

ESE Patient Advocacy Group (PAG) Board

Board Composition

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| Chair: | President-Elect of the European Society of Endocrinology. |
| Full members: | Each PAG community can delegate 1-2 members per community (the number is dependent on the size of the PAG community). ESE EYES Representative (proposed by ESE EYES Committee). ESE Nurse Committee Chair (or member/representative proposed by the Nurse Committee). ESE Rare Disease Committee Chair (or member/representative proposed by the Rare Disease Committee). |
| Ex-officio members: | 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

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| 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. |
| 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. |

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 and other Committee Chairs can be called upon to attend meetings, if needed.
- The President 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 when circulated to the Committee members. Minutes will also be circulated to the Executive Committee.
- 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.
- The Chair should not serve a second consecutive term of office, unless there are exceptional circumstances identified by the Executive Committee.

ESE Team Member Responsibility: ESE Business Development Manager.