



The EMRaDi project aims to

- increase the transparency of needs and availability of services in the field of rare diseases in the Euregio Meuse-Rhine (EMR)
- develop EMR models of rare disease patient pathways in order to draw up patient-oriented recommendations in synergy with national and European developments
- improve the network of health care providers, health insurance providers and patient organisations and raise (public) awareness of rare diseases

PROJECT PARTNERS



lead partner



In each country of the EMR, a roof RD patient organization cooperates with the EMRaDi project and can support you: VSOP (NL), Achse (DE) and RaDiOrg (BE).

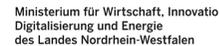
The following institutions also support the EMRaDi project as associated partners: AOK Rheinland/Hamburg, CZ, Mutualités Libres, Jessa Ziekenhuis, ZOL and Universitätsmedizin Mainz.

Project duration

start: October 2016

end: September 2019

The EMRaDi project, undertaken via the Interreg V-A Euregio Meuse-Rhine programme, is supported by the European Union, the European Regional Development Fund and the regional authorities



Rare diseases do not stop at borders



Information brochure

www.emradi.eu



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CALL FOR RARE DISEASE PATIENTS, RELATIVES AND PROFESSIONALS



WHAT IS "EMRADI"?

"EMRaDi" stands for **Euregio Meuse-Rhine Rare Diseases**. The EMRaDi project is a cross-border cooperation that is part of the European Union INTERREG V-A Euregio Meuse-Rhine programme.

This project involves health insurers, university hospitals, patient associations and a university in the Euregio Meuse-Rhine (EMR).

The EMR is made up of five sub-regions:

- the Flemish Province of Limburg (Belgium)
- the Walloon Province of Liege (Belgium)
- the German-speaking community (Belgium)
- the Region of Aachen (Germany)
- the southern part of the Province of Limburg (the Netherlands)

Thanks to their long experience in cross-border healthcare, the project partners have decided to join forces in the specific field of rare diseases. This EMRaDi project is innovative in the sense that it is a patient-oriented and cross-sectoral project. The consortium of partners includes the major health players who support rare disease patients and their relatives in their day-to-day rare disease patient pathway.

- Are you - or do you have a relative - affected by one of the following diseases?
- Are you involved in the care of patients affected by one of these diseases?
- Are you part of an organization that represents patients affected by these diseases?

- *Chronic myeloid leukemia (CML)*
- *Duchenne muscular dystrophy*
- *Galactosemia type 1*
- *Huntington disease*
- *Phenylketonuria (PKU)*
- *Polycythemia vera (PV)*
- *Reit syndrome*
- *Silver-Russel syndrome*

Would you like to share with us what your life with the disease is like? Would you like to tell us about the difficulties you encounter in your daily life and care pathway in our regions?

Then you might be interested to **participate in our project** to tell us about your needs and share your experience!

- To participate in the project, subscribe on www.emradi.eu/en/contact
- For questions, contact us at info@emradi.eu

The EMRaDi project focuses on **eight rare diseases that are used as "tracers"**, two diseases per disease group we focus on in EMRaDi project (syndromal, hematological, neurological, and metabolic rare diseases).

The objective is then to use the results for these rare diseases to help the other rare disease groups of patients and to make global recommendations and developments for cross-border healthcare of rare disease patients in the Euregio Meuse-Rhine (EMR).

We will also gather quantitative data in the three EMR countries on a longer list of rare diseases, this will help to have a better picture of the situation of rare disease patients in our border region.

To find out more, visit www.emradi.eu/en/project-activities

Timing of the study:
September 2017 - September 2018