

DECLARATION OF INTENT

ON COOPERATION ON RARE DISEASES IN THE EUREGIO MEUSE-RHINE

The Euregio Meuse-Rhine Rare Diseases (EMRaDi) project is a cross-border cooperation in the Euregio Meuse-Rhine between health insurers, hospitals, patient associations and universities (www.emradi.eu/en/). The project was funded in its initial phase from October 2016 until March 2020 as part of the European Union INTERREG V-A EMR programme.

Based on the EMRaDi project outcomes and recommendations, the project partners and associated partners recognize the importance to continue their cooperation in the field of rare diseases in the Euregio Meuse-Rhine.

They sign this Declaration of Intent to pursue the development of follow-up joint actions, policies and projects on local, regional, national, cross-border and European levels to improve the quality of life of people living with a rare disease and their families in the Euregio Meuse-Rhine and beyond. This will be in the scope of (1) holistic care, (2) telemedicine and (3) European Solidarity, in line with the position presented on 5.12.2019 in Brussels to European representatives (see factsheet in annex).

Partners and associated partners undertake to meet, at least once a year, within the **EMR Health Forum**¹ to continue their cooperation on the topic of rare diseases, expand it to other relevant stakeholders and plan joint actions, policies and projects.

Annex: Factsheet EMRaDi

The EMRaDi partners

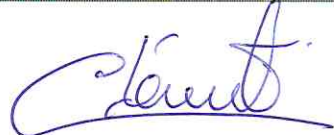




The associated partners

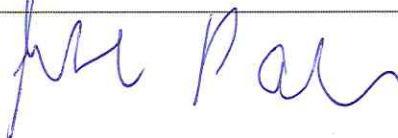





¹ The EMR Health Forum has existed since 2013 and was created on the basis of previous INTERREG cooperation: it gathers on a regular basis hospitals, health insurance providers, universities, patient associations and other healthcare providers. The "EMR Health Forum" works thanks to the partners' own funds. Durability is ensured by the will of its members to continue their historical cooperation in the EMR and to continuously improve their cross-border actions.

Date and place : 17.02.2020, Liège
The EMRaDi partners (in alphabetical order)

| | |
|--|---|
| Alliance Nationale des Mutualités Chrétiennes / Landsbond der Christelijk mutualiteiten (BE) |  Jean-Pierre DESCAN, Director of International Affairs |
| Centre Hospitalier Universitaire de Liège |  Prof. Pierre GILLET, Medical Director and Prof. Vincent BOURS, Head of the Human Genetic Department |
| Mutualité chrétienne Verviers-Eupen / Christliche Krankenkasse Verviers-Eupen (BE) |  Christian MARECHAL, Deputy Regional Director |
| Solidaris / Nationaal verbond socialistische mutualiteiten (BE) |  Alain COEUR, Director of the department of European and International affairs |
| Universitätsklinikum Aachen (DE) |  Prof. T. H. ITTEL, Chief Executive Officer and Medical Director and Prof. J. B. SCHULZ, Director of the Department of Neurology and Speaker of the Center for Rare Diseases Aachen |
| Maastricht Universitair Medisch Centrum + / academisch ziekenhuis Maastricht (NL) |  Prof. M. VAN DIEIJEN-VISSER, Chairman of the Executive Board and Prof. H. BRUNNER, Head of Human Genetics, Co-Coordinator Rare Diseases |
| Universiteit Maastricht (NL) |  Prof. H. BRAND, Head of the Department of International Health |
| Vereniging Samenwerkende Ouder- en Patiëntenorganisaties (VSOP) betrokken bij erfelijkheidsvraagstukken (NL) |  Cor OOSTERWIJK, Director |

The EMRaDi associated partners (in alphabetical order)

| | |
|---|---|
| <p>Allianz Chronischer Seltener Erkrankungen (ACHSE) (DE)</p> |  <p>Ute PALM, Executive Board</p> |
| <p>Mutualités Libres / Onafhankelijke Ziekenfondsen (BE)</p> |  <p>Christian HOREMANS, Expert International Affairs</p> |
| <p>Rare Diseases Organization Belgium (RaDiOrg) (BE)</p> |  <p>Eva SCHOETERS, Coordinator</p> |

With the support of