

EAACI Patient Organisations Committee

1. Mission and Vision

The European Academy of Allergy and Clinical Immunology (EAACI) is an association of clinicians, researchers and allied health professionals, dedicated to improving the health of people affected by allergic diseases. With more than 12,000 members more than 120 countries and over 70 National Allergy Societies, EAACI is the primary source of expertise in Europe for all aspects of allergy. EAACI's mission is to provide the most efficient platform for scientific communication and education in the field of allergy and immunology, ultimately striving to ease the lives of patients.

EAACI's aims include

- Promoting basic and clinical research;
- Collecting, assessing and disseminating scientific information;
- Functioning as a scientific reference body for other scientific, health and political organisations;
- Encouraging and providing training and continuous education; and
- Promoting good patient care in this important area of medicine

The EAACI Patients Organisations Committee ('POC') aims to be the Patients reference body in the field of Allergy, and its members work together to achieve their critical role by:

- Providing EAACI with the patient and carer real life experience of living with allergic diseases and asthma;
- Representing patients of all nationalities and promoting patient-centred healthcare in the specialty;
- Encouraging patient organisation members to actively engage and contribute patient perspectives through participation in EAACI Sections, Interest Groups, Working Groups, Committees, and Task Forces;
- Building cross-sector alliances and promoting collaboration between patient group members and other EAACI members (like-minded medical and health professionals, academics, and researchers), policy makers, and industry representatives;
- Bringing patient organisations from around the world to discuss and promote patient-organisation led education, advocacy and research initiatives and build awareness of the burden of allergic diseases and asthma;
- Encouraging connection and collaboration with patient advocacy forums, particularly in Europe, to share their wider work within EAACI;
- The POC reports annually to the EAACI Executive Committee or at any time requested by the ExCom.

2. Application for Membership and benefits

The following criteria for EAACI POC membership must be met:

- Legitimacy (the PO must be established as a legal entity in host country)
- Transparency (activities and governance are clearly described on PO website or official document)
- Independence (governed by its members)
- Democracy (election of governing bodies)
- Representation (of relevant patients)
- Commitment (to a vision, shared with EAACI)



Benefits and Expectations of Membership

The benefits of POC membership include:

- Participation in a global network of like-minded patient organisations with opportunities to share best practices to better utilise resources;
- Collaboration with patient organisations around Europe and the globe to gain different perspectives on key issues;
- Engagement in global research efforts these efforts often initiate from a local priority;
- Attendance at EAACI Annual Congresses and Focused meetings and the opportunity to interact and network with world-renowned experts in the field of allergy/immunology; and
- Reaching a global audience of diverse stakeholders to raise awareness, promote activities and events.

Along with benefits, there are expectations of the POC members including:

- Active participation in at least one Section, Interest Group, Working Group or Task Force representing and reporting back to POC on activities;
- Active participation in (at least one of) EAACI Committees and Clinical Village;
- Active engagement in at least one of POC's Annual Strategic Priority initiatives including mentoring new members;
- Periodic input to EAACI Patient communication channels website, newsletter, social media (submitting testimonials, informative webinars, articles etc);
- Meaningful participation in EAACI's Annual Congress, Focused Meetings, lobbying and outreach initiatives;
- Prompt response to POC information requests.

Participation will be tracked and be used as a basis of determining levels of financial support to attend Annual Congresses and other EAACI events, when available.

The application form can be accessed here: POC Member form\EAACI-POC Membership Application
Form.docx

3. Governance

The Patient Organisation Committee will be governed as any EAACI Committee by a board consisting of a Chair, Co-Chair, Secretary and four regular board members.

The role of the governing structure is to oversee and support the development of the POC activities, ensuring that the views of all members are coordinated and included in informing the development of the patient organisation activities. The POC will oversee the members delivery of these.

The POC board will consist of 7 members including:

- 1. Chair provides General strategy, direction and leadership;
- 2. Co-Chair Partner in oversight and succession planning role for a Chair's last term, pending on fulfilling his/her's assignments and ExCom evaluation;
- 3. Secretary Responsible for administration (organisation of the meetings, finance management, minutes, reports, correspondence, etc); and
- 4. Four regular board members who will lead designated activities.



Chair and Co-Chair

The Patient Organisation Committee will have a Chair and a Co-Chair elected through the EAACI Nomination Process described below. Either the Chair and /or Co Chair position must be filled by a European member of the POC, the other position can be fulfilled by an international representative.

The Chair and Co-chair positions are named by the EAACI Executive Committee upon review and discussion of the applications. EAACI solicits nominations, generally two months before the EAACI Congress asking for applications for various governance roles.

Term 2 years, with the possibility of renewal for a second term. The term will follow the Executive Committee renewal process. The Chair and Co-Chair will overlap for Chair's final term to ensure continuity.

Secretary

A Secretary will be elected from the members of the POC. Nominations are to be sent by e-mail to the out-going Secretary and Co-Chair. Nominations will be presented to the Committee members to elect the Secretary. The elected candidate will be presented to the ExCom for consideration and approval.

Term 2 years, with the possibility of renewal for a second term. The term will follow the Executive Committee renewal process.

Regular board members

The Chair and Co-Chair will review the applications and choose those felt to be most suited to the role and present these applications to the ExCom for their consideration and approval.

Application Process for POC board

All EAACI Patient Organisation members who wish to be involved in the POC board at any level will need to submit an application that must include:

- a personal statement of why they are applying for the POC board role;
- a brief summary of the skills and experience that they bring to the role, including a current CV;
- any involvement that they may currently or previously had on EAACI Sections, Committees, Interest Groups, Working Groups, Task Forces
- a signed Declaration of Conflicts of Interest Form

The application form can be accessed here: POC board <u>Applications\2019-2021 - Application Form - POC board Positions.docx</u>

Roles and Responsibilities

1. Chair

- Chairs POC board to organise POC member activities;
- Provides overall leadership and the direction of the POC, including mentoring role for the Co-Chair as a part of succession planning;
- Delegates responsibilities to ensure broad member participation, develops meeting agendas;
- Collaborates and /or participates with various Scientific and Organising Committees regarding POC participation in Annual Congress and focused meetings, ideally on featured panels;



- Works closely with EAACI leadership to integrate patient perspectives into the scientific community;
- Prepares POC Annual Budget and Annual Report to EAACI Executive Committee;
- Spearheads external funding support in close collaboration with the EAACI leadership, keeping in mind that any funding support requires consent by the EAACI treasurer;
- Works closely with other Committee members and with EAACI leadership to secure support.

2. Co-Chair

- Co-Chairs POC board, providing input to meeting agendas, assignment/delegation of responsibilities to ensure broad participation, implementation tracking;
- Leads development of POC Advocacy activities at EU level and global levels, coordinating closely with likeminded organisations;
- Supports external funding efforts, organises Committee activities, delegates responsibilities to ensure broad participation;
- Liaises with Sections, Interest Groups, and Task Forces; leads POC membership on assignments/reporting;
- Participates in succession planning, identification mentoring of future leadership.

3. Secretary

- Supports the Chair and Co-Chair in ensuring the smooth functioning of the Patient Organisation Committee.
- Inputs to meeting agendas, assignment of responsibilities, implementation tracking;
- Drafts minutes of all meetings; circulates for comment then submits final agendas and minutes with EAACI HQ;
- Works closely with Co Chair to ensure the active POC engagement on Interest/ WG Groups, Sections, Task Forces, and EAACI Committees;
- Is responsible for development and implementation of POC activities Calendar, coordinating closely with EAACI HQ staff;
- Supports the dissemination of the EAACI Public Campaigns to raise awareness on topics related to allergy and clinical immunology;
- Partners with Chair, Co-Chair and others on securing external funding support;
- Liaises with EAACI HQ on administration, including solicitation of funds, processing paperwork, drafting sponsor reports with POC board (to be completed within one month of each event).

4. Other POC board members specific tasks

- Clinical Village Lead—organises activities relative to establishing and covering presence at each Congress and focused meeting;
- Communications Comm Chair- is responsible for development and implementation of Publications Calendar, coordinating closely with EAACI HQ staff

4. Activities

EAACI Annual Congress and Focused meetings

For EAACI Annual Congresses and focused meetings the Patient Organisation Committee will work with the local Scientific and Organising Committee to ensure that there are appropriate patient organisation speaker or moderator roles on select panels or dedicated workshops.



In addition, the Committee (with members) may develop a patient focused, lay friendly, workshop to share data with stakeholders in the field of allergy and clinical immunology and disseminate knowledge related to the daily management and treatment of patients with allergic diseases or with other immunological diseases in the community.

The POC will maintain a presence in the **Clinical Village** at all relevant meetings.

EAACI Patient Organisations Committee Booth

At EAACI Annual Congress and Focused meetings the Committee will work with members to organise and deliver a booth at the Clinical Village which provides promotion of the patient organisations' activities.

EAACI Public Campaigns

The POC Committee and patient organisation members will be invited to support the EAACI public campaigns to raise awareness on topics related to allergy and clinical immunology.

EAACI Advocacy at the EU level and globally

The patient organisation members have a key role in supporting and advocating on behalf of patients in Europe, as well as globally. Patient organisations can be invited by EAACI to:

- Advice and support of EAACI advocacy activities;
- Help EAACI to integrate and promote policies for allergic patients, their families as well as caregivers;
- Request and advocate for research in the allergy and clinical immunology field;
- Help EAACI integrate patient perspectives to the scientific community.

Many patient organisation members of the EAACI POC already actively involved in advocacy organisations will seek to ensure that there is collaboration between EAACI and these partner stakeholders and not duplication.

Participation in EAACI IG/WG, Task forces, Committees etc

The Patient Organisation Committee members can participate in EAACI bodies such as Sections, IG, WG, TF, Committees. The POC board will develop a procedure to ensure continuity and (a) competent representative(s) as delegates in those bodies.

4. Reporting and budget

The Chair of the POC board shall report at least once a year to the EAACI Executive Committee of its activities, as any other EAACI Committee.

The Committee may apply for funding to the EAACI Executive Committee, following established rules, similar to other EAACI Bodies, each annual budget cycle.