

MTG Minutes



MTG6 / HCPs meeting:

Date: 14.11.2025

Time: 10:00 – 11:00

Meeting chairs: Svetlana Lajic, Nicole Reisch, Manuela Brösamle, Giorgio Dal Maso, Jette Kristensen, Alessandro Lazzerini, Zuzana Smith, Teresa Valencia

1. Opening

The meeting began with a brief introduction to the agenda and key topics related to the MTG1 group.

1.1. Introduction of new EPAG representative – Teresa Valencia

- New ePAG, Teresa, introduced herself as President of the Spanish national association “Adisen – Asociación Nacional de la Enfermedad de Addison y otras Enfermedades Endocrinas Raras.”
- Key points about the association:
 - Represents patients with rare endocrine conditions ranging from adrenal to pituitary disorders.
 - Although national, the association supports Spanish-speaking patients worldwide.
 - Member of the Spanish federation of endocrine disease associations (FEDE), the International Adrenal Consortium and the European Adrenal Network.
- Teresa expressed that it is an honour to join Endo-ERN and that she hopes to work together to continue improving care for patients with rare endocrine diseases in Europe.

2. General Updates

2.1. Upcoming Meetings & Events

- GA 2026: 20–21 April in Athens; MTG1 session planned.
- Three virtual MTG1 meetings annually

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- Upcoming events: Winter School Varna, ECE Prague, ESPE Marseille.

2.2. Communication and dissemination

- All Endo-ERN webinars (including MTG1 webinars) are available on YouTube for educational use.
- Members were encouraged to:
 - Re-watch relevant sessions.
 - Recommend the webinar collection to younger colleagues as an educational resource.

2.3 Evaluation and registries – rREC

- Work packages 3 and 5 (evaluation and registries) were briefly reviewed.
- The EREC system was emphasised as the key registry.
- Each HCP is responsible for:
 - Adding new cases to EREC annually.
 - Keeping data updated for evaluation and reporting.

2.4. CPMS:

- The importance of regular use of the Clinical Patient Management System (CPMS) was stressed.
- For MTG1, CPMS case discussions are scheduled:
 - Every second month, on Tuesdays at 15:00 CET.
- HCPs were strongly encouraged to:
 - Propose and schedule CPMS cases through the coordination office.
 - Use the coordination office email to register cases.
- CPMS activity is a key expectation for MTG1 HCPs within Endo-ERN and is supported by Endo-ERN and the European Commission.

2.5 Webinars – past activity and plans

- Webinars remain a popular and central activity for MTG1.
- In 2025, five webinars were organised across MTGs, including MTG1.
- Responsibility for proposing webinars is shared: Not only MTG1 chairs (Svetlana, Nicole) and ePAGs, but all MTG1 members may propose topics.
- Suggested content for webinars:
 - Project results and updates
 - Clinical reviews or case summaries
 - Topics covering disorders within MTG1's scope.

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2.6. Ongoing Projects

- Talent Program (February 2026, Rome). MTG1 will participate in the 8th TALENT meeting in Rome (February 2026), focusing on transition in rare endocrine diseases.
- Red Winter School (March 2026, Varna). MTG1 will also participate as lectures in the RED Winter School in Varna, Bulgaria.
- Transition project: survey + letters; one paper published, one submitted. MTG1 is actively involved in the Endo-ERN transitional care working group, together with other MTGs.
- CH Care Pathway: to be circulated soon for comments.

2.7. New Clinical Practice Guideline – Hypoadrenalism

- Topic: Replacement treatment in hypoadrenalism.
- Leads: Svetlana Lajić (paediatric), Eston Husabi (adult).
- Working group (12–15 experts) to be formed; members invited to express interest.

3. Research Update

Presenter: Prof. Nicole Reisch

- An update was given on the prenatal dexamethasone (DEX) study now open in Germany.

Purpose

- To evaluate prenatal DEX treatment in pregnancies at risk for a fetus with classic congenital adrenal hyperplasia (CAH).

Key design elements:

- Treatment must start very early in pregnancy:
 - Before 7 weeks post conception or before 9 weeks post last menstruation.
- Comparison of two dosing regimens:
 - Standard “experimental” dose: 20 µg/kg DEX.
 - Lower dose: 7.5 µg/kg DEX, based on pharmacokinetic modelling.

4. Closing

Prof. Svetlana thanked all participants for their contributions and ongoing work within MTG1.

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Action points summary

1. All MTG1 HCPs
 - Continue regular entry of new patients into the EREC registry.
 - Schedule CPMS cases for MTG1 sessions (every second Tuesday at 15:00 CET) via the coordination office.
2. All MTG1 members
 - Propose and/or volunteer to organise webinars, especially on:
 - Adrenocortical tumours/adrenocortical carcinoma.
 - Other MTG1-relevant topics and project outputs.
 - Share educational needs or ideas with the chairs or coordination office.
3. ePAG members
 - Provide input on topics and issues they would like to see addressed in webinars and other MTG1 activities.
4. Hypoadrenalinism guideline working group
 - Interested colleagues to contact the paediatric and adult leads to express interest in joining the guideline group.
 - Leads to finalise group composition and initial research questions with Endo-ERN.
5. CH care pathway
 - Draft CH care pathway (MTG1 & MTG7) to be circulated to HCPs for comments and then finalised within the JARDIN project.
6. Prenatal DEX study
 - MTG1 members to refer eligible pregnancies in Germany to the study centres in Berlin and Munich.
 - Chairs to update the group when additional countries join the trial.