

Disorders of Calcium & Phosphate Homeostasis (MTG2) GA

Corinna Grasemann, Eva Kassi, Martha Kirchoff,

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Funded by
the European Union

Work package 1

Management & Coordination



- 1st MTG-2 meeting: March 18th 2026, 4 pm
- 2nd MTG-2 meeting: September/ October 2026, TBA

WP specific contact persons

- WP1 (Management & Coordination): Corinna Grasemann
- WP2 (Communication and Dissemination): Martha Kirchhoff
- WP3 (Continuous Monitoring): Eva Kassi
- WP4 (CPMS) Eva Kassi and Corinna Grasemann
- WP5 (Registries) Natasha Appelman-Dijkstra
- WP6 (Training and Education): Eva Kassi
- WP7 (CPG and CGST): Martha Kirchhoff

Work package 2

Communication & Dissemination



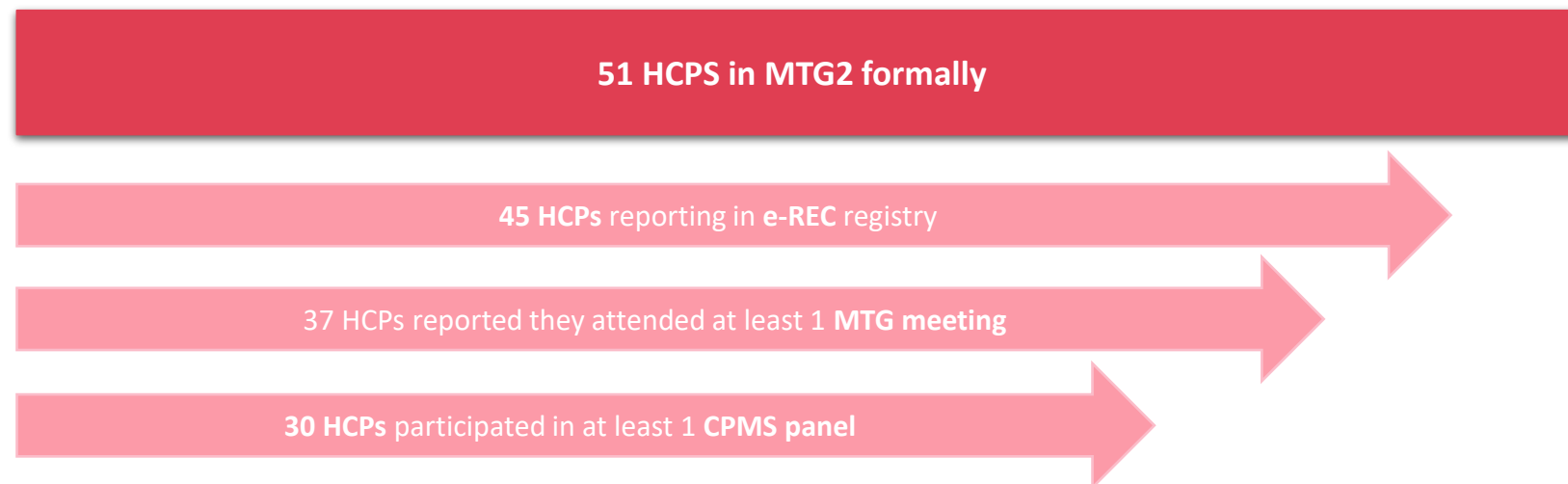
Patient Information Material

- *Recommended medical check-ups and examinations for XLH – English - published*
- *Recommended medical check-ups and examinations for XLH – German – published*
- *We have prepared the Check list for transitioning patients with XLH (in collaboration with Transition working group)*
- *Patient information material for XLH, Hypophosphatasia and Hypoparathyroidism – Greek (not published yet)*

New publications

During 2025 8 publications have been added in the list of publications related to MTG-2

MTG2 HCPS - 2025 Stats



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



European
Reference
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MTG2 – 2025 Stats

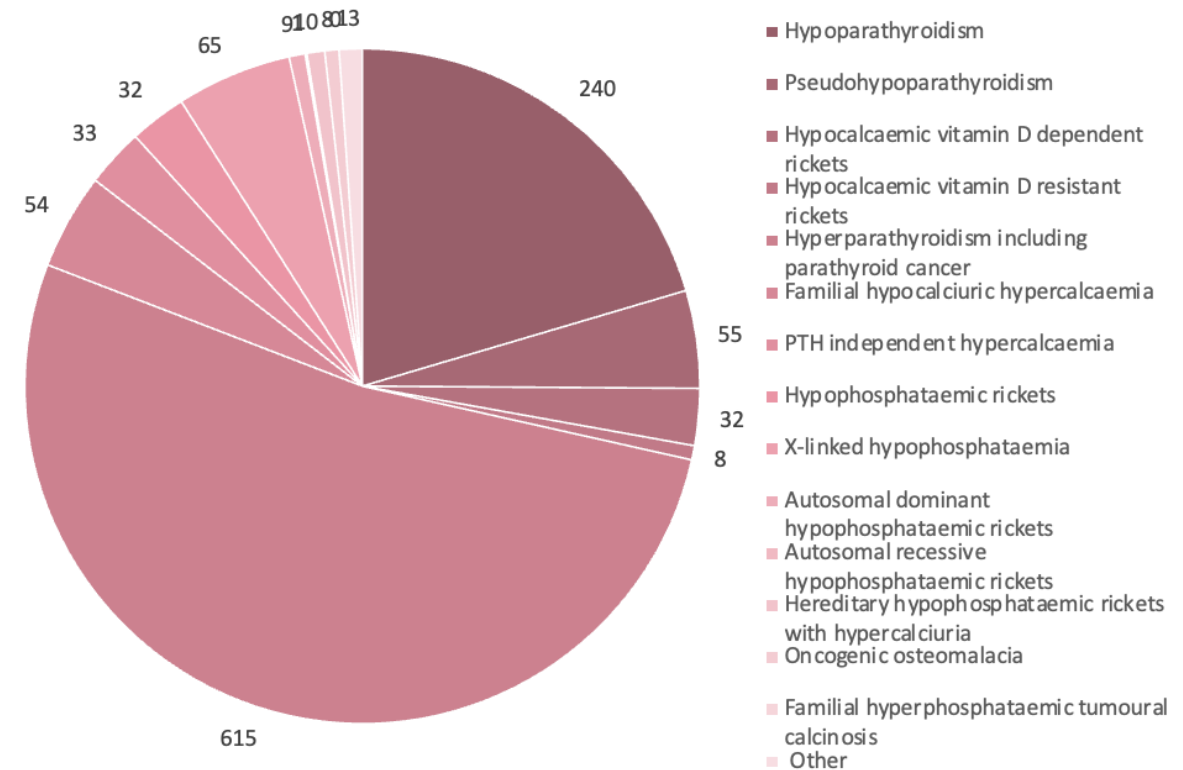
1,175 new
patient cases
in 2025

8 publications
with at least 2
member
states in 2025

1
Webinar
held in
2025

9 CPMS
cases in
2025

No. of new patients per MTG2 sub thematic area



Work package 3

Continuous Monitoring/Evaluation



- New data requested for HCP evaluation :
- Number of rare endocrine patients received/ referred from other EU countries in 2025 in your HCP
- Number of Ukrainian patients referred to or treated for rare endocrine conditions in your HCP in 2025
- Emergency/ potential crisis situations

All HCPs will be using e-REC by end of 2026

Work package 4

CPMS updates



Information about CPMS:
<https://endo-ern.eu/cpms/>

Wednesdays every other month at 2pm

Wednesday, 13 May @14:00-15:00 (CEST)
Wednesday, 8 Jul @14:00-15:00 (CEST)
Wednesday, 9 Sep @14:00-15:00 (CEST)
Wednesday, 11 Nov @14:00-15:00 (CEST)

Joint BOND and MGT-2 CPMS meetings have been held and are scheduled

<https://ern-euro-nmd.eu/cpms-helpdesk/>

Work package 4

CPMS updates



10 case discussions in 2025 and 4 in 2026 so far,

14 case discussions in total since January 2025.

Still issues (Institutions (HCPs) and DPO approval?)

<https://ern-euro-nmd.eu/cpms-helpdesk/>

Work package 5

Registries



EuRREB – the European Registries for Rare Endocrine and Bone conditions. It consists of [EuRRECa](#) and [EuRR-Bone](#)

Prof. Natasha Appelman

Work package 5 Registries



New specific condition module has been launched on April 2026 :
Three meetings (from 30th June 2025 to 9th March 2026) and one Delphi survey)



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centres

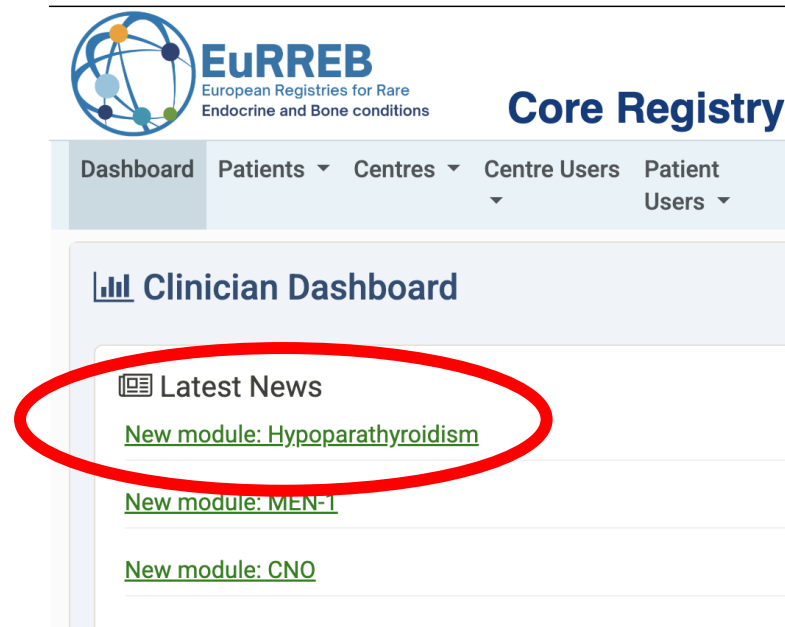
Women's Reproductive Health	All	2026	0/0	Tim Korevaar / Natasha Appelman-Dijkstra	No active study yet
Hypoparathyroidism	MTG2	2026	0/0	Maria Yavropolou / Corinna Grasemann / Eva Kassi	No active study yet

Work package 5

Registries



New specific condition module has been launched on April 2026 :
Three meetings (from 30th June 2025 to 9th March) and one Dlephi survey)



The module collects information on

- Clinical manifestation (at presentation and during the life-course)
- Genetic testing
- Comorbidities
- Laboratory results
- Treatment

Work package 5

Registries



Working groups

A	B	C	D	E	F	G
Surgical hypopara	Diagnostic Evaluation including imaging	Autoimmune HPT including testing	Genetic HPT including, testing (testing time)	Treatment and Monitoring	Bone Outcomes	Pregnancy
Marieke Snel	Marieke Snel	Maria Luisa Brandi	Maria Luisa Brandi	Maria Luisa Brandi	Maria Luisa Brandi	Maria Yavropoulou
Aglaia Kyrilli	Rachel Crowley	Francesca Giusti	Francesca Giusti	Francesca Giusti	Francesca Giusti	Natasha Appelman
	Claudio Marcocci	Maria Yavropoulou	Maria Yavropoulou	Luis Cardoso	Palermo Andrea	Valeria Hasenmajer
	Guido Zavatta	Liesbeth Winter	Natasha Appelman	Femke van Haalen/Natasha Appelman	Femke van Haalen	Aglaia Kyrilli
		Eva Kassi	Claudio Marcocci	Tanja Sikjaer	Daniel Grigorie	Charlotte Verroken
		Evert van Velsen	Rachel Crowley	Rachel Crowley	Giovanna Mantovani	
			Giovanna Mantovani	Giovanna Mantovani	Maria Yavropoulou	
			Eva Kassi	Eva Kassi	Eva Kassi	
			Line Underbjerg	Maria Yavropoulou	Evert van Velsen	
			Giulia Del Sindaco	Evert van Velsen	Guido Zavatta	
			Aglaia Kyrilli	Guido Zavatta	Valeria Hasenmajer	
			Charlotte Verroken	Giulia Del Sindaco	Giulia Del Sindaco	
				Rosaria M. Ruggeri	Rosaria M. Ruggeri	
				Aglaia Kyrilli	Vit Zikan	
				Charlotte Verroken	Aglaia Kyrilli	

Pregnancy	Pediatric outcomes	Functional and Psychosocial Assessment	Demographic and General Clinical Data	Long term complications
Maria Yavropoulou	Luisa Desanctis	Tanja Sikjaer	Maria Yavropoulou	Palermo Andrea
Natasha Appelman	Malgorzata Gabriela Wasniewska	Maria Yavropoulou	Eva Kassi	Claudio Marcocci
Valeria Hasenmajer	Corinna Grasemann	Claudio Marcocci	Charlotte Verroken	Maria Yavropoulou
Aglaia Kyrilli	Tommaso Aversa	Pascal Houillier		Pascal Houillier
Charlotte Verroken	Domenico Corica	Eva Kassi		Evert van Velsen
	Tiziana Abbate	Aglaia Kyrilli		Valeria Hasenmajer
		Charlotte Verroken		Line Underbjerg
				Rosaria M. Ruggeri
				Vit Zikan

Work package 5 Registries



In light of the new ESE guidelines which advocate genetic testing in every case with non-surgical hypoparathyroidism - which is not available in every country- there was a biotechnology company who was willing to support this

- Endo-ERN
- WP5
- Transversal work package on genetic testing
- MTG-2 chairs

have launched an initiative to develop a comprehensive and balanced **checklist/statement on collaboration** between

- pharmaceutical industry,
- diagnostic laboratories,
- patients / families
- ERNs

Work package 5

Registries



An integrated clinical pathway has been developed to guide clinicians from initial suspicion through to genetic testing and follow-up.

- As a first step, please consult the **Checklist for Genetic Testing Eligibility in Idiopathic Hypoparathyroidism**, which serves as the entry point and helps identify appropriate patients based on clinical features (e.g. early onset, family history, syndromic features, or unexplained hypocalcaemia).
- For detailed instructions, refer to the **Guidance Note for Healthcare Providers (HCPs): How to Use the Checklist**, which supports consistent interpretation of the criteria and helps avoid unnecessary testing.
- Once eligibility is confirmed, clinicians may proceed to the **Standard Operating Procedure for Genetic Testing in Hypoparathyroidism**, which outlines the practical workflow, including **informed consent**, sample collection, test selection, and submission to the designated laboratory.
- Please note that genetic testing should only be initiated following CPMS consensus recommendation.

Work package 6

Training & Education



Webinars (2025)

Clinical Practice recommendations for the diagnosis and management of XLH (**29th Oct 2025**)

Planned webinars for the next 12 months

- 1) Hypophosphatasia : diagnostic and therapeutic approach (will be held on **16th September 2026**. Speakers : Prof. Aliya Khan, Prof. Maria-Luisa Brandi)
- 2) Calcium sensing disorders in children and adults (communication has been started with Prof Rejnmark (positive response), Prof Thakker and the rest (waiting) (will be held **in fall** - TBD)
- 3) Joint webinar on Klinefelter?)

There was no Endorsed event and training updates of interest

Work package 7 CPG&CDST



Updated local guidelines or new treatment options to share

- International guideline for HHRH – hereditary hypophosphatemic rickets with hypercalciuria are in progress

Any other business (AOB)

- ??



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Thank you!