

## PRESS RELEASE

### Rare diseases aren't rare.

### How can European solidarity improve the daily life of 30 million citizens?

### Recommendations for an EU approach on rare diseases



*“Today, the 30 million Europeans living with a rare disease and their family members (often the main carers) remain a marginalised and largely invisible population, with little information about their diseases and their rights, few treatments, and a high level of psychological, social and economic vulnerability.”<sup>1</sup>*

On the 5<sup>th</sup> of December, the INTERREG project “EMRaDi” presented its recommendations for a European Union approach on rare diseases at the European Parliament in Brussels. These recommendations were presented by Caroline Glaude (Christian Mutual Health Fund, lead partner of the project) and then addressed during a panel discussion involving key stakeholders:

- **E. Terol**, member of the European Commission DG SANTE working for the European Reference Network;
- **C. Friel**, who worked on the European Court of Auditors’ special report on cross-border healthcare;
- **M. Bolz-Johnson** from Eurordis, the European association of patients with a rare disease;
- **V. Bours**, Head of the genetics department of CHU Liège, member of an ERN (European Reference Network) and of the EMRaDi project;
- **T. Clemens**, Expert in health policy from Maastricht University, also member of the EMRaDi project.

This event was co-hosted by MEPs **Frédérique Ries** (Renew Europe) and **Pascal Arimont** (EPP), who respectively made the opening and closing speech. The EMRaDi partners proposed three main approaches summarised below:

#### 1. Holistic care: Organizing the care to take into account all the needs of people living with a RD

The EU should create a supportive legislative framework to support health care providers and health insurance funds to develop holistic care and care coordination services for RD patients.

#### 2. Telemedicine: Developing reimbursement of telemedicine for RD

The EU should support the establishment of clear rules on reimbursing telemedicine for RDs in ERNs and in a cross-border context, and an easy access to the best available expertise for RD patients.

#### 3. European solidarity: Structuring the coordination and the solidarity for RD at EU level

The EU should implement the European Pillar of Social Rights, with attention paid to people affected by a RD, and support the creation of a European agency for RD.

A [factsheet](#) with our detailed recommendations is available on the [project website](#) with [press material](#).

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<sup>1</sup> Abstract from “Achieving Holistic Person-Centred Care to Leave No One Behind A contribution to improve the everyday lives of people living with a rare disease and their families” – EURORDIS – May 2019

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