

Call for testimonies on rare diseases



EMRaDi - A pilot project in the Euregio Meuse-Rhine

In order to improve the cross-border healthcare to patients affected by rare diseases, the EMRaDi project partners are looking for patients, relatives and professionals. Through interviews and focus groups, they want to identify the difficulties encountered in the daily lives and care pathways of patients with a rare disease in the different regions of the Euregio Meuse-Rhine.

The “EMRaDi project”, acronym of “Euregio Meuse-Rhine Rare Diseases” is a cross-border project between five regions of Belgium, Germany and the Netherlands¹.

It focuses on [eight specific rare diseases](#) :

Rare disease groups	Specific rare diseases
Neurological diseases	Huntington disease
	Duchenne muscular dystrophy
Hematological diseases	Chronic myeloid leukaemia (CML)
	Polycythemia vera (PV)
Syndromal diseases	Silver-Russell syndrome
	Rett syndrome
Metabolic diseases	Galactosemia type 1
	Phenylketonuria (PKU)

The EMRaDi partners are looking for patients affected by one of the rare diseases and for relatives, patient associations and health professionals. In order to register for the cross-border study, candidates can fill in the form on the website www.emradi.eu/en/contact or send an e-mail to info@emradi.eu.

Rare diseases are rare, but patients with a rare disease are numerous.

By definition, a disease is called “rare” if less than one person out of 2,000 is affected. About 27 to 36 million European citizens (6-8 % of EU population) are affected by a rare disease. In the Euregio Meuse-Rhine, up to 300.000 people, often children, suffer from rare diseases - to which we need to add relatives, friends and other people impacted by the presence of the disease.

Because of the rarity of the diseases, these patients usually experience difficulties in obtaining the right diagnosis and treatment and in organizing their everyday lives. Due to the specificity of symptoms and difficulty of diagnosis associated with rare diseases, most patients undergo a long and arduous journey before they even find out that they have a rare disease. Knowledge is often scattered and in many cases, finding the right professional/institution proves very difficult.

Such patients legitimately prefer medical treatment and support as close as possible to their home. In the Euregio Meuse-Rhine, rare disease patients are forced to seek care across borders within “foreign” healthcare systems. Clarification of available resources (especially appropriate treatment and financial reimbursement) is essential. For these reasons, joining forces in the Euregio Meuse-Rhine is important, in spite of the challenges of different health care systems and languages.

¹ The Euregio Meuse-Rhine is a cross-border cooperation between five sub-regions: the Flemish Province of Limburg (Belgium), the Walloon Province of Liège (Belgium), the German-speaking community (Belgium), the Region of Aachen (Germany), the southern part of the Dutch Province of Limburg (Netherlands).

EMRaDi: a cross-border project

During this three-year project (01-10-2016 to 30-09-2019), the partners operating within the Euregio Meuse-Rhine are joining forces in order to achieve substantive improvements in integrated cross-border care for rare disease patients. They aim at developing solutions for optimized rare disease patient pathways, making the provision of relevant information more effective, and improving networking and training related to rare disease care.

The consortium of partners includes different major health players who support rare disease patients and their relatives in their day-to-day patient pathway in the Euregio Meuse-Rhine: two mutual health insurance funds from Belgium (the Mutualité chrétienne, the lead partner of the project, and the Mutualités socialistes/Solidaris), the three University Hospitals from the Euroregion (University Hospital Aachen with the Centre for Rare Diseases, the MUMC+/Academic Hospital Maastricht and the University Hospital of Liège), the Dutch national patient alliance for rare and genetic diseases (VSOP) and Maastricht University.

The results of the project will also be used to help other groups of patients with rare disease and to make global recommendations and bring about developments for cross-border healthcare of rare disease patients in European border regions.

The field of rare diseases is a perfect example of a context in which European cooperation has a clear added value and it is receiving increasing attention on national and European levels. Thanks to European impulse, national plans on rare diseases were developed in many Member States (including Belgium, Germany and the Netherlands) and European Reference Networks have been created.

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 regional cofinancing (Région Wallonne, Provincie Limburg, Land Nordrhein-Westfalen).

More information on the project and its activities can be found on the website www.emradi.eu.

A media kit is available on the website with the press release in 4 languages ([FR](#)-[NL](#)-[DE](#)-[EN](#)):

- Poster and brochure for the call for patients, relatives and professionals
- Project factsheet
- Presentation of project partners and contact persons
- Map of Meuse-Rhine Euroregion

Contact persons for the press:

For Belgium: Health insurance fund - Mutualité chrétienne Verviers-Eupen
Caroline Glaude - EMRaDi project Coordinator
Caroline.Glaude@mc.be - +32 (0)498 70 15 68

For the Netherlands: Maastricht University
Timo Clemens - Researcher
timo.clemens@maastrichtuniversity.nl - +31 (0)43 38 81971

For Germany: University Hospital Aachen with the Centre for Rare Diseases
Christopher Schippers - Coordinator of the Center for Rare Diseases of Aachen
cschippers@ukaachen.de - +49 (0)241 80 85651



lead partner



With the support of



Wallonie

