European Society of Endocrinology

ESE Patient Advocacy Group (PAG) Board

Board Composition

Chair:	A member of the Executive Committee, designated by the Executive Committee.
Full members:	Each PAG community can delegate 1-2 members per community (the number is dependent on the size of the PAG community).
Ex-officio members:	ESE President ESE Rare Diseases Committee Chair or member. ESE Nurse Committee Chair or member. ESE Chief Executive Officer ESE Director of Strategic Partnerships.
Co-opted members:	No Co-opted members have been defined.

Quorum

There is no formal quorum; the board aims to achieve a representation of at least 50% of its PAG Community Representatives.

Duration of Service

Chair:	Co-terminous with office.
Full members:	Co-terminous with the affiliation of their PAG in the ESE PAG membership scheme, and the individuals status as formal patient representative of their PAG.
Ex-officio members:	Co-terminous with office.

Reporting

The ESE Chair provides regular updates to the ESE Executive Committee, when and as needed.

Meetings

The ESE PAG Board will meet twice per year:

- An in-person meeting will take place at the occasion of the annual European Congress of Endocrinology (usually in May).
- A digital meeting will take place in the period November - January.

When and as needed, the Board can be called for additional meetings for discussion of more specific activities (eg, planning for the annual congress. World Hormone Day).

Remit

The key purpose of the PAG Board is:

1. To be the forum where the needs and interests of Patient Advocacy and Support Groups are the focus.
2. To provide a forum to discuss issues of interest and suggest solutions for identified challenges where a common interest exists. Areas of common interest may relate to general educational efforts, disease awareness building efforts, stakeholder strategies, policy related initiatives, society and partner interactions, positioning of endocrinology in Europe.
3. To provide a forum to inform and discuss about ESE strategy, upcoming activities and opportunities.
4. To inform ESE of ongoing key activities planned and developed by PAGs
5. To improve communication and strengthen partnerships between ESE and its PAG Affiliate Members.
6. To secure that all information related to PAGs in the ESE communication channels (website, social media) is up-to-date and relevant.
7. In general, to advise and inform ESE structures (Committees, Focus Areas)

about specific areas of discussion and where needed and appropriate, initiate follow-up discussion and action.

Additional notes

- All Board members are requested to be individual members of the European Society of Endocrinology under the 'Allied HealthCare Professional' scheme. This secures that the board members receive all up-to-date information about the Society and its activities, and access to the benefits of individual membership.
- Board members should make every effort to attend the meetings: in case this is not possible, the board member can be substituted by another member of the PAG Community, provided this person also has the status of patient representative within that PAG.
- 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 Board 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.

Current membership

Chair

Mirjam Christ-Crain, Switzerland, co-terminous with office, (President-Elect, 2025-2027).

Full members

Jo Grey, CEO of the Association of Multiple Endocrine Neoplasia Disorders.
Johan de Graaf, Chair of the Dutch Pituitary Foundation.
Caroline Andrews, Verity PCOS.
Beate Bartes, Thyroid Federation International and Vivre sans Thyroide.
Antonella Campodall'Orto, Associazione Italiana Pazienti Addison.
Margaret Walker, International Prader-Willi Syndrome Organisation (IPWSO).
Julia Priestley, British Thyroid Foundation.
Arlene Smyth, Turner Syndrome Support Society.

PAG Affiliate Members

Ines Alvez, ANDO (Portugal).
Elise Foltet, Bijniervereniging
Manuela Brösamle, AGS-Eltern- und Patienteninitiative e.V.
Petra Bruegmann, European MEN Alliance e.V. / Netzwerk Hypophysen. und Nebennieren-erkrankungen e.V.
Katja Hansen, Danish Addison Disease Association.
Maité-Delphine Dubois, Acromégales, Pas Seulement, France.
Sue Elford/Kaz Williams, CAH Support Group, UK.
Helen Hopkins, Parathyroid UK.
Johanne Amara, Hypoparathyroidisme, France.
Marc Buedenbender, LetsCureACC, France.
Muriel Marks, World Alliance of Pituitary Organizations, Netherlands.
Perny-Ann Nilsen, hypoPARA, Norway.
Jay Sheppard, The Pituitary Foundation, UK.
Harald Rimmele, Bundesverband Schildrüsenkrebs, Germany.
Philippa Sharman, Addison's Disease Self Help Group UK and Ireland.
Leslie Edwin, Cushings Support and Research Foundation (CSRF).
Diana Vitali, SOD Italia.
Marta Baranska, The Pituitary Gland Association Poland
Magdalena Weimer, Stowarzyszenie na rzecz osób z chorobą (Polish Association for People with Addison's Disease and Adrenal Insufficiency)

December 2025

Laila Ertnes, HYBI
Inger-Margrethe Stavdal Paulsen, Osteogenesis Imperfecta Federation Europe

Ex-officio
Wibeke Arlt, co-terminous with office, ESE President (2025-2027)
Elena Valassi, co-terminous with office, ESE Rare Disease Committee Co-Chair (2024-2028)
Aldons Chua, ESE Nurse Committee Representative (2024-2028)
Dirk De Rijdt, ESE Director of Strategic Partnerships.

ESE Team Member Responsibility: ESE Business Development Manager.