



European
Reference
Network



Endo-ERN

MTG8 HCP meeting

Saturday May 10, 2025

Edward Visser, Athanasia Stoupa, Beate Bartès, Esther Bloem

MTG chairs



Funded by
the European Union

WP1 Management & Coordination

2025

Chairs: Meet multiple times

HCP MTG8 meeting 2025 - 3 per year

Q1: *(none)*

Q2: General Assembly - 10th May

Q3: 8th of September 4-5pm

Q4: 4th of December 11-12pm

WP2 Communication & Dissemination



European Reference Network Endo-ERN

Rare Endocrine Conditions ▾ About Us ▾ For Professionals ▾ For Members ▾ For

Home / Members

Index
| Members

Check these areas to help us communicate / disseminate your activities

- Cite Endo-ERN
- Disease Expansion
- Endorsement
- Member Surveys
- System logins
- Updating Contacts
- Webinar Planning
- Termination Policy

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?

WP3 Evaluation



The image shows two screenshots of the Endo-ERN website. The top screenshot displays the 'Endo-ERN Publications Database' with a search filter interface. The filter includes fields for 'Condition / Disease', 'Author(s)', 'MTG' (set to 'Sex Development & Maturation (MTG7)'), 'Year', 'Keyword', and 'ORPHAcode / other'. Below the filter, it indicates '121 publication(s) found matching the search criteria'. The bottom screenshot shows the 'Submission Form' with fields for 'Name *', 'Email *', 'Country', 'HCP/RC *', 'DOI * (number only e.g. 10.1159/000508985)', and 'ORPHAcode *'. It also includes a section for 'Other Endo-ERN HCP/RC or ERN involved in the publication' with 'Country *' and 'HCP/RC *' dropdowns, and 'Add' and 'Remove' buttons.

MTG8 details: 10 publications in 2024

ENDO-ERN affiliated centers:

- University Medical Center Groningen ; Institute of Oncology “Prof dr. Ion Chiricuta” CLUJ NAPOCA ;
- University Medical Center Groningen ; Karolinska University Hospital
- Hospital Universitari Vall d’Hebron *2
- University Medical Center Groningen ; Charité Universitätsmedizin Berlin
- Hôpital Universitaire de Bruxelles (HUDERF-Erasme)
- University Medical Center Groningen; Leiden University Medical Center ; APHP, Hôpital Cochin
- Amsterdam UMC ; University Medical Center Utrecht ; Copenhagen University Hospital, Rigshospitalet ;
- University Hospital Essen
- University Medical Center Utrecht

Topics:

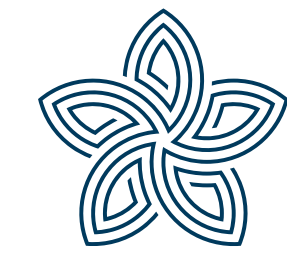
Pediatric Primary Hypothyroidism, CH, FTC, Graves’ disease

Submit their publications with the correct Endo-ERN acknowledgment/citations throughout the year via this [link](#).

WP4 Healthcare & CPMS



European
Reference
Network



Endo-ERN

Next meeting: Wednesday 2nd Jul @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 2nd Jul 2025

Wednesday 1st Oct 2025

Wednesday 7th Jan 2026

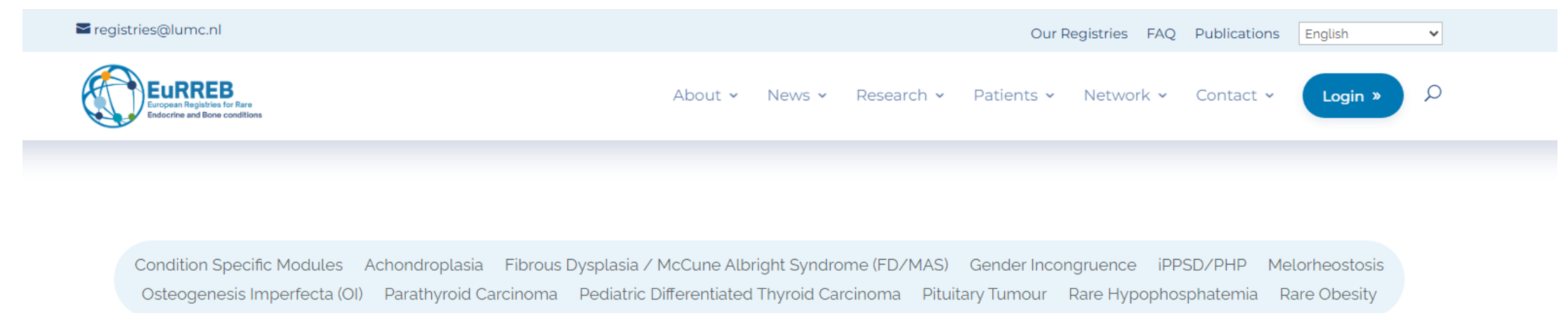
[CPMS Recurring Meetings - Endo-ERN](#)

WP5 Registries, data management & analysis



E-REC = needed for continuous monitoring!

[Pediatric Differentiated Thyroid Carcinoma | EuRREB](#)



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 \leq 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 ≤ 18 years) with differentiated thyroid carcinoma
- Established in collaboration with [EuRRECa](#) (European Registries for Rare Endocrine Conditions)

Objectives:

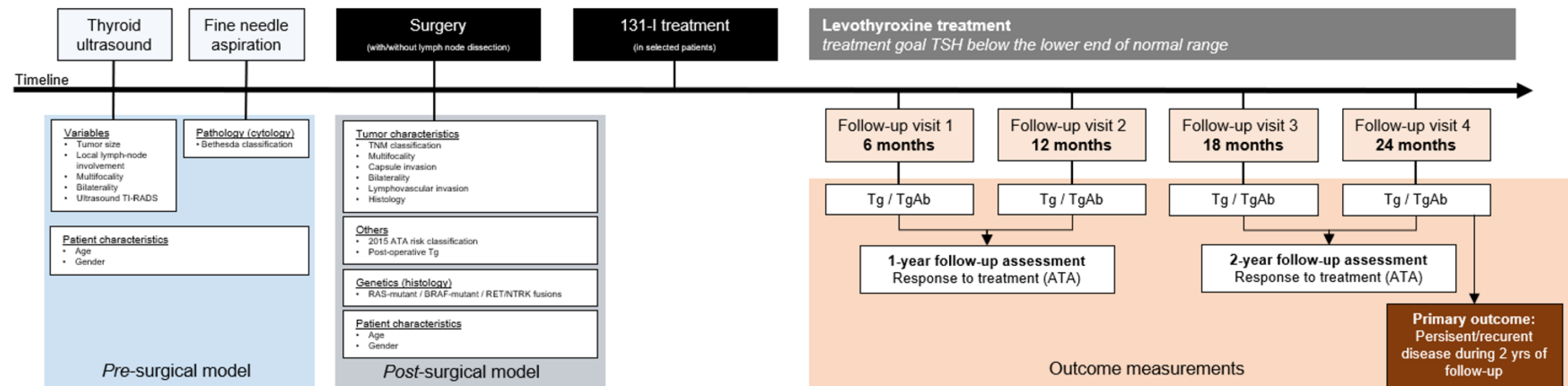
1. Evaluation of [incidence](#) and [outcome](#) of pediatric DTC in Europe
2. Identification of [risk factors](#) for persistent/recurrent disease of pediatric DTC
3. To perform collaborative European [prospective \(intervention\) studies](#)

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



N=200 kinderen

WP6 Education & Training



Webinars 2025:

TOPIC SUGGESTIONS & SUGGESTIONS/VOLUNTEERS TO PRESENT:

- TSH resistance (Pr Luca Persani, Milan, Italy) → date to be confirmed
- Schedule TSH resistance survey across different European centers (Laura Fugazzola/Luca Persani)
- Thyroid dysfunction induced by anti cancer drugs (ICI's, immune check points, TKI's: tyrosine kinase inhibitors etc)
- MEN syndromes (?)
- Other suggestions??

Webinar Organising
Information - Endo-ERN

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



The screenshot shows the Endo-ERN website interface. At the top, there are logos for the European Reference Network and Endo-ERN, along with navigation links: Rare Endocrine Conditions, About Us, For Professionals, For Members, and For. A sidebar on the left contains a menu with options: Index, Info, Criteria, Hosts (highlighted), Apply, and Previous. The main content area displays a listing for a potential host:

Potential Host: Ospedale San Raffaele, Milan, Italy

All Endo-ERN network members receive points in the 2025 exchange. For the 2025 exchange, **the potential host office.**

Hosted at the Amsterdam University Medical Centre

MTGs: 1,8

Timing: open

Specialities/Topics: (in training) who specialise in parathyroid and adrenal endocrine tumors, endocrine tumor nuclear medicine

- Turner's, DSD, CAH, Hypogonadism, Klinefelter's
- Thyroid disease (nodules, congenital hypothyroidism, cancer)
- Wolfram syndrome and rare diabetes
- Panhypopituitarism
- Hyperinsulinism and genetic obesity
- Calcium-phosphorus metabolism pathology

Our paediatric outpatient clinic also deals with transition and offer a multidisciplinary approach to many pathologies. There are both day clinics and day hospitals.

Interdisciplinary meetings are organised at our centre and we already host both residents in Paediatrics and specialists from other Italian centres.



European
Reference
Network



Endo-ERN

WP7

Clinical Practice Guidelines & Clinical Decision Support Tools

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

ETA guidelines in progress:

“Screening for and management of “primary” thyroid disease in syndromic genetic conditions”

(Thania Stoupa, Michel 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?

