Meeting minutes

Endo-ERN Steering Committee & Advisory Board (SCAB) meeting

Date & time: Tuesday 20 January 2026, 09:30-11:30

Location: Online

Attendance (47): Natasha Appelman-Dijkstra, Marta Barańska, Beate Bartès, Nienke Biermasz, Charlotte van Beuzekom, Esther Bloem, Lexi Breen, Petra Brügmann, Marc Büdenbender, Aimee Casey, Frederic Castinetti, Evangelia Charmandari, Mariya Cherenko, Hedi Claahsen, Giorgio Dal Maso, Johan de Graaf, Olaf Dekkers, Ulla Doehnert, Thomas Eggermann, Jadranka Elezovic, Charlotte Gaasterland, Greta Ginski, Corinna Grasemann, Claus Højbjerg Gravholt, Olaf Hiort, Charlotte Höybye, Violeta Iotova, Andrea Isidori, Eva Kassi, Martha Kirchhoff, Svetlana Lajic, Pietro Maffei, Mohamad Maghnie, Marek Niedziela, Anna Nordenström, Susan O'Connell, Alberto Pereira, Dirk Prawitt, Felix Reschke, Mark Sherlock, Zuzana Smith, Teresa Valencia, Gerlof Valk, Edward Visser, Diana Vitali, Emily White

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Agenda items

1. **Opening and Welcome**

- The meeting opened with a welcome and acknowledgements of two personal losses in the Endo-ERN community over the past year (Jette Kristensen and Juliane Leger).

2. **Review of (outstanding) action points from the previous meeting (Charlotte van Beuzekom)**

- Two items were highlighted: MTG1 to schedule its first meeting in 2026 and webinars to be scheduled for early 2026 (with confirmed speakers and dates) to support an accreditation package.

3. **Work Package updates**

   - **WP1 Management & Coordination (Charlotte van Beuzekom)**

- A new ePAG representative (Teresa Valencia) was welcomed.
- The term of the ESE Rare Disease Committee representative (Gudmundur Johannsson) was noted as ending in 2026 and a replacement process is required. A recent appointment to the ESPE Advisory Committee (Pietro Maffei) was also noted.
- EU4Health ERN grant: 11 deliverables due in November 2025 were submitted on time, evaluation by the European Commission and external evaluators is expected.
- A first periodic technical and financial report (covering the first two grant years) is being prepared, submission planned by end-February 2026.

- Future ERN funding advocacy: updates were shared on coordinated stakeholder engagement and political outreach for post-2027 funding.
- Endocrine Connections special issue: status update shared, progress described as slower than desired, with reviewer availability and paper submission timing noted as contributors.
- Next special issue (Endocrine Oncology) planning: aim for 8–10 papers (one per MTG and one per working group), free of charge, Coordinating Office to invite members for topic proposals, MTG chairs to select, target to launch portfolio at GA Athens.
- General Assembly (Athens, 20–21 April 2026): hotel and dinner booking reminders were provided, including the need to pre-book dinner tickets.
- ECE 2026 (Prague, May 2026) and ESPE 2026 (Marseille, September 2026): Endo-ERN symposium/booth plans and draft session topics were noted.

WP2 Dissemination (Aimee Casey)

- Social media: strong LinkedIn growth reported in late 2025, continued modest growth on Facebook, webinar recordings are performing well on Endo-ERN YouTube
- Topic newsletters: dedicated topic newsletters were introduced to help members choose content areas (e.g., guidelines/virtual consultations, training/events, research).
- Patient materials: a structured submission and review workflow was proposed (English summary, disclosure of medical information, MTG chair review when needed, and a disclaimer on website publication).
- Rare Disease Day (28 February 2026): communications and patient-story sharing initiatives were highlighted. Patients and carers who have used ERN member centers or ERN-supported services to share their experiences.

WP3 Evaluation (Emily White)

- Continuous monitoring 2025: data collection started 1 January 2026, key deadlines were restated (e-REC numbers by 31 January 2026 and additional patient figures by 28 February 2026).
- New requested indicators include: cross-border EU patients, Ukrainian patients treated, and emergency/crisis-related indicators (optional/exploratory for 2025).
- Publications: members were reminded to submit publications directly via the Endo-ERN website for review and inclusion.
- A Q&A session on continuous monitoring was scheduled for 21 January 2026 at 16:00 CET.

WP4 Healthcare & CPMS (Greta Ginski)

- CPMS statistics: user and case numbers were reviewed, including urgent cases and cross-ERN collaborations in case discussions.

- Mobile app: members were encouraged to install the
  CPMS 2.0 app (and EU Login app) as a workaround for firewall/browser issues and to facilitate meeting participation.Meeting invites: duplicate calendar invites were reported as a legacy issue, members were advised to confirm meeting dates directly in CPMS and/or via the Endo-ERN website.
- A troubleshooting resource was mentioned for common CPMS access problems (e.g., EU Login/app issues and IT guidance).
- MTG4 and MTG5 were noted as not currently having a recurring CPMS meeting series.

  - **WP5 Registries, data management & analysis (Natasha Appelman-Dijkstra)**

- e-REC participation increased year-on-year, continuous monitoring usage appears to be driving engagement.
- Core registry participation increased (44 centers reported, 42% of eligible HCPs), with growth in reported cases.
- Orphanet code changes are monitored, members can request updates when codes change or are missing.
- Registry updates included: a new prompt on patients referred from a foreign country (Ukraine will be one of them), an autosave function (removing the need for manual save) and preparation for expanded life-course outcomes prompts (including sex/age-relevant questionnaires).
- Hypoparathyroidism module development was noted, integration discussions with WP7 and the genomic testing working group were mentioned.

  - **WP6 Education and Training (Violeta Iotova)**

- Endorsements: endorsed events continued, the need for additional webinars was repeated to support the next accreditation package.
- Clinical exchanges: limited uptake was reported, two applicants requested two-week exchanges and were approved, remaining exchange capacity remains available.
- Webinars: members and MTGs were invited to propose topics and speakers, a joint webinar plan with another ERN was mentioned.
- Rare Disease Winter School: planned to open on 28 February 2026 in Varna, faculty and student participation numbers were reported, with Erasmus+ support noted.

  - **WP7 Clinical Practice Guidelines & CDST's (Charlotte Gaasterland)**

- 3 ongoing CPGs were referenced: Congenital hypopituitarism, Hypoadrenalism replacement therapy and Hypothalamic obesity
- SOP for CPGs was distributed prior the SCAB meeting. No remarks received which means approval by the SCAB.
- Endorsement strategy: survey results were summarized (77 responses across countries/MTGs), including desired endorsement meaning, relevance/quality criteria, and an indicative threshold for agreement with recommendations.
- A Delphi procedure across ERNs is underway to define a minimum 3 criteria set for endorsed documents beyond formal clinical practice guidelines.

WP8/WP9 Capacity building, best practice sharing & other activities for Ukraine (Charlotte van Beuzekom)

- Dedicated webpage for Ukrainian clinicians was launched late last year, a contact database is being built and expanded.
- A joint webinar with eUROGEN is planned (18 February), aimed at Ukrainian clinicians (open to all).
- Clinical Exchange 2026 includes a Ukrainian participant.
- 2026: planned AI translations of the webinar library and possibly other materials.

4. Working Groups updates

WG Genomic Testing (Thomas Eggermann & Dirk Prawitt)

- Working group status: 31 participants from 10 countries; meetings held every 2–3 months.
- Paper: "what the endocrinologist expects from genomic testing and reporting" is in pre-submission, targeting completion by April 2026.
- Collaboration: engagement with the European Society of Human Genetics (ESHG) was discussed (alignment on teaching/masterclass content and website visibility), collaboration should be free of industrial influence.
- ERDERA diagnostic research workstream: members can submit unsolved exome/genome cases (with local HCP sign-up responsibilities), MTGs were asked to nominate at least one representative to coordinate next steps.
- Sponsored genomic testing: a draft checklist/blueprint on handling offers from pharmaceutical companies was prepared and is to be disseminated, clarification was requested on whether/how such a document should be endorsed.

WG Transition in Care (Ulla Döhnert)

- Transition checklists: at least one checklist example from each MTG was received, finalisation expected after the February TALENT meeting in Rome.
- A transition-in-care survey manuscript was submitted to Endocrine Connections and is under review.
- Coordination with other transition-of-care groups continues, an overarching ERN transition-of-care structure is being formalised at EU request, including a youth panel (open to new participants).
- A rare disease transition workshop was planned for end-February in Belgium, with Endo-ERN representation planned (Ulla Döhnert (paediatric endocrinology), Claudio Auteri (patient representative))

- **WG Research (Alberto Pereira, Olaf Hiort & Charlotte van Beuzekom)**

- An open call for chairs remains unanswered, several members expressed interest but no chair(s) were identified.
- Members were encouraged to step forward for chair positions (including encouragement noted from Alberto Pereira and Olaf Hiort).
- The intended scope includes connecting clinical expertise with basic research and supporting consortium formation/participation in relevant research calls such as the ERDERA JTC 2026, positioning Endo-ERN as a clinical partner offering expertise in rare endocrine conditions.
- The EndoCompass publication was noted, including a specific review article about RD research in Endocrinology by Alberto Pereira and Olaf Hiort. The article addresses 5 focus areas for research into rare conditions
- Proposed actions to implement these focus areas : Map the research landscape within Endo-ERN and the wider ERN ecosystem, raise awareness of persistent underfunding of endocrine research despite its impact on the EU population and highlight patient impact and unmet needs in rare endocrine conditions.

5. Other RD project updates

- ERDERA JTC 2026 call highlighted: “Resolving unsolved cases in rare genetic and non-genetic diseases through variant validation and new technological approaches”. 4 proposal initiatives were mentioned.
- Members involved in proposal initiatives were encouraged to make Endo-ERN participation visible (e.g., by marking institutional affiliation).
- ERDERA Networking Support Scheme noted: up to €30,000 per event; next deadline 7 April 2026.

6. Next meeting

- SCAB session during Endo-ERN General Assembly, Athens (Greece): 20 April 2026. Time: 09:00-10:00

Meeting minutes

Tasks / decisions / information

#	Description	Responsible	Due date	Task (T) Decisions (D) Information (I) *select what is appropriate*
1	Finalize early-2026 webinar schedule	MTG chairs		T
2	ESE Rare Disease Committee representative replacement.	Coordinating office		T
3	Submit the first periodic technical/financial report for the EU4Health ERN grant	Coordinating office	End of Feb 2026	T
4	Support completion of the Endocrine Connections special issue	MTGs		T
5	Send invitations to members for topic proposals for the Endocrine Oncology special issue	Coordinating office		T
6	Share Rare Disease Day (28 Feb 2026) campaign materials and invite patient stories / participation	Coordinating office	28 Feb 2026	T
7	Download CPMS 2.0 app and ensure EU Login app works	All HCPs	April 2026	T
8	Submit 2025 e-REC numbers for continuous monitoring.	All HCPs	31.01.2026	T
9	Continue registry updates, request Orphanet code changes as needed.	All HCPs		T
10	Submit additional continuous monitoring patient figures to the EC platform	All HCPs	28.02.2026	T
11	Circulate and discuss the updated endorsement strategy and proceed with the Delphi work on minimum criteria for endorsed documents.	WP7	GA Athens	T
12	Finalize and submit the working group paper on expectations for genomic testing and reporting.	WG Genomic Testing	GA Athens	T
13	Each MTG to nominate at least one person to support ERDERA diagnostic workstream participation (data interpretation task force / liaison).	MTG Chairs		I
14	Re-open call for chairs for the transversal research working group; interested members to step forward.	Coordinating office		T
15	Consider applying to ERDERA Networking Support Scheme (max €30,000/event); next deadline.	Interested Endo-ERN members	7 April 2026	I