

# Disorders of Calcium & Phosphate Homeostasis (MTG2) HCP Meeting

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# Work package 1

## Management & Coordination



### Meetings for the next 12 months

- General Assembly 20-21 April 2026 in Athens, Greece
- 1<sup>st</sup> MTG-2 meeting: March 18th 2026, 4 pm
- 2<sup>nd</sup> MTG-2 meeting: September/ October 2026, TBA

### WP specific contact persons

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

# Work package 2

## Communication & Dissemination



### Publications, Webinars, Talks, 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 (Transition working group)*
- *Patient information material for XLH, Hypophosphatasia and Hypoparathyroidism – Greek*
- *(not published yet)*

### Upcoming Webinars ( to be discussed in WP6)

#### Patient information material →

New publications/patient information to be endorsed/updated/disseminated?

*During 2025 6 publications have been added in the list of publications related to MTG-2*

- HCPs can send us patient information material in their language/or in English  
Send any new publication (already endorsed by ENDO-ERN) or to ask for endorsement in case they fulfill the criteria
- Use correct logos, templates for Endo-ERN

## Work package 3

### Continuous Monitoring/Evaluation

#### Overview for MTG2

HCPs endorsed for MTG2 = ?

e-REC reporting HCPs = ?  
Continuous Monitoring HCPs completed = ?

- ? HCPs took part in at least 1 CPMS panels
- ? HCPs have met the minimum patient requirements for MTG2 conditions
  
- New data requested :
- 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 3

### Continuous Monitoring/Evaluation

#### Evaluation key things

- If you have papers due to be published please use the correct Endo-ERN citation (findable at the member area of the website)
- Ensure that your Hospital mentions Endo-ERN and links to our website from their own website

# 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)

**Any cases for upcoming meetings ? Any proposal for care topic to discuss?**

Need help? Contact the helpdesk!  
<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](#)

Any issues or barriers to using the affiliated registries?

**EuRREB Annual Report:**

<https://eurreb.eu/reports/>

**Registries Drop-In sessions:**

Every second Friday at 14:00 (UTC+1/+2) and every fourth Wednesday at 10:00 (UTC+1/+2) [EuRREB](#) organises an online Drop-In (support) session via [Zoom](#).

# Work package 5

## Registries



New specific condition molecule is under development :  
Hypopara- core module

Co-ordinator : Prof. Natasha Appelman

# Work package 6

## Training & Education



Plan and schedule webinars for the next 12 months

Each MTG is to host at least **3 webinars per year** and include ePAGs

### PROPOSALS:

- Hypophosphatasia : diagnostic and therapeutic approach
- Osteogenesis imperfecta : skeletal and non-skeletal challenges(JOINT BOND) ?

Endorsed events and training updates of interest

## Work package 7 CPG&CDST



**Are there any updated local guidelines or new treatment options you would like to share?**

- International guideline for HHRH – hereditary hypophosphatemic rickets with hypercalciuria are in progress
- Expert group meets once a month
- To be completed summer 2026
  
- Further development of Burosumab???
- Approval for children under one year of age???

## Any other business (AOB)



- Updates from your HCP/Organisation
- Research or information you would like to share

Thank you for participating!