

European Reference Networks

A flagship EU action helping patients with rare, low-prevalence, and complex diseases

What are European Reference Networks (ERNs)?

Established under [Directive 2011/24/EU](#) on patients' rights in cross-border healthcare, the European Reference Networks (ERNs) are virtual networks of healthcare providers established in the European Union (EU) and Norway specialised in treating patients with rare, low-prevalence and complex diseases.

European Reference Networks gather knowledge, experience, and expertise, and support individual health professionals to provide a more accurate diagnosis and the best available treatment.



More than **6 000 rare diseases** affect the daily life of up to 36 million people in the EU.



A rare disease is defined in the EU as one that affects fewer than **5 persons out of 10 000**



Using a dedicated, secure IT platform, patient cases can be evaluated by a team of European experts without requiring patients to leave their own country.

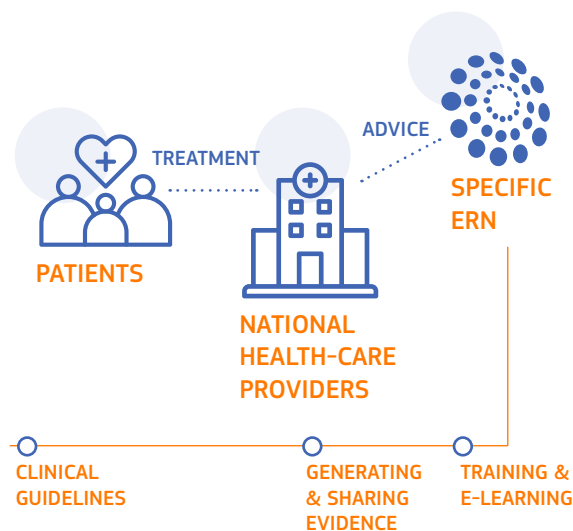
Knowledge travels so that patients don't have to.



European Reference Networks:

- **review individual patient cases** (more than 3 800 to date) by convening virtual discussions among experts belonging to healthcare providers supported by a dedicated, secure IT platform funded by the European Commission. The experts discuss clinical cases to agree on diagnoses and treatments.
- **develop clinical practice guidelines and other clinical decision support tools for a specific rare disease to guide clinicians, and training courses for healthcare providers.**
- **facilitate networking and large clinical studies** that would otherwise be impossible, pooling data across the EU to better understand rare and complex diseases and help develop treatments.
- **develop and maintain rare disease registries** with the data of patients referred to them.
- **involve patients** through European Patient Advocacy Groups, **bringing their voice to the heart of the ERNs' activities.**

The 24 ERNs established so far cover many rare diseases, including rare bone disorders, rare cancers, rare endocrine conditions, rare neurological and neuromuscular diseases, to name a few.



These 24 ERNs were launched in 2017, comprising more than 900 specialised clinical centres located in more than 300 hospitals in 26 Member States.

In 2024, they comprise 1 619 specialised clinical centres located in 382 hospitals across all 27 EU Member States and Norway.



How do patients access ERNs?

With their written consent and following the rules of their national health system, **patient cases can be referred by their healthcare provider to the relevant ERN member** in their country for advice on the establishment of a diagnosis or a treatment.



How do healthcare providers facilitate a virtual discussion?

Healthcare providers may suggest seeking the help of the relevant ERN, after exploring the treatment possibilities existing in their own country.

They can contact members of the ERNs in their own country to have their patient's case referred, but only once a patient provides explicit written consent to referral and sharing his/her healthcare record.

After receiving the request, ERN coordinators can convene a virtual advisory board of specialists across disciplines via a dedicated, secure, IT platform – the CPMS (Clinical Patient Management System) – enabling them to securely share patient data, discuss the case, formulate a diagnosis, and/or prescribe a treatment, if available.

The patient's home healthcare provider remains the patient's single point of contact, discussing experts' input at every step of the diagnosis and treatment.



Onni's story - rare epilepsies

When a four-year-old boy in Finland suffering from 20-30 seizures per day was referred by his doctor to a specialist at the university hospital in Helsinki, a review of his electroencephalogram (EEG) tests and brain magnetic resonance imaging (MRI) led to the diagnosis of a rare form of epilepsy caused by a malformation in his brain. At first, his parents were relieved that it was not a tumour. But the hospital team didn't know much about the boy's type of epilepsy. He was one of only a few people in Finland to have this disease and only a small number of medical centres in the world have experience.

The hospital team approached the ERN 'EpiCARE' for help. With the consent of Onni and his parents, they uploaded Onni's records to the CPMS. A team of specialists from Italy, UK, France, Spain, Romania, Sweden, and the Netherlands reviewed his case and the available research. They recommended cutting-edge GammaKnife® radiosurgery, only available in two centres, as the treatment with the lowest risk and the best chance of success.

Onni and his family travelled to Marseille where the epilepsy team at the University of Marseille is very experienced in this type of surgery. Following the surgery, his condition improved significantly. Although he still has seizures, their number has been drastically reduced.

Fictional example, based on a real ERN patient case



How do healthcare professionals benefit from ERNs?

Healthcare professionals can benefit from virtual discussions of rare disease cases.

In addition, they can access clinical practice guidelines developed by the ERNs, as well as education and training materials and online courses.

Finally, they can participate in researcher exchange programmes, and in large-scale research studies.



Useful links

[European Reference Networks](#) (Europa website)



[ERN Brochure](#) (Publications Office of the EU, 2023)



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Luxembourg: Publications Office of the European Union, 2026

PDF ISBN 978-92-68-34743-0

doi: 10.2875/7059004

EW-01-26-005-EN-N