Virtual Consultations

All European physicians can access a virtual consultation with Endo-ERN experts and their multidisciplinary teams (MDT) by using the Clinical Patient Management System (CPMS).

A virtual consultation can be used to:

- Establish a diagnosis
- Discuss possible new treatments or treatments not available locally
- Optimize and improve existing treatment

The Endo-ERN experts and MDT team convene a patient panel with the information provided by the treating physician via the CPMS platform. After discussing the case in-depth, the experts can issue a report on the discussion to the treating physician with recommendations to help them manage the patient's care and possible diagnosis.
CPMS allows the patient to access international rare disease experts and receive support from their local treating physician. No international travel required.

Find out more about virtual consultations.

What is Endo-ERN

Endo-ERN is a network of **100+ Reference Centres** (RCs) in **28 EU member states** that offers access to clinical experts for patients with rare endocrine conditions.

Sign up for our newsletter to be kept up-to-date on Endo-ERN activities

What is a rare disease / condition?

Between 5,000 and 8,000 rare diseases affect the daily lives of around 30 million people in the EU. With the diversity of diseases and conditions this is 1 in every 2000 people in the EU.

Find an Expert

RareEndoERN

endo-ern.eu

Endo-ERN is Funded by the European Union

European
Reference
Network

Endo-ERN
European Reference Network
on Rare Endocrine Conditions

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endo-ern.eu

Why European Reference Networks (ERNs)?

Health systems in the European Union aim to provide high-quality, cost-effective care, but this is particularly difficult with rare conditions. ERNs were created by the European Commission to ensure accessibility of expertise and that, when it comes to rare diseases, the medical knowledge and expertise travel, rather than the patients.

Clinical Practice Resources

Accessing experts through virtual consultations improves accessibility of care for patients with rare endocrine conditions. Endo-ERN experts are also developing clinical practice guidelines and clinical decision support tools on an ongoing basis. These expert-led tools will facilitate the harmonization of clinical practice, and improve patient outcomes in the long-term.

Registries

EuRREB
European Registries for Rare Endocrine and Bone conditions

The aim of the registries is to offer patients, health care professionals, and researchers the opportunity to participate and use high-quality, patient-centred registries for rare endocrine and bone/mineral conditions.

e-REC (e-reporting)

This registry only captures new clinical encounters and no personal data. e-REC allows continuous reporting of core indicators of activity and enables clinical networks to objectively map the conditions.

Core Registry

Core Registry captures Patient Reported Outcome Measures (PROMs) and allows a clinician to monitor a patient for a longer period. It also includes Condition Specific Modules which cover the work of dedicated multidisciplinary study groups.

Find out more about EuRREB.

Main Thematic Groups

All activities within Endo-ERN are organized by Main Thematic Group (MTG). The MTGs were established according to the usual classification of endocrine conditions.

1. Adrenal
2. Disorders of Calcium & Phosphate Homeostasis
3. Genetic Disorders of Glucose & Insulin Homeostasis
4. Genetic Endocrine Tumour Syndromes
5. Growth & Genetic Obesity Syndromes
6. Hypothalamic and Pituitary Conditions
7. Sex Development & Maturation
8. Thyroid

Find out more about Main Thematic Groups.

Training & Education

Endo-ERN members are very active and share their expertise in a variety of ways including:

- Webinars
- Endorsed Events
- Educational Library
- Clinical trials
- Publications

European Patient Advocacy Group (ePAGs) & Patient Information

ePAGs are members of our work packages and MTGs and bring the experience of the patient to every activity that we are engaged in.

They also bring patient information that might be useful for your patients.

Patient Information