MTG Minutes





MTG6 / HCPs meeting:

Date: 14.11.2025 **Time:** 10:00 – 11:00

Meeting chairs: Nienke Biermasz (Adult chair), Evangelia Charmandari (Paediatric chair), Marta Baranska

(ePAG), Johan de Graaf (ePAG), Diana Vitali (ePAG).

1. Opening

The meeting began with a brief introduction to the agenda and key topics related to the MTG6 group (Pituitary diseases).

2. General Updates

2.1. General updates on Endo-ERN activities for MTG6

- GA 2026: 20–21 April in Athens; MTG6 session planned.
- Three virtual MTG6 meetings annually (next planned for Feb & Apr/May 2026).
- Upcoming events: ENEA Marseille, Winter School Varna, Polish QoL webinar (24 March), ECE Prague, ESPE Marseille.
- Communication: Monthly Digest, patient info materials requested, social media follow-up encouraged.
- Monitoring: Continuous monitoring starts 1 Jan; EREC must be updated; publications to be submitted continuously.
- CPMS: Monthly case discussions; HCPs encouraged to submit cases or questions.
- Prolactinoma module in development; experts invited to join discussions.
- Women's Health module expanded from pregnancy module.
- Registry structure increasingly professionalized.

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3. Patient Journey - Update by Emily White

- First EU-level patient journey using EURORDIS framework.
- 52 patients registered; 36 full responses.
- Key themes: difficulty accessing specialised support, emotional burden, holistic care needs.
- Clinical review stage now: seeking 6–10 experts from ≥6 countries.
- Publications planned; first paper targeted for January.

4. Survey on Psychosocial Consequences - Presented by Iris Pelsma

- Survey on psychosocial consequences of pituitary disease.
- Available in many languages; open until Feb 2026.
- 461 respondents in first three weeks.
- Centres encouraged to share QR code; additional languages possible.

4. Open discussion

- Evangelia Charmandari: Asked about publications → confirmed planned.
- Patient journey and survey expected to guide guidelines & presentations.

Action Points:

- Submit GA2026 MTG6 input All members
- Keep EREC updated All centres
- Submit publications All centres
- Submit CPMS cases/questions Clinicians
- Volunteer for patient journey review Interested clinicians
- Registry team to collaborate with Sophie on imaging Registry team
- Share psychosocial survey QR code All centres
- Report additional language needs All centres