EUROPEAN CANCER PATIENT COALITION

NOTHING ABOUT US, WITHOUT US!

ECPC GENERAL ASSEMBLY 2015 MINUTES

21st June 2015, Brussels, Belgium
Hotel Renaissance, Rue du Parnasse 19, 1050 Brussels

CONTENTS

ATTENDENCY

PRESENT

Meeting started at 9.00

The ECPC President Francesco De Lorenzo (FdL) and Secretary Jana Pelouchova (JP) invited the Members with voting rights to present themselves and deposit any proxies held. After the list of members with voting rights was established, the following were noted:

29 voting members present.

0 proxies have been recognised by the Board.

29 total votes have been recognised by the Board.

ITEM 1: ADOPTING THE MINUTES OF THE AGM 2014

The draft Minutes were presented by the Board and a printed version distributed among the Members (Annex 1 and 1bis).

Sarunas Narbutas (SN) took the floor to ask the Board what has been done in the field of cross border healthcare. ECPC Public Affairs Coordinator Francesco Florindi (FF) updated the audience on ECPC's initiative in this field, mentioning that ECPC is in contact with the European Commission's relevant unit dealing with the implementation of the Cross Border Healthcare Directive. ECPC is aware that only 8 Member States had at the time implemented the Directive, while the remaining 20 had either restrictive implementing measures in place, or no measures at all. FF explained that an official report on the Directive's implementation will be published in Autumn 2015. FF also mentioned that ECPC's questionnaire on "Europe of Disparities" contains explicit questions on ECPC Members' understanding and opinion on cross border healthcare, and therefore invited all Members to reply on these points.

SN also inquired the Board regarding the identification of centres of expertise within the framework of the Cross Border Healthcare Directive. FdL replied that ECPC has a strong collaboration with the Organisation of European Cancer Institutes (OECI), the association which reunites all European cancer excellence centres. Such collaboration is strengthened the work Pietro Presti (PP) was doing on behalf of ECPC within the OECI's BenchCan project, exactly on the topic of assessing and evaluating centres of expertise and excellence in treating cancer in Europe. Furthermore, FdL reminded the audience that in 2016 the European Commission will launch a Joint Action on Rare Cancers, and that ECPC is already at the forefront of the initiative, being the only patient organisation directly involved in the two key projects on which the Joint Action will be based: RARECARE and RARECAREnet.

VOTE ON THE 2014 AGM MINUTES

27 votes in favour.

0 votes against.

2 abstentions.

The General Assembly approved the minutes of the 2013 General Assembly.

ITEM 2: ANNUAL REPORT IT ACTUALY DID NOT TAKE PLACE

FdL took the floor to present the ECPC Annual Report (Annex 2). A presentation (Annex 2bis) was delivered to the General Assembly on Friday 19th of June, in order to ensure the General Assembly meeting enough time to debate Item 4 of the General Assembly Meeting agenda.

FdL briefly recapped the content of the presentation held on Friday 19th June, underlining that ECPC had gone a long way from its inception to becoming Europe's largest cancer patient association. ECPC credibility rose to new heights in 2014 and 2015 thanks to the fact that ECPC has been involved in Europe's most important policy initiatives on cancer: the Joint Action on Cancer Control, the Expert Group on Cancer Control and the European Medicines Agency Patients' and Consumers' Working Party.

ECPC demonstrated to attract a growing number of collaborations with fundamental stakeholders in the field of cancer: the European Society for Medical Oncology (ESMO), the Organisation of European Cancer Institutes (OECI), the Cancer Drug Development Fund (CDDF), the European Cancer Concord (ECC) etc.

FdL reported that ECPC took active roles in more than 30 international events in 2014, including key congresses like ESMO2014, ASCO2014 and the European Health Forum in Gastein.

These policy successes are based on the solid policy work done by ECPC, in particular in the field of monitoring and lobbying EU legislations, like the General Data Protection Regulation, the Cross Border Healthcare Directive and the Clinical Trials Regulation. This policy work went hand in hand with a series of meeting ECPC obtained with key policy makers, first and foremost with the European Commissioner for Health Vytenis Andriukaitis in February 2014.

FdL reminded the audience of the hard work done by ECPC in raising awareness on the needs of cancer patient. Two campaigns in 2014 were particularly effective: the World Pancreatic Cancer Day and the launch of the Immuno-Oncology Policy Action Framework.

FdL stressed how ECPC enhanced and ameliorated its relationship with ECPC Members and provided examples of joint initiatives organised in 2014 and 2015.

Finally, FdL praised the General Assembly for the input provided to the document "Europe of Disparities" which was discussed on Saturday 20th June within the Annual General Meeting. FdL underlined how the document will truly be cancer patients' policy strategy to defeat inequalities in Europe, as it has received input and comments from the varied and solid ECPC Membership.

ACTION POINTS

- ECPC shall further enhance cooperation with Members through targeted initiatives at local level.

VOTE ON THE ECPC ANNUAL REPORT

The General Assembly unanimously approved the Annual Report.

ITEM 3: APPROVAL OF BUDGET

ECPC Vice President and Treasurer Vlad Voiculescu (VV) introduced the ECPC financial report, which was distributed to the Members in paper (Annex 3).

VV explained the total income in 2014 increased by 154% (an additional amount of 204.264 euro) in comparison with 2013. This was thanks to the continued efforts of rebuilding the positive reputation of ECPC and reinstating the trust of our sustaining partners by proposing innovative projects.

Description	EUR
Total costs	**353.295,17**
Total income	**336.872,38**
Result	**-16.422,79**

ECPC Director Mihaela Militaru (MM) added that ECPC also increased the number of funders, therefore diversifying its funding sources. The majority of the funding still comes from unrestricted grants from pharmaceutical companies, but ECPC has also increase the funding from non-industry sources. Furthermore, MM underlined that ECPC has been also working more closely with its Members willing to organise large events at the European level. In this perspective, MM explained that ECPC is planning do more consultancy work for its Members interested in organising disease-specific events/policy initiatives at the European level.

FF took the floor to provide more insight on the funding of the Immuno-Oncology Portal (IOP). IOP is funded by 6 pharmaceutical companies on an equal base, but none of them is involved in the drafting of the content of the project. The project is run in collaboration with independent academics and contractors chosen by ECPC.

MM and FF also clarified that ECPC cannot apply for operational grants issued by the European Commission Directorate General on Health and Consumer Protection (DG SANTE), due to a very strict interpretation of the programme's terms of reference. The programme is, in fact, accessible only to those organisations which submitted a funding request in 2013. FF explained that ECPC and many other patients and civil society organisations which did not apply in 2013 have strongly advocated against such interpretation and have publicly criticised DG SANTE. MM further explained that, in response to this situation, in all ECPC projects in 2014 and 2015 there is explicit mention of the running costs for the organisation, including staff costs.

MM and FF also commented on ECPC's participation in EU funded projects. MM explained that between 2014 and the first half of 2015 ECPC collaborated to the creation of 9 consortia to apply for Horizon 2020 calls. However, all 9 bid failed, even if the quality of the projects was very high and the consortia were composed by high level research institutes. FF specified that one of the 9 projects was evaluated by the European Commission with a score of 14,5 out of 15 points, but, although the score was very high, it was not even included among the "selected but not funded" projects.

FdL took the floor to underline that, notwithstanding the exceptionally unfavourable results of the bids to Horizon 2020, ECPC demonstrated to have a very strong connection with European academia, since many of the consortia proactively contacted ECPC to participate to the projects.

VV continued the report on ECPC finances, explaining the details of ECPC's accounting system. Several comments from the audience arose regarding the fact that the figures presented were not clear. In particular, Mai Nielsen (MN) reminded VV that he is obliged to submit the balance sheet to the General Assembly, in pursue of article 13 of the ECPC statute, and also that ECPC shall publish an account of ECPC capital, and that such document shall be approved by the General Assembly. SN asked the Board to hold a separate vote on such balance sheet. VV committed to present to the Members a clarified figures regarding ECPC budget. VV underlined that, according to Belgian legislation, ECPC is not obliged to keep a balance sheet, nonetheless, he will present such document to the Membership by the end of September and will make it publicly available on the ECPC website (Annex 4).

Regarding the costs incurred by the ECPC Board, FdL pointed out that the policy of the ECPC Board is to participate to international events and conferences only when such participation is covered by the organisers.

Audit Committee Member Pietro Presti (PP) took the floor to summarise the ECPC Audit Committee report (Annex 5) on 2014 budget. PP reported that the Audit Committee particularly appreciated ECPC's efforts to find new sustaining partners and differentiate funding sources. PP underlined that this is particularly important for the sustainability of the organisation. Furthermore, PP recommended the General Assembly to vote in favour of the 2014 budget, and agreed with previous comments that more transparency and clarity is needed from the side of the treasurer, including the publication of the balance sheet.

FdL suggested not to impose membership fee for 2016.

ACTION POINTS

- VV to disseminate a clearer document on ECPC budget, including the balance sheet for 2014. All documents will be uploaded on ECPC website.

VOTE ON THE 2014 FINANCIAL REPORT

24 votes in favour.

0 votes against.

5 abstentions.

The General Assembly approved the 2014 Financial Report.

VOTE ON THE 2015 BUDGET

29 votes in favour.

0 votes against.

0 abstentions.

The General Assembly approved the 2015 Budget.

VOTE ON 2015 MEMBERSHIP FEES

29 votes in favour.

0 votes against.

0 abstentions.

The General Assembly decides not to impose membership fees for 2016.

ITEM 4: AMENDMENT OF THE ECPC STATUTE

FdL took the floor to introduce the work done by the Board regarding the amendment of the ECPC statute. In pursue of the decision of the ECPC General Assembly in 2013 and 2014, the Board undertook all necessary measures to transfer the siege of ECPC from the Netherlands to Belgium. FdL and FF reminded the General Assembly the process necessary to accomplish the transfer of the siege without interrupting ECPC's legal entity, therefore preserving all the existing contracts and agreements unaltered. Such process, communicated to the General Assembly during the 2014 AGM is included in the minutes approved and available on the ECPC website.

The last step of the process is to amend the current ECPC Statute to comply with the requirements of the Belgian legislation. FF reported that the new version of the statute has been prepared by ECPC notary, Actalys, in collaboration with the Office. FdL explains that the Board took this chance to introduce few changes to the ECPC statute, in order to make the organisation more resilient and solid, in particular ensuring continuity between one Board mandate and the next. FdL introduced the changes suggested by the Board and previously shared with all ECPC Members (Annex6). FF presented the amendments received from ECPC Members in writing (Annex 7) and disseminated to all ECPC Members before the AGM. Hard copies of both documents are shared with the Members.

FdL suggested to open the debate discussing article per article the draft statute produced by the notary, focusing on the amendments presented by the ECPC Board or by the ECPC Members who submitted their comments in writing. If any Member wanted to present a new amendment, they were free to indicate so during the debate. For those articles that have been amended, the General Assembly would proceed immediately to vote them. Once all the articles have been debated or amended, the General Assembly would proceed to vote on the whole new draft statute. The General Assembly agreed to the proposal made by FdL.

FF projected Annex 8, which is the new version of the statute as produced by the notary including, in track changes, all the amendments proposed by the Board (Annex 6) and by the ECPC Members (Annex 7).

FF proceeds by reading Annex 8 article per article, amending it on the spot when decided by the General Assembly.

Articles 1, 2, 5, 8, 9, 13, 14, 15, 16, 18, 19 have not been debated.

Article 3
The General Assembly took note of Hannu Tavio (HT), Kathy Oliver (KO) comments. The ECPC Board agrees with both comments, as they better formulate the concept of the article and amended the draft consequently. KO comment 1 is taken as model to amend other provisions in the draft accordingly. The amendments were approved by the General Assembly.

Article 4
KO submitted one amendment. FdL explains that the Board wants to facilitate the inclusion as Full Members of organisations representing rare cancers, which, because of the nature of rare cancers, might not fulfil the criteria set by the current statute, and therefore does not agree with KO's amendments. KO's amendment was not approved by the General Assembly.

The General Assembly took note of Jan Geissler (JG) and Tadeusz Wlodarczyk (TW) and KO comments. JG comments 2 and 3 related to article 4 have been integrated in the draft. The amendments have been approved by the General Assembly.

TW comment 1 is not approved by the General Assembly.

In the context of the debate regarding Article 4, the General Assembly discussed if enlarging the definition of Full Member to include organisations within the WHO Europe Region. The General Assembly decided not to amend such point, on the base that such change would imply a change of scope and mission to the organisation.

Article 6
The General Assembly took note of the comments from JG and KO. The Board welcomed the comments. SN and Shajjad Rizvi (SR) argued that the provisions in article 6.3.b regarding the conditions of terminations of membership are unclear and can be misinterpreted, leaving the Board with too much power of discretion. Following the debate in the General Assembly the Board submits amendments to the article 6. The amendments have been approved by the General Assembly.

Article 7
One amendments was submitted by KO, which was approved by the General Assembly.

The General Assembly took note of comments submitted by JG and KO. KO comment 4 is not accepted by the General Assembly, as it is not up to the ECPC statute to determine which national authority is competent for providing the certificates mentioned in article 7.7.a. The Board presented an amendment in line with JG comment 4. The amendment has been approved by the General Assembly.

Article 10
One amendments was presented by TW. The Board welcomes the amendment, but suggest to limit the number of Members of the Scientific Committee to 5 to contain costs. The General Assembly approved the amendments.

The General Assembly took note of the comments sent by JG, KO. KO comment 6 is not accepted: FF reported to the General Assembly that, under Belgian law, ECPC will be obliged to provide to the General Assembly an independent audit if the budget of the organisation exceeds 500.000 EUR.

JG comment 5 and KO comment 7 were welcomed by the Board, which presents an amendment to article 10.4.b.iv, mentioning that the Scientific Committee is chaired by the ECPC President, while the Past President remains only a member *ex officio* of the Scientific Committee, without formal role. The amendment was approved by the General Assembly.

JG comment 6 and KO comment 8 were welcomed by the Board. FdL explained that the objective of establishing the Friends of ECPC committee and the Scientific Committee is to strengthen ECPC capacity to achieve the association's mission. The General Assembly remains the primary not to substitute the General Assembly as the primary role in defining and orienting ECPC strategy. To this end, the Board submitted an amendments allowing ECPC Full and Associate members to suggest candidates for the Scientific Committee and to suggest Expert Members. Nonetheless, FdL explained that the Board would like not to subject the ECPC Expert Members willing to collaborate to the Scientific Committee to an election process, as this vote on people is not in line with the objective of the Committee. The amendments were approved by the General Assembly.

Elisabetta Iannelli (EI) took the floor to suggest to move the provisions related to the Scientific Committee and the Friends of ECPC Committee to two new sub-headings: 10.5 and 10.6 respectively, without further changes to the text. The General Assembly approved the amendment.

Article 11
One amendment was proposed by KO. The amendment was approved by the General Assembly.

The General Assembly took note of KO comment 9. FdL clarifies that no amendments to this provision were suggested by the Board. The provisions regarding the membership fee remain unchanged: every year, the General Assembly decides if imposing a fee to ECPC Members.

Article 12
The General Assembly took note of JG comment. The Board welcomed the comment and suggested an amendment in line with JG proposal. VV suggested to further amend the Board amendment, in line with the comments of several Members regarding Item 3 of the General Assembly agenda. MM commented that whatever the provision in article 12, Belgian legislation will require ECPC to produce specific budgeting document once the overall budget of the organisation will exceed 500.000 EUR. FdL intervened to remind the audience that also in 2015 ECPC will keep satisfying the strict financial requirements of the European Medicines Agency (EMA), as a demonstration of ECPC independence and transparency. SN asked for public disclosure of all ECPC financial documents from previous General Assembly meetings, which were not available at the time of the AGM. VV responded that such documents will be updated as soon as possible. VV amendment to the Board amendments was approved by the General Assembly.

Article 17
The General Assembly took note of TW comment. FF explained that the provisions in article 17.4 are required by Belgian law. The General Assembly did not accept TW comment.

ACTION POINTS

ECPC will publish all the official documents related to previous AGMs on the ECPC Website.

VOTE ON THE NEW ECPC STATUTE

FF produced a consolidated version of the draft statute (Annex 9) following the debate of Item 4 of the General Assembly meeting agenda. The General Assembly voted the adoption of Annex X as the new ECPC statute.

22 votes in favour.

1 vote against.

6 abstentions.

The General Assembly approved the adoption of the new statute.

FdL concluded the vote by thanking the Office for the hard work done to organise the process of amendments. He clarified that the newly approved statute will have to be translated in French by a legal translator and adopted by an ECPC Extraordinary General Assembly (EGA) in Brussels, to comply with the Belgian law. Date and time of the EGA will be communicated to all ECPC Members. However, FdL explained that such EGA will represent a mere administrative step: no modification whatsoever will be made to the statute as it has been approved by the General Assembly. FdL clarified that the new statute will enter into force once the Belgian authorities will approve ECPC's registration as a legal entity in Belgium. Until that moment, the current ECPC statute remains valid.

ITEM 5: NUMBER OF BOARD MEMBERS 2016-2019

FdL reminded the General Assembly that elections will be held in 2016 to renew the ECPC Board. In line with article 7 of the ECPC statute, the General Assembly shall determine the number of Board Members.

FdL proposed to keep the current number of Board Members, which is 7. The General Assembly approved the proposal.

Meeting ended at 12.30.

Minutes taken by ECPC Secretary Jana Pelouchova, in collaboration with Francesco Florindi ECPC Public Affairs Coordinator.

ANNEXES

ANNEX 1: ECPC AGM 2014 MINUTES

ANNEX 1BIS: ANNEXES TO THE ECPC AGM 2014 MINUTES

ANNEX 2: ECPC ANNUAL REPORT 2014

ANNEX 2BIS: FDL PRESENTATION ON THE ANNUAL REPORT 2014

ANNEX 3: FINANCIAL REPORT

ANNEX 4: BALANCE SHEET

ANNEX 5: AUDIT COMMITTEE REPORT

ANNEX 6: ECPC NEW STATUTE DRAFT WITH AMENDMENTS FROM THE BOARD

ANNEX 7: AMENDMENTS RECEIVED VIA EMAIL FROM ECPC MEMBERS

ANNEX 8: ECPC NEW STATUTE – AGM WORKING DOCUMENT

ANNEX 9: NEW ECPC STATUTE APPROVED BY THE GENERAL ASSEMBLY