
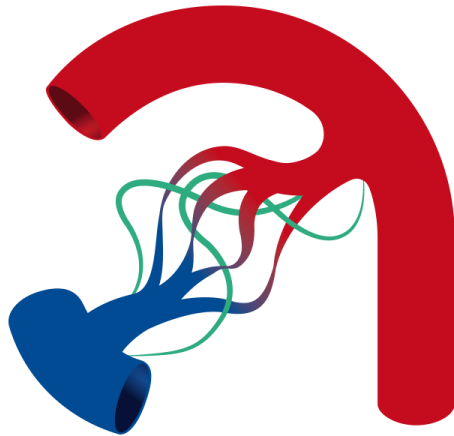




European Reference Network

for rare or low prevalence complex diseases

 **Network**
Vascular Diseases
(VASCERN)



9.20-9.35 VASCERN's Enlargement & Cooperations (Marine Hurard, Guillaume Jondeau)

- Welcome to our New Affiliated Partners 2020
- Update on New Healthcare Providers Full Members 2021
- National networks of Referral HCPs: sharing good practices(3'per country)

Netherlands (Leo Schultze Kool & Caroline van den Bosch)

Sweden (Erik Bjorck)

France (Guillaume Jondeau for the FAVA-Multi network)

 [#VASCERNdays2020](https://twitter.com/VASCERNdays2020)



7 Affiliated Partners *teams*

Welcome to the new ones who joined this year!

	HCP	RDWG	HCP Expert Center Lead and 2nd Representatives	Country	Date of official affiliation
Associated National Centres	Center for vascular anomalies in paediatric patients Department of Paediatric and Adolescent Surgery Children's Hospital University Hospital Graz	VASCA	Dr. Paolo GASPARELLA Prof. Emir HAXHIJA	Austria	November 2019
	Medical University Innsbruck, Expert Center for Genetic Aortopathies) / Department of Cardiac Surgery	HTAD	Dr. Julia DUMFARTH	Austria	May 2020
	Hospital Universitario Vall d'Hebron	HTAD	Dr. Gisela TEIXIDÓ / Dr. Arturo EVANGELISTA	Spain	August 2019
	The Cyprus Institute of Neurology and Genetics, Department of Cardiovascular Genetics & Laboratory of Forensic Genetics	HTAD & MSA	Dr. George TANTELES / Dr. Evy BASHIARDES / Dr. Anna KERAVNOU	Cyprus	February 2020
	University Medical Centre Ljubljana, Dermatovenereological clinic	PPL	Dr. Tanja PLANINŠEK RUČIGAJ	Slovenia	November 2019
National Coordination Hub	Centre Hospitalier de Luxembourg	HTAD	Prof. Klaus KALLENBACH	Luxembourg	February 2020
	Mater Dei Hospital (National Coordination Hub)	HTAD & MSA	Dr. Maryanne CARUANA / Dr. Kevin CASSAR	Malta	January 2020



Dr. Julia DUMFARTH
Cardiac Surgeon



Dr. Evy BASHIARDES
Molecular Biologist



Dr. George TANTELES
Consultant in Clinical Genetics



Prof. Klaus KALLENBACH
Cardiac Surgeon



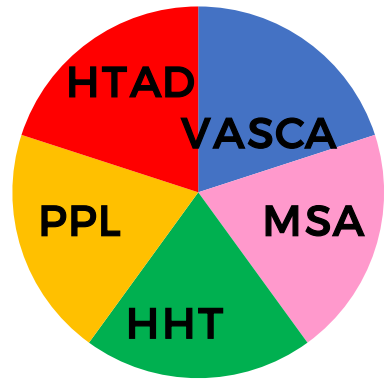
Dr. Maryanne CARUANA
Cardiologist



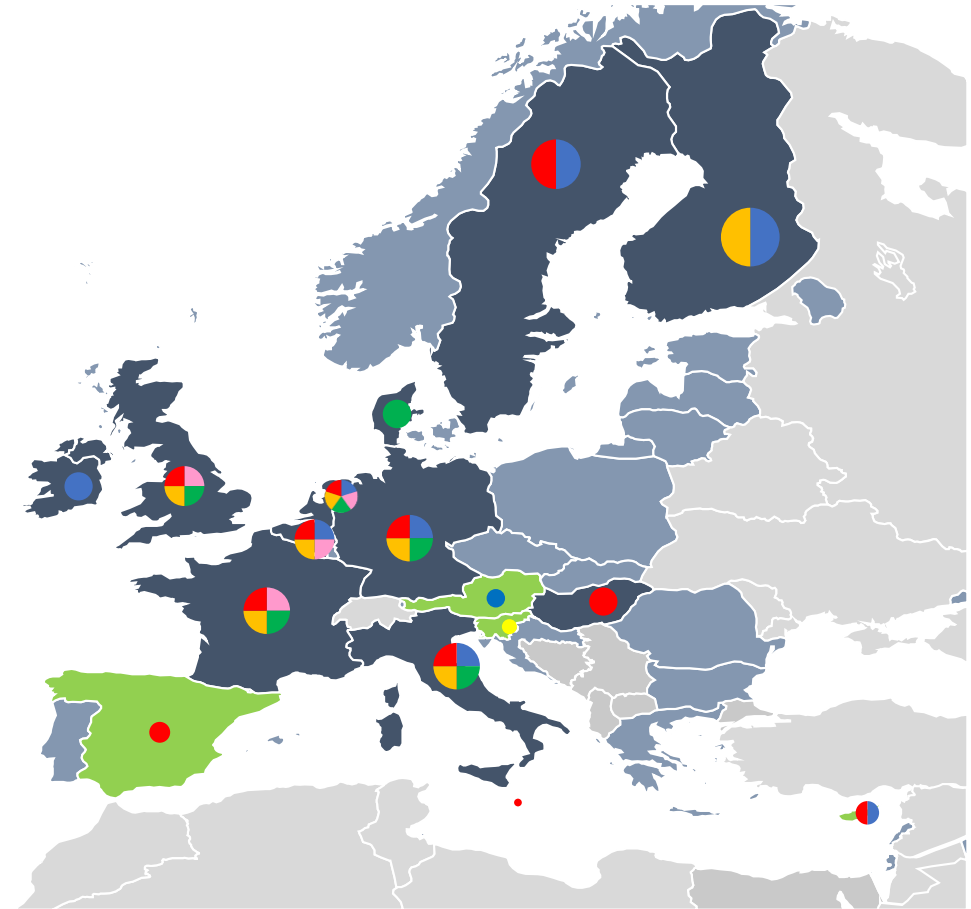
Dr. Kevin CASSAR
Vascular Surgeon



VASCERN Members in 2020

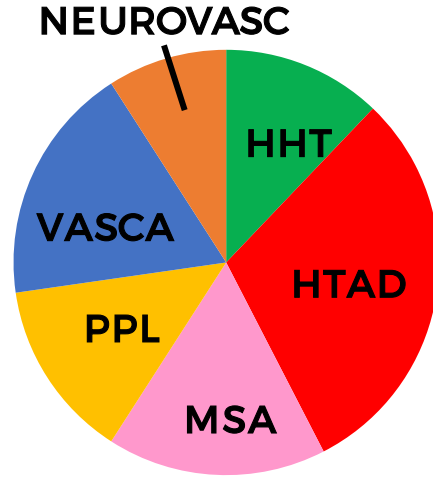


-  HCPs Full Members since 2016
-  Affiliated Partners since 2019-2020 (*Spain, Slovenia, Malta, Austria, Cyprus, Luxembourg*)
-  Other EU or EEA countries for the future

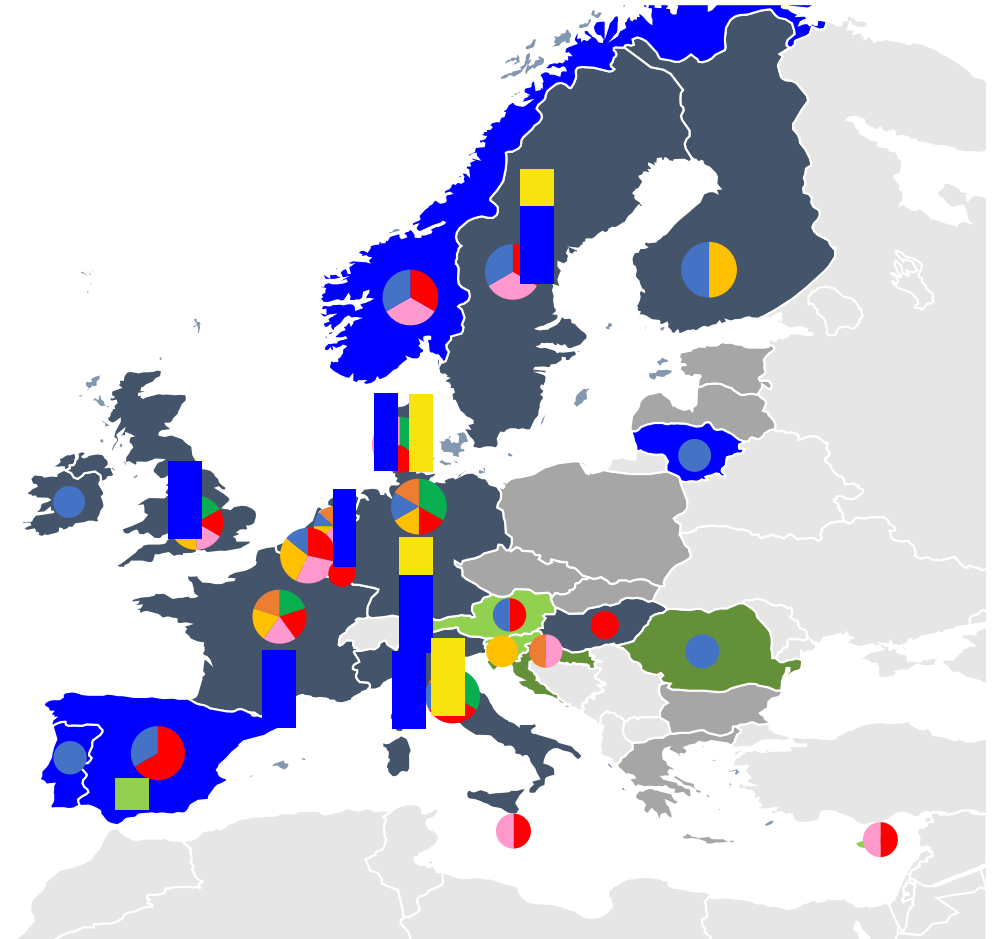




VASCERN tentative map 2021 onwards



-  HCPs Full Members since 2016
-  Affiliated Partners 2019-2020
-  HCPs full members from 2021 (*Lithuania, Norway, Portugal, Spain + countries already in 2016*)
-  Future Affiliated Partners (*Croatia, Romania*)
-  Ongoing evaluation (*Denmark, Germany, Italy, Sweden*)
-  Other EU or EEA countries for the future

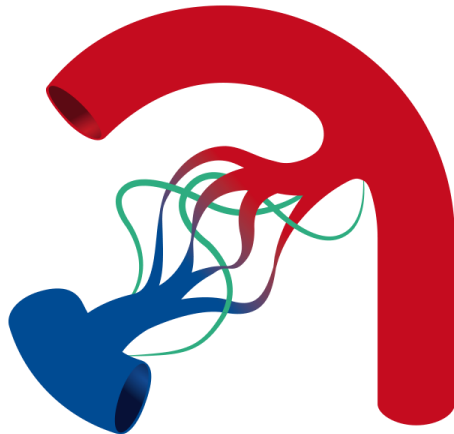




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National networks of Referral HCPs: sharing good practices (3'per country)

Netherlands (Leo Schultze Kool & Caroline van den Bosch)

Sweden (Erik Bjorck)

France (Guillaume Jondeau for the FAVA-Multi network)



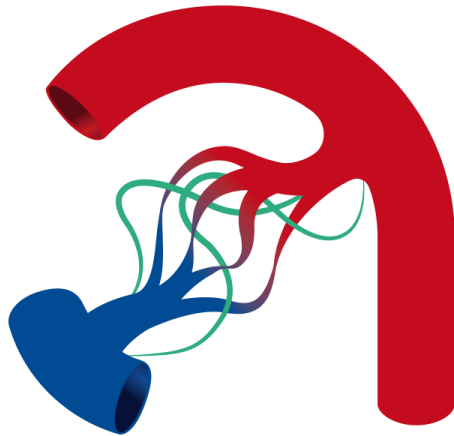
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Network

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VASCERN National Network for VASCA in the Netherlands

Caroline van den Bosch
Leo J Schultze Kool



Laying the foundation for the National Network

The ground work: Consensus Document for IH

- Hevas organised meetings with the Dutch centres of expertise to come to a shared Consensus Document for Infantile Hemangioma in 2008
- Version II (2013) and III (2017) followed
- Official IH Guidelines to be finalized in 2020 (initiated by Dutch Association for Dermatology in cooperation with the National Network)



Formalising the National Network

Hevas organised the first meeting in 2018 to encourage the centres of expertise to work together as a formal National Network because:

- Importance of sharing information on care and research
- Requirement by the government to remain a centre of expertise in the Netherlands (new call in the Netherlands expected in 2021)
- Linking to VASCERN



National Network NL

The National Network of centres of expertise for congenital vascular anomalies is a partnership between:

- Radboudumc in Nijmegen
 - Amsterdam UMC
 - Erasmus MC-Sophia Children's Hospital in Rotterdam
 - Wilhelmina Children's Hospital in Utrecht
 - Patient organisation HEVAS
- VSOP (Dutch Support Organisation for Rare diseases) initiated the project Connect Extended in 2018: building common websites for centres of expertise
- National Network + HEVAS + VSOP compiled the content in 2019/2020, now online: <https://aangeborenaatafwijkingen-expertise.net/>



National Network NL: Future

- First medical conference on Vascular Birthmarks of the Network
12 November 2020 (>480 doctors/obstetricians/nurses subscribed already)
- Collaboration in research programs/clinical trials



National Network NL: challenges

- Do not fulfill the minimum criteria set by VASCA (but are approved by the Dutch Government)
- Collaboration instead of competing needs a mind change
- Recognition (ego?)
- Centers not in VASCA also want to be part of VASCERN
- Access to Grants (EJP-RD)

- Legal status of the National Network ?
- The National Network decides on the representing center in VASCA ?

Slides Plenary 22thOct Vascern days

Erik Björck

National network VASCERN Sweden

- Difficult find time -> Covid made it easier -> Zoom
- Six clinical genetics departments
- 2 – fall , 2 - spring
- Aim:
 - - Discuss difficult cases
 - - To make the genetic testing co-herent
 - - To spread ERN-info

NB! Parallella cardiogenetic network on-going

Clinical genetics growing up and move away from home [to other clinics]

When should other clinics test?

- Dissection/clinical significant aorta ascendens dilatation <50 mm without obvious cause
- Two first degree-relatives (D/CSAAD) no age-limit
- Obvious syndrome instead make a referral to genetic out-patient clinic


This experiment already done oncogenetics

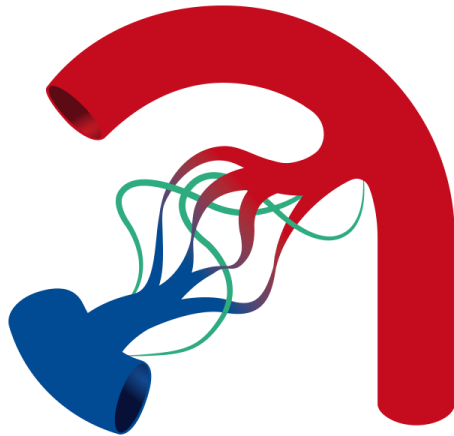
- Started as informal network
- Now Government funded network



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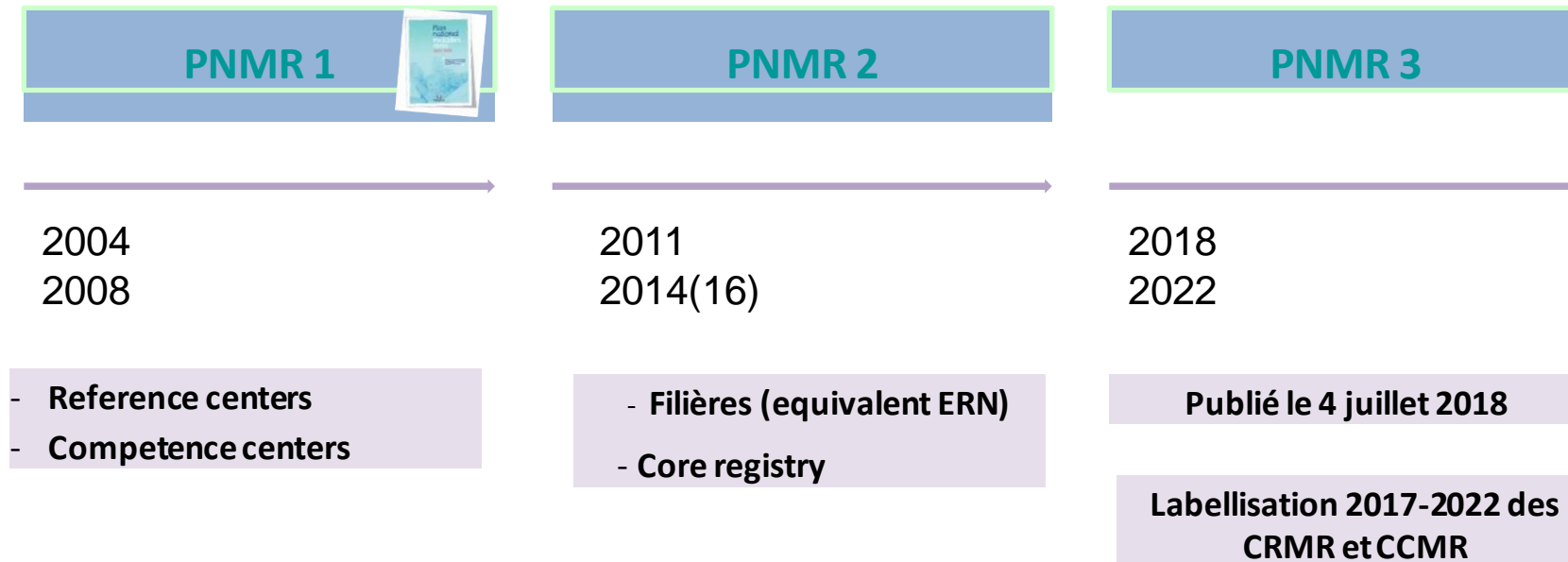
France national networks for rare vascular diseases

Guillaume Jondeau for the FAVA-Multi network

 [#VASCERNdays2020](https://twitter.com/VASCERNdays2020)

Les Plans Nationaux Maladies Rares :

Patient associations

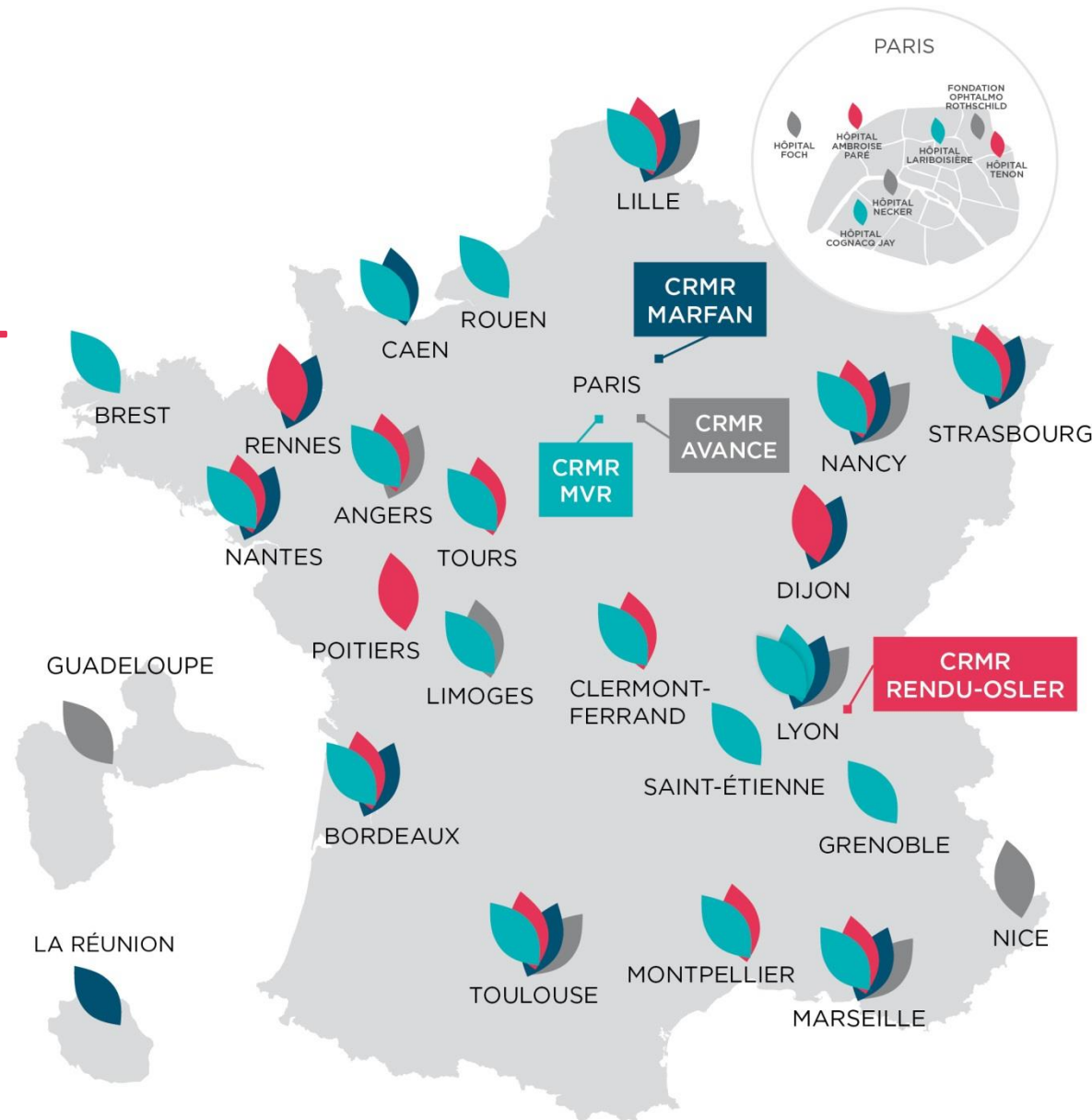


Today

- Reference centers : **109**
 - Annual evaluation: nb patients, publications, patient association
 - Annual funding:
- Competence centers: **387**
 - local care, no funding
- Filière: **23**
 - Gather CRM from related pathologies (FAVAMulti = VASCERN)
 - Annual funding
- Expert laboratories (genetic++)
- Patient associations **220**
- BNDMR (national registry on rare diseases)
- Plan France génomique

FAVAMulti

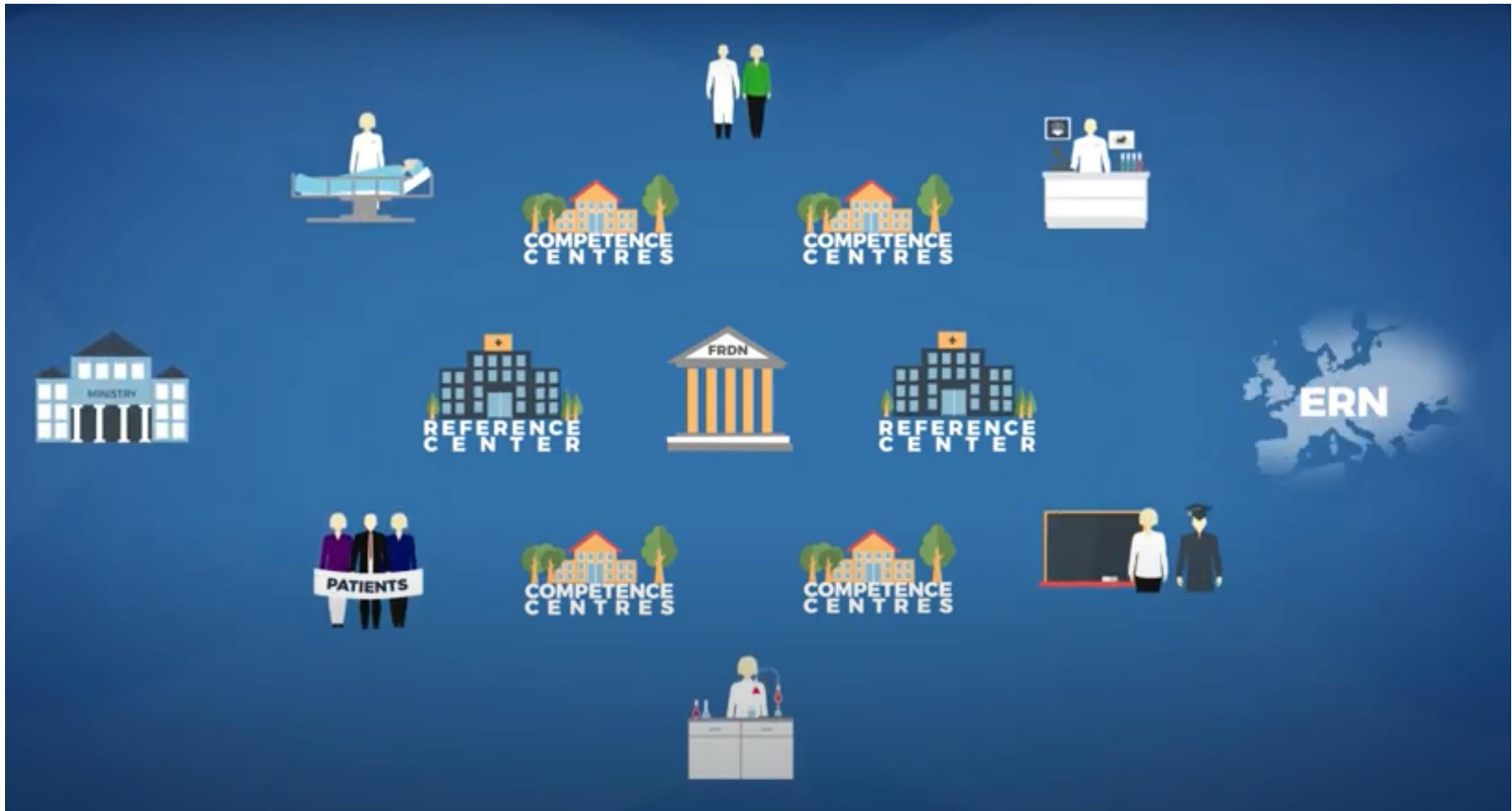
- HTAD
- MSA + PPL
- VASCA
- HHT



Monthly meetings

- Case discussion
- Commun studies
- Administrative issues
- Plan France génomique

www.favamulti.fr



[Watch a 4-minute video on the French National Rare Disease Networks](#)