



[Statement]

## EURORDIS calls on European Commission to secure UK Healthcare Providers' post-Brexit involvement in European Reference Networks

**16 February 2018, Brussels** – EURORDIS-Rare Disease Europe calls on the European Commission to secure the continuous and sustained involvement of UK healthcare providers as members of the newly established European Reference Networks (ERNs) in the forthcoming Brexit negotiations with the UK government.

This will help to secure strong mutual benefit for both the European Union and United Kingdom, specifically:

- a. Ensuring EU and UK patients benefit from the pooling of scarce expertise in rare and complex diseases through ERNs;
- b. Creating a critical mass of expertise, patients and their data in 'ready-made communities' attracting investment in EU & UK markets, accelerating research and therapeutic innovation development; and
- c. Securing a safe and sustainable specialised workforce through ERN cross-border training and education activities.

Rare diseases do not see borders. Many patients and expertise are often isolated, making it difficult, if not impossible, to access appropriate and often life-saving care and treatment. Whilst rare diseases are rare, the collective incidence of rare diseases is common, affecting an estimated 30 million people living in Europe.

**No one country can solve the problems posed by rare diseases alone and community action between countries is essential to successfully meet the needs of this vulnerable patient population.**

Coordinated and targeted action under the newly established ERNs offers a real and tangible opportunity to draw on the collective expertise and experience of over 900 expert centres, connecting 300 hospitals across 26 Member States, to revolutionise healthcare, break the isolation of patients, reduce health inequality and pave the way for faster diagnosis and access to expert advice, diagnosis and treatment. ERNs offer our community hope that 30 million people lives will be improved through the ERN strategy - **Share, Care and Cure.**

The European Union can take pride in what has been achieved since the EU Commission Communication: Rare Diseases Europe's Challenges (2008) and the EU Council Recommendation on Action in the Field of Rare Diseases (2009) and more recently with the Directive 2011/24/EU on the application of patients' rights in cross-border healthcare.

Through fostering strong collaboration over the past decade between experts, researchers, hospitals and countries, we have created a critical mass, developed competencies and built the infrastructure needed to take affirmative and lasting action to tackle this crucial European health issue.

Rare diseases are rare. And expertise, experience and knowledge is rarer. ERNs have been successful in spearheading the collective intellectual acumen of leading experts and researchers from across the EU who are now members of ERNs:

- 70% of healthcare providers in the ERNs come from France, Italy, Germany, the Netherlands and the United Kingdom.
- 1 out of 4 of the 24 ERNs (6 in total) are led by UK hospitals, with 10% of ERN healthcare provider members coming from UK hospitals (>90).

- The high-level expertise of UK centres and clinicians in a wide range of clinical areas is, and has been for years, extremely valuable to the rare diseases field across Europe.

It is undisputable that each individual expert, researcher or hospital are 'leading lights' for their specialisation, **but they are stronger together under the ERNs.**

The promise ERNs offer should not be constrained by barriers that risk fragmenting collaboration or by taking a step backward to create silos of clinical practice. We have an opportunity to safeguard the intellectual might of ERNs and prevent any loss of expertise from ERNs.

Taking affirmative action now will have a direct and lasting impact on people living with a rare disease, a vulnerable group of EU citizens, preventing the increase of inequalities and as a result ensuring nobody is left behind.

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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. Follow [@eurordis](#) or see the [EURORDIS Facebook page](#). For more information, visit [eurordis.org](#).

## Rare diseases

The European Union considers a disease as rare when it affects less than 1 in 2,000 citizens. Over 6,000 different rare diseases have been identified to date, affecting an estimated 30 million people in Europe and 300 million worldwide. 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.

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