

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

Date & time: Monday 20 April 2026, 09:00-10:00 hrs

Location: Crown Plaza Hotel Athens, Greece

Attendance (47): Beate Bartès, Jerome Bertherat, Nienke Biermasz, Charlotte van Beuzekom, Esther Bloem, Marc Büdenbender, Patricia Carl, Aimee Casey, Natalie Ferard, Frederic Castinetti, Evangelia Charmandari, Hedi Claahsen, Johan de Graaf, Olaf Dekkers, Charlotte Gaasterland, Claus Højbjerg Gravholt, Olaf Hiort, Charlotte Høybye, Violeta Iotova, Andrea Isidori, Eva Kassi, Laura Maag, Pietro Maffei, Susan O'Connell, Alberto Pereira, Luca Persani, Nicole Reisch, Bernd Rosenbichler, Athanasia Stoupa, Edward Visser, Diana Vitali, Emily White

Agenda items

1. Funding grants

- *Current Endo-ERN grant* runs from 1 Oct '23 to 1 Oct '27. Official Interim report – technical and financial - was submitted to the EC and is currently under review. Part of the review is a Project Review Meeting with external reviewer and EC, which took place 8 April and was a constructive and very positive meeting. Future ERN funding advocacy is taking place. ERN coordinators and other stakeholders try to get Rare Diseases and the ERNs strategically well positioned in future EU funding programs for post-2027 funding.
- The *FIRENDO* network launched a [new call](#) in April this year. An award of max Euro 60.000 will be granted for the 2026-2027 period to fund a collaborative research project between a FIRENDO member institution and a healthcare provider (HCP) that is a member of Endo-ERN **outside of France**. Submission deadline May 3rd, 2026
- ERDERA offers several [funding opportunities](#)
 - *JTC2026*: 5 submitted pre-proposals (Appelman, Leiden: Bone, Kircher, Luebeck: DSD, Persani, Milan: Rare Thyroid Disorders, Romanet, Marseille: MEN1, Bonomi, Milan: CHH). Invitations for full proposal expected in May, with deadline 8 July.
 - *Networking Support Scheme*: Permanently open call from May 2025 until funds are exhausted (expected April '29). Applications for funding up to Euro 30.000 per networking event can be submitted at any time and are reviewed in six-monthly collection rounds. 2 Endo-ERN submissions in the first round of which the submission by Andrea Isidori for the next TALENT meeting has been selected for funding.
 - *Clinical Trials Call*: will be soon available

Meeting minutes



2. Journals – special issues & collaboration

- In 2021 first Endo-ERN special issue in *Endocrine*
- In 2022 collaboration with *Endocrine Connections* started with special series celebrating 5th year of Endo-ERN which resulted in collaboration until today.
- To raise awareness of the Endocrine Connections partnership and high-quality publications of previous and current special issues, collaborative set-up and organization of joined webinars was initiated.
- Endocrine Connections *proposal for continued collaboration* was discussed:
 - Hedi Claahsen: Benefit for having a journal is clear but benefit of Endocrine Connections as a small impact journal is not directly clear e.g. EJE or other EU journals might be more beneficial
 - Jerome Bertherat – noted that Faisal Ahmed communicated this previously, that a desire is to make Endocrine Connections THE rare endocrine journal
 - We don't want to be/feel responsibility to publish (only) in a specific journal such as this, therefore it should be transparent that this is not exclusive partnership
 - Many HCPs have full APC for different journals, not Endocrine Connections necessarily
 - Emily White noted that APC in various HCPs can be applied, 100% for Endocrine Connections for instance in AUMC, and should be noted prior to project start/ early in a process to pick a journal
 - Edward Visser wondered how the benefit of this collaboration will be assessed/ measured
 - *Summary*: A more clear advantages and disadvantages analysis is desired in considering this proposal
 - Professional benefits / discount not very incentivizing
 - Payment is still in question
- Next special issue in *Endocrine Oncology*. Request for topic proposals to all members resulted in 5 proposals. These will be sent around to the SCAB members for your review and completion, aiming for 1 paper per MTG, with a max of 8-10 papers. We also need 2-4 guest editors.

3. Positions and roles

- The term of Gudmundur Johannsson as Endo-ERN representative in the *ESE Rare Disease Committee* ends in 2026 and a replacement process was started by the Coordination Office which resulted in 4 expressions of interest (Nienke Biermasz, Michal Krsek, Ulrike Schierloh, Anna Angelousi). Reflection was requested on how this person is selected.
 - Claus Gravholt: As broad a representation as possible is preferable i.e. adult representation in the ESPE RDAC and paediatric representation in the ESE RD Committee.
 - Edward Visser: Consider timeline of the serving time of those volunteering (not all ending in 2028)
- Functioning of all clinical committees in ESE is being discussed with the desire to professionalize these roles.
- Currently we focus on the educational matters more so than others in the RD Committees. Olaf Hiort noted that Endo-ERN was formed to standardize the care delivery in EU, a different one from the societies.
- Idea to maintain triage between ESE, ESPE and Endo-ERN committees and to formalize responsibilities, position and key role. Good communication is essential.

Meeting minutes



- Olaf Hiort informed the SCAB that the *next paediatric chair* needs to be found as he steps down at the next GA (March 2027) so the successor should be in place from then onwards. He advised to find someone from the next generation with new ideas. Those with interest can begin learning asap, in particularly through the start of next grant applications. Olaf Hiort offered to meet and discuss the tasks and workload with interested parties. Olaf Dekkers wondered if a replacement protocol should be applied. Expressions of interest for the position should be made to Olaf and Alberto.

4. GA 2027

- Currently exploring possibilities to organize the next GA2027 linked to ESPE2027 (Gothenborg), ECE2027 (Basel) or else as – due to limited EC funds - in the current grant budget a yearly f2f meeting was not anticipated for. Meeting rooms and catering is the main coverage needed as we will not reimburse travel and accommodation.
- Andrea Isidori kindly offered to check the possibilities to connect to the next TALENT meeting in Rome and use University rooms, which then needs to be rescheduled to March. The coordination office will reach out to Andrea Isidori to exchange the needed facilities etc. The venue will be announced prior to the summer period.

5. Other

- Susan O’Connell volunteered to lead a survey to look at the smaller Member States and see what the impact and benefits of ERNs are to those healthcare systems.
- Next SCAB meeting to be scheduled

Tasks / decisions / information

#	Description	Responsible	Due date	Task (T) Decisions (D) Information (I) <i>select what is appropriate</i>
1	Draft a clear advantages and disadvantages analysis to better consider and decide upon the Endocrine Connections collaboration proposal	Coordinating Office + SCAB	Next SCAB meeting	T + D
2	Support completion of the Endocrine Connections special issue	MTGs	July 2026	T
3	Send topic proposals for the Endocrine Oncology special issue to MTGs to complete	Coordinating office	May 2026	T
4	ESE Rare Disease Committee representative replacement.	Coordinating office + SCAB	July 2026	T
5	Endo-ERN paediatric chair replacement	Coordinating Office + SCAB	September 2026	T

Meeting minutes



6	Explore options and decide upon venue & date GA2027	Coordinating Office	July 2026	T + D
7	Lead a survey to look at the smaller Member States and see what the impact and benefits of ERNs are to those healthcare systems	Susan O'Connell	2026	T
8	Schedule next SCAB meeting	Coordinating Office	May 2026	T