

## ESE Patient Advocacy Group (PAG) Board

### **Board Composition:**

Chair:	A member of the Executive Committee, designated by the Executive Committee.
Co-Chairs:	Three representatives from the PAG Affiliate Members.
Full members:	Each PAG approved as a PAG Affiliate Member to ESE can delegate one representative to the Board.
Ex-officio members:	ESE President. ESE Rare Diseases Committee Chair or member. ESE Nurse Committee Chair or member. Endo-ERN representative. ESE Chief Executive Officer. ESE Director of Strategic Partnerships.

**Quorum:** There is no formal quorum, but the board aims to achieve a representation of at least 50% of its PAG Affiliate members.

### **Duration of service:**

Chair:	ESE representatives are co-terminous with office.
Co-Chairs:	2 years (starting at the 1st Board meeting after election, remaining until they are no longer formal representative of their PAG).
Ex-officio 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

**Reporting:** The ESE Co-Chair reports to the Clinical Committee. The Chair of the Clinical Committee 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 October – November.

**Remit:** The key purpose of the PAG Board is:

- 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, provided this person also has the status of patient representative to that PAG.
- Any potential conflicts of interest should be declared at the start of the meeting or as they arise.
- Co-Chairs are being elected on the process of a) solicitation of candidates, b) letter of motivation to be provided by candidates, c) election process facilitated by ESE with each PAG affiliate member having one vote, d) three highest ranked candidates will be appointed as Co-Chairs.
- The Board will liaise with other ESE Committees as appropriate.

## Current Membership:

### Chair

Wiebke Arlt, ESE President-Elect.

### Co-Chairs

Jo Grey, CEO of the Association of Multiple Endocrine Neoplasia Disorders.

Peter Lakwijk, Treasurer of Thyroid Federation International.

Johan de Graaf, Chair of the Dutch Pituitary Foundation.

### Full members

Nes Alvez, ANDO (Portugal).

Caroline Andrews, Verity PCOS.

Beate Bartes, Thyroid Federation International, Vivre sans Thyroïde.

Johan Beun, AdrenalNet and The Dutch Adrenal Society NVACP.

Manuela Brösamle, AGS-Eltern- und Patienteninitiative e.V.

Petra Bruegmann, European MEN Alliance e.V. / Netzwerk Hypophysen.  
und Nebennieren-erkrankungen e.V.

Antonella Campodall'Orto, Associazione Italiana Pazienti Addison.

Jette Christensen, Danish Addison Disease Association.

Maité-Delphine Dubois, Acromégales, Pas Seulement, France.

Sue Elford, CAH Support Group, UK.

Liz Glenister, Parathyroid UK.

Natalie Grosset, Hypoparathyroidisme, France.

Marguerite Hughes, IPWSO.

Cathérine Lamy, LetsCureACC, France.

Muriel Marks, World Alliance of Pituitary Organizations, Netherlands.

Perny-Ann Nilsen, hypoPARA, Norway.

Julia Priestley, British Thyroid Foundation.

Ren Renwick, The Pituitary Foundation, UK.

Harald Rimmel, Bundesverband Schilddrüsenkrebs, Germany.

Vick Smith, Addison's Disease Self Help Group UK and Ireland.

Arlene Smyth, Turner Syndrome Support Society.

Kaz Williams, CAH Support Group.

### Ex-officio members

Jérôme Bertherat, ESE President.

Sebastian Neggels, ESE Rare Diseases Committee Chair or member.

Sherwin Criseno, ESE Nurse Committee Chair or member.

Alberto Pereira, Endo-ERN Representative.

Helen Gregson, ESE Chief Executive Officer.

Dirk De Rijdt, ESE Director of Strategic Partnerships.

ESE Team member responsibility: ESE Strategic Partnerships Director.