

## Rare Disease Committee

### Committee Composition

Co-chairs: Co-chair 1: A member of the Executive Committee, designated by the Executive Committee.  
Co-chair 2: Representative of Endo-ERN nominated by Endo-ERN and who is a member of the European Society of Endocrinology.

Full members: Up to eight members.  
An open call for the available ESE representative positions will be advertised. ESE members can apply themselves or nominate someone else. Current Committee members can also make nominations. This Committee will review and vote on the applications/nominations received. The Committee Chair will then propose the new member(s) to the Executive Committee, who will ratify the new member(s).

ENDO-ERN representatives will be proposed by the Committee and ratified by the Executive Committee.

Ex-officio members: ESE President.  
ESE President-Elect.  
ESE Science Committee Chair.  
ESE Clinical Committee Chair.  
ESE Education Committee Chair.  
EYES Committee Representative.

Co-opted members: Up to two additional members may be co-opted for a limited period to fulfil a specific role, subject to Executive Committee approval. Input may also be sought from patient advocacy groups.

### Quorum

*There should be at least 50% of ESE representatives and 50% of Endo-ERN representatives and one of the Chairs (excluding Ex-officio members).*

### Duration of Service

Chair: Four years.

Full members: Four years. During the introduction of this Committee membership may be staged so that not all Committee members retire at the same time.

Ex-officio members: Co-terminous with office.

Co-opted members: Up to two years, but with the option to extend to four years in total with approval from the Executive Committee.

### Reporting

The Committee reports to the ESE Executive Committee through the Executive Committee Rare Disease Committee Chair.

### Meetings

Two meetings per year (held alongside the annual ECE and another ESE/Endo-ERN meeting). Meetings can be held via telecon/video conference, if required.

The work of the committee is very important. Committee members are expected to attend all committee meetings and to participate in committee related email communications.

Committee members who do not attend three consecutive meetings (or one meeting in a year if meetings are held annually) will be asked to step down, other than in exceptional circumstances.

## **Remit**

1. To develop a specific policy of ESE towards rare endocrine and metabolic diseases.
2. To foster collaboration, cooperation and coordination of activities in the area of rare diseases between ESE and Endo-ERN (including EURRECA) that are relevant to the activities of ESE, such as:
  - To assess educational needs and find collaborative solutions for rare disease-relevant educational platforms for healthcare professionals and patients, focusing on improving QoL, transition from pediatric to adult care and the prevention of, and long-term management of complications and co-morbidities.
  - Clinical guidelines.
  - Endo-ERN activities at the annual European Congress of Endocrinology through representation on the ECE POC.
3. To develop collaborations with other ERNs and specialist societies operating in the rare-endocrine disease and metabolic landscape, ensuring optimal outcome for collective efforts at the institutional level.
4. To raise awareness of research and clinical trials into rare endocrine and metabolic diseases and support efforts to ensure this area receives appropriate focus from funding bodies.
5. To promote and facilitate cross-border care and multidisciplinary consultation, supporting ERN's efforts in ensuring access to appropriate diagnostic tools and improved remote support through telemedical innovations.
6. To improve awareness and engagement of researchers and clinicians with rare-diseases registries for the benefit of patient outcomes.
7. To provide a platform for collaboration with Patient Advocacy Groups ensuring ESE and ERNs continue to support Patient-led and patient- centered initiatives in healthcare.
8. To raise public awareness of rare-diseases through collaboration with European institutions and relevant national and international organisations.
9. To manage the allocation of budget in relation to rare diseases activity.

## **Additional notes**

- All Committee members need to be paid up members of the European Society of Endocrinology.
- The work of the committee is very important. Committee members are expected to attend all committee meetings and to participate in committee related email communications.
- Committee members who do not attend three consecutive meetings (or one meeting in a year if meetings are held annually) will be asked to step down, other than in exceptional circumstances.
- The Committee will liaise with other ESE Committees as appropriate.
- All papers and minutes must be treated in strictest confidence.
- The use of an AI 'otter' to join meetings/take notes at a committee meeting is not permitted unless expressly authorised by the Chair.
- All Committee members must act in the best interest of the Society and of ERNs.
- Any potential conflicts of interest should be declared at the start of the meeting or as they arise, and the member concerned should take no part in the discussion.
- The Chair should not serve a second consecutive term of office, unless there are exceptional circumstances identified by the Executive Committee.

- The Society is committed to equal opportunities and the promotion of equality, diversity and inclusion and where possible this committee should follow the principles of [ESE's Equality, Diversity and Inclusion Policy](#).
- Committee membership should represent the key areas of interest; geographical spread; and gender considerations.

## **Current membership**

### Co-chairs

Elena Valassi, co-terminous with office (ESE Executive Committee, 2024-2028).

Alberto Pereira, co-terminous with office (Endo-ERN Representative 2019-2025).

### Full members

#### *ESE representatives:*

Krystallenia Alexandraki, Greece, (2020-2026)\*.

Diego Ferone, Italy, (2020-2026)\*.

Sofia Llahana, UK (2024-2028)

Adrian Daly, Belgium (2024-2028)

#### *Endo-ERN representatives:*

Gudmundur Johannsson, Sweden, (2020-2026)\*\*.

Marek Niedziela, Poland, 2024-2028 (ESPE Representative).

Luca Persani, Italy, (2024-2028).

Dimitra Vassiliadi, Greece, (2024-2028).

### Ex-officio

Jérôme Bertherat, France, co-terminous with office (President, 2023-2025).

Wiebke Arlt, UK, co-terminous with office (President-Elect, 2023-2025).

Eleanor Davies, UK, co-terminous with office (Science Committee Chair, 2023- 2027).

Martin Fassnacht, Germany, co-terminous with office (Clinical Committee Chair, 2021-2025).

Gregory Kaltsas, Greece, co-terminous with office (Education Committee Chair, 2024-2028).

Barbara Altieri, Germany, EYES Committee Representative (2022-2026).

ESE Team member responsibility: Head of Scientific Programmes.

\*ESE representatives extended for two years.

\*\*Gudmundur Johannsson (Sweden) extended for two years.