

## Minutes of 2018 General Assembly of the European Cancer Patient Coalition

Sunday 10 June 2018, Brussels, Belgium

Hotel Renaissance, Rue du Parnasse 19, 1050 Brussels

### Table of Contents

Attendance.....	2
Adoption of minutes of 2016 Annual General Assembly .....	2
Vote on the 2016 Annual General Assembly Minutes.....	2
Formal introduction of ECPC Board to the General Assembly .....	2
Introduction of the ECPC Secretariat to the General Assembly .....	2
Presentation of the 2017 Annual Report.....	3
Voting to adoption the 2017 Annual Report .....	6
Presentation of the 2017 Financial Report and 2018 Budget .....	6
Voting on the 2017 Financial Report and 2018 Budget.....	7
Number of the Board members for the 2019 elections .....	7
Voting on the Number of the Board members for the 2019 elections .....	7
Special power for ECPC Director to appear in front of Notary.....	8
Voting on Legal Entity Appointed Representative.....	8
Modifications to the ECPC Statute.....	8
Proposal to change Article 4 – Members.....	8
Voting on Article 4 – Members .....	8
Voting to change Article 6 – Termination of membership. ....	9
Proposal to change Article 10 – Committees .....	9
Voting to change Article 10 – Committees .....	10
Modification of Article 13 – General Assembly .....	10
Voting to change Article 13 – General Assembly.....	10
Modification of Article 14 – Agenda .....	10
Voting to change Article 14 – Agenda .....	10
General Regulations.....	10
Voting to adopt the General Regulations. ....	11
Final Remarks.....	11
Annexes.....	11

## Attendance

### **Meeting started at 9.00**

The ECPC President Francesco De Lorenzo (FdL) chaired the meeting. As ECPC Secretary Jana Pelouchova (JP) was not present due to illness, ECPC Director Lydia Makaroff took the minutes.

There were 30 Full Members present, with no proxies. There were 13 Associate Members present.

The list of ECPC full and associate members present was collected by ECPC Community & Communications Manager Anna Rek (AR) (Annex 1).

## Adoption of minutes of 2016 Annual General Assembly

The draft Minutes were presented by the Board and a printed version distributed among the Members (Annex 2).

## *Vote on the 2016 Annual General Assembly Minutes*

The General Assembly unanimously approves the minutes of the 2016 General Assembly.

## Formal introduction of ECPC Board to the General Assembly

FdL formally introduced the ECPC Board to the General Assembly:

Francesco De Lorenzo (President)

Kathi Apostolidis (Vice-President)

Jana Pelouchova (Secretary, absent, apologies)

Andrew Winterbottom (Treasurer)

Matti Järvinen (absent, apologies)

Ken Mastris (absent, apologies)

Maude Andersson

## Introduction of the ECPC Secretariat to the General Assembly

FdL introduced the ECPC Secretariat to the General Assembly. FdL noted that this is LM's second year as Director of ECPC, and she has been doing a very good job, not only at running the office but building the relationship with the Members. He reminded the General Assembly that the office in Brussels is the best friend of all the European cancer patient organisations.

FdL introduced Isabelle Manneh-Vangramberen (IMV), ECPC Head of Health & Research Programmes. He noted that Isabelle has been doing a very good job in the health and research projects, which have become more important, with more important and funded projects. This work reflects the mission of ECPC, and ECPC has been giving a substantial contribution to all kinds of European research. Currently, the Scientific Committee has been able to contribute very little, because the ECPC Board is involved in running the organisation. Most of the work on research projects has been done by IMV. FdL remarked that he worked closely with IMV on the research projects, and has received good feedback from all stakeholders on their collaborations with IMV. FdL remarked that IMV is doing excellent work managing the ECPC Working Group on Rare Cancers, and all the stakeholders are happy. FdL also introduced Max Schravendeel, the Junior Health & Research Officer, who had just been hired and will be fully

dedicated to health and research projects. IMV noted that over the past years, ECPC has grown from being involved in 3 projects to being involved in 14 health and research projects, and introduced Theodoros Yfantis (TY), who has completed one month of his six-month internship in the ECPC Health & Research team.

FdL introduced Anna Rek (AR), the Community & Communications Manager. FdL noted that she is the oldest longest-serving member of the staff, who was hired to enable a much stronger connection with ECPC members. She has been working very well to connect with Members via face-to-face meetings, phone calls, email, and social media. AR is responsible for our relationships with all 440 of our members. All those Members who would like to be connected with ECPC are now able to work closely with ECPC. AR is able to find patients with specific kinds of cancer and send them to the European Medicines Agency for important meetings. She also managed the Working Group on Bladder Cancer. The Working Groups are one tool that enables ECPC Members to work more closely with ECPC on particular projects.

AR asked the members of the General Assembly to contact her directly if they are not receiving the ECPC newsletter, or if they would like to be more involved in any of the ECPC projects. AR also asked the members of the General Assembly to let her know if they would be willing to travel to the European Medicines Agency to share their personal experiences of particular cancers or cancer treatments in order to provide feedback. AR also thanked the members of the General Assembly for their work reviewing the European Society of Medical Oncology's clinical and patient guides on specific types of cancers. AR also thanked the members of the General Assembly for responding to the numerous surveys that ECPC has sent out to its Members over the past year. FdL remarked that Anna has been translating a lot of ECPC materials into other languages to make it easier for more Members to use this information.

FdL introduced Alex Felicivas (AF), the new Head of EU Affairs, who replaced Francesco Florindi (FF) last year. FdL remarked that AF has also reinvigorated the ECPC Legal Network, which will now focus on social issues, such as informal carers and the right to work. There is still a lot of work to do on expanding and protecting the social rights of cancer patients. FdL notes that AF previously worked as a consultant for a European gastroenterology federation, on European Obesity Day, and also at the European Commission's DG SANTÉ in the Cabinet of Commissioner Andriukaitis. FdL remarked that AR is working very well on all cancer policy topics at ECPC.

### [Presentation of the 2017 Annual Report](#)

FdL presented the 2017 ECPC Annual Report (Annex 3) to the General Assembly, and a printed version distributed among the Members. FdL noted that ECPC Members are the most important part. FdL presented the 2017 calendar of activities, and remarked on the great deal of work that had been done by the ECPC office and Board. FdL noted that the 2017 work fits within the 2019-2019 ECPC strategy.

FdL noted that ECPC has been working on capacity-building, and the 2017 Annual Meeting welcomed 180 participants representing 141 different organisations from 42 different countries.

FdL noted the two white papers that we launched in 2017: The Value of Innovation in Oncology, and the White Paper on Cancer Carers. He also noted that the ECPC had managed to get a paragraph on the importance of civil society introduced into the 2017 WHO Cancer Resolution. FdL noted that if ECPC didn't exist, then cancer patients would not be directly represented in the European Commission's second Joint Action on Cancer Control, CanCon.

FdL gave an overview of the other awareness campaigns that ECPC had conducted in 2017, including World Cancer Day, Bladder Cancer Awareness Month, World Thrombosis Day, Make Sense of Head & Neck Cancer Week, Pancreatic Cancer Awareness Day, and European Prostate Cancer Awareness Day.

FdL presented the ECPC work on nutrition and physical activity. FdL noted that he and Isabelle Manneh-Vangramberen (IMV), ECPC Head of Health & Research Programmes, were authors on a poster at the European Society for Medical Oncology congress of the results of a survey conducted in collaboration with the Sapienza University of Rome, and a manuscript has now been submitted to a peer-reviewed journal. FdL congratulated IMV on the work that she did to produce the booklet "Living well during cancer treatment" that outlined the results of the ECPC survey, and gave cancer patients information on nutrition and physical activity.

FdL also presented IMV's work on the Innovative Medicines Initiative PREFER project on patient preferences, and outlined how ECPC is working with academia and regulatory agencies in developing guidelines on how patient preferences should be included in the drug development lifecycle, from pre-clinical to post-marketing.

Kathi Apostolidis (KA) talked about the importance of the European Commission's eSMART project, a clinical trial that allows cancer patients to use mobile phones to report side-effects of chemotherapy.

FdL noted that most EU Health and Research projects last more than one year, and have to be followed up by the ECPC office and the Board. FdL noted that one of the proposed changes to the statute that will be presented to the General Assembly is to give the Past President the responsibility to chair the Scientific Committee. The Scientific Committee will be restricted to giving recommendations on research projects, but it will still be the ECPC Board who will make the decisions. FdL remarked that currently the ECPC President is involved too much in running the day-to-day activities of the organisation.

Viorica Cursaru (VC) from Myeloma Euronet Romania asked to make a short comment on the role of the Past President in the Scientific Committee. She noted that the Past President should be the institutional memory of the organisation, but VC had never heard of the Past President being an active member of an organisation, especially after serving two Presidential terms. VC noted that she respected the ECPC President, but recommended that the Past President should not be the Chair of the Scientific Committee. She also noted that she would like to see some representatives from Central and Eastern Europe in the next Scientific Committee.

FdL replied that ECPC Members can nominate ECPC experts for the Scientific Committee, and the final composition of the Scientific Committee is decided by a vote of the ECPC Board.

FdL asks LM to read out Article 7.10 of the ECPC Statute: “The Past President maintains continuity of knowledge and procedures in the transition from one Board to the next. The Past President is entitled ex officio to attend the meetings of the Board, with a consultative role, without holding voting rights. The Past President is not a Board Member. The Board is obliged to inform the Past President of the Meetings of the Board and invite him/her. The Past President's comments shall be noted like any other Board Members.”

Maydad Gissin (MG) from the Israel Cancer Association and Israel Ostomy Association raised the issue of medical cannabis. MG noted that this month Israel will decide about import and export to other countries, as well as medical clinical trials. MG noted that medical cannabis has helped some cancer patients, and requested that ECPC examine the issue at the level of EU policy.

Jacob Hansen (JH) from the Danish Cancer Organisation "The Thistles" noted that they supported the statement from Israel, and seconded the request that ECPC should work more in this area.

FdL welcomed the feedback from MG and JH and noted that ECPC will examine the issue of medical cannabis at the level of EU policy.

FdL invited Isabelle Manneh-Vangramberen (IMV), ECPC Head of Health & Research Programmes to summarise the outcomes of the Working Group on Rare Cancer on Friday 8 June.

IMV noted that the Working Group on Rare Cancer was established in parallel to the Joint Action on Rare Cancers. IMV noted that at the meeting on Friday 8 June, there 83 people requested to join the meeting, even though the room had a capacity of 60 people. IMV explained that she has worked with MS and TY created a survey on medical education for rare cancer patients that has been translated into 5 languages. IMV encouraged all the Members of the General Assembly to prepare for the upcoming call from the European Reference Networks to nominate national centres of excellence for rare diseases.

FdL invited Roberto de Miro (RdM) to summarise the outcomes of the meeting of the ECPC Legal Network for Cancer Patients on Friday 8 June.

RdM explained that the Legal Network for Cancer Patients will work with Alex Felicivas (AF), ECPC Head of EU Affairs, to examine work-life balance and other social issues. AF will send to all ECPC Members a questionnaire to investigate the social difficulties that patients and their carers experience, and what kind of protections they have regarding employment, both salaried and self-employed. RdM explained that even if a person has recovered their health, they may not have recovered their social inclusion or their right to paid leave. The Legal Network for Cancer Patients would like to fight for flexible working, in both the time and place of work, and encourage teleworking. Life insurance and pension rights are also issues of interest. RdM added that ECPC will issue another call for lawyers to join the ECPC Legal Network for Cancer Patients. The Legal Network for Cancer Patients will also work with AF to produce a one-page ten-point manifesto for the upcoming European Parliament elections.

KA noted that ECPC also produced a manifesto for the previous European Parliament elections. KA added that ECPC are here to help Members, especially smaller organisations, to conduct political advocacy. Only if everyone works together can we make a difference.

FdL asked Andrew Winterbottom (AW), ECPC Treasurer and CEO of Fight Bladder Cancer UK, to summarise the outcomes of the meeting of the Working Group on Bladder Cancer on Friday 8 June.

AW explained that ECPC has completed a bladder cancer patient experience survey, which was translated into 7 different languages, and received over 1,000 responses. AW will be presenting the results of the Survey at the Public Health England conference in Liverpool. AW announced that the bladder cancer patient organisations will be officially launching a World Bladder Cancer Patient Coalition, which will have its first meeting in Barcelona in March 2019. He called on ECPC Members to let him know if they are aware of any bladder cancer patient organisations who would like to join.

FdL noted that the ECPC Bladder Cancer White Paper had been a great success. KA noted that if anyone wants to establish a new bladder cancer patient organisation, they can reach out to ECPC for assistance.

Another member noted that there is a relationship between the parasitic disease of schistosomiasis and bladder cancer, and wished AW the best of luck for the establishment of the World Bladder Cancer Patient Coalition.

#### *Voting to adoption the 2017 Annual Report*

The General Assembly unanimously approved the 2017 Annual Report.

#### *Presentation of the 2017 Financial Report and 2018 Budget*

FdL invited ECPC Treasurer Andrew Winterbottom (AW) to present the 2017 Financial Report and 2018 Budget, and a printed version distributed among the Members (Annex 4). AW noted that each expense and each revenue item was associated with a project budget, so ECPC can track where all the costs have gone. ECPC has introduced a regular reporting system, so ECPC knows when they are spending too much, and when they are not spending enough. The staff keep timesheets so ECPC knows how many hours staff spend on each project. AW noted that there was an independent audit, who gave an unqualified opinion. AW noted that ECPC's revenue is likely to grow again in 2018.

FdL invited the Chair of the ECPC Audit Committee, Pietro Presti (PP), to give his remarks.

PP thanked the ECPC staff in the office for their work, the ECPC Board for their vision, and his colleagues on the Audit Committee. He noted that in the past five years, ECPC has built a beautiful office, a great membership, and a sound strategy. He noted that all the ECPC activities have been run very well, and that in order to ensure the structure and sustainability of the organisation, he recommends that the General Assembly votes to approve the General Regulations, which will be presented later in the meeting.

Seda Kansu (SK) from Pembe Hanim Turkey asked to be sent information on how to request the creation of a new Working Group.

Viorica Cursaru (VC) from Myeloma Euronet Romania asked for an explanation of the budget category “Joint Actions and Donations”

ECPC Financial Officer, Jiska Bolhuis (JB) explained that ECPC is a subcontractor in the Joint Action in Rare Cancer. Also, the Union for International Cancer Control had nominated ECPC to receive all the BeNeLux (Belgium, Netherlands, Luxemburg) donations in the Country 2 Country 4 Cancer Ride.

FdL noted that he is very proud of the transparency of ECPC. The ECPC Board is minimising the cost of travel. He noted that he receives no financial benefit ECPC. He invited other organisations to let ECPC know if they would like to use the ECPC use financial templates in their own organisations.

#### *Voting on the 2017 Financial Report and 2018 Budget*

The clear image on ECPC assets and statement of income and expenditure for the past financial year, and budget for the next financial year were unanimously approved.

The General Assembly unanimously voted to release the ECPC Board from responsibility related to the 2017 Annual and Financial report.

#### *Number of the Board members for the 2019 elections*

FdL noted that the ECPC statute states that “The Board consists of at least five and at most nine individuals. The General Assembly decides on the number of Board Members, one year before the election of new Board.”

#### *Voting on the Number of the Board members for the 2019 elections*

The General Assembly unanimously voted that there the 2019-2021 ECPC Board will consist of seven individuals.

Viorica Cursaru (VC) from Myeloma Euronet Romania requested that there be more representation from Eastern Europe on the ECPC Board.

FdL invited her to nominate herself as a Board member.

VC stated that she was 70 years old, which was too old to be a Board member, and that there should be an age limit for ECPC Board members.

FdL noted that there were originally ECPC Board members from Poland and Romania, but both had resigned. A Board member from the Czech Republic remains on the ECPC Board.

### Special power for ECPC Director to appear in front of Notary

Anna Rek (AR), Community & Communications Manager, explained that Lydia Makaroff, ECPC Director, needs to be appointed as the Legal Entity Appointed Representative of ECPC in order to communicate any modifications of the ECPC Statute to the Notary.

### *Voting on Legal Entity Appointed Representative*

The General Assembly unanimously appoints Lydia Makaroff, ECPC Director, as a Legal Entity Appointed Representative of ECPC

### Modifications to the ECPC Statute

FdL presented the proposed changes to the ECPC Statute, and a printed version distributed among the Members (Annex 5)

### Proposal to change Article 4 – Members

FdL proposed expanding 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 ECPC.

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

FdL proposed replacing "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".

Another member noted that ECPC experts are individuals that should have an allegiance to ECPC. There is a concern that the ECPC experts may represent the interests of their other institutions, rather than the interests of cancer patients.

FdL notes that this issue has already been addressed by the Memoranda of Understanding that ECPC has signed with organisations such as ESMO, EORTC, and EAU.

### *Voting on Article 4 – Members*

Modifications to the Statute are decided upon by a two thirds voting majority of the members present or represented at the General Assembly. The modification was unanimously approved by full members present.

### Proposal to change: Article 6 – Termination of membership

FdL explained that 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".

#### *Voting to change Article 6 – Termination of membership.*

Modifications to the Statute are decided upon by a two thirds voting majority of the members present or represented at the General Assembly. The modification was unanimously approved by full members present.

### Proposal to change Article 10 – Committees

FdL notes that the as ECPC is becoming increasingly involved in EU research projects. Changing the Statute will give a continuity of ECPC's research involvement without any interruption or misunderstandings. Changing the Statue to give the Immediate Past President the role of Chair of the Scientific Committee would ensure continuity of expertise.

Viorica Cursaru (VC) from Myeloma Euronet Romania notes that while FdL has been a good president, it is unhealthy to have this legally binding statement in the Statute. It is unwise to automatically make Past Presidents become Chair of the Scientific Committee. It is better that Past Presidents simply observe Board meetings. They should be in institutional memory, not involved in the day to day activities of the Scientific Committee.

Nicolas Philippou (NP), Audit Committee Member and CEO of the Cyprus Association of Cancer Patients and Friends, notes that he was quite sceptical at first, but believes that this change will be good for the sustainability of the organisation. The Union for International Cancer Control as a President-Elect, President, and Past President.

Cezar Irimia (CI) from the Federation of Cancer Patients Associations Romania states that this change is a deviation from the democratic principles of the organisation. CI does not agree with the proposal to amend the Statute, in the sense that the former president of the ECPC becomes ex officio chair of the ECPC Scientific Committee. CI notes that in 2019, the newly elected board must have their full power, and their full competence in electing the 2019 Scientific Committee. If the Statute was changed, the Board could not decide on the Chair of the Scientific Committee, although it has been given the full responsibility to carry out ECPC projects. The proposal is discriminatory to the other members of the Scientific Committee who may also want to be Chair. The Past President becomes an automatic member, while the other experts must be selected and evaluated by the Board. The proposal violates the legal principle of symmetry. If another member of the Scientific Committee no longer meets the selection criteria, the Board can revoke their membership. However, in the condition in which the Chair is not elected, the position of Chair cannot be given nor revoked by the Board. Furthermore, if the Past President becomes the Chair of the Scientific Committee, there could be a potential conflict between the President and the Past President, which could harm ECPC activities.

Pietro Presti (PP), ECPC Audit Committee Chair and Managing Director at "Edo ed Elvo Tempia" Foundation, notes that the resolutions adopted by the Scientific Committee are non-binding for the ECPC Board.

KA adds that it is important to ensure continuity and that everything continues smoothly.

Jelena Burianova (JB) from Mamma HELP Czech Republic states that it is not possible to mix research and policy. She requests that scientists have the authority and responsibility to run the Scientific Committee. JB uses the analogy of politicians running a nuclear power plant.

#### *Voting to change Article 10 – Committees*

Yes: 23

No: 6

Abstained: 1

The motion is approved by 76% of members present. Modifications to the Statute are decided upon by a two thirds (66%) voting majority of the members present or represented at the General Assembly.

Cezar Irimia (CI) from the Federation of Cancer Patients Associations Romania states that he agrees with the Czech Republic, and that he will take a public position stating that ECPC should not mix politics with research.

#### *Modification of Article 13 – General Assembly*

FdL explains that 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".

#### *Voting to change Article 13 – General Assembly*

Modifications to the Statute are decided upon by a two thirds voting majority of the members present or represented at the General Assembly. The modification was unanimously approved by full members present.

#### *Modification of Article 14 – Agenda*

FdL explains that 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".

#### *Voting to change Article 14 – Agenda*

Modifications to the Statute are decided upon by a two thirds voting majority of the members present or represented at the General Assembly. The modification was unanimously approved by full members present.

#### *General Regulations*

KA presented the General Regulations (Annex 6), and a printed version was distributed among the Members. KA noted that the General Regulations give an idea of the role of each Board member and staff member.

FdL states that the General Regulations reflect the organisational structure of ECPC, with well-defined roles for the Board and the staff. If an individual would like to stand for election to

the ECPC Board, the General Regulations will give them a good overview of their roles and duties. It also gives more details about the Audit Committee, Scientific Committee, and Working Groups.

#### *Voting to adopt the General Regulations.*

Adoption and modifications to the Statute are decided upon by a regular voting majority of the members present or represented at the General Assembly. The General Regulations were adopted unanimously.

#### Final Remarks

Andrew Winterbottom (AW), ECPC Treasurer and CEO of Fight Bladder Cancer UK, remarks that ECPC has moved forward over the last couple of years. AW notes that the Board works to represent the entire membership of ECPC.

KA reminds the General Assembly that Anna Rek (AR), Community & Communications Manager, is here to be the contact point with the Members, and encourages the Members of ECPC to write to her in any language to share news and ideas.

FdL states that the ECPC Board wants ideas from ECPC members. FdL thanks the Board for their involvement and support. FdL thanks the office staff for doing the best that can possibly be done, with particular thanks to Anna Rek and Eleonora Varntoumian (EV), ECPC Congress and Communications Intern, for organising the Annual Congress.

AR remarks that it was six months of hard work to organise the Annual Congress, but seeing all the ECPC members in this room is the best reward that one could possibly get. AR remarks that the Annual Congress was a great success, and that each year ECPC is getting better, and the Annual Meeting has now evolved into an Annual Congress.

FdL closes the meeting and thanks the participants warmly.

#### **The meeting ended at 11:45**

#### Annexes

Annex 1: List of ECPC full and associate members present at 2018 ECPC AGM

Annex 2: Minutes of the 2016 ECPC Annual General Assembly

Annex 3: 2017 ECPC Annual Report

Annex 4: 2017 Financial Report and 2018 Budget

Annex 5: Modifications to the ECPC Statute

Annex 6: ECPC General Regulations