



Press release

## First 23 European Reference Networks for Rare Diseases

### A milestone for 30 million patients in Europe

**15 December 2016, Brussels, Belgium** - The European Commission today announces the first [23 European Reference Networks](#) for rare diseases (ERNs). This momentous step comes after years of collaboration and efforts between rare disease patients, clinical experts, and policy makers in EU Member States, at the European Commission and the European Parliament to bring the ERNs to fruition.

Over the last ten years, EURORDIS has advocated for and taken an active part in discussions on ERNs between patients and national and European policymakers. Yann Le Cam, EURORDIS Chief Executive Officer, commented, “This is a historic day for us. We have been advocating for the creation of ERNs since 2006, based on the EurordisCare Surveys on access to diagnosis and care in Europe involving 12,000 patients & their families. The ERNs are a concrete example of how European collaboration can directly benefit patients, promoting clinical excellence across the EU and European patient healthcare pathways.”

He continued, “EURORDIS is delighted by the enthusiasm and commitment to clinical excellence and collaboration from nearly 1,000 healthcare providers (hospital centres of expertise for rare diseases, each gathering several medical experts) from 26 countries that led to this outstanding result. We stand at a point in history - by connecting patients, experts and hospitals through ERNs, we will revolutionise rare disease patients’ access to high-quality care and will be able to measure the improvement of patient health outcomes. This will help to break isolation of patients, tackle the silos that experts work in and help to reduce the current inequality in care reported between rare diseases and between Member States.”

Terkel Andersen, President of the EURORDIS Board of Directors added, “The creation of these ERNs is thanks to the dedication and cooperation of patient advocates, clinical leaders, the European Commission and members of its expert group on rare diseases, colleagues within Member States, and partners in the European Joint Action on Rare Diseases. At EURORDIS we thank our members and funders, in particular AFM-Téléthon, for the support they have provided over the years, which has allowed us to continue to advocate for ERNs.”

#### Patient-centric ERNs

Patients are playing a crucial role in shaping ERNs to ensure that the networks truly reflect their needs.

EURORDIS has played an integral role in the development of ERNs, including as a European Commission provider (based on a competitive call for tender) that led the Partnership for Assessment of Clinical Excellence in European Reference Network Consortium (together with HOPE, the European Hospital and Healthcare Federation, and Accreditation Europe ASBL) to develop a two-part manual and toolbox for used by ERN applicants and the independent bodies that assess ERN applications.

EURORDIS is also working to ensure that patients are at the centre of the new networks. Through the creation of [European Patient Advocacy Groups](#) (ePAGs), which bring together members and non-members of EURORDIS, the organisation has structured the rare disease community to ensure that patients are represented at the core of the governance and development of ERNs. By doing so, new European healthcare pathways coming from ERNs will truly reflect the needs of patients.

Democratically elected ePAG representatives (who sit on the Board of their respective ERN) will collect and relay patients view on how ERNs should be governed. There are already **84 highly motivated ePAG representatives** working in collaboration with clinicians and the patients they represent to ensure that ERNs accurately reflect patients' experiences and perspectives.

These ePAG representatives were also involved in all applications that were submitted from networks seeking to become ERNs, thus helping to ensure that all applications incorporated the views of patients. EURORDIS is supporting these partnerships between patient representatives and clinicians so that they have the knowledge and skills needed to advocate for patient-centric ERNs.

### European Reference Networks in practice

The ERNs create a clear governance structure for knowledge sharing and care coordination across the EU. They are networks of centres of expertise, healthcare providers and laboratories that are organised across borders.

They give hope to the rare disease community, hope that the 30 million lives affected by rare diseases in the EU will be improved through diagnosis, care and treatment, which is spearheaded by the collective experience, expertise and knowledge of leading clinicians and researchers.

**Through these networks, nearly 1,000 hospital centres of expertise will be linked, connecting thousands of experts, researchers and doctors.** Medical expertise in a rare disease is often limited and scattered across Europe and rare disease patient populations are small. Through ERNs, doctors and researchers will connect and share their expertise across borders. This will improve clinical excellence and in turn patients' access to better treatment and care pathways in the country where they live. Knowledge sharing and data collection in each ERN will be facilitated through the creation of an IT platform.

### ERN grouping structure

EURORDIS also fervently advocated for the thematic grouping structure of ERNs that has been adopted. It would be impossible to create an ERN per disease; by structuring the ERNs according to thematic disease grouping, it is possible to ensure that no rare disease patient is left behind or excluded from the benefits of the clinical excellence of ERN.

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## EURORDIS-Rare Diseases Europe

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 700 rare disease patient organisations from more than 60 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe.

By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

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## Rare Diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6000 different rare diseases have been identified to date, affecting over 60 million people in Europe and the USA alone. Due to the low prevalence of each disease, medical expertise is rare, knowledge is scarce, care offering inadequate and research limited. Despite their great overall number, rare disease patients are the orphans of health systems, often denied diagnosis, treatment and the benefits of research.

## Press contacts

*Eva Bearryman*

Communications Manager, EURORDIS

Tel: +33 1 56 53 52 61

[Eva.bearryman@eurordis.org](mailto:Eva.bearryman@eurordis.org)

*Lara Chappell*

Communications Director, EURORDIS

Tel: +33 1 56 53 52 60

[lara.chappell@eurordis.org](mailto:lara.chappell@eurordis.org)