

## ePAGs & coordinators meeting

**Date:** Tuesday 02.12.2025

**Location:** online

**Attendance (20):** Marta Baranska, Beate Bartès, Charlotte van Beuzekom, Esther Bloem, Lexi Breen, Manuela Brosamle, Marc Büdenbender, Aimee Casey, Jadranka Elezovic, Johan de Graaf, Olaf Hiort, Martha Kirchhoff, Jette Kristensen, Laura Maag, Giorgio Dal Masso, Alberto Pereira, Bernd Rosenbichler, Teresa Valencia, Diana Vitali, Emily White.

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## DISCUSSION TOPICS

### Opening and welcome (Charlotte van Beuzekom)

- Charlotte van Beuzekom opened the meeting, informed participants that format with indicative timing per item was introduced to help keep the meeting within the one-hour slot.

### New ePAG Member presentation (Laura Maag)

- Laura Maag was welcomed as a new ePAG representative for [Surrénales France](#), a French patient organisation dedicated to adrenal diseases. She is the mother of a 17-year-old with CAH, has long volunteered with the organisation, contributed to the European Adrenal Emergency Card, and works professionally in AI/translation with a PhD in machine learning.
- Surrénales France (founded 1996, public-interest association) has just under 1,000 patient and family members, is run by a volunteer board and advised by adrenal experts in a national reference-centre network. It covers a wide range of adrenal conditions (Addison's, various forms of adrenal insufficiency, Cushing's, CAH, hyperaldosteronism, phaeochromocytoma and other adrenal tumours) and aims to inform and support patients, refer them to specialised centres, advocate for better care and access to medicines, and maintain active communication channels with families.

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## New ePAG Member presentation (Teresa Valencia)

- Teresa Valencia was welcomed as a new ePAG representative and is President of [ADISEN, a Spanish national association for Addison's disease and other rare endocrine disorders](#). ADISEN, created after Teresa's long diagnostic journey, is a non-profit, volunteer-run organisation of patients, families and supporters that also serves Spanish-speaking patients worldwide.
- The association supports people with various rare endocrine diseases (including all types of adrenal insufficiency, pituitary–adrenal adenomas, CAH, septo-optic dysplasia and others), is a member of FEDER and the Adrenal International Consortium, and responds to a high volume of enquiries. It focuses on information, awareness-raising and helping undiagnosed patients access care, but still faces challenges such as inconsistent emergency treatment of adrenal crises and reluctance to prescribe emergency hydrocortisone. For 2026, ADISEN plans stronger advocacy across Spain's regions to standardise care.

## GA2026 (Charlotte van Beuzekom)

- The next Endo-ERN [General Assembly](#) will take place on 21–22 April 2026 in Athens, Greece.
- At the time of the meeting, six ePAG representatives were registered, MTG2, MTG4 and MTG7 were still lacking representatives.
- All ePAGs were encouraged to register, travel reimbursement rules are described in a separate email from the coordination office.
- New this year: ePAG representatives can already be reimbursed for travel costs prior to the GA, so they do not have to wait long after the meeting.
- The programme includes a 15-minute ePAG presentation slot on Tuesday 21 April. ePAG members are invited to volunteer to give this presentation and to propose topics. If no volunteer comes forward, the coordination team will contact specific ePAGs based on their ongoing work.

## ECE 2026 (Charlotte van Beuzekom)

- The [European Congress of Endocrinology](#) (ECE) will be held in Prague, 9–12 May 2026. Endo-ERN will host a symposium on 12 May (11:20–12:50) covering Endo-ERN initiatives, genomic testing, the paediatric thyroid cancer registry, RTH-β, and an ePAG presentation on acromegaly patient journeys.
- There will also be a shared Endo-ERN booth, where ePAGs can display their materials according to a booth schedule.
- ESE's new structure groups patient organisations into seven communities, with Congress grants for 12 representatives, including two for Endo-ERN/ePAGs.

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- Endo-ERN has obtained extra funds to help more ePAGs attend. Congress access will be free for all ESE-affiliated patient organisations and Endo-ERN ePAGs.
- ESE is working on how best to manage non-HCP access to the commercial exhibition while keeping patient advocates involved.

## Patient Journeys (Emily White)

- Emily explained that patient journeys are patient-driven tools that map the care pathway, highlighting expectations, barriers and needed improvements, and are intended to inform clinicians, policymakers and guideline developers.
- The acromegaly patient journey has a validated baseline (with broad ePAG input). It is now undergoing clinical review by MTG6 experts from six countries, and a dedicated acromegaly patient representative is being recruited to review the final version and possibly present it.
- For future patient journeys, the methodology has been refined and will be shared in the new year. To avoid duplication with other projects, Endo-ERN will first map gaps and identify where its input is most needed. The next priority is a MEN1 patient journey, which Emily will start together with Petra and MTG4 chairs.

## Communications update (Aimee Casey)

- The Patient resources page on the Endo-ERN website is live, searchable by MTG, condition and language, with improved navigation. ePAGs are invited to explore it and give feedback.
- A streamlined process for adding new patient materials was agreed: content from Endo-ERN members and ePAGs can be published after topic approval by MTG chairs, with named medical reviewers for any medical advice. All materials will be clearly labelled as informational only.
- The EURORDIS Rare Barometer survey has 93 responses for Endo-ERN conditions, ensuring a tailored mental-health report (expected spring 2026). ePAGs are asked to keep promoting the survey.
- The Endo-ERN logo and standard website text have been shared with ePAG organisations; Aimee will resend them where needed and support website updates.
- For Rare Disease Day 2026, a joint ERN campaign called *“Meet our Heroes”* is being developed to highlight ePAG experiences. The exact format is still being defined; ePAGs will be updated and invited to participate voluntarily.

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## Youth panel in the ERN-wide transversal transition group (Diana Vitali)

- Diana is coordinating the participation of a young patient with septo-optic dysplasia in the ERN-wide young-patients panel of the transition group.
- Each ERN may nominate two young patients; Endo-ERN currently has one open place.
- Ideal candidates are young patients with good English skills and interest in advocacy.
- Diana encouraged ePAGs to look for suitable young people within their communities and contact her or the organizing team.

## Upcoming Important Dates

- Next SCAB Meeting: 20 January, 2026, online
- Endo-ERN General Assembly 2026, 20 and 21 April 2026, Athens, Greece
- ECE 2026, 9-12 May 2026, Prague, Czech Republic,
- I-DSD meeting (relevant to MTG7) Lübeck, 1–3 July 2026.
- ESPE 2026, 8-10 September 2026, Marseille, France

## 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	Indicate interest in attending the GA and register	ePAGs	5 January 2026	T

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2	Inform the coordination team if they wish to attend ECE2026	ePAGs	01 February 2026	T
3	Finalise the ePAG speaker for the patient-journey slot at ECE2026 and for the ePAG speaker slot at GA2026	Coordination team	01 February 2026	T
4	Prepare and circulate the booth schedule prior to ECE2026	Coordination team	01 May 2026	T
5	Complete the acromegaly patient journey (including clinical and patient review)	Emily	Q1 2026	T
6	Initiate work on the MEN1 patient journey with Petra and MTG4 chairs	Emily	Q1 2026	T
7	Continue sharing the Rare Barometer survey while it remains open.	ePAGs		T
8	Resend website text and logo to Diana, Teresa and others who request it.	Aimee	01 January 2026	T
9	Keep ePAGs informed about the “Meet our Heroes” campaign and coordinate volunteers.	Aimee	ongoing	T