



PRESS RELEASE

Launch of European Reference Networks: connecting doctors to improve healthcare for 30 million rare disease patients across Europe

28 February 2017, Leuven – Today, on the 10th edition of [Rare Disease Day](#), the European Commissioner for Health & Food Safety Vytenis Andriukaitis, launches [24 European Reference Networks \(ERNs\)](#).

The new ERNs start their work on 1 March. They are virtual networks bringing together nearly 1,000 healthcare providers across Europe to tackle complex or rare medical conditions that require highly specialised treatment and a concentration of knowledge and resources. They are being set up under the EU Directive on Patients' Rights in Healthcare ([2011/24/EU](#)).

[See Commissioner Andriukaitis' comments at today's ERN launch event at the University Hospital in Leuven, Belgium.](#)

Yann Le Cam, Chief Executive Officer of EURORDIS-Rare Diseases Europe, commented at the event, “The ERNs are the first concrete demonstration of how cross-border, EU action can bring direct benefits to rare disease patients. Nearly 1,000 healthcare providers will be connected to share their expertise and knowledge of diseases, resulting in direct improvements in diagnosis, care and treatment for patients. 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.”

EURORDIS and the rare disease patient community has advocated tirelessly over the last 10 years for the creation of the ERNs and is now looking forward to seeing the real-life results of these networks to create improvements in healthcare and health outcomes for patients.

Patients are represented at the core of the governance and development of ERNs through the ePAGs ([European Patient Advocacy Groups](#)), created by EURORDIS; democratically elected ePAG representatives will collect and relay patients' views on how ERNs should be governed to the Board of their respective ERN.

In practice

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 – **the expertise will travel, rather than the patient.**

The ERNs will be supported by European cross-border telemedicine tools. Knowledge sharing and data collection in each ERN will be facilitated through a common virtual clinical board. The exchange

of patient information will remain completely confidential. This virtual board can also store clinical data and medical images collected by each network.

To ensure that every one of the thousands of rare diseases that exist is covered by an ERN and that no rare disease patient is left behind or excluded from the benefits of the clinical excellence of ERNs, the networks are organised according to 24 thematic [disease groupings](#).

In practice, ERNs will develop new innovative care models, eHealth tools, medical solutions and devices. They will boost research through large clinical studies and contribute to the development of new pharmaceuticals, and they will lead to economies of scale and ensure a more efficient use of costly resources, which will have a positive impact on the sustainability of national healthcare systems, and for tens of thousands of patients in the EU suffering from rare and/or complex diseases and conditions.

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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.

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