

Participating Countries



Join Us

Let's work together toward a future where vascular anomalies are better understood, better treated, and better lived with.

To learn more or take part, contact your participating clinic or visit:

www.vascern.eu/group/vascular-anomalies/narrative-project/



**THANK YOU FOR
YOUR SUPPORT!**




Be part of the NARRATIVE Project

A European natural history study to advance the understanding and treatment of Vascular Anomalies



Co-funded by
the European Union





About the NARRATIVE project

NARRATIVE is a Europe-wide research project led by the Vascular Anomalies (VASCA) group of European Reference Network on Rare Multisystemic Vascular Diseases (VASCERN). This ground-breaking initiative represents a major advance in the clinical study of vascular anomalies (VAs), and we want you to be part of it.

***Together, let's change the
future of vascular
anomaly care.***

Why is this project important?

Vascular anomalies (VAs) are rare genetic conditions caused by abnormal blood or lymphatic vessel development. They can take many forms and often have a serious impact on daily life. While scientific progress has enabled more personalised treatments, we still know too little about how these conditions evolve over time.

The NARRATIVE project aims to better understand how vascular anomalies progress by studying their natural history and identifying key drivers in order to improve diagnosis, treatment, and quality of life.

What will NARRATIVE achieve?

Our goal is to create a comprehensive long-term registry of vascular anomaly patients that combines clinical, genetic, imaging, laboratory, and patient-reported data.

This registry will help us:

- 1 Identify risk factors for disease progression
- 2 Understand the impact of VAs on quality of life
- 3 Develop more effective and personalised treatments
- 4 Define outcome measures for future clinical trials

We plan to enrol over 1,200 patients across Europe within three years, with data collected at multiple time points through a network of multidisciplinary clinics and patient organisations.

How can you get involved?

If you or your child is living with a vascular anomaly, you can take part in the NARRATIVE project. Participation is voluntary, involves no extra visits or additional tests. It's based entirely on your regular care and won't affect your treatment in any way.

What does participation involve?

As a participant, you will be asked to share clinical information such as genetic data, medical images, and answer questionnaires about your health and quality of life, most of which is already collected as part of your routine care. This information will be added to a secure research registry and collected over time to help researchers monitor how vascular anomalies evolve and respond to treatment.

Your privacy and safety are our top priority. All data will be collected with your informed consent, stored securely, and fully anonymised. The project has been approved by an ethics committee.

Why should you participate?

Your experience can help others. By taking part in NARRATIVE, you'll be supporting research that leads to better care for people living with vascular anomalies.

Your participation will:

- ★ Support the development of new and more effective therapies
- ★ Advance personalised approaches to treatment
- ★ Ensure that patient voices guide research priorities