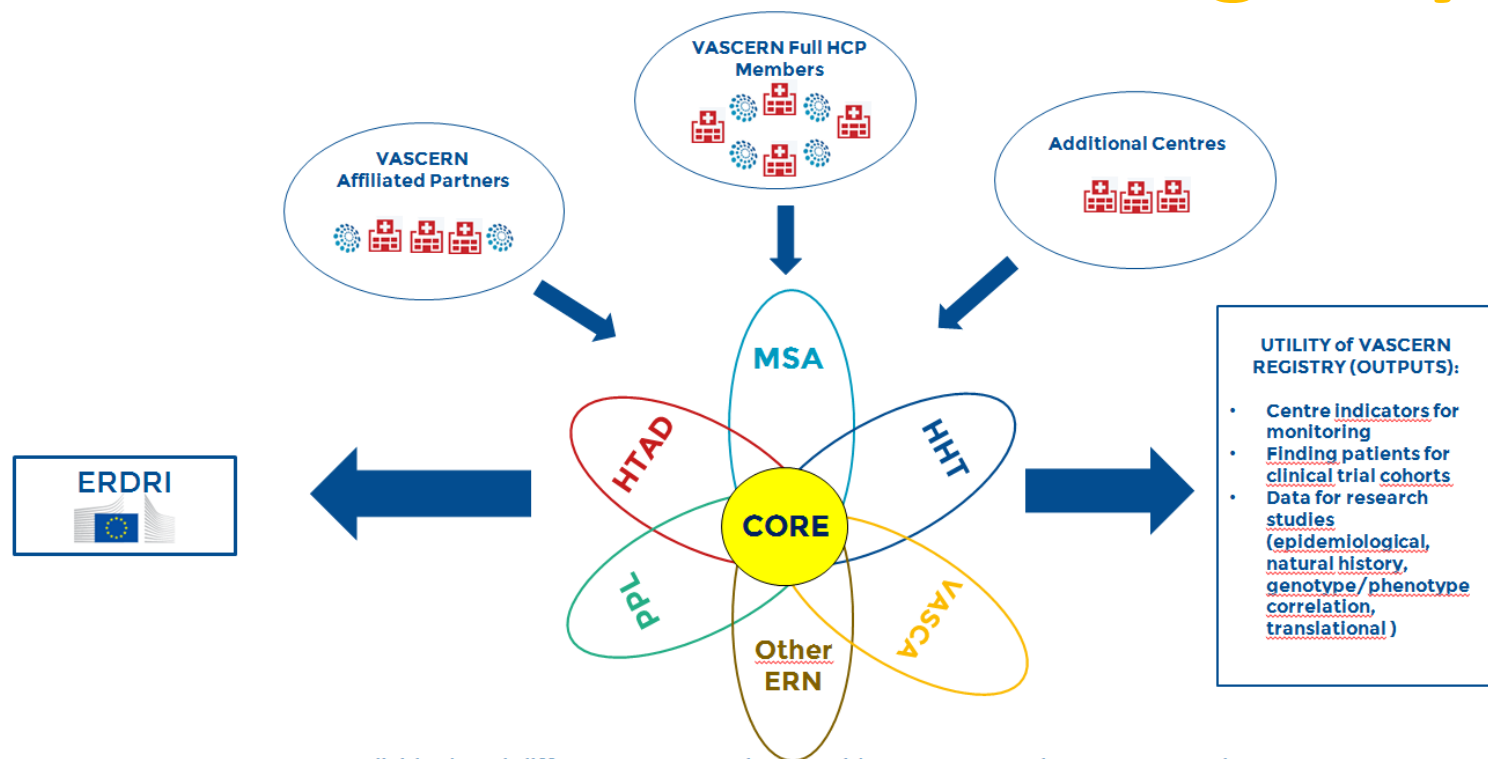
Rare diseases covered by VASCERN

+ Hereditary Haemorrhagic Telangiectasia

+ Hereditary Thoracic Aortic Diseases

+ Medium Sized Arteries

Structure of VASCERN Registry



Individual and different RDWG registries with common EU dataset core and additional RD-specific metadata.

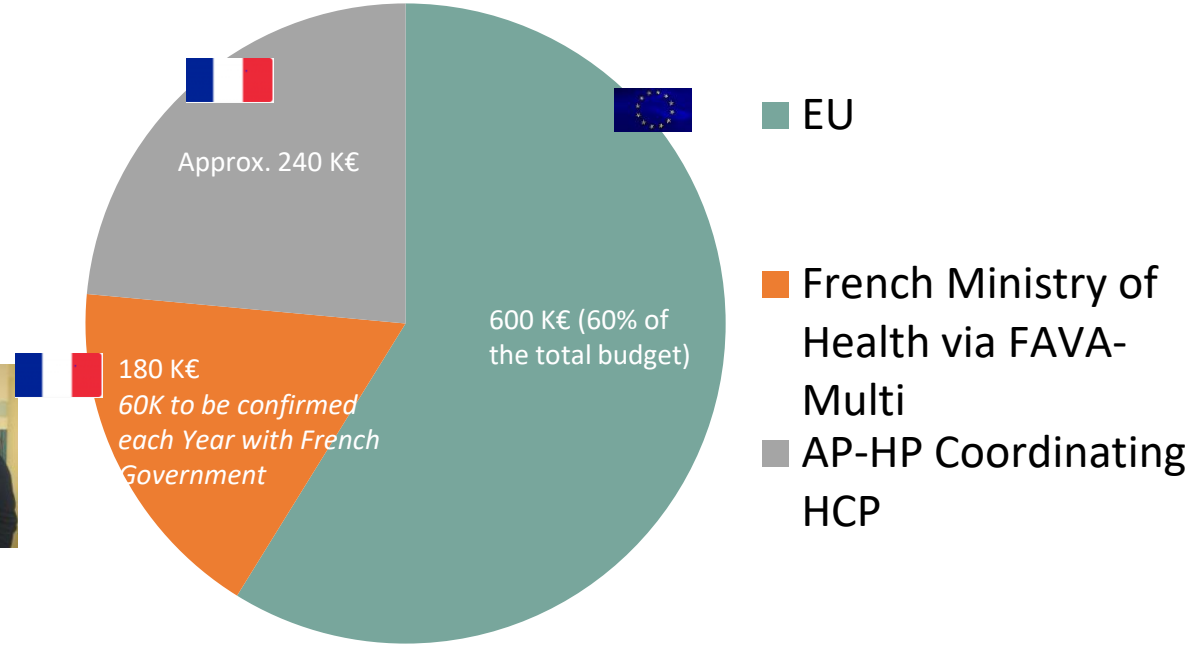


Research

- Cooperative publications already ongoing
- Registry on-going projects
 - Possibilities :+++ Natural history, New diseases description (find similar patients), Evaluate new therapies, Specific questions on specific population
 - Funding from the EU: 200 K€ for 3 years: just make the registry. Who is going to enter the data ? Other funding EJPRD
 - Interoperability with electronic flow charts (BNDMR)
 - Complications : international, regulation different among countries, funding above registries (specific calls)
- Patient based project 101 genomes
 - Variabilité clinique population avec une seule mutation FBN1 récurrente
- Exchange between centers
- Specific calls...



Funding Year 3- 5





VASCERN

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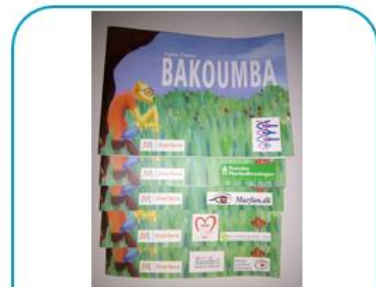


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Latest News



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EU languages



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