



Endo-ERN

European Reference Network  
on Rare Endocrine Conditions



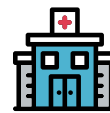
European  
Reference  
Network

# RARE DISEASE DAY 28 FEBRUARY 2023

**1 IN 2000**  
**PEOPLE**  
LIVE WITH A RARE DISEASE

Did you know that **rare diseases** affect the daily lives of up to **36 million** people in the EU?

**This hospital** is a member of **Endo-ERN**, a virtual network of 111 Reference Centres (RCs) in 28 countries\* that offer access to clinical experts for patients with **rare endocrine conditions**.



111

Reference  
Centres

The objective of **Endo-ERN** and all European Reference Networks (ERNs) is to ensure that it is the **medical knowledge and expertise that travel, rather than the patients**.



28

Countries

## Secure Virtual Consultations

with international experts, no travel required using the Clinical Patient Management System (CPMS).



## Rare Disease Registries

offer access to high-quality, patient-centered registries for rare endocrine conditions. The European Registries For Rare Endocrine Conditions are called EuRECa.



## European Patient Advocacy Groups (ePAGs)

represent patients within Endo-ERN. The ePAGs help communicate the availability of virtual consultations, rare disease registries and helpful patient information to their members.



## Rare Disease Research

including an overview of studies by our members and a listing of associated publications.



## Training & Education

Involves knowledge sharing between our members in-person (Exchange Programme) and on-line (webinars).



[www.endo-ern.eu](http://www.endo-ern.eu)

Do you want to know more  
about Endo-ERN?  
Sign up for our newsletter!



\*Total includes 14 affiliated partners