

## PRESS RELEASE

### 28<sup>th</sup> February 2019 Euregio Meuse-Rhine Rare Disease Day



On 28<sup>th</sup> February it will be International Rare Disease Day\*.

On this occasion, the INTERREG project “EMRaDi” will organise the first **Euregio Meuse-Rhine Rare Disease Day**. The focus is on cross border healthcare and three central themes: 1. Awareness - 2. Undiagnosed - 3. Cross Border Healthcare & Cross-border Cooperation. The programme consists of plenary sessions, joint presentations and roundtable discussions on the accessibility to cross-border healthcare for rare diseases.

The purpose of the day is to assess the current situation, to review the positive and negative developments, to explore the solutions to implement, as well as to mobilise the key players. Discussions between healthcare professionals, health insurers and patient organisations will aim to contribute to improve the healthcare quality for patients with a rare disease in the Euregio Meuse-Rhine, in border regions and at a European level.

Due to the specificity of their symptoms, rare disease patients represent extraordinary challenges for all those involved in the healthcare systems. Most patients undergo a long and arduous journey before they even find out that they have a rare disease. Finding the right healthcare professional can prove very difficult. In the Euregio Meuse-Rhine (EMR), it can imply seeking care across borders. Clarification of available resources (especially appropriate healthcare and financial reimbursement) is essential. Joining forces in the EMR is therefore important, despite the challenges of different healthcare systems and languages. The EMRaDi partners have already identified possible solutions to improve the situation, such as designing specific patient-care pathways and proposing preferential procedures for granting access to cross-border care and to reimbursement with no advance payment for RD patients.

This event will take place on 28<sup>th</sup> February in Maastricht from 10am to 5pm at the Amrâth Grand Hotel de l’Empereur, Stationsstraat 2, 6221 BP Maastricht. The complete programme can be accessed at [www.emradi.eu/en](http://www.emradi.eu/en) (in the Events section).

**Given its success, the maximum number of participants has been reached but we would be delighted to welcome the press during the event.**

The day is organised by VSOP (Dutch roof organisation for rare disease patients) in collaboration with the Christian Mutual Health Fund Verviers Eupen, the National Union of Socialist Mutual Health Funds, the National Alliance of the Christian Mutual Health Funds, the University of Maastricht and the university hospitals of the Euregio: CHU Liège, Uniklinik RWTH Aachen and Maastricht UMC+.

The outcomes of the day will help to pursue the developments of the project, which in turn will culminate in an event with political stakeholders in late 2019, and an event for the general public in February 2020.

The EMRaDi project is part of the European Union INTERREG V-A Euregio Meuse-Rhine programme and is financially supported by the European regional development fund (ERDF), as well as by the Belgian, Dutch and German regional partner authorities. The Interreg V-A Euregio Meuse-Rhin (EMR) programme invests almost 100 million euros in the economic and territorial development, innovation and social inclusion of this cross-border region, where over 5,5 million people live.

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\* A rare disease is a disease that affects less than one person out of 2,000. There are at least 6000 different ones. In the Euregio Meuse-Rhine, from 240,000 to 320,000 people are affected by a rare disease.

For more information about the project and our next events, please check [www.emradi.eu/en](http://www.emradi.eu/en) or send an e-mail to [info@emradi.eu](mailto:info@emradi.eu).

**Press material is available on the website with the press release in 4 languages ([FR](#)-[NL](#)-[DE](#)-[EN](#)):**

- Programme of the rare disease day in the Euregio Meuse-Rhine
- Project factsheet
- Presentation of the project's partners and of the contact persons
- Euregio Meuse-Rhine map
- Press release of 11<sup>th</sup> October 2017, explaining the EMRaDi in detail

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