



EURORDIS European Reference Networks Post-Brexit Statement

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EURORDIS calls for the European Commission to secure the continuous and sustained involvement of UK Healthcare Providers, as members of the newly established European Reference Networks, in the forthcoming negotiations with the UK government, securing strong mutual benefit for both European Union and United Kingdom, specifically:

- a. EU and UK patients benefiting from the pooling of scarce expertise in rare and complex diseases under European Reference Networks;
- b. Creating the critical mass of expertise, patients and their data in 'ready-made communities' attracting investment in the EU & UK market, accelerate research and therapeutic innovation development;
- c. Securing safe and sustainable supra-specialised workforce through ERNs cross-border training and education activities.

Rare Diseases do not see borders, many patients and expertise 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 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 European Reference Networks 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 improve through the ERN strategy - Share, Care and Cure.

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 the critical mass, developed our competencies and built the infrastructure needed to take affirmative and lasting action to tackle this crucial European health issue.

Whilst rare diseases are rare, expertise, experience and knowledge is rarer. ERNs have been successful in spearheading the collective intellectual acumen of the leading experts and researchers from across the EU under their membership, with 70% Healthcare Providers (HCPs) Members of the Networks, coming from the France, Italy, Germany, the Netherlands and United Kingdom. 1 out of 4 of the 24 European Reference Networks (6 ERNs) are led by UK hospitals, with 10% ERN HCP Members from UK hospitals (>90 HCP Members). 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.

It is unquestionable, for the rare disease community, that individually each expert, researcher or hospital are 'leading lights' for their specialisation, but together we know more! The promise ERNs offer us should not be constrained through barriers that risk fragmenting collaboration or by taking a backward step creating silos of clinical practice. We have an opportunity to safeguard against diminishing the intellectual might of ERNs, preserve against any loss of scarce experts 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 'leaving no one behind'.