



European  
Commission

# EUROPEAN REFERENCE NETWORKS

## Helping patients with rare or low-prevalence complex diseases



European  
Reference  
Networks

# Share. Care. Cure.

Health



## WHAT ARE EUROPEAN REFERENCE NETWORKS?

The **European Reference Networks (ERNs)** gather doctors and researchers with high expertise in the fields of **rare or low-prevalence** and **complex diseases**. They are “virtual networks” which discuss the diagnosis and the best possible treatment for patients from all over Europe.

**24 ERNs** were launched in 2017, involving more than 900 **highly specialised healthcare** teams, located in more than 300 hospitals in **26 European countries**.

## CAN EUROPEAN REFERENCE NETWORKS HELP YOU?

The ERNs help patients with rare or low-prevalence complex diseases. A disease is defined as **rare** when it affects fewer than one in 2 000 people, is serious, chronic and often life-threatening. Between **5 000** and **8 000** of **rare diseases** affect daily life of around **30 million people in the EU**.

a number of factors or symptoms and which are not common. They require a **multidisciplinary approach** with several possible diagnoses, are often difficult to test and interpret and/or have a high risk of complications.

For such cases, the **ERNs** can bring the **expertise** that is often **missing within your region** or your country.

Low-prevalence and complex diseases are conditions that combine



## WHICH DISEASES ARE CURRENTLY COVERED BY THE ERNS?

Each of the **24 ERNs** address a specific area of intervention, though they also often work together.

- **ERN BOND**: bone disorders
- **ERN CRANIO**: craniofacial anomalies and ear, nose and throat (ENT) disorders
- **Endo-ERN**: endocrine conditions
- **ERN EpiCARE**: epilepsies
- **ERKNet**: kidney diseases
- **ERN-RND**: neurological diseases
- **ERNICA**: inherited and congenital anomalies
- **ERN LUNG**: respiratory diseases
- **ERN Skin**: skin disorders
- **ERN EURACAN**: adult cancers (solid tumours)
- **ERN EuroBloodNet**: oncological and non-oncological hematological diseases
- **ERN eUROGEN**: urogenital diseases
- **ERN EURO-NMD**: neuromuscular diseases
- **ERN EYE**: eye diseases
- **ERN GENTURIS**: genetic tumour risk syndromes
- **ERN GUARD-HEART**: diseases of the heart
- **ERN ITHACA**: congenital malformations and rare intellectual disability
- **MetabERN**: hereditary metabolic disorders
- **ERN PaedCan**: paediatric cancer
- **ERN RARE-LIVER**: hepatological diseases
- **ERN ReCONNET**: connective tissue and musculoskeletal diseases
- **ERN RITA**: immunodeficiency, autoinflammatory and autoimmune diseases
- **ERN TRANSPLANT-CHILD**: conditions and complications linked to the transplantation in children
- **VASCERN**: rare multisystemic vascular diseases



## HOW DO YOU ACCESS THE EUROPEAN REFERENCE NETWORKS?

Your doctor will advise you on the appropriate **level of care**, for your illness. After having explored the possibilities within your own region or country and following a personalised analysis of your specific situation, your doctor may suggest cooperation with the relevant ERN.

Your doctor remains your **single point of contact** if you are referred to an

ERN. Yet, they will have access to the ERN expertise, can **share data**, collect the experts' input and discuss it with you at every step of the diagnosis and treatment.

**Please note that each country has specific rules** and arrangements for the referral of patient cases to other specialists, and notably to ERNs.





## HOW DOES A EUROPEAN REFERENCE NETWORK HELP YOUR TREATMENT?

### VIRTUAL ADVISORY BOARD

When your case goes to an ERN, your doctor will convene a “**virtual**” panel of medical experts from across different disciplines and countries. They share your medical information, including for example CT scans, lab tests, X-rays, and analyse and discuss it together. Your doctor can therefore collect input from other colleagues and use it to improve your diagnosis or to find the best possible treatment for you.

### CLINICAL PATIENT MANAGEMENT SYSTEM

ERN members use a dedicated IT platform - the Clinical Patient Management System (CPMS) - for **sharing data** and discussing them, which has been specifically designed for this purpose.

Your data is only entered into this system with your explicit, written consent. Specific measures protect and

safeguard **personal data**, in accordance with European data protection law. You may additionally agree for your data to be used for research purposes and/or to set up registries, which will help the research in this field. This will require a separate consent from your side.

### OTHER WORK

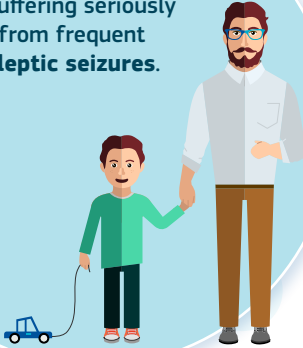
ERN specialists do not only discuss individual cases. They also invest in **joint research** activities, **work together** on clinical guidelines and organise trainings for healthcare professionals.

### PATIENTS ARE REPRESENTED WITHIN THE ERNS

The **patients** are the **core** of the ERNs. Patients’ organisations are key partners and played an important role in the creation of the ERNs. They help to work towards better accessibility, clinical excellence and patient outcomes.

# DAVID'S STORY

David is a 4-year old boy suffering seriously from frequent **epileptic seizures**.



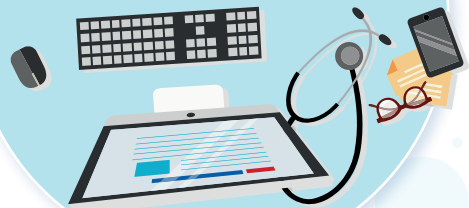
David's doctor refers him to a **specialist** in the **university hospital** in the capital for a better **diagnosis** and **treatment**.



**EEG tests** and brain MRIs explain the **epileptic seizures**, but the expertise of the hospital team is too limited to choose the right treatment. They decide to consult the **ERN "EpiCARE"**.



The hospital team enters david's file into the online system, with the consent of David and his family.



**Specialists** from Italy, France, Spain, Romania, Sweden and the Netherlands **analyse** the case and discuss the different options.



Based on similar recent cases, the **panel advises** to use a **specific radiosurgery** operation technique.

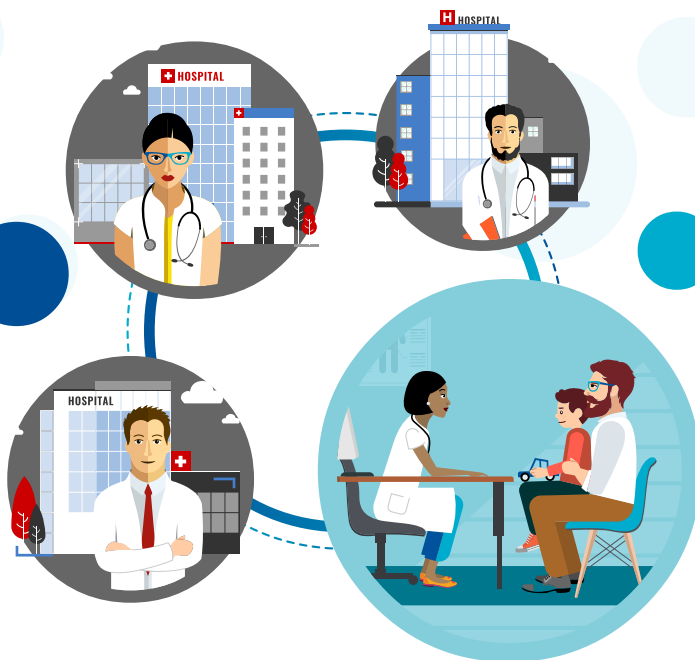


David gets operated, with a **significant improvement** of his condition in the following months.



*Fictional example, based on a real ERN patient case in 2018*

<https://ec.europa.eu/avservices/video/player.cfm?sitelang=en&ref=I164244>



## MORE INFO

**General on ERNs:**  
[ec.europa.eu/health/ern](http://ec.europa.eu/health/ern)

**Information on the ERNs in Ireland:**  
<http://www.rarediseases.ie/>

**Patient info on cross-border healthcare:**  
[europa.eu/youreurope/citizens/health/planned-healthcare/get-more-info](http://europa.eu/youreurope/citizens/health/planned-healthcare/get-more-info)