



Dear ECPC Members, colleagues and friends,

As a representative of the working group I have the honour to deliver the result of our work.

ECPC has made a long journey in developing the services and advocacy in favour of the European cancer patients. Along the years the perspective of active cancer patients' partnership in the care process has enlarged. Nowadays their rights are better accepted and abilities better taken into account through the care and political processes. For the patient organisations the development requires to foster their professional capacities aside the traditional patient oriented approach.

These changes affect the governance of patient organisations. ECPC Board put a group of members to review the needs for modernize the Statutes and General Regulations of ECPC in order to cope with the changed requirements.

ECPC as a patient organisation

ECPC is a patient organisation. Its priorities in decisions come from the needs of its members and cancer patients. The success in activities demands an effective implementation of the decisions made by the General Assembly and the Board, where the every-day performances are delegated to the professional staff. The working balance between the Board and the professional staff is vital for successful work. It makes the base for the working culture of the association.

The assignment

According to assignment of President Ken Mastris the group was to assess and reform the Statutes and General Regulations of governance to be **transparent, democratic, and easy to understand**.

The suggestion of the Governance group

The Group of Governance found several points to be reformed in the documents of ECPC governance. The main needs discovered are:

- Ideas and Practices which ECPC has approached and/or implemented over the years are not reflected in the Statutes, in other words there is an inconsistency between stipulated principles and the practice
- Aside from the legal changes made by the lawyer, it was a real need to align the Statutes to the procedures enforced by changes in Belgian law, other EU Patients' Organizations and, at the same





time, to set forth more professional procedures for board-reelection and performance

- A need to foster the professional perspective in day to day-activities and balance the duties between the board and office/director
- To make the Statute and General Regulations more simple and understandable for non-native English
- To balance the scientific and patient oriented activities (patients' real life needs and -situations)
- To prioritize the work for European patients' equal access to treatment and care in all regions

Because of a limited time frame the group did not have the opportunity to discuss the substance and design of the needed alterations in details. We also had to limit our work to the Statutes only. The Governance group suggests that The Board makes a proposal for the AGM for an open discussion of the lines of development in the governance of ECPC, and lengthens the assignment of the group.

Please see suggested changes to ECPC Statute.

Sincerely,

Ranveig Røtterud

Member of the ECPC Working Group on Governance





List of all members of the Working Group on Governance:

- Conchi Biurrun; Federation of Women with Breast Cancer (Spain)
- Ernst-Gunther Carl; Bundesverband Prostatakrebs Selbsthilfe e. V. (Germany)
- Ewa Carlsson; Sarkomföreningen (Sweden)
- Viorica Cursaru; Myeloma Euronet Romania (Romania)
- Matti Jarvinen; Finnish Prostate Cancer Association (Finland)
- Magdalena Magiera; Glioma Center Foundation (Poland)
- Constantine Nicolaidis; Cyprus Association of Cancer Patients and Friends (Cyprus)
- Ranveig Roetterud, Bladder Cancer Norway (Norway)

