



Treatment Abroad Section  
National ERN Coordinator MDH  
Administration Block  
Mater Dei Hospital  
Msida MSD 2090

Tel: (+356) 2545 7158

[carol.fenech.1@gov.mt](mailto:carol.fenech.1@gov.mt)

---

## Information about ERNs

### What are European Reference Networks?

European Reference Networks (ERNs) are virtual networks involving healthcare providers across Europe. They aim to facilitate discussion on complex or rare diseases and conditions that require highly specialised treatment, and concentrated knowledge and resources. This system facilitates equality of care for patients with complex or rare diseases within the European Union.

### Who benefits?

- Patients with complex or rare diseases
- Clinicians and Healthcare Professionals
- Researchers in the field of complex and rare diseases
- Countries where there is no specialisation in the field of the specific complex and rare disease

### How does it work?

- To review a patient's diagnosis and treatment, ERN coordinators convene 'virtual' advisory panels of medical specialists across different disciplines, using a dedicated IT platform and telemedicine tools.
- The process and criteria for establishing an ERN and for selecting its members are set in EU legislation.
- Check the brochure for more information: [European Reference Networks \(ERNs\) \(europa.eu\)](http://europa.eu)

### How can I be referred?

Locally a patient with a Rare Diseases/condition needs to be referred for discussion with the ERNs by the Consultant through a standard procedure similar to the Treatment Abroad referral procedure

### What is the role of Mater Dei Hospital in the ERNs?

MDH is the National coordinating hub for all the current 24 European Reference Networks and is an Affiliated Partner in all the ERNs. A National Coordinator for ERNs who is part of the Treatment Abroad Section within MDH is the focal point for all ERN and CPMS based activities. Carol Fenech can be reached on 25457158 or on email: [carol.fenech.1@gov.mt](mailto:carol.fenech.1@gov.mt) for further information.

### What is the CPMS?

The Clinical Patient Management System is an online tool developed by the EU so that networking among the different Clinicians is possible through the ERNs

### Is Patient data safe when uploaded online?

The CPMS is a safe environment where patient information can be shared in a secure and protected manner. Patient personal information is not uploaded and the data provided online is of the rare disease. All data is therefore anonymised and there is no risk of data protection infringement. The patient may also give consent to be contacted for research purposes and to be listed in the Rare Disease register. No data is processed without prior patient's consent

## ERNs

The first ERNs were launched in March 2017, involving more than 900 highly-specialised healthcare units from over 300 hospitals in 26 EU countries. These will double in the coming year because a new membership drive has been launched because of the success of the networks. 24 ERNs are working on a range of thematic issues including bone disorders, childhood cancer and immunodeficiency. All ERNs have a website with all the required information per network including the rare diseases covered and the Members and affiliated partners involved. The following list of ERNs has been approved: -

ERN BOND – Bones <https://ernbond.eu/>

ERN CRANIO - Craniofacial anomalies and ear, nose and throat (ENT) <https://ern-cranio.eu/>

ENDO-ERN – Endocrine Conditions <https://endo-ern.eu/>

EpiCARE – Epilepsies <https://epi-care.eu/>

ERKNET – Kidneys <https://www.erknet.org/>

ERN-RND – Neurological Diseases <https://www.ern-rnd.eu/>

ERNICA – Inherited and congenital anomalies <https://ern-ernica.eu/>

ERN LUNG – Respiratory diseases <https://ern-lung.eu/>

ERN-Skin – Skin disorders <https://ern-skin.eu/>

EURACAN – Rare adult cancers (solid tumours) <https://euracan.eu/>

ERN-EuroBloodNet – Haematological diseases <https://eurobloodnet.eu/>

EURO-NMD – Neuromuscular diseases <https://ern-euro-nmd.eu/>

ERN-EYE – Eyes <https://www.ern-eye.eu/>

ERN GENTURIS – Genetic tumour risk syndromes <https://www.genturis.eu/l=eng/Home.html>

GUARD-HEART – Diseases of the heart <https://guardheart.ern-net.eu/>

ERN ITHACA – Rare congenital malformations and rare intellectual disabilities <https://ern-ithaca.eu/>

MetabERN – Hereditary metabolic conditions <https://metab.ern-net.eu/>

ERN PaedCan – Paediatric Cancer (Haematology) <https://paedcan.ern-net.eu/>

Rare-LIVER – Hepatological diseases <https://rare-liver.eu/>

ReCONNET -Connective tissue and musculoskeletal diseases <https://reconnet.ern-net.eu/>

RITA – Immunodeficiency, autoinflammatory and autoimmune diseases <https://ern-rita.org/>

TransplantChild – Transplantation in children <https://www.transplantchild.eu/>

VASCERN – Rare multisystemic vascular diseases <https://vascern.eu/>

EUROGEN – Urogenital diseases and conditions <https://eurogen-ern.eu/>

## Clinical Focal Points

Each ERN has its local Clinical focal points all based at MDH. Please contact Carol Fenech, National Coordinator for ERNS at MDH for further information on 25457158 or email her on [carol.fenech.1@gov.mt](mailto:carol.fenech.1@gov.mt)

## Legislation

- [Directive 2011/24/EU](#) on patients' rights in cross-border healthcare
- Commission [delegated decision \(annex\)](#) defining the criteria and conditions that healthcare providers and the ERNs should fulfil
- Commission [implementing decision \(annex\)](#) defining criteria for establishing and evaluating ERNs
- Commission [Implementing Decision \(EU\) 2019/1269](#) of 26 July 2019 amending [Implementing Decision 2014/287/EU](#)

The ERN initiative receives support from several EU funding programmes, including the [Health Programme](#), the [Connecting Europe Facility](#) and [Horizon 2020](#).

## Coordination

The ERN initiative is mainly driven by EU countries. The Board of Member States is the formal body in charge of the approval and termination of networks and memberships as provided in the Commission's Implementing Decision. The Board is comprised of representatives of all EU countries and EEA countries.

## Monitoring system

18 ERN indicators for the [ERN monitoring system](#) were adopted by the Board of member States and presented at the [4th ERN Conference](#).

This framework will help build a quality improvement system, define appropriate outcomes of the ERNs and identify areas of success and potential pitfalls and to demonstrate the added value of the ERNs.

## Communication material

- [Information flyer for patients and healthcare professionals](#) (all EU linguistic versions available)
- [Flyer](#) (all EU linguistic versions available)
- [Brochure](#) (all EU linguistic versions available)
- Video clips:
  - [Rare diseases: how the European Reference Networks support patients](#)
  - [Rare diseases: how the European Reference Networks support health professionals](#)
  - [ERN featured in the « EU protects » campaign, how the EU connected experts to treat epilepsy](#)
  - [Information video for patients and healthcare professionals](#) (available with subtitles in all EU languages and Norwegian)
  - [The stories of Elisa, Paula, Jasper and Daniel](#) (available with subtitles in all EU languages and Norwegian)
  - [Presentation of the ERNs](#) (Video clip available in all EU languages and Norwegian, with or without subtitle)

## Learning opportunities and networking

The ERNs also provide and promote learning through webinars, courses and exchange programmes to clinicians and healthcare professionals in tertiary centres who are also members of the ERNs, as well as collaborations and networking initiatives amongst healthcare professionals on the ERNs respective rare disease group.