ENDO ERN GA

MTG8 HCP meeting
Athens, 21st April 2026

MTG8 chairs

Edward Visser, Athanasia Stoupa, Beate Bartès, Esther Bloem

Funded by
the European Union

WP1 Management & Coordination

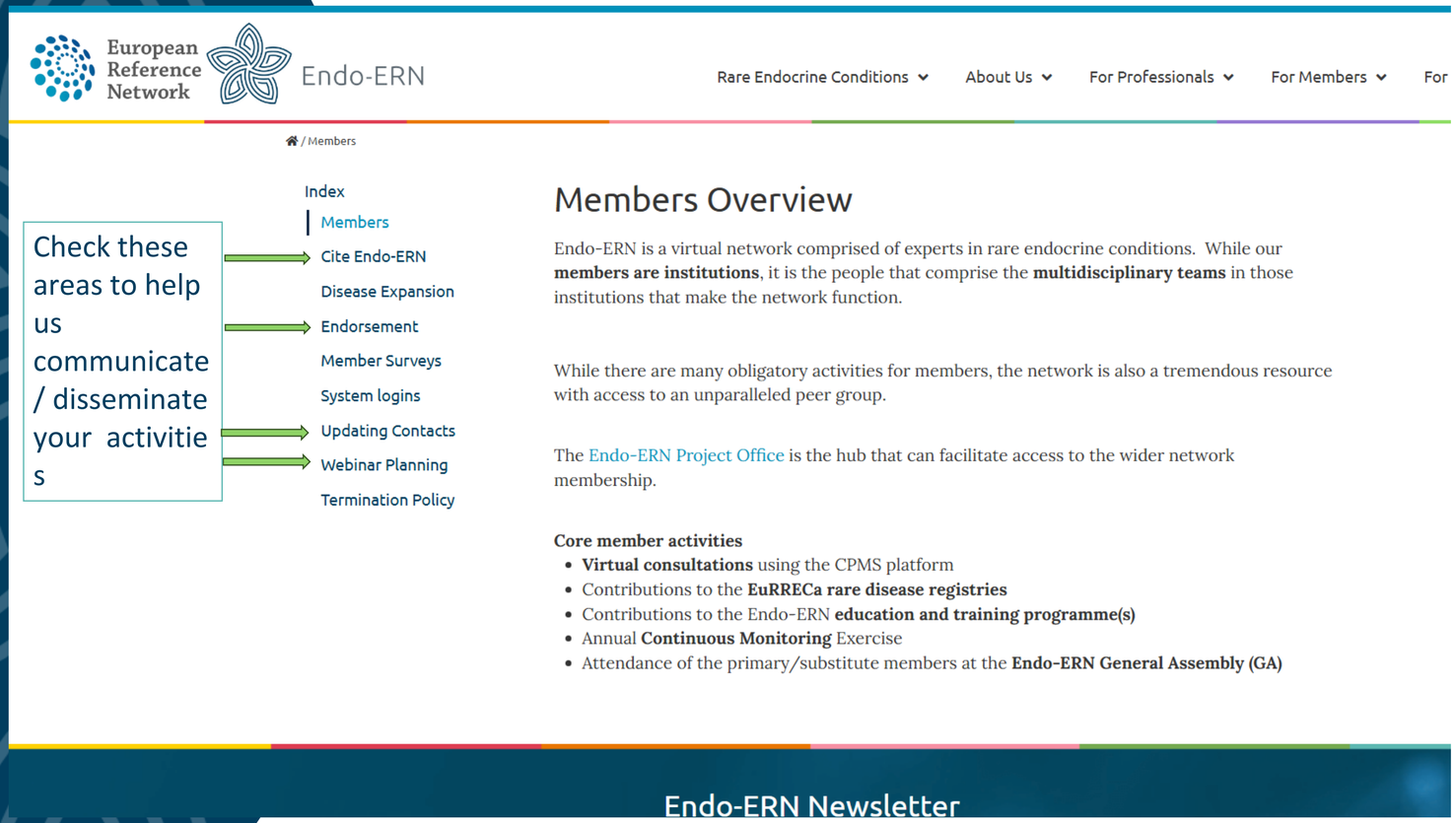
HCP MTG8 meeting 2026 - *3 per year*

Q1: 28th January 2026

Q2: General Assembly - Athens, 20-21 April 2026

Q3: 14th of September 4 pm

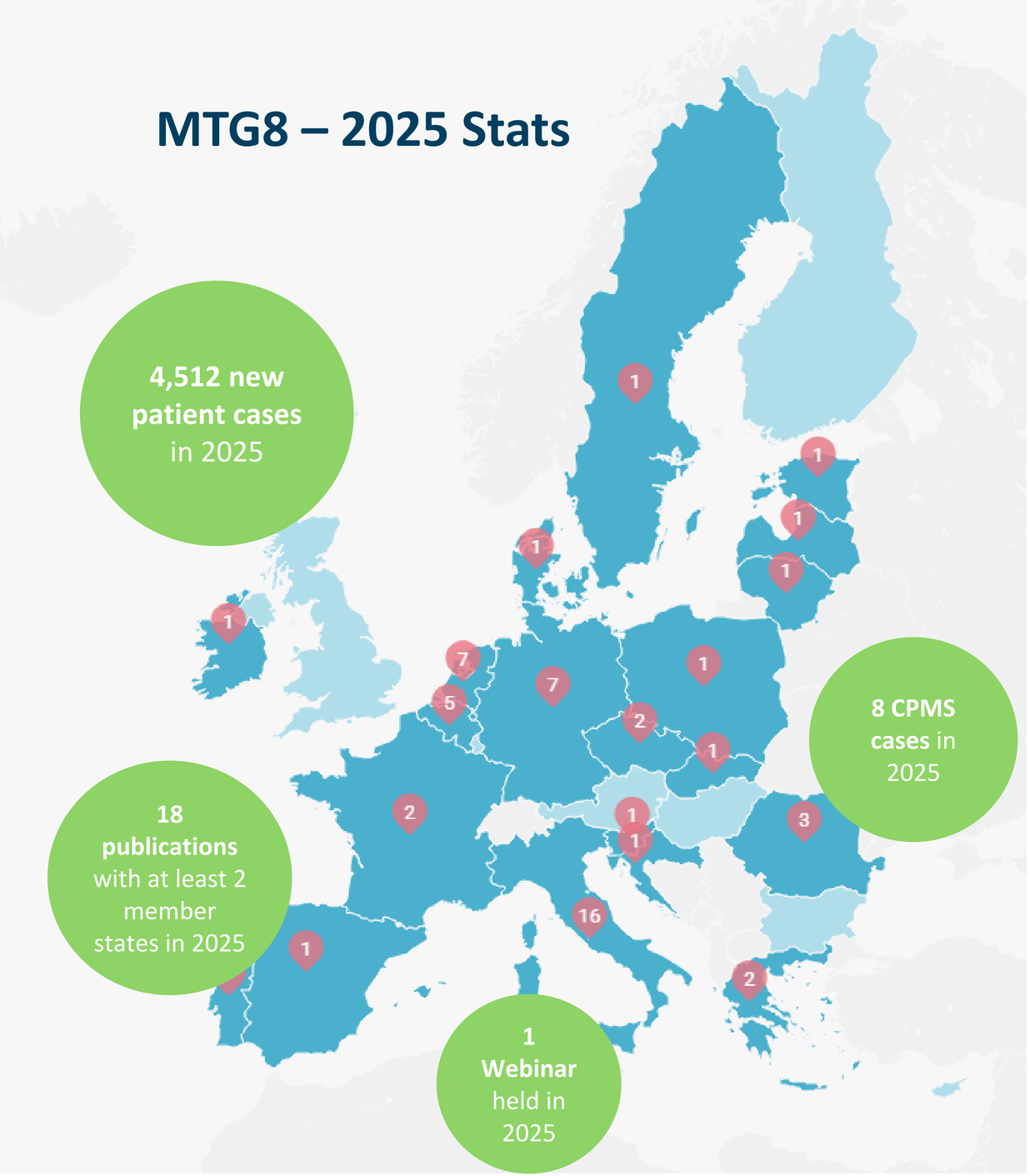
WP2 Communication & Dissemination



Check these areas to help us communicate / disseminate your activities

Has everyone subscribed to newsletter/ LinkedIn?

MTG8 – 2025 Stats



4,512 new patient cases in 2025

8 CPMS cases in 2025

18 publications with at least 2 member states in 2025

1 Webinar held in 2025

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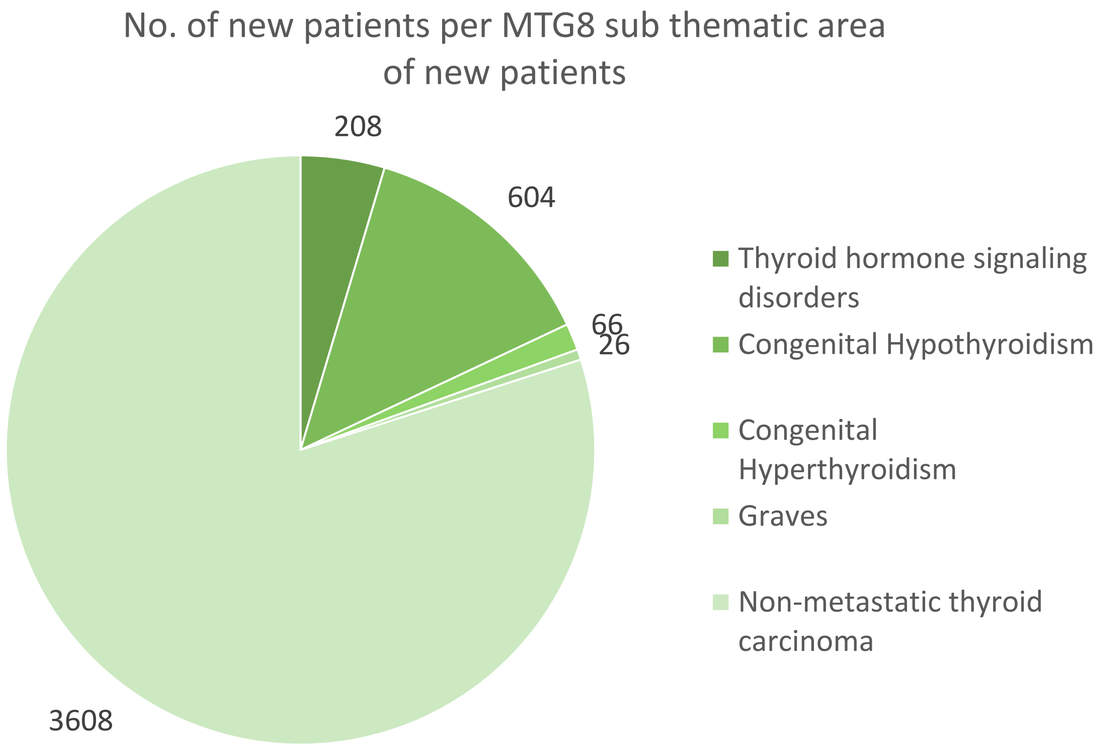
WP3 Evaluation



MTG8 HCPS - 2025 Stats

54 HCPS in MTG8 formally

52 HCPs reporting in **e-REC** registry

45 HCPs reported they attended at least 1 **MTG meeting**

29 HCPs participated in at least 1 **CPMS panel**

- 36 HCPs have **different** EC & e-REC totals
- 9 HCPs **do not have** Endo-ERN logo/url at their website
- 15 HCPs who did not measure patient satisfaction – this is based on your HCP **NOT your department** usually

WP4
Healthcare & CPMS

Next meeting: **Wednesday 1st July @09:00 CET**

Who will present case/ care topic in next 2 meetings?

REMINDER:

- Log into CPMS 2.0
- **Update personal expertise profile !!**
- Check existing patients in system are accurate
- You need DPO to decide if DPIA is needed for CPMS 2.0 before enrolling patients
  - DPO/DPIA issues – contact cpmshelpdesk@endo.ern-net.eu

MTG8:
Every 3 months, 1st Wednesday @09:00 - 3 CASE SLOTS
Wednesday 1st Jul 2026

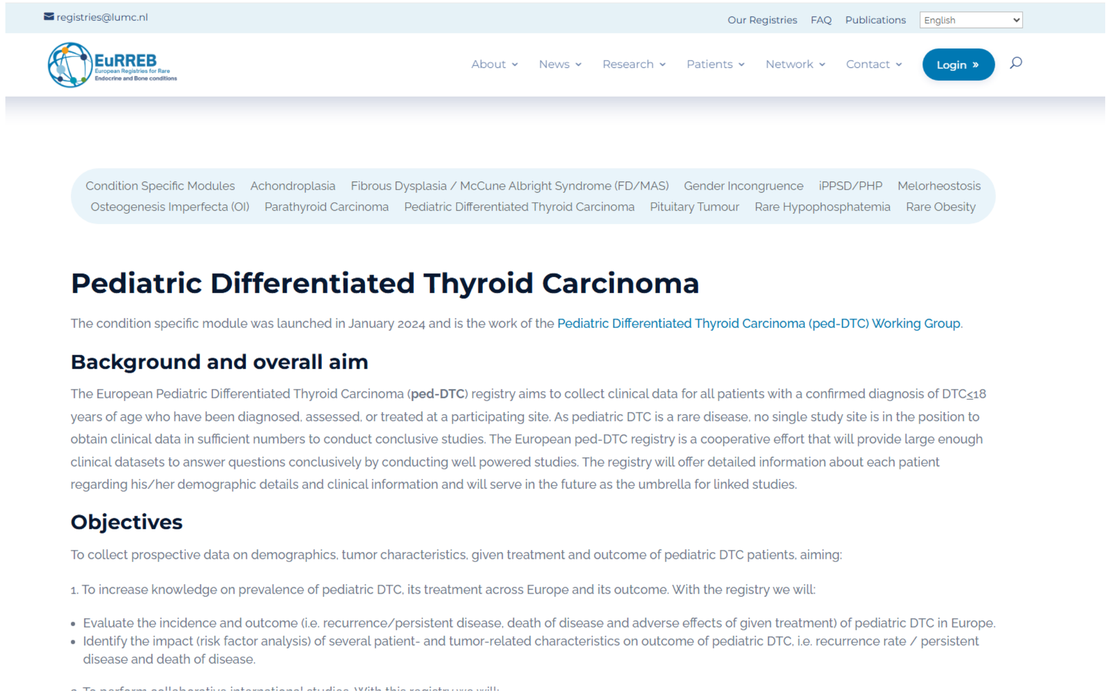
CPMS Recurring Meetings - Endo-ERN

How to improve CPMS?
Only pt cases?
General clinical management issues?
HCPs/countries responsible for each slot?

WP5 Registries, data management & analysis

E-REC = needed for continuous monitoring!

[Pediatric Differentiated Thyroid Carcinoma | EuRREB]



Ped-DTC registry (launched february 2024)

- European prospective data collection of children (aged ≤ 18 years) with differentiated thyroid carcinoma
- Established in collaboration with EuRRECa (European Registries for Rare Endocrine Conditions)

Objectives:

1. Evaluation of incidence and outcome of pediatric DTC in Europe
2. Identification of risk factors for persistent/recurrent disease of pediatric DTC
3. To perform collaborative European prospective (intervention) studies

Slide Courtesy of Dr Sarah Clement

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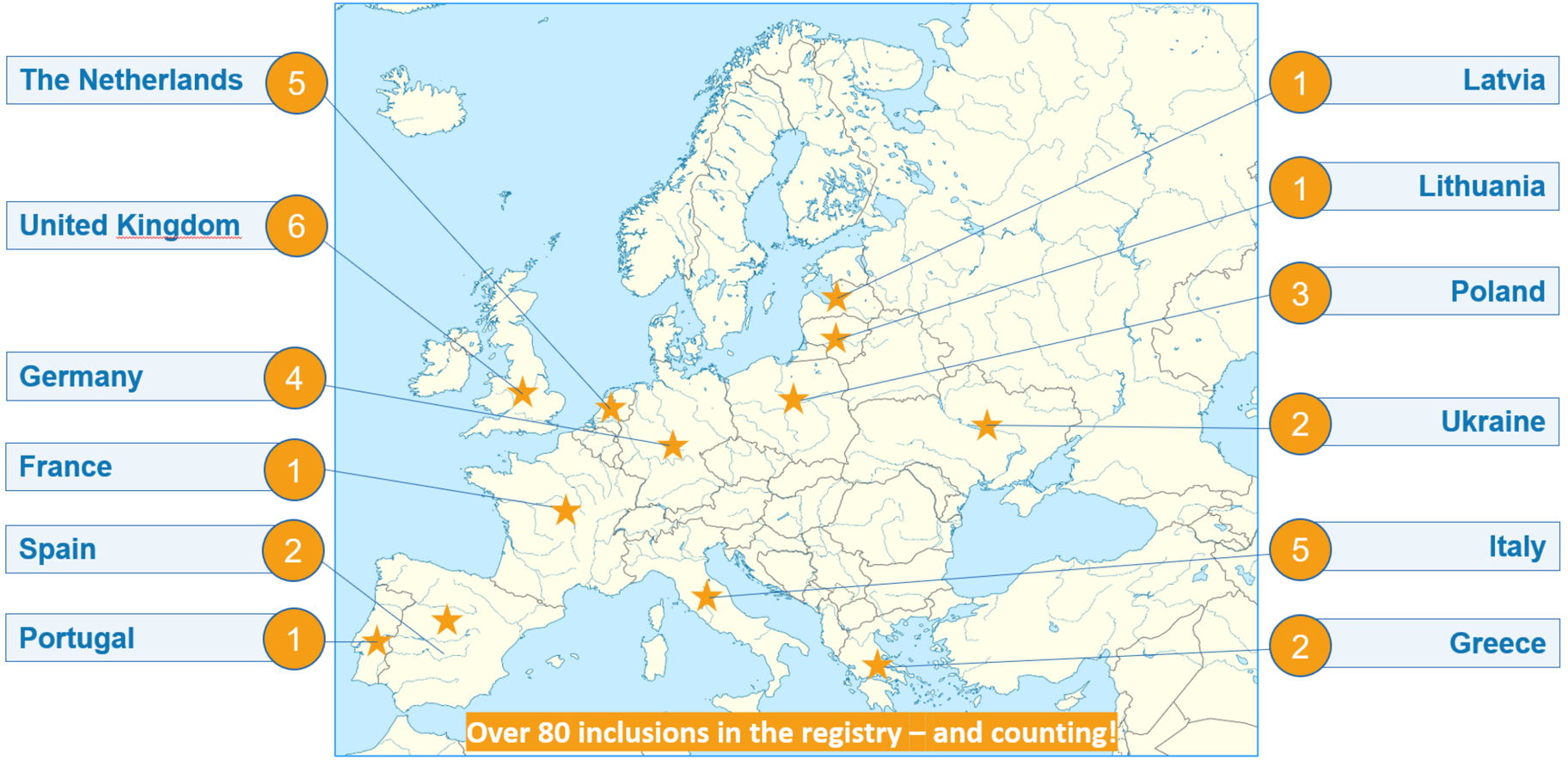
Participating centers ped-DTC registry

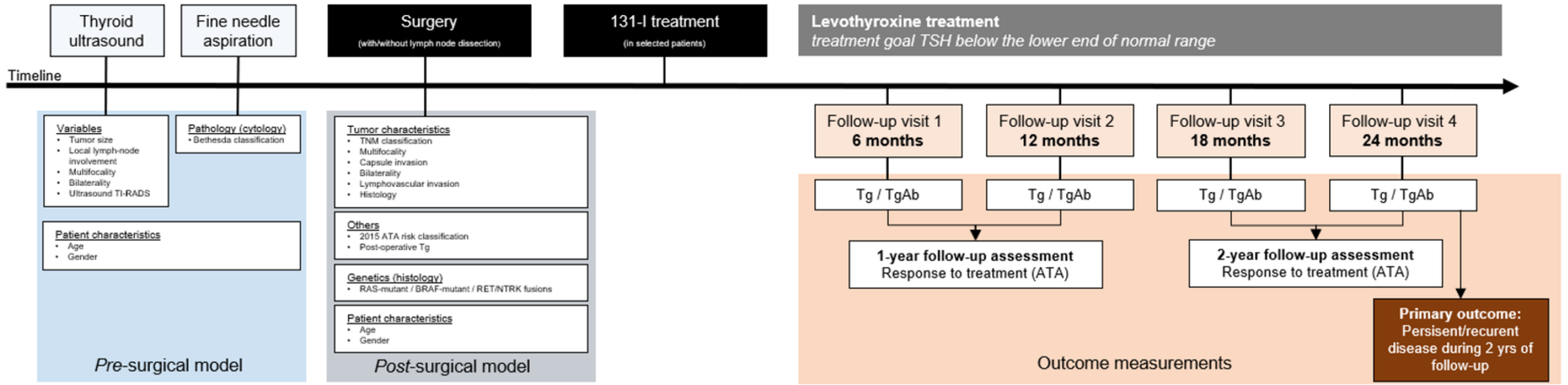


Slide Courtesy of Dr Sarah Clement

First linked study: ped-DTC STRATIFY (inclusion period october 2024 – October 2026)

Primary Objective- Ped-DTC STRATIFY:

to establish accurate pre- and post-surgical prediction tools



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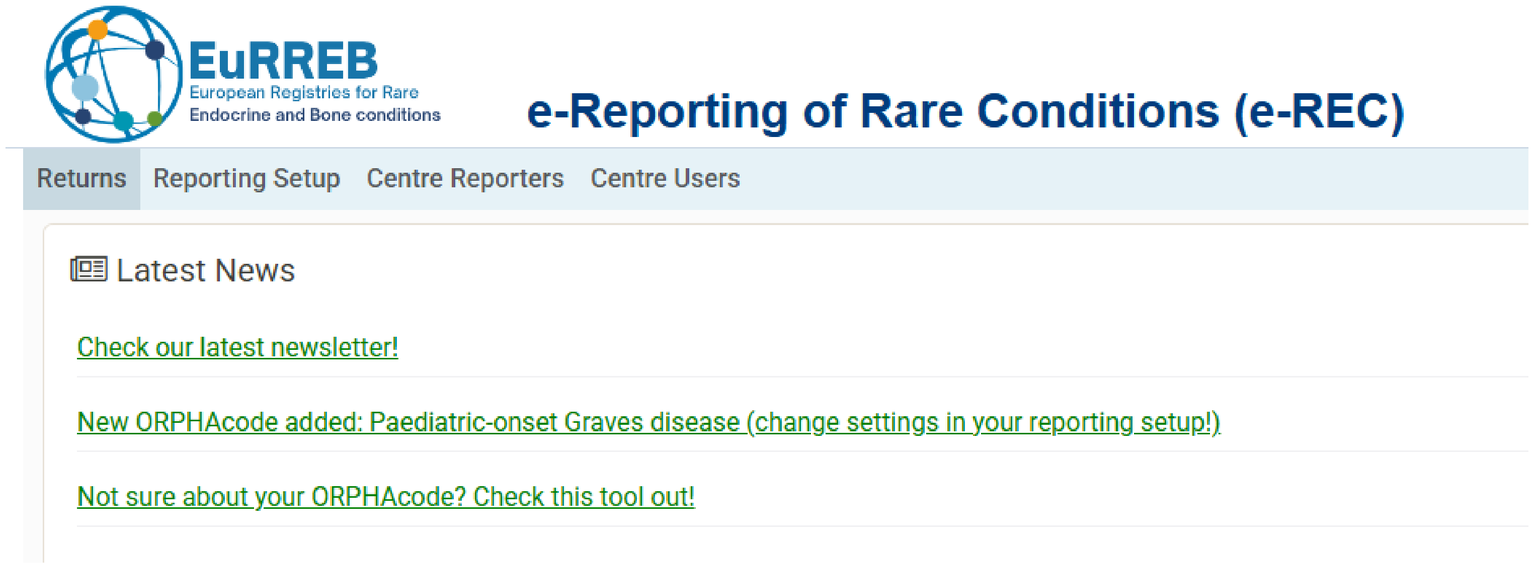
Slide Courtesy of Dr Sarah Clement

Registry in progress for ped Graves' disease

Current situation:

- Pediatric-onset Graves disease is a rare disease
- ORPHA 525731
- Registration in e-REC database since April 2025



Future Goals (1)

- Improving immunological outcome in pediatric Graves disease → higher % permanent remission
- Evaluating the 2022 ETA Guideline treatment strategy with prolonged ATD treatment → does longer treatment duration results in higher % permanent remission
- Identifying predictors of low chance of permanent remission → personalized treatment strategies with earlier definitive treatment
- New treatment strategies improving the immunological outcome of pediatric Graves

Future Goals (2)

- Setting up a core registry for pediatric Graves disease
- Looking for partners to collaborate in building the core registry together with Amsterdam (C Mooij, P van Trotsenburg) and Paris (A Stoupa)
- Building a large European cohort of pediatric Graves' patients to primarily evaluate treatment outcomes and identify disease characteristics (possibly identifying patient characteristics associated with low permanent remission chances)
- Contact c.mooij@amsterdamumc.nl, athanasia.stoupa@aphp.fr if interested or questions

WP6 Education & Training

Webinars 2025-2026

Webinar on TSH resistance on 7th October 2026
(Pr Luca Persani, Milan, Italy + team)
→ **TSH resistance survey across different European centers**

Webinar Organising Information - Endo-ERN

- Cancer-therapy related endocrine toxicities

On 20th May, 4-5 pm (CET)

- MEN syndromes

- Pediatric Graves' update (C Mooij, other speaker?)

- Other suggestions??

Who wants to co-organize?
Looking forward for 2 enthusiastics to co-organize the webinars!

Clinical Exchanges in MTG8 - if you can host, keep this in mind for next open call

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Clinical Exchange Programme

The call for 2026 applications closed 30 November, 2025. Subscribe to the newsletter to be kept up-to-date for 2027.

The **ERN Clinical Exchange Programme** has been designed to share knowledge, strengthen the clinical capacities across the network and to stimulate collaboration between healthcare professionals in European Reference Networks (ERNs) and beyond. The mission of Endo-ERN is to reduce present inequalities in rare disease care for patients with rare endocrine conditions.

FYI – If you are looking for funding please be aware that the 2025 Erasmus+ call for funding is now open.

Dates for 2027 : TBC

WP7
Clinical Practice Guidelines & Clinical Decision Support Tools

Any guideline updates to be suggested/ submitted for Endo-ERN endorsement?

ETA guidelines to be finalised:

“Screening for and management of thyroid disease in syndromic genetic conditions”
(A Stoupa, M Polak)

WP8/9
Capacity building and best practice sharing for Ukraine

Capacity building and best practice sharing with Ukraine is the active engagement of physicians in Ukraine in the same manner as their European counterparts.

Ukrainian physicians are invited to express their interest by completing this survey (at Endo-ERN website)

Any contacts with Ukrainian endocrinologists?

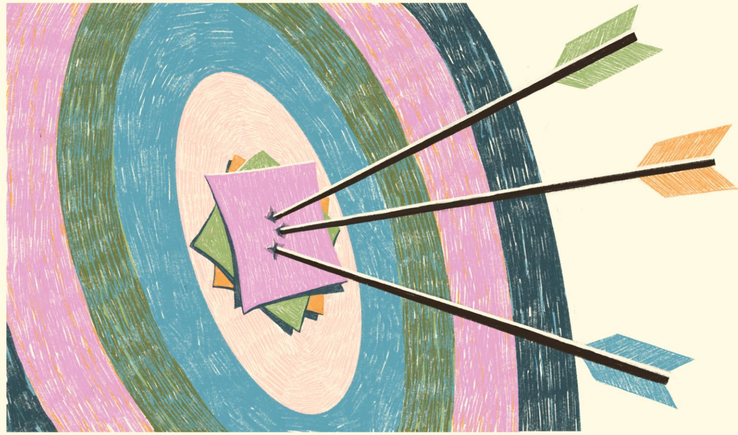
Endo-ERN network representatives that have existing relationships with Ukrainian physicians are invited to share this page with their contacts.

General Discussion

Ongoing research/topics of priority for MTG8

Goals for next year?

What else?

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