



Endo-ERN

European Reference Network
on Rare Endocrine Conditions



European
Reference
Network

Contact

Endo-ERN Coordinating Center:
Amsterdam UMC
The Netherlands
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www.endo-ern.eu

What are European Reference Networks?

Virtual expert networks that aim to tackle complex or rare diseases. The cooperation between expert healthcare centres will cause the expertise to travel, rather than the patients.

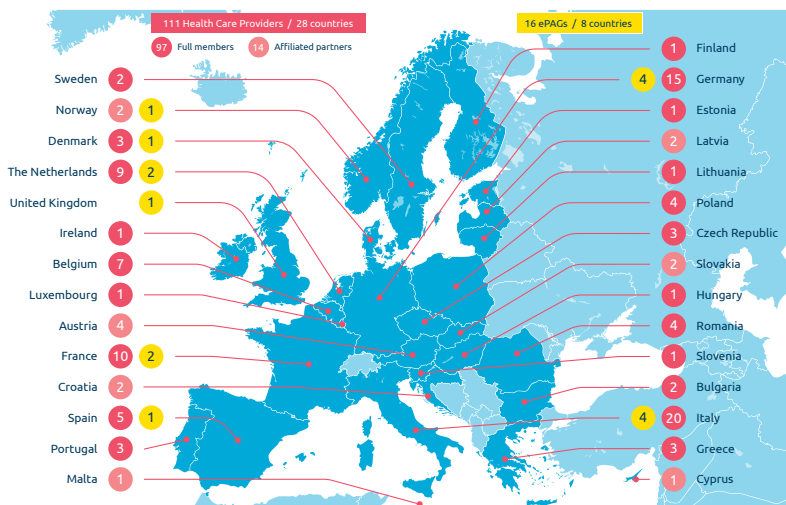
This is possible with the use of the CPMS (Clinical Patient Management System), a virtual consultation platform, that is operational since 2018.

Which (groups of) diseases are covered by Endo-ERN?

- 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

Where can you find us?

Endo-ERN has collaborating reference centres in 28 countries and patient advocacy group representatives (ePAGs) from 8 countries.



Check out www.endo-ern.eu for more information!



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What can we do for you?

Endo-ERN's mission is to reduce and ultimately abolish inequalities in care for patients with rare endocrine conditions in Europe.

Increase awareness amongst general public and health care professionals by:

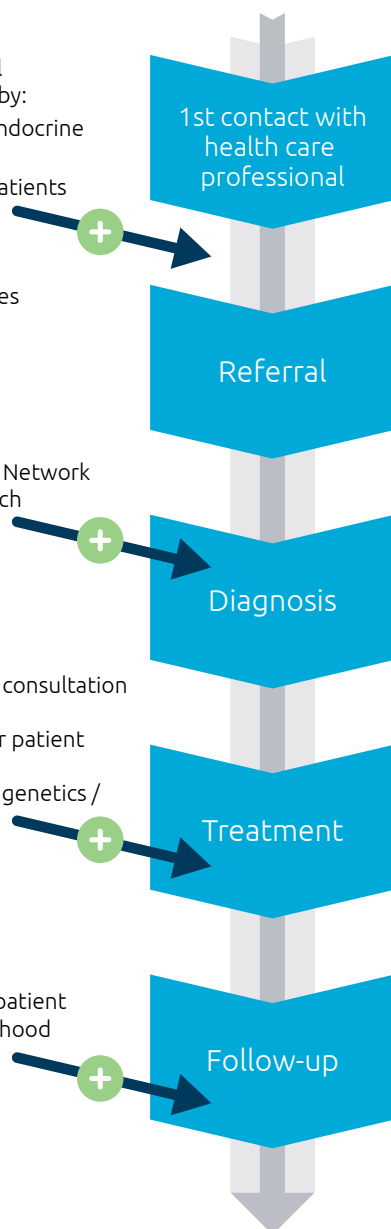
- Dissemination of information on endocrine conditions
 - Collaboration of Network with patients associations
 - Conferences
 - Network website
 - Actions towards health authorities

- Guidelines
- Individual care plan defined by the Network
- Facilitation of clinical trials / research

Shorten delay in diagnosis by:

- Multidisciplinary diagnostic expert consultation
- Use of telemedicine
- Patient pathway monitoring (tracer patient method)
- Access to specific diagnostic tools: genetics / lab-hormonal measurements

- Education of patients
- Instructions to GP's following the patient
- Transition from childhood to adulthood
- QoL surveys
- Training of delegates
- Prevention of complications and co-morbidities



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