

## ENDO ERN GA

MTG8 HCP meeting  
Athens, 21<sup>st</sup> 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: 28<sup>th</sup> January 2026

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

Q3: 14<sup>th</sup> of September 4 pm

# WP2 Communication & Dissemination





European  
Reference  
Network



Endo-ERN

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Members Overview

Endo-ERN is a virtual network comprised of experts in rare endocrine conditions. While our **members are institutions**, it is the people that comprise the **multidisciplinary teams** in those institutions that make the network function.

While there are many obligatory activities for members, the network is also a tremendous resource with access to an unparalleled peer group.

The [Endo-ERN Project Office](#) is the hub that can facilitate access to the wider network membership.

Core member activities

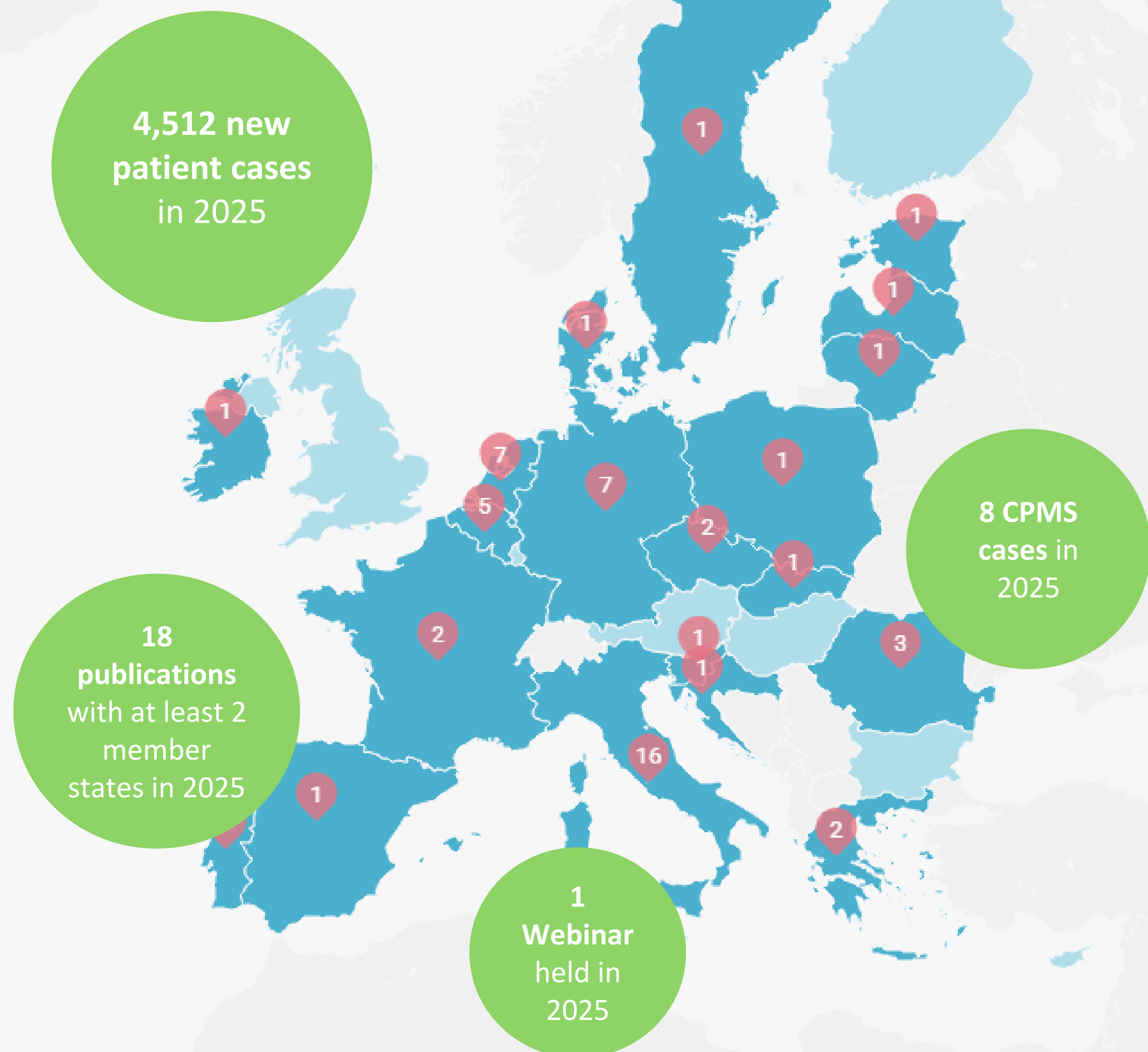
- **Virtual consultations** using the CPMS platform
- Contributions to the **EuRRECa rare disease registries**
- Contributions to the Endo-ERN **education and training programme(s)**
- Annual **Continuous Monitoring** Exercise
- Attendance of the primary/substitute members at the **Endo-ERN General Assembly (GA)**

Endo-ERN Newsletter

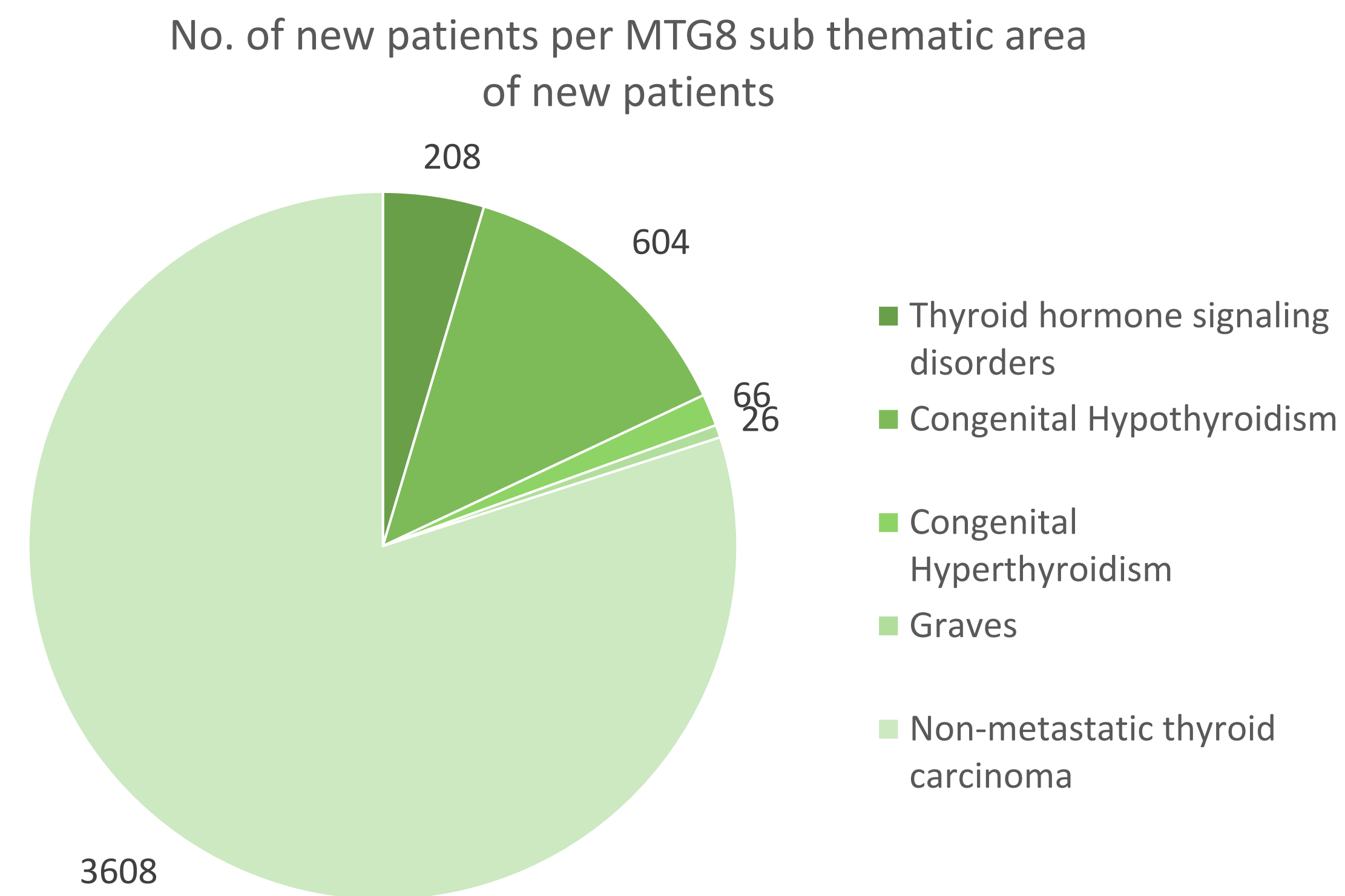
*Has everyone subscribed to newsletter/ LinkedIn?*



## MTG8 – 2025 Stats



## 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



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Next meeting: Wednesday 1<sup>st</sup> 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](mailto:cpmshelpdesk@endo.ern-net.eu)

### MTG8:

Every 3 months, 1<sup>st</sup> Wednesday  
@09:00 – 3 CASE SLOTS

Wednesday 1<sup>st</sup> Jul 2026

[CPMS Recurring Meetings - Endo-ERN](#)

### How to improve CPMS?

Only pt cases?

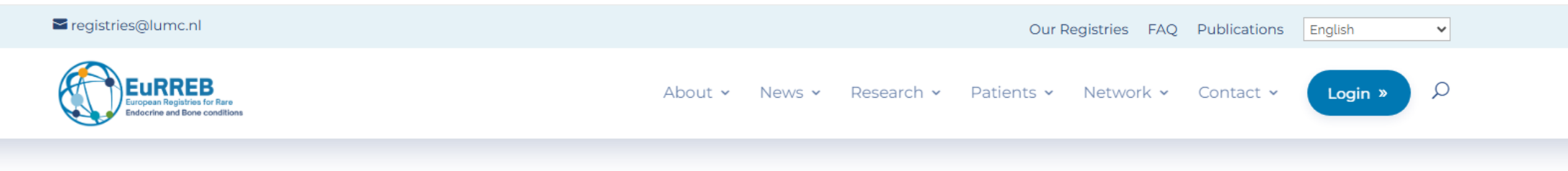
General clinical management  
issues?

HCPs/countries responsible for  
each slot?

# WP5 Registries, data management & analysis

E-REC = needed for continuous monitoring!

[Pediatric Differentiated Thyroid Carcinoma | EuRREB](#)



Condition Specific Modules   Achondroplasia   Fibrous Dysplasia / McCune Albright Syndrome (FD/MAS)   Gender Incongruence   iPPSD/PHP   Melorheostosis  
Osteogenesis Imperfecta (OI)   Parathyroid Carcinoma   Pediatric Differentiated Thyroid Carcinoma   Pituitary Tumour   Rare Hypophosphatemia   Rare Obesity

## Pediatric Differentiated Thyroid Carcinoma

The condition specific module was launched in January 2024 and is the work of the [Pediatric Differentiated Thyroid Carcinoma \(ped-DTC\) Working Group](#).

### Background and overall aim

The European Pediatric Differentiated Thyroid Carcinoma (**ped-DTC**) registry aims to collect clinical data for all patients with a confirmed diagnosis of DTC≤18 years of age who have been diagnosed, assessed, or treated at a participating site. As pediatric DTC is a rare disease, no single study site is in the position to obtain clinical data in sufficient numbers to conduct conclusive studies. The European ped-DTC registry is a cooperative effort that will provide large enough clinical datasets to answer questions conclusively by conducting well powered studies. The registry will offer detailed information about each patient regarding his/her demographic details and clinical information and will serve in the future as the umbrella for linked studies.

### Objectives

To collect prospective data on demographics, tumor characteristics, given treatment and outcome of pediatric DTC patients, aiming:

1. To increase knowledge on prevalence of pediatric DTC, its treatment across Europe and its outcome. With the registry we will:
  - Evaluate the incidence and outcome (i.e. recurrence/persistent disease, death of disease and adverse effects of given treatment) of pediatric DTC in Europe.
  - Identify the impact (risk factor analysis) of several patient- and tumor-related characteristics on outcome of pediatric DTC, i.e. recurrence rate / persistent disease and death of disease.
2. To perform collaborative international studies. With this registry we will:



## Ped-DTC registry (launched february 2024)

- European prospective data collection of children (aged  $\leq 18$  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](#)

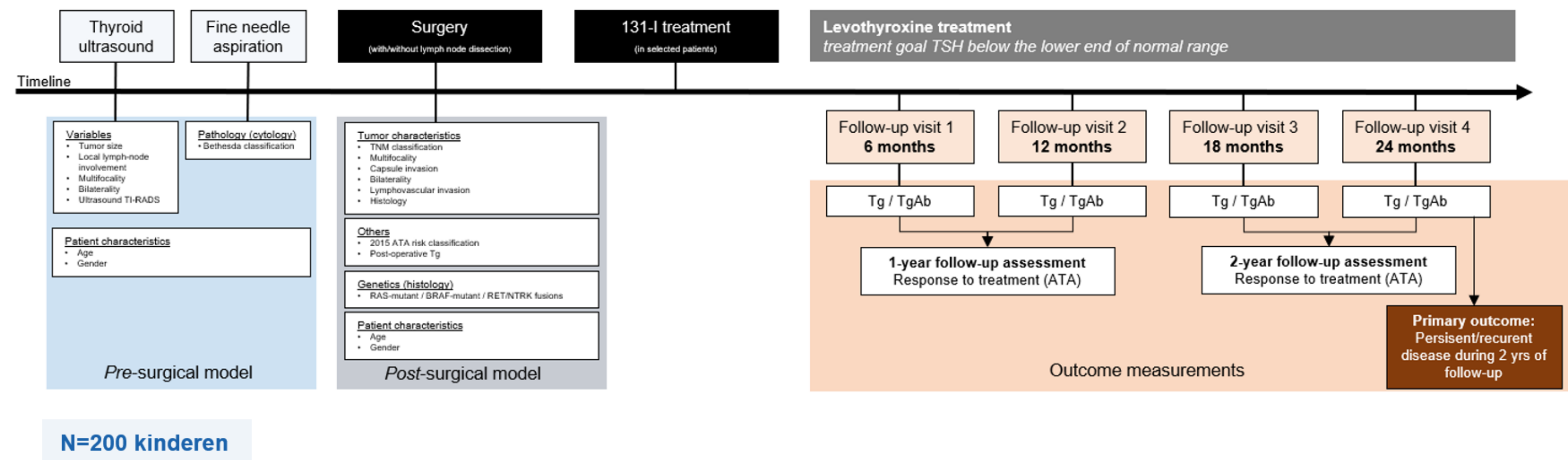


## Participating centers ped-DTC registry



## 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





# 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



## e-Reporting of Rare Conditions (e-REC)

Returns Reporting Setup Centre Reporters Centre Users

Latest News

[Check our latest newsletter!](#)

[New ORPHAcode added: Paediatric-onset Graves disease \(change settings in your reporting setup!\)](#)

[Not sure about your ORPHAcode? Check this tool out!](#)

## 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](mailto:c.mooij@amsterdamumc.nl), [athanasia.stoupa@aphp.fr](mailto:athanasia.stoupa@aphp.fr) if interested or questions

# WP6 Education & Training



## Webinars 2025-2026

Webinar on TSH resistance on 7<sup>th</sup> 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 20<sup>th</sup> 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.

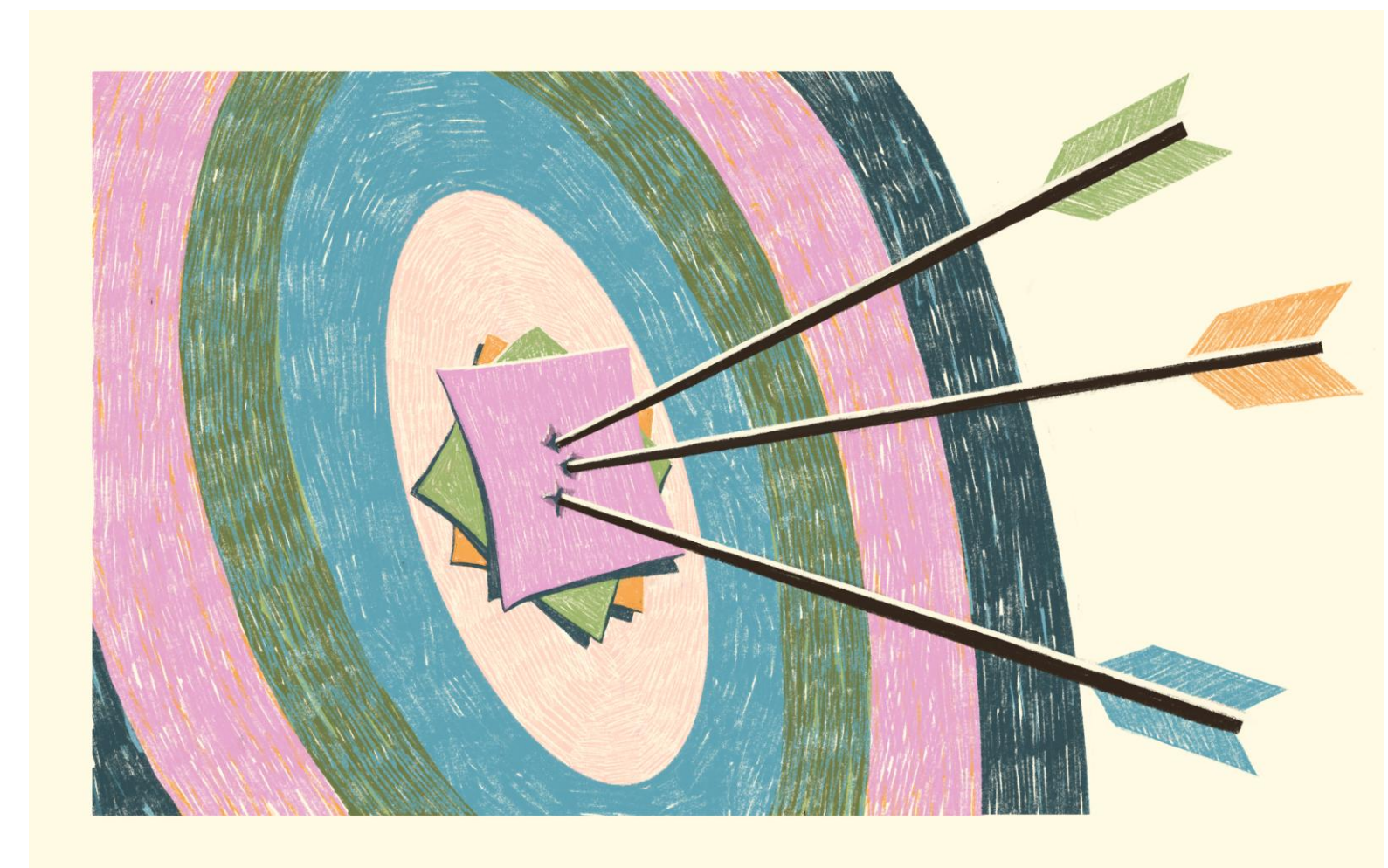


# General Discussion

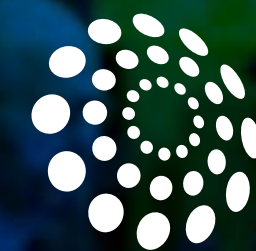
Ongoing research/topics of priority for MTG8

Goals for next year?

What else?







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