

VASCERN Registries EU Grant Project (2020-2023)

https://vascern.eu/what-we-do/patient-registries/



VASCERN

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

Timeline

Summer 2020: Constitution of the datastewards team

dedicated to each of the 5 RDWGs registries. They will

October 2020: Specific disease-datasets for the HTAD,

May 2021: Specific disease-datasets for the PPL and

As of January 2021: FAIRification process ongoing

liaise with each Healthcare Provider.

MSA and HHT registries defined.

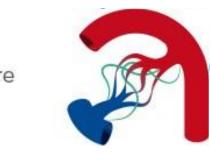
(ontologies/semantic modelling).

VASCA registries defined.

Implementation:

can be entered.

At a local level



As rare diseases are rare and patient numbers are therefore often limited, sharing of data is absolutely crucial. A European-wide registry is universally recognised as beneficial for epidemiological studies, and hopefully trials of new drugs, or of repurposed drugs, in the treatment of rare diseases. With this VASCERN Registries project, we aim to reach the objective of developing our rare disease registries in order to reinforce our research capabilities and the knowledge about rare vascular diseases. Our project can be viewed as either a unique registry, with the core data elements required for all rare vascular disease patients and the specific disease elements varying for each 5 Rare Disease Working Groups (RDWGs), or 5 different registries with a common core making interoperability and epidemiological studies on the whole population of patients seen within the ERN possible.

The VASCERN Registries Project Team European **Patient Advocacy Group MSA-WG Project Management & Coordination HHT-WG Team EJP-RD** Support Team

Data stewards

registries.

<u>HHT Registry CIROCO – Hereditary Haemorrhagic</u> **Telangiectasia**:

- Registry Lead and HHT-WG Co-Chair: Dr. Sophie DUPUIS-
- Registry Project Manager: Evelyne DECULLIER
- Registry Developer: Jean-Philippe ALLARD

HTAD Registry – Heritable Thoracic Aortic Diseases:

- Registry Lead and HTAD-WG Co-Chair: Prof. Guillaume **JONDEAU**
- Registry Project Manager: Samira LARIBI
- Data Stewards: Marie-Capucine TELLIER and Claire BATISTA

MSA RaDiCo Registry – Vascular Ehlers-Danlos Syndrome:

- Registry Leads: Dr. Sonia GUEGUEN and Dr. Michael FRANK (MSA-WG Co-Chair)
- Registry SEDVASC Project Manager: Eve KLISING
- Datamanager SEDVASC: Huong DANG
- ETL Expert on RaDiCo plateform: Xuan-Bach NGUYEN-LE

The European FAIR HHT, HTAD and MSA vEDS registries The European FAIR VASCA and PPL registries will be will be built on the basis of existing French national designed, including the core dataset and their specific diseases datasets.

VASCA Registry – Vascular Anomalies:

- Registry Lead, VASCA-WG Co-Chair and Registry-WG Chair: Prof. Leo SCHULTZE KOOL
- Registry Project Manager & Data Steward: Pim KAMERLING
- Data Steward: Bruna DOS SANTOS VIEIRA

PPL Registry – Pediatric and Primary Lymphedema:

- Registry Lead and PPL-WG Chair: Dr. Robert DAMSTRA
- Registry Project Manager & Data Steward: Pim KAMERLING

VASCERN ePAG (European Patient Advocacy Group):

ePAG advocate for the Registry-WG and ePAG Deputy Co-Chair for the VASCA-WG: Maria BAREA

VASCERN Project Management & Coordination Team:

- Project Manager: Marine HURARD
- Project Officer: Natasha BARR
- Project Assistant: Karen DAOUD

The VASCERN Registries VASCERN Full HCI Additional Centres VASCERN Affiliated UTILITY of VASCERN **MSA** REGISTRY (OUTPUTS): Centre indicators for Finding patients for clinical trial cohorts **ERDRI** Data for research CORE natural history, genotype/phenotype Individual and different RDWG registries with common EU dataset core and

Goals of our Registries

additional RD-specific metadata.

- Adhere to the FAIR principles
- Be linked to ERDRI (the European Platform of Rare Diseases)
- Start with optimizing links eHR to registries

What is a FAIR database?

The FAIR data principles are a set of principles used to make data Findable, Accessible, Interoperable and Reusable (FAIR). They also provide the guidelines for good scientific data management and stewardship in order to maximize the use of valuable research data by the scientific community.

Our 5 Work Packages

Informed consent / Medical ethics approval

May 2023: FAIR registries running / First patient data

- 1. Project Management and Coordination (horizontal)
- 2. Dissemination and communication (horizontal)
- **Evaluation (horizontal)**
- Creating new registries: Core dataset, VASCA and PPL registries (core)
- Adaptation of existing registries (HTAD, MSA, HHT) (core)









