

## ECPC General Regulations

The Statute of the European Cancer Patient Coalition describes the need for General Regulations in Articles 10 and 16. The General Regulations must be adopted and amended by regular majority of the General Assembly of the European Cancer Patient Coalition.

### 1. ECPC vision

ECPC works for a *Europe of equality*, where all European cancer patients have *timely and affordable access to the best treatment and care available*, throughout their life. ECPC believes that *cancer patients are the most important partners* in the fight against cancer and against all the cancer-related issues affecting our society. Policy makers, researchers, doctors and industry should recognise cancer patients as *co-creators* of their own health.

### 2. ECPC mission

- Support, empower, and connect Members of the European Cancer Patient Coalition and other cancer patient organisations;
- Foster co-operation among cancer patients' organisations through joint activities;
- Ensure that state-of-the-art cancer care practices are shared across the EU;
- Make cancer a priority for action on the European health policy agenda;
- Have an active role in shaping European and national healthcare policies that impact on cancer patients,
- Promote access to sustainable innovation through the adoption of the Health Technology Assessment (HTA) cooperation process in all of the EU Member States;
- Promote access to cross border healthcare services to cancer patients;
- Contribute to change or create EU and national laws to satisfy cancer patients' needs;
- Call for research on survivorship issues and advocate for better healthcare and social services for people with cancer. With specific reference to the right to Cancer Rehabilitation, which is fundamental to facilitate the return to normal life, regaining the quality of life and swift return to work.

### 3. ECPC objectives

The Objectives of the European Cancer Patient Coalition are set out in Article 2 of the ECPC Statute.

The Association's objective is to foster the cooperation between cancer patient organizations in the European Union and to develop a common policy, and everything that is related to this in the broadest sense, either directly or indirectly. The Association shall attempt to achieve this objective by such means as:

- a) Promoting the interests of cancer patient associations in the European Union;
- b) Promoting the interests of all cancer patients and their caregivers in the European Union;
- c) Acting as intermediary between the European Union and other European institutions for all matters relating to cancer patient associations, cancer patients and care policy;
- d) Acting as intermediary for and on behalf of cancer patient organizations and scientific organizations, political parties, (commercial) organizations, national health services, health insurers, the pharmaceutical industry and other institutions that influence or may influence the interests of cancer patients and their caregivers;
- e) Enabling cancer patient organizations to develop common positions on European health policy issues and to influence decisions that have an impact on cancer care provisions and on health inequalities across the entire European Union;
- f) Exchanging information and points of view on European health policy in general and cancer in particular, all in the broadest sense.

### 4. ECPC strategic plan

Every three years, a Committee including the President, the Vice-President, the Chair of the Scientific Committee, the Chair of the Audit Committee, and the Secretariat prepares a Strategic Plan for the approval of the ECPC Board. The Strategic Plan covers the three-year term of the Board. The plan is presented to the ECPC General Assembly.

The objectives of the Strategic Plan are the baseline of every staff member's objectives and performance indicators.

### 5. Area of application.

These regulations are applicable to all employees, and, where applicable, interns and members of the Board, the Scientific Committee, the Audit Committee, and the Working Groups of the EUROPEAN CANCER PATIENT COALITION with head office at RUE MONTOYER 40, 1000 BRUSSELS, BELGIUM.

### 6. ECPC organisational structure

The Association's bodies are the General Assembly, the Board, and the Secretariat.

The General Assembly consists of all the members of the association represented by their legal representative. Only full members are entitled to vote at the General Assembly. The General Assembly is ECPC's general guiding body. The General Assembly determines the overall policies and activities of ECPC. It is ECPC's highest decision-making body (Article 13 of the ECPC Statute).

The Board is ECPC's strategic body (Article 8 of the ECPC Statute). The Board has authority to decide and act for ECPC in all matters except for those exclusively reserved for the General Assembly, by law or by the Statute. The Board consists of at least five and at most nine individuals. The board elects from its midst at least: a president, a vice-president, a secretary and a treasurer. The remaining duties board members shall divide among themselves.

The Secretariat is managed by the Director. The Board appoints a Director who is accountable to the Board. The Director manages the Secretariat and is responsible for day-to-day operations (Article 8 of the ECPC Statute).

#### 7. The General Assembly

The General Assembly shall be chaired by the president of the Board or, in his or her absence, the Vice-President. If the Vice-President is not present, the meeting shall be chaired by another Board member.

All members have the right to participate at the General Assembly, but only full members have voting rights. The General Assembly decides on the number of Board Members, one year before the election of new Board. The General Assembly shall approve the clear image on ECPC assets and statement of income and expenditure.

#### 8. The Board

The Association is managed by the Board. The managing tool of the association is the Action Plan which the Board prepares in cooperation with the Secretariat.

The Board members are physically located throughout Europe, and are responsible for the strategic oversight of ECPC. ECPC Board members are elected by the General Assembly.

The decisions of the board are made jointly. Board decisions must be approved by the majority of the Board. Board decisions can be made during a Board meeting, via a Board teleconference, or via email. If a board member does not reply to an email from the Director within 7 days, their implicit approval can be assumed.

Some tasks of governance and responsibilities of the main activities in the Action Plan are divided between the board members (the champions).

#### **Board members**

ECPC Board members are elected by the General Assembly. When acting for ECPC, all Board members will:

- Prepare the annual report and action plan within the first six months of the year
- Meet at least two times per year in Brussels
- Render the account to the General Assembly (Article 3 of the ECPC Statute)
- Provide strategic guidance in the creation, implementation, and evaluation of the Action plan
- Represent the association (Article 9 of the ECPC Statute)
- Put the needs and priorities of ECPC above those of their national organisations
- Hire and work with the Director, and if necessary dismiss the Director following due process
- Treat all ECPC Members fairly and equally, regardless of nationality
- Not fail to attend two consecutive Board meetings without good reason and sufficient notice.
- Respond in a timely manner to requests from the Secretariat on matters requiring their approval
- Establish, and if necessary dismantle, the Scientific Committee
- Assist in fundraising for ECPC
- Create and monitor the mission of ECPC
- Develop long-range plans for ECPC
- Fulfil the legal responsibilities of ECPC
- Add value to ECPC
- Monitor the annual budget and annual financial statements, in collaboration with the Director and Audit Committee
- Review operations and activities, and delegate administration of the financial activities to the Director and Financial Officer
- Treat all Secretariat staff members fairly, equally, and without bullying, harassment, or discrimination, in compliance with Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation.

## **President**

The ECPC President is elected by the other ECPC Board members, and is a key external representative of the Board, in partnership with the Vice President. Their tasks include:

- Chairs the General Assembly and the Board meetings, prepares agendas in collaboration with the Secretary, the Director and the Chair of the Scientific Committee
- Initiates the process for the annual ECPC Action Plan and presents that Action Plan within the first 6 months of the year
- Keeps the Board at the governance level of thinking at meetings and in all discussions and ensures together with the Secretary the implementation of its decisions
- Oversees the governance processes and association's liabilities and ensures that the laws and regulations concerning the association are followed
- Oversees and develop the personnel policy of ECPC Secretariat in cooperation with the director and the Chair of the Scientific Committee
- Listens to and reflects concerns the Secretariat staff have about the role of the Board, and reflects concerns the Board has about the organization to the Director
- Leads the evaluation and salary review process of the Director and communicates the results of the evaluation and salary review process to the Director
- Serves as the key external spokesperson for the organisation in conjunction with the Vice-President and other Board members

## **Vice-President**

The ECPC Vice-President is elected by the other ECPC Board members, and is a key external representative of the Board, in partnership with the President. Their tasks include:

- Outside the daily management of the organisation, the Vice-President may act jointly with another Board member to represent the organisation with regard to third parties (Article 9 of the ECPC Statute)
- Chairing the General Assembly in the absence of the President
- Working with the Secretariat and Board to produce the Board strategy document
- Serving as a spokesperson for the organisation in conjunction with the President and other Board members
- Assists the President in the execution of their duties

## **Secretary**

The ECPC Secretary is elected by the other ECPC Board members, and oversees and cooperates in the planning, implementing and assessing of administrative processes in the Board and in the office. Their tasks include:

- Prepares, in co-ordination with the President the agenda for the meetings and the organization
- Ensuring the appropriate and effective processes of documentation
- Supporting the Director in employer activities in personnel administration
- Ensuring that the register of the members of the organization is maintained and up to date
- Representing the Board and ECPC in line with their other Board duties and personal expertise
- Representing the association in regard to third parties according to the statute (Article 9 of the ECPC Statute)

## **Treasurer**

The ECPC Treasurer is elected by the other ECPC Board members, and oversees and develops the financial processes of the organisation in corporation with the Audit Committee, the Director, and the Financial Officer. The Treasurer is authorised to directly view ECPC bank accounts statements. Their tasks include:

- Monitoring and reviewing the financial aspects of the association
- Preparing the annual financial statement and budget
- Ensuring that appropriate financial systems and controls are in place
- Advising on fund-raising and grant requests
- Plans and submits suggestions for the financial standing of the organization
- Represents the Board and ECPC in line with their other Board duties and personal expertise

The Annual Report is the evaluation tool that summarises the major activities that have been conducted by the organisation each year and an overview of the finances.

### 9. The Secretariat

The Secretariat is based in Brussels and is led by the Director. The Secretariat is responsible for implementing strategic decisions made by the General Assembly and the Board.

The Secretariat is divided in departments as per below with the following responsibilities:

- Advocacy and EU Affairs
- Partnerships and Communication
- Health and Research Programmes
- Finance, Human Resources & Administration

The staff report to the Director and work together in close collaboration.

## **Director**

The Director is responsible for supporting the development of the organization's activities in line with the Board's decisions. Their primary task is to ensure that all organizational aspects, including membership capacity-building, project and people management, financial organization and communications, while ensuring the sustainability of ECPC.

- Reporting directly to the President and the Board
- Manage the day-to-day affairs of the organisation
- Participate in Board meetings
- Ensure that the Board is kept fully informed on the condition of the organisation and important factors influencing it
- Develop and implement a 3-year strategic plan as well as an annual Action Plan, in close consultation with the Board
- Oversee the management of all operations including program implementation
- Oversee fundraising activities to ensure sustainability
- Represent the organization to external audiences through media relations and participation in conferences and forums, in consultation with the Board
- Ensure that ECPC develops programs to regularly inform Members improve the advocacy capacities of the Members
- Develop and maintain a working environment that attracts, retains and motivates good quality staff.
- Promote active and broad participation by Members in all areas of ECPC's work
- Maintain official records and documents, and ensure compliance with regulations
- Maintain a working knowledge of significant developments and trends in the field
- Publicize the activities of the organisation and its programs and goals
- Establish sound working relationships with stakeholders
- Be responsible for the recruitment, employment, and release of all personnel, including staff, interns, contractors, and volunteers
- Ensure that job descriptions are developed, that regular performance evaluations are held, and that sound human resource practices are in place
- Encourage staff development and education
- Oversee all financial assets and ensure that auditing systems are in place
- Work with the staff, Audit Committee and the Board in preparing a budget; see that the organisation operates within budget guidelines, and provide timely financial reports to the Board

## **Advocacy and EU Affairs Team**

- Reporting directly to the Director
- Assist the President in preparing for events and presentations
- Assisting the Board and Director in designing and implementing policy strategy
- Advocating for patients' rights within EU Institutions
- Develop & maintain relations with stakeholders (NGOs, industry, academia etc.)
- Event organisation (particularly with European Parliament)
- Contribute to the policy aspects of EU and industry-funded projects

Staff within the Advocacy and EU Affairs department may have the following titles:

- Junior EU Affairs Officer
- EU Affairs Officer
- Senior EU Affairs Officer
- EU Affairs Manager
- Senior EU Affairs Manager
- Head of EU Affairs

## **Partnerships and Communication Team**

- Reporting directly to the Director
- Build the relationships between ECPC and its Members
- Manage the ECPC Annual Congress
- Develop and implement capacity-building projects
- Develop and implement communication and awareness projects
- Connect the European Society for Medical Oncology (ESMO) and the European Medicines Agency (EMA) to cancer patient organisations throughout Europe
- Reinvigorate ECPC's online community
- Manage ECPC Partnership Database
- Develop and manage traditional and social media
- Manage the ECPC website
- Produce, design and disseminate the ECPC Newsletter
- Produce, design and disseminate the ECPC Annual Report

Staff within the Partnerships and Communication department may have the following titles:

- Junior Partnerships and Communication Officer
- Partnerships and Communication Officer
- Senior Partnerships and Communication Officer
- Partnerships and Communication Manager
- Senior Partnerships and Communication Manager
- Head of Partnerships and Communication

#### **Health and Research Programmes Team**

- Reporting directly to the Director
- Managing, implementing, and tracking the health and research programmes, including European Union's Research and Innovation framework programmes, Innovative Medicines Initiative projects, Horizon 2020 projects, Innovative Training Network projects, European Reference Networks, and Joint Actions on Rare Cancers.
- Representing ECPC in health and research events, conferences, and meetings
- Liaising with project partners and stakeholders
- Determining and planning the resources (time, money, equipment) required
- Planning and drafting project proposals, including budget allocations for ECPC
- Integrating contributions from the Director and ECPC Board members
- Ensure the timely preparation and submission of project financial reports
- Compiling, reviewing, and editing of project progress reports
- Promoting the deliverables of the projects

Staff within the Health and Research Programmes department may have the following titles:

- Junior Health and Research Officer
- Health and Research Officer
- Senior Health and Research Officer
- Health and Research Manager
- Senior Health and Research Manager
- Head of Health and Research Programmes

#### **Finance, Human Resources & Administration Team**

- Reporting directly to the Director and indirectly to the Treasurer
- Financial administration
- Budget management
- Drafting the annual financial statement in cooperation with the Treasurer and the Director
- Drafting the annual budget in cooperation with the Treasurer and the Director, with input from the Board and the Audit Committee
- Drafting project budgets in cooperation with the Head of Health and Research Programmes and the Director, with oversight by the Treasurer and the Audit Committee
- Coordination with the Audit Committee
- Financial reporting for EU projects – in cooperation with the Head of Health and Research Programmes
- Human resources strategy and implementation – in cooperation with the Board and the Director
- Drafting and evaluating supplier/subcontractor contracts
- Drafting and evaluating employee and volunteer contracts
- Monthly human resources reporting, salaries and benefits
- Advice and recommendations in relation to Belgian legal requirements, rules and regulations, as well as tax benefits
- Co-ordinating the regular independent external auditing of the organisation

Staff within the Finance, Human Resources & Administration department may have the following titles:

- Junior Financial Officer
- Financial Officer
- Senior Financial Officer
- Head of Finance and Human Resources
- Chief Financial Officer

#### 10. Audit Committee

In line with European Cancer Patient Coalition Statute, the Audit Committee is elected by European Cancer Patient Coalition General Assembly, among its Members (Article 12.7 of the ECPC Statute). Candidates for an Audit Committee position shall have proved professional or institutional experience in accounting, auditing, economical, management, and/or juridical activities. The three Audit Committee Members have the same three-year term as the ECPC Board. The Audit Committee is responsible for overseeing the financial and operational management of European Cancer Patient Coalition minimizing any associated risk, monitoring relevant procedures and internal policies, approving European Cancer Patient Coalition Budgets and end-of-year Financial Accounts and reviewing the Board decisions that are implemented. The Audit Committee also supervises compliance with the articles of association and regulations, as well as resolutions adopted by the Association. The Audit Committee can also make recommendations and suggestions to the Board and to the Secretariat on organisational, operational and strategic topics and/or issues. The Audit Committee will meet at least twice a year via face-to-face meetings and/or teleconferences.

#### 11. Scientific Committee

The Scientific Committee is a consultative body to the Board (Article 10.5 of the ECPC Statute). The Board shall consult the Scientific Committee for the development and implementation of scientific activities of the association. The Scientific Committee consults and supports the work of the Board related to research projects, information materials and any other activity involving the creation and dissemination of scientific information. The Chair of Scientific Committee participates in the drafting of the strategic and action plans, and, in collaboration with the Health and Research team, takes part in the Working Groups of research projects and in the Work Packages of the Joint Actions supported by the European Commission. The Chair of the Scientific Committee informs the Board on the progress of the aforementioned projects and Work Packages at least twice per year.

The Scientific Committee will review relevant research proposals, and within ten days give a recommendation to the Board if the European Cancer Patient Coalition should join the proposal consortium. The Scientific Committee's opinion shall illustrate the benefits of participating in the research activities as well as any possible concern or reason to move away from a given activity or the decision not to join it. To guarantee the continuity of scientific program and projects of European Cancer Patient Coalition, it is strongly recommended that the Past President of the ECPC Board is appointed as the Chair of Scientific Committee, and remain in charge of the Scientific Committee for three years. The Scientific Committee will meet at least twice a year via face-to-face meetings and/or teleconferences. Staff members from the ECPC Secretariat will coordinate the activities of the Scientific Committee and provide administrative support.

#### 12. Working Groups

The Working Groups are established by the Board of the European Cancer Patient Coalition on specific issues that require particular attention of the organisation. The European Cancer Patient Coalition can establish working groups in order to guarantee patients' concerns and experiences are accurately reflected, and that patient organisations will be able to contribute in the projects developed by the European Cancer Patient Coalition.

Working Group members consist of representatives from ECPC's Full and Associate Members, non-member organisations, as well as patients and experts with an interest in the project. The number of members of the Working Groups is not limited, and all cancer patient organisations are invited to participate.

The Working Group will meet via face-to-face meetings and/or teleconferences. Staff members from the ECPC Secretariat will coordinate the activities of the Working Groups and provide administrative support.