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, phenotypic descriptions of new diseases, natural history 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**

**Project Management & Coordination Team**
- **MSA-WG**
- **PPL-WG**
- **HTAD-WG**
- **VASCA-WG**

**Data stewards**
- The European FAIR HHT, HTAD, and MSA vEDS registries will be built on the basis of existing French national registries.

**The European FAIR VASC ERA Patient Advocacy Group (ePAG)**

**VASCA Registry – Vascular Anomalies:**
- Registry Lead, VASCERA Registry-WG Chair: Prof. Leo SCHULTZ KOOL
- Registry Project Manager & Data Steward: Prof. KAMENLING
- 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: Prof. KAMERLING

**VASCA/ePAG (European Patient Advocacy Group):**
- ePAG advocate for the Registry-WG and ePAG Deputy Co-Chair for the VASCERA-WG: Maria BERDA

**VASCA Project Management & Coordination Team:**
- Project Manager: Marine HURARD
- Project Officer: Natasha BARR
- Project Assistant: Karen DAGOU

**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.

**Goals of our Registries**
- Adhere to the FAIR principles
- Be linked to ERORI (the European Platform of Rare Diseases)
- Start with optimizing links of registries

**What’s in a VASCERN Registry?**

- Individual and different RDWGs registries with common EU dataset core and additional RD-specific metadata.
- Relevant and interoperable datasets with a common core making epidemiological studies possible.
- 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.

**Our 5 Work Packages**

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

**Timeline**

1. Summer 2020: Constitution of the data stewards team dedicated to each of the 5 RDWGs registries. They will liaise with each Healthcare Provider.
2. October 2020: Specific disease-datasets for the HTAD, MSA and HHT registries defined.
3. May 2021: Specific disease-datasets for the PPL and VASCERA registries defined.
5. Implementation:
   - At a local level
   - Informed consent / Medical ethics approval
6. May 2023: FAIR registries running / First patient data can be entered

**Reference:**

[https://vascern.eu/what-we-do/patient-registries/](https://vascern.eu/what-we-do/patient-registries/)