

Meeting minutes



ePAGs & coordinators meeting

Date: Tuesday 09.09.2025

Location: online

Attendance (14): Marta Barańska, Charlotte van Beuzekom, Esther Bloem, Lexi Breen, Petra Brüggmann, Marc Büdenbender, Patricia Carl-Innig, Aimee Casey, Jadranka Elezovic, Nathalie Ferard, Johan de Graaf, Martha Kirchhoff, Zuzana Smith, Emily White

DISCUSSION TOPICS

Opening and welcome (Charlotte van Beuzekom)

- Charlotte welcomed members, noted both coordinators could not join due to travel and introduced Marc Büdenbender and Laura Maag as new ePAGs.
- She noted Jette's serious health issues but emphasized that undergoing treatment gives some positive effect.
- Arlene Smyth has stepped down due to other commitments but hopes to keep joining ESE and ESPE meetings.

New ePAG Member presentation (Marc Büdenbender)

- Background: Economist from Germany, career in Switzerland (communications, marketing, government affairs/lobbying incl. Brussels).
- Patient story: Diagnosed 2017 with adrenal cancer, two recurrences in 2019 with multiple metastases, surgery in early 2020, currently tumor-free. Underwent 10 chemo cycles, 3 open surgeries, and more than 7 years of mitotane treatment.
- Patient organization work: Since 2021 active within the international "[Let's cure ACC](#)" patient organization focused on connecting patients to the medical world and research, maintains a database of 150+ ACC experts in 50+ countries, coordinates a German ACC patient group. They have 13 ambassadors (roughly half US / half Europe) with varied backgrounds (patients, nurse, medical professionals).
- Discussion: Charlotte asked about the group's research involvement. Organization is often engaged at the grant application stage and later for patient input/feedback, current momentum driven by a Dutch private donor, funding several projects. His lobbying experience could support Endo-ERN's sustainability/funding efforts.

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Evaluation Activities (Emily White)

- Thanks to those who completed the activity overview, reminders to outstanding ePAGs to submit.
- Purpose is clarified again: support and insight of activities, not control.
- After complete submissions, results will be shared in order to make future decisions on roles, tasks and activities

Patient Journeys (Emily White)

- Patient Journeys - Update: Pilot journey - Acromegaly (June–Sept 2025) using an Endo-ERN–adapted EURORDIS protocol. Rationale: long time to diagnosis (4–10+ years), existing network data/guidelines, and broad centre coverage.
 - Method & targets: Mixed-methods baseline, min. 20 patients across 6 EU countries, Delphi refinement, clinical review with more than 6 countries, and rollout via CPGs (PDF/handbook/video/web). Engagement so far: 43 joined, 31 provided feedback
 - Key lessons: Defining scope of patient; scope needs early MTG chair engagement, to hit 6-country target, translation steps must be built in, validation is an ongoing maintenance process (yearly/biennial updates), need ePAG input on the most useful final formats, map existing journeys to avoid duplication (e.g., craniopharyngioma already covered).
- Discussion: Johan asked for response counts and country breakdown, raising concerns about language barriers (English only survey) and potential country bias due to dissemination timing (holiday period). Johan also described a pharma-initiated project (company engaged a self-employed specialist) with 12 patients per DE/NL/UK, clinician involvement, aiming for publication), noting the partnership is about patient journeys (not medicines). Charlotte/Aimee see potential for Endo-ERN to connect if objectives align, Johan to explore at his meeting in Amsterdam.

Collaborative project on drug shortage (Johan de Graaf & Petra Brüggmann)

- Data analysis continues, multiple medicine-specific workgroups formed, survey effort larger and slower than expected, lessons learned on scope and coordination. Key lessons: the survey grew too large (30 printed pages), creating complexity.
- EMA and WHO also conducting broader surveys, Endo-ERN group was among the first focused efforts in endocrine medicines

Communications update (Aimee Casey)

- Patient resources section live since July (more than 100 searchable items, approvals via MTG chairs), ongoing clean-up and expansion (including general resources like social security/benefits)
- Website change form process reiterated, logo audit reminder, how to cite Endo-ERN guidance to be re-circulated with minutes.

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- Branding & citation: Please place the Endo-ERN logo and the approved explanatory text on your websites/materials; contact Aimee for formats/space constraints. There is a specific way to cite Endo-ERN in papers; Aimee will circulate the text and link with these minutes.
- Patient-focused webinars (2026): Propose 2 sessions (e.g., travel with medications/crisis management, working with rare disease, transition of care, working with your care team). Volunteers/topics welcome; aim to have one planned by June 2026; also encourage ePAG participation in clinician webinars.
- Adrenal patient forum (ESE): being disseminated.
- EURORDIS Rare Barometer: info webinar this Thursday; subject expected to be mental health (per Johan de Graaf). Materials are typically translated and social assets provided to ease dissemination.
- Q&A: Lexi asked whether the Endo-ERN logo could be used in conference presentations, and Aimee confirmed that it can.

EURORDIS joint activities (Johan de Graaf & Petra Brügmann)

- [EURORDIS Open Academy](#): May 2026; applications open until 17 October 2025.
- EURORDIS leadership: CEO Virginie Bros-Facer stepped down; EURORDIS has begun the process to find a new CEO.
- ESPE - planning to formalize patient engagement; Johan de Graaf & Arlene Smyth advised mirroring ESE's model; an ePAG's position/expectations document is being prepared.
- EDERA research programs: Johan reviewed 12 proposals (cardio/nephro/lung/blood), none endocrinology. Encourage Endo-ERN to form consortia and submit endocrine-focused proposals; amounts sought range €1.4–2.9M; online/onsite EDERA meeting on 4 October 2025 referring-patient role in research. Charlotte noted a new Endo-ERN research working group is being set up to boost endocrine-focused applications.
- EMA legislation: Potential change could limit patients to attendance without input; Dutch patient origination co-signed a letter to the Ministry; Johan will share document, but its in Dutch and should be translated.
- ePAGs steering group (chaired by Ines Hernando): Letter on role of patients within ERNs to be circulated for signatures.

Upcoming Important Dates

- World Orphan Drug Congress Europe: October 27–29, 2025, Amsterdam
 - Endo-ERN partners with free participation options for ePAG members.
- ePAGs & coordinators meeting, 02 December 2025, online
- Next SCAB Meeting: 20 January 20, 2026, online
- Endo-ERN General Assembly 2026, 20 and 21 April 2026, Athens, Greece

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- ECE 2026, 9-12 May 2026, Prague, Czech Republic,
- ESPE 2026, 8-10 September 2026, Marseille, France
- Q&A: Travel logistics (Athens): Nathalie requested two hotel nights for ePAGs due to flight timings; Charlotte: likely doable; team will confirm.

Closing Remarks:

- Charlotte thanked all for their updates, questions, and contributions.

Action Items:

#	Description	Responsible	Target date	Task (T) Decisions (D) Information (I) <i>select what is appropriate</i>
1	Send outstanding activity overviews to Emily.	ePAGs	ASAP	T
2	Provide country breakdown & language notes	Emily White		T
3	Explore “get-to-know” meeting between Endo-ERN and the pharma company behind the craniovergenoma project; report back.	Johan de Graaf		T
4	Athens GA — confirm 2 hotel nights for EPaGs	ENDO-ERN team	Until next ePAG&coordinators meeting	T
5	Website branding & text: Place Endo-ERN logo and approved affiliation text, contact Aimee for formats.	ePAGs		I