

Disorders of Calcium & Phosphate Homeostasis (MTG2) HCP Meeting

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Funded by
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Work package 1

Management & Coordination



Meetings for the next 12 months

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

WP specific contact persons

- WP1 Corinna Grasemann and Team: NEW **Affiliation!**
- 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



Publications, Webinars, Talks, Patient Information Material

- New publications/patient information to be endorsed/updated/disseminated?
- Using correct logos, templates for Endo-ERN
- **Upcoming Webinars :**
 - 1) Wednesday 29 October at 17:00-18:00 (CET)
Clinical Practice recommendations for the diagnosis and management of X-linked hypophosphatemia
 - 2) JOINT ERN ENDO/BOND webinar (3rd or 10th December ?)
Calcium Sensing disorders in children and adults
- **Patient information material →**
HCPs can send us patient information material in their language/or in English (endorsed by local scientific organizations)
- Send any new publication (already endorsed by ENDO-ERN) or to ask for endorsement in case the fulfill the criteria

Work package 3

Continuous Monitoring/Evaluation



Overview for MTG2

HCPs endorsed for MTG2 = 48

e-REC reporting HCPs = 42

Continuous Monitoring HCPs completed = 46

- 34 HCPs took part in at least 1 CPMS panels
- 44 HCPs have met the minimum patient requirements for MTG2 conditions

It is important to keep e-REC data up to date by year - end so the data accurately reflects rare disease patients in Europe

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, starting in January
Schedule to be provided

Upcoming ENDO-ERN/ BOND meeting in November 18th 17:00-18.00 (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 2pm) and fourth Wednesday (at 4pm) of every month EuRREB organises an online Drop-In (support) session via Zoom.

<https://eurreb.eu/drop-in-sessions/>

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:**
 - Osteogenesis imperfecta : skeletal and non-skeletal challenges(JOINT BOND) ?
 - Hypophosphatasia : diagnostic and therapeutic approach ?
 - Dental aspects in XLH ?
- Clinical Exchange Programme (closed 30 November 2025)
- 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?

-Management of Hyperparathyroidism: recommendations of the working group of the Bone Section of the Hellenic Endocrine Society” (PubMed)

- Management of Hypoparathyroidism : recommendations of the working group of the Bone Section of the Hellenic Endocrine Society” (PubMed)

Any other business (AOB)



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

Thank you for participating!