Rare Disease Committee

Committee Composition

Chair:	A member of the Executive Committee, designated by the Executive Committee.
Full members:	Typically, up to eight members. An open call for the available Committee 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). One member to be a representative of ESE EYES (proposed by ESE EYES Committee). One Endo-ERN representative and one ESPE representative will be proposed by the Committee and ratified by the Executive Committee.
Ex-officio members:	None stated.
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

Fifty percent (50%) of Full Members (including the Chair) +1

Duration of Service

Chair:	Four years.
Full members:	Four years. 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 additional members may by co-opted for a limited period to fulfill a specific role, subject to Executive Committee approval.

Reporting

The Committee re ports to the ESE Executive Committee through the Rare Disease Committee Chair.

Meetings

Two meetings per year; meetings can be held via telecon/video conference.

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 Committee will liaise with other ESE Committees as appropriate and other Committee Chairs can be called upon to attend meetings, if needed.
- The President and/or President-Elect can be invited to attend or choose to attend a meeting – either in full or for a specific agenda item.
- All papers and minutes must be treated in strictest confidence.
- Minutes of meetings will be sent to the President/ President-Elect when circulated to the Committee members. Minutes will also be circulated to the Executive Committee.
- 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.
- 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.

ESE Team member responsibility: Head of Scientific Programmes.

November 2026