

Meeting minutes



ePAGs & coordinators meeting

Date: Tuesday 10.06.2025

Location: online

Attendance (16): Marta Baranska, Beate Bartes, Charlotte van Beuzekom, Esther Bloem, Petra Brüggmann, Patricia Carl-Innig, Aimee Casey, Giorgio Dal Maso, Jadranka Elezovic, Nathalie Ferard, Olaf Hiort, Jette Kristensen, Alberto Pereira, Bernd Rosenbichler, Diana Vitali, Emily White.

DISCUSSION TOPICS

Opening and welcome

Charlotte van Beuzekom welcomed all attendees.

New Applications for ePAG Membership

- Three organizations showed interest:
 - *Let's Cure ACC* (France): Application submitted.
 - *Association Surrénales* (France): Application submitted (right after the meeting)
 - *European Life Science and Knowledge Institute*: Application under review; lacks clear endocrine focus.

Evaluation Activities

- Emily White presented the ePAG evaluation report structure.
- Focus: highlight ePAG contributions, not enforce compliance.
- Participants will receive reports and will be asked to verify scoring accuracy.
- Proposal to weigh activities differently depending on role discussed.

Patient Journeys

- First patient journey: Acromegaly

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- Survey hosted via EU Survey, with focus on:
 - Translation validation by native speakers.
 - Consent clarity.
 - Outreach begins in Germany, Netherlands, and France.

Collaborative project on drug shortages

Petra Brüggmann provided updates:

- Ongoing analysis of survey data.
- Country- and chapter-specific expert groups forming.
- Coordination with Endo-ERN, ESE, and ESPE to formalize project.

Lookback at GA and Joint Congress Copenhagen

Jadranka Elezovic provided feedback on the GA and Joint Congress:

- GA: 144 attendees, including 13 ePAGs.
 - Presentations by Patricia Lars-Innig and Lars Greiner highlighted evolving treatments and patient organisation cooperation.
 - Joint congress: 9 ePAGs participated at the joint booth; the initiative that was applauded for its visibility and collaborative impact.
 - Presentation by Lexi Breen at Endo-ERN symposium on Challenges associated with late diagnosis of intersex variations and its links to gender identity

Reminders:

- Reimbursement deadline: June 16, 2025
- Book travel/accommodation 5–6 months in advance to stay within EU reimbursement rules (maximum amounts).

New Patient Resources page on website

Aimee Casey showcased the redesigned page:

- Filter by condition, MTG, and language; possibly country.

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- Emphasis on usability and visibility.
- Only 1% of site traffic currently goes to patient resources.

Decisions:

- Country filter will be retained for now after discussion.
- Giorgio requested direct filtered links—Aimee to check technical feasibility.

EURORDIS joint activities

EURORDIS Open Academy & EMA Representation

Petra urged members to explore:

- Open Academy training: free, multilingual, and high quality.
- EMA representation issue: vote loss under new EU regulation.

Rare Barometer Updates

- Ongoing surveys and upcoming mental health survey.
- Emphasis on responding and leveraging findings for policy impact.

Upcoming Dates

- Next SCAB Meeting: September 2, 2025
- World Orphan Drug Congress Europe: October 27–29, 2025, Amsterdam
 - Endo-ERN partners with free participation options for ePAG members.

Closing Remarks:

- Charlotte thanked all participants for their contributions.

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Action Items:

#	Description	Responsible	Target date	Task (T) Decisions (D) Information (I) <i>select what is appropriate</i>
1	Follow up with EURORDIS and inform members upon progress about the new ePAGs	Charlotte van Beuzekom		T
2	Finalize and distribute evaluation reports	Emily White	In 2 weeks	T
3	Validate survey translations – Polish	Martha Baranska		I
4	Create a Joint Congress feedback form	Jadranka Elezovic	ASAP	T
5	Submit reimbursement forms for the GA	ePAGs	16.06.2025	
6	Finalize patient resource page & share for feedback	Aimee Casey	In 4 weeks	T
7	Sign the joint statement defending patient voting rights at EMA.	ePAGs		I