

Proposal to change Article 4 - Members

Reasons:

Expand full membership

Member states within the European Free Trade Association have jointly concluded free trade agreements with the European Union, and as cancer patient organisations within these Member States face similar issues to cancer patient organisations within the European Union, it is appropriate to grant them full membership. This amendment also ensures that if countries leave the European Union, cancer patient organisations will not lose their membership privileges within the European Cancer Patient Coalition.

Rights of full and associate members

The European Cancer Patient Coalition greatly values the work of its associate members. The following amendment would clarify the benefits of associate membership of the European Cancer Patient Coalition.

Replace "Expert members" with "ECPC experts"

Currently the "expert members" are ex-officio members of the ECPC General Assembly. Under the current Statute, any scientific experts nominated by ECPC Members are part of the General Assembly of the organisation, without the explicit agreement or knowledge of the scientific experts. Therefore, this is a mistake in the Statute that needs to be corrected. The proposed changes to the statute would mean that ECPC experts are in a separate category rather than grouped with the patient organisations that are the "full members" and "associate members".

Proposed text changes:

Article 4 – Members

1. The Association has the following types of members:
 - a. "Full members", being cancer patient organizations in the European Union, **former member states of the European Union, or member states of the European Free Trade Association** that satisfy the membership requirements;
 - b. "Associate members", being cancer patient organizations domiciled in the European Union that do not satisfy the membership requirements or cancer patient organizations based in a country outside the European Union;
 - c. **"Expert members", being professional organizations, associations or individuals satisfying one or more of the following criteria:**
 - i. **Proven understanding of cancer patients' needs;**
 - ii. **Knowledge of key scientific, economic, social topics related to the needs of cancer patients;**
 - iii. **Record of previous engagement in favour of cancer patients, in line with the Association's objectives.**

3. The Board can offer the expert membership to organisations or individuals who fulfil the criteria as of article 1.e;

a. Full Members and Associate Members can suggest to the Board candidates to be considered for the Expert Membership

6. All members have the right to participate at the General Assembly but only the "full members" have the voting rights. They have no rights other than those granted to them under the statute. Unless provided otherwise, associate members have the same obligations as full members. Both "full members" and "associate members" have the right to contribute to ECPC projects and apply for ECPC patronage of their events.

Proposal to change: Article 6 – Termination of membership

Reason

Replace "Expert members" with "ECPC experts"

The proposed changes to the statute would mean that ECPC experts are in a separate category rather than grouped with the patient organisations that are the "full members" and "associate members".

Proposed text changes:

Article 6 - Termination of membership

3. Notice of termination by the Association shall be given under a resolution adopted by the General Assembly of which resolution the member shall be informed in writing by the Board. The Association may terminate the membership by the end of the financial year. Notice of termination shall be given and the reasons therefore stated.

Notice of termination shall be given by the Association if:

- a. A member does not fulfil its obligations towards the Association or does not do so on time, including - but not exclusively - those referred to in article 5;
- b. A member engages in behaviour that contravenes with the objectives and mission of ECPC;
- c. A member does not satisfy the requirements for membership. At the member's request, the Board may subsequently decide to admit the legal entity concerned as an associate or expert member.

6. With regard to extraordinary or expert members, the General Assembly may decide to terminate the agreement concluded by the Association and the associate or expert members. The Board shall notify the associate or expert member thereof in writing

Proposal to change Article 10 - Committees

Chair of Scientific Committee

As the European Cancer Patient Coalition is becoming increasingly involved in EU research projects. In 2018, ECPC is a partner in eight research projects funded by the European Commission, with another three proposals awaiting review by the European Commission. There is a need to improve the role and activity of the Scientific Committee. Furthermore, some of these EU Research Projects, such as IMI PREFER, are five-year projects that continue past the current mandate of the Board. Changing the Statute will give a continuity of ECPC's research involvement without any interruption or misunderstandings. As the President has three years' experience of the research conducted by ECPC, the Immediate Past President is in the best position to understand the administration and follow up the research projects. Changing the Statute to give the Immediate Past President the role of Chair of the Scientific Committee would ensure continuity of expertise. The important contribution of ECPC to European research has been recognised by having our current President also on the Science Policy Committee of the European Academy of Cancer Sciences, the Board of Cancer Core Europe, the General Assembly of the Worldwide Innovative Networking (WIN) consortium in personalized cancer medicine, and the Board of the Cancer Drug Development Forum.

Replace "Expert members" with "ECPC experts"

The proposed changes to the statute would mean that ECPC experts are in a separate category rather than grouped with the patient organisations that are the "full members" and "associate members".

Article 10 – Committees **and Experts**

- During the process of the ECPC Board elections, Full Members and Associate Members can each suggest to the ECPC Board one candidate to be considered for the list of ECPC experts. Following these nominations, the ECPC Board can create a list of ECPC experts, being individuals satisfying one or more of the following criteria:
 - a) Proven understanding of cancer patients' needs;
 - b) Knowledge of key scientific, economic, social topics related to the needs of cancer patients;
 - c) Record of previous engagement in favour of cancer patients, in line with ECPC's objectives.The list of ECPC experts will be renewed at each ECPC Board election. The number of ECPC experts on the expert list will not exceed the total number of ECPC "full members" and "associate members".
- 4. The "audit committee" consists of three members to be elected from its members by the General Assembly. "Full members" and "associate members" can be appointed as members of the audit committee. A majority of full members shall compose the Audit Committee. The audit committee is charged with the activities outlined in article 12. An audit committee member cannot simultaneously sit on the Board. The ECPC Audit Committee shall elect a Chair from its midst.
- 5. The "Scientific Committee" consists of at least three and maximum five expert members ECPC experts. Only "expert members ECPC experts" can be appointed as members of the Scientific Committee. The Past President is a member ex officio of the Scientific Committee and is the Chair of the committee. In the event that the Immediate Past President renounces this position, the Scientific Committee is chaired by a person nominated by the ECPC Board. The Chair of the Scientific Committee must be a Board member or an ECPC expert. The Scientific Committee is a consultative body to the Board. The Board can to will consult the Scientific Committee for the

research activities and the scientific issues the development and implementation of scientific activities of the association, in line with the norms fixed by the General Regulation.

- a) Members of the Scientific Committee shall be nominated by the Board and shall have terms which coincides with the Audit Committee. Each ECPC Member can suggest candidates for the Scientific Committee, among the ECPC Experts Members;
- b) The resolutions adopted by the Scientific Committee do not bind the Board;
- c) ~~The Scientific Committee is chaired by the ECPC President~~

6. ~~The "Friends of ECPC" Committee consists of all representatives of "full members", representatives of "associate members", and expert members ECPC experts. Only representatives of "full members", representatives of "associate members", and expert members ECPC experts can be appointed as members of the "Friends of ECPC" Committee. The "Friends of ECPC" Committee functions as a consultative body for the Association, providing expert insights on matters relevant to the objectives of the organisation.~~

- a) ~~The President entertains relationship with the "Friends of ECPC" Committee. The President can participate to the Committees meeting, but does not participate to the decisions taken by the Committee.~~
- b) ~~The "Friends of ECPC" Committee meets annually on the occasion of the General Assembly meeting.~~

Proposal to change Article 13 - General Assembly

Replace "Expert members" with "ECPC experts"

The proposed changes to the statute would mean that ECPC experts are in a separate category rather than grouped with the patient organisations that are the "full members" and "associate members".

4. Board members, ~~extraordinary and expert members~~ do not have voting rights on the General Assembly.

Proposal to change Article 14 - Agenda

Replace "Expert members" with "ECPC experts"

The proposed changes to the statute would mean that ECPC experts are in a separate category rather than grouped with the patient organisations that are the "full members" and "associate members".

Article 14 – Agenda

3. Together with the convening notice for the General Assembly meeting, the provisional agenda will be brought to the attention of the full, associate and expert members by publishing it in a public notice and sending it to them. The definitive agenda shall be published or sent at least four weeks before the day on which the General Assembly meeting is held.

4. The agenda for the Annual General Assembly meeting shall in any event contain:

- a) Adoption of the minutes of the previous General Assembly meeting; The Board's annual report;
- b) The Board's financial report;
- c) The report of the Association's audit committee;
- d) The report of the Association's scientific committee;
- e) Adoption of the clear image on ECPC assets and statement of income and expenditure for the past financial year;
- f) Determining the membership fee of full members;
- g) Determining the contributions of the associate ~~and expert members~~ and any other contributions;
- h) Adoption of the budget for the next financial year;
- i) The granting of discharge to the Board members;
- j) The filling of vacancies in the Board;
- k) Adoption of the list of ECPC experts;
- l) Any other business.