

MTG1 HCP meeting

Tuesday 25 November 2025

11:00 – 12:00 CET

MTG1 chairs:

Svetlana Lajic, Nicole Reisch, Manuela Brösamle, Marc Büdenbender, Giorgio Dal Maso, Jette Kristensen, Alessandro Lazzerini, Laura Maag, Zuzana Smith



Funded by
the European Union

WP1 Management & Coordination

Endo-ERN General Assembly 2026

- 10th Endo-ERN GA: 20–21 Apr 2026, Athens (Crowne Plaza). Invitations sent in Oct to main/sub reps. Details [here](#).

MTG1 meetings for 2026

- We are working to expand participation in these meetings, and careful planning will be important to increase attendance.
- There will be an MTG1 meeting at the GA 2026, where the MTG1 chairs will inform attendees of the dates of the next two online meetings in 2026.
- Topics to be discussed at the GA2026?

WP1 Management & Coordination

Upcoming Events:

- Visit [Endo-ERN](#) › Upcoming events for all dates



Upcoming Events

FUNCTIONING NEUROENDOCRINE TUMOUR SYNDROMES: BIOCHEMICAL, GENETIC, IMAGING WORKUP AND THERAPEUTIC MANAGEMENT

November 6th – November 8th, 2025

Recordati Rare Diseases Foundation is hosting a European Society of Endocrinology (ESE) endorsed course that is suitable for endocrinologists, nuclear medicine, physicians, pathologists, and oncologists. [...]



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REGISTRO: Aggiornamento in tema di ipopituitarismo (Update on hypopituitarism)

December 2nd, 2025

This event will be conducted in Italian. Serie di Webinars SIE-SIEDP sulle malattie endocrine rare per specialisti italiani (Joint SIE-SIEDP webinars in rare endocrine diseases: [...])

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SAVE THE DATE: European Neuroendocrine Association

December 3rd – December 5th, 2025

Check out the programme of this 9th workshop organised by the European NeuroEndocrine Association. The theme of the event is Changing the Paradigms Over 20 [...]

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REGISTER: International Conference on Clinical Research Networks for Rare Diseases

December 9th – December 10th, 2025

Reigster now for the 2nd International Conference on Clinical Research Networks for Rare Diseases, organised by IRDiRC, ERDERA, and Rare Diseases International. This event will [...]

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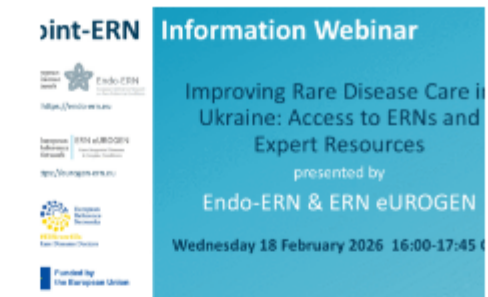


REGISTER: Joint-ERN Information Webinar for Ukrainian Physicians

February 18th, 2026

👉 Endo-ERN & ERN eUROGEN Collaborative Event Improving Rare Disease Care in Ukraine: Access to European Reference Networks (ERNs) and Expert Resources ⓘ Wednesday 18 [...]

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SAVE THE DATE: Rare Endocrine Diseases Winter School, Varna, Bulgaria

February 28th – March 3rd, 2026

Save the date and look out for more information in the coming weeks. This Winter School will feature international speakers from Endo-ERN. A small group [...]

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REGISTER: Corticotroph tumors and Postoperative Quality of Life – Perspectives from a Neurosurgeon, an Endocrinologist and a Patient

March 24th, 2026

Register now for a webinar from MTG6 planned for Tuesday, 24 March 16:00–18:00 CET. Webinar Chair: Prof. Nienke R. Biermasz Endo-ERN MTG6 Adult Chair Agenda [...]

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SAVE THE DATE: Endo-ERN General Assembly (GA)

April 20th – April 21st, 2026

Dates: Monday 20 and Tuesday 21 April 2026 Location: Athens, Greece Programme: Start: Monday, 20 April 2026 9:00 starting with SC/AB Meeting followed by general [...]

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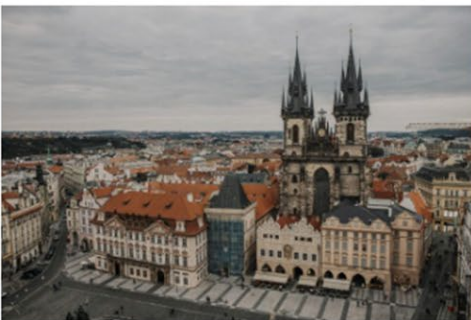


SAVE THE DATE: European Congress of Endocrinology (ECE) 2026


This event will be from May 9th to May 12th, 2026

The European Congress of Endocrinology (ECE) will take place in **Prague, Czech Republic, from 9 – 12 May 2026.**

Save the Date! Further details will be announced in due course.



Event summary

Event	European Congress of Endocrinology (ECE) 2026
Date	May 9 th – May 12 th , 2026
Location	Prague, Czechia
Organisation	European Society of Endocrinology (ECE)
Website	Visit event website
WP	WP6 Education and Training
	Add this event to your calendar

SAVE THE DATE: European Society of Paediatric Endocrinology (ESPE) 2026


This event will be from September 8th to September 10th, 2026

Save the date for the 64th ESPE 8-10 September, 2026 to be held in Marseilles, France.



More information will be available closer to the event.

Event summary

Event	European Society of Paediatric Endocrinology (ESPE) 2026
Date	September 8 th – September 10 th , 2026
Location	Marseilles, France
Organisation	European Society for Paediatric Endocrinology
	Add this event to your calendar

WP2 Communication & Dissemination

- New publications, materials or events to be endorsed/updated/disseminated
- Please follow Endo-ERN at our socials:

<https://www.linkedin.com/company/rareendoern>
<https://www.facebook.com/rareendoern>
<https://www.youtube.com/@rareendoern>
www.endo-ern.eu

WP3 Evaluation



- Evaluation allows for continuous improvement and sharing of best practices across the network. For Endo-ERN members there is self-evaluation annually, and an external review as part of the AMEQUIS cycle, every 5 years.
- Attendance at MTG-specific meetings is expected for all HCPs and counts toward performance scoring. If you cannot attend, please forward the invite to a colleague to attend on behalf of your HCP.
- Ensure that HCP members are entering data into e_REC for the continuous monitoring process
- Please feedback any challenges you are having

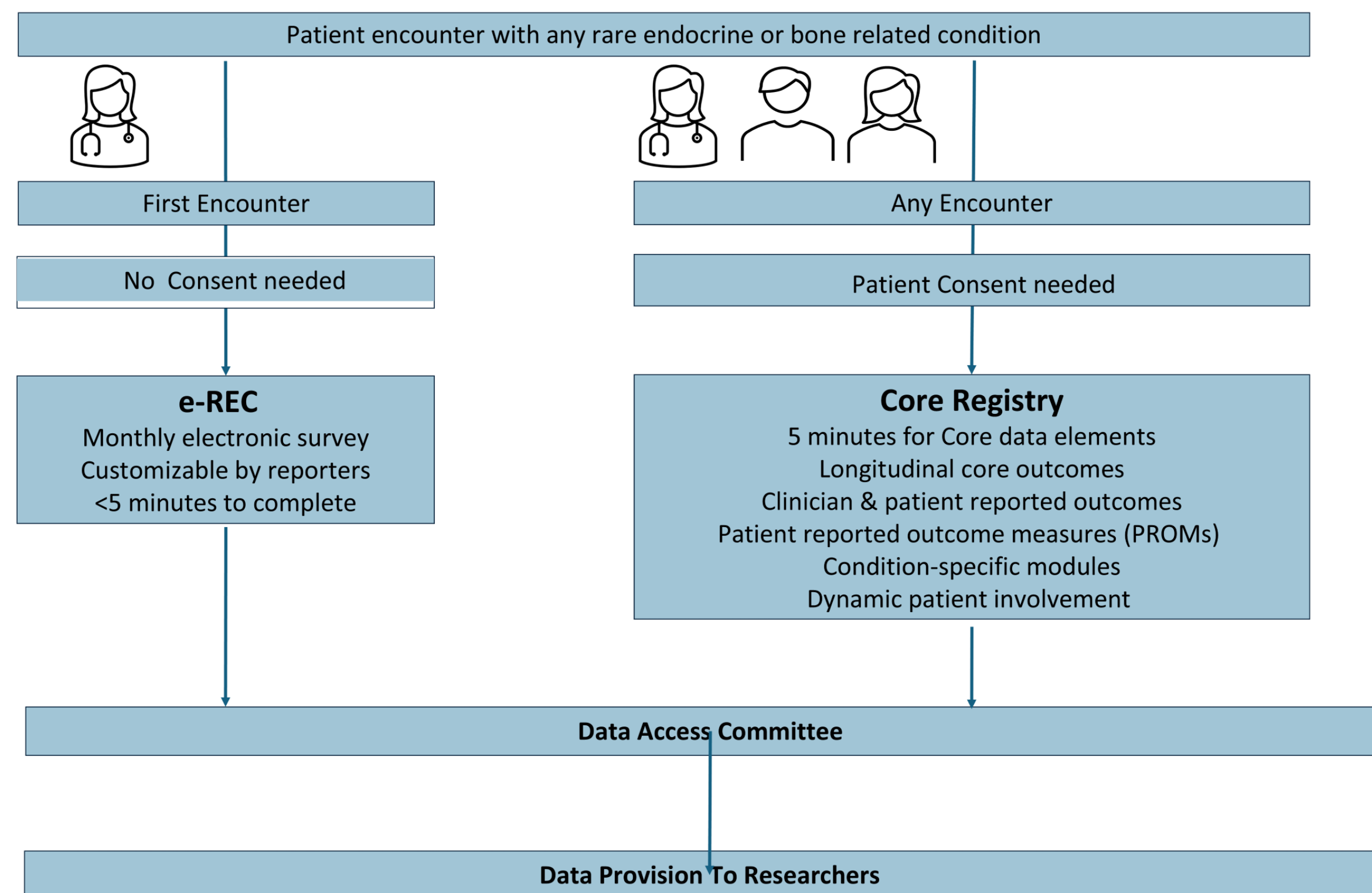
WP4 CPMS

WP5 Registries

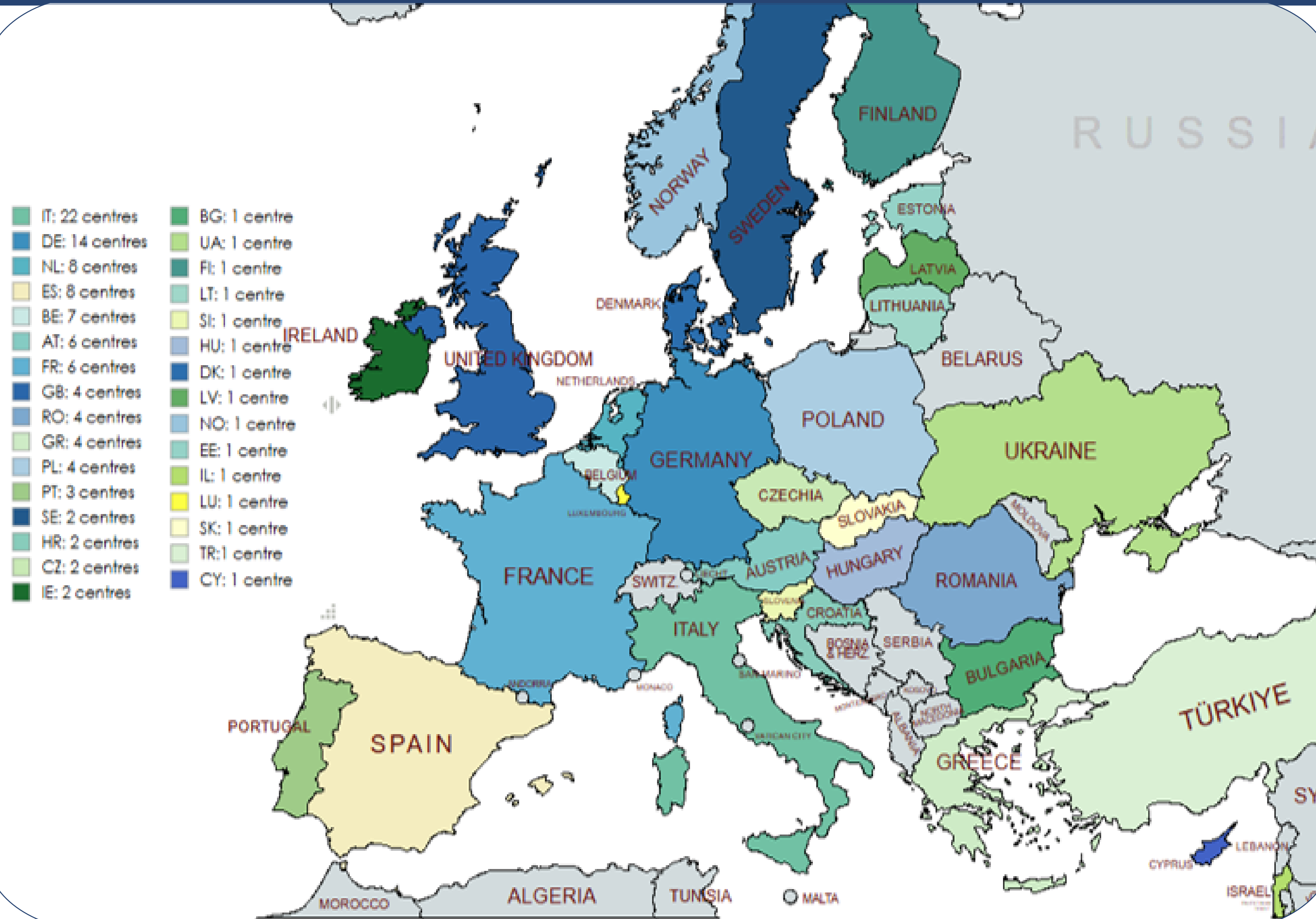
EuRREB registry

- There are several disease specific modules under construction.

The Registries in a Nutshell



Centres Reporting in e-REC



July 2018 – December 2024

Active reporters:

113 centres from 32 countries
(5 non-EU)

HCPs ERN affiliation

Endo-ERN only - **62**

Endo-ERN and ERN-BOND - **29**

ERN-BOND only - **3**

Not affiliated to either – **19**

Number of patients in e-Rec:

56573 cases

(41933 in adults, 14640 in children)

Full report at eureb.eu



WP6 Education & Training

- Current Clinical exchange Program call open until 30 November
- Have a webinar topic for 2026? Send your suggestions to adrenal@endo-ern.eu

WP6 Education & Training



- MTG1 involvement in Winter School, Varna, Bulgaria

SAVE THE DATE: Rare Endocrine Diseases Winter School, Varna, Bulgaria

This event will be from February 28th to March 3rd, 2026

Save the date and look out for more information in the coming weeks. This Winter School will feature international speakers from Endo-ERN. A small group of a maximum of 30 participants will be treated to a diverse sessions including lecturers, case presentations, roundtable discussions and plenty of time to interface with international experts.

Event summary

Event	Rare Endocrine Diseases Winter School, Varna, Bulgaria
Date	February 28 th - March 3 rd , 2026
Time	13:30 – 11:30 hr
Location	Varna, Bulgaria
Contact	
WP	<div>WP6</div> Education and Training

[Add this event to your calendar](#)

WP7 Clinical Practice Guidelines & Clinical Decision Support Tools

Topics for next guidelines chosen:

- Primary hypoadrenalism, focus on treatment and monitoring target
- Hypothalamic obesity treatment and management (of craniopharyngioma) in children and adults
ESE have initiated same topic, have responded positively to collaboration with Endo-ERN and ESPE
- Update on the 3rd CPG on transition



WP8/9 Capacity building and best practice sharing for Ukraine

Any contacts with Ukrainian endocrinologists?

REGISTER: Joint-ERN Information Webinar for Ukrainian Physicians

This webinar will be on February 18th, 2026

👉 Endo-ERN & ERN eUROGEN Collaborative Event

Improving Rare Disease Care in Ukraine: Access to European Reference Networks (ERNs) and Expert Resources



📅 Wednesday 18 February, 16:00–17:45 CET / 17:00–18:45 EET

📍 Online (Zoom, English with Ukrainian live captions)

This joint webinar will explore how Ukrainian clinicians and patient representatives can collaborate with European Reference Networks (ERNs) to strengthen rare disease care. The programme will introduce the ERN system, feature insights from **Endo-ERN** and **ERN eUROGEN**, and outline how to engage through the **Clinical Patient Management System (CPMS)**.

Speakers include **Tetiana Kulesha**, ePAG representative from **Orphan Diseases of Ukraine**, with additional speakers to be confirmed. A case example and Q&A are planned to illustrate how ERNs connect expertise across Europe to benefit patients in Ukraine.



European
Reference
Network



Endo-ERN