

ECPC GENERAL ASSEMBLY 2016

MINUTES

5th June 2016, Brussels, Belgium

Hotel Renaissance, Rue du Parnasse 19, 1050 Brussels

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ATTENDANCE

PRESENT

Meeting started at 9.30

The ECPC President Francesco De Lorenzo (FdL) chaired the meeting. ECPC Secretary Jana Pelouchova (JP) took the minutes. FdL and 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:

46 Full Members present. 1 proxy has been recognised by the Board (Beata Ambroziewicz for Roman Slomkowski, CARITA FOUNDATION, Full Member). 47 total votes have been recognised by the Board.

11 Associate Members present.

The list of participants and the proxy were collected by JP and included to the minutes of the meeting (Annex 1 and Annex 2).

ITEM 1: ADOPTING THE MINUTES OF THE AGM 2015

The draft Minutes were presented by the Board and a printed version distributed among the Members (Annex 3 and 3bis).

VOTE ON THE 2014 AGM MINUTES

47 votes in favour.

0 votes against.

0 abstentions.

The General Assembly approved the minutes of the 2015 General Assembly.

ITEM 2: CREATION OF THE AD HOC COMMITTEE FOR CONFIRMATION OF ELIGIBILITY

In line with the Guide for Elections (Annex 4) and with article 10.1, the Board creates an ad hoc Committee in charge of checking that the elected candidates for the 2016-2019 Board and Audit Committee mandates satisfy the criteria set in article 7.7 of the ECPC statute.

FdL calls for three volunteers to express their willingness to be part of the Committee and independently oversee to the task. FdL clarifies that the volunteers should not belong to the same association of any of the elected candidates, to ensure full independence of the Committee decision. Three volunteers expressed their wish to collaborate:

- Jacqueline Daly, from East Galway & Midlands Cancer Support, Ireland;
- Michael Leahy, from Clare Cancer Support, Ireland;
- Konstantinos Apostopoulos, from Agkagliazo Achaia, Greece.

VOTE ON THE CREATION OF THE AD HOC COMMITTEE

The General Assembly unanimously approves the creation of the ad hoc Committee, composed of:

- Jacqueline Daly, from East Galway & Midlands Cancer Support;
- Michael Leahy, from Clare Cancer Support;
- Konstantinos Apostopoulos, from AGALIAZO Achaia.

ITEM 3: FINANCIAL REPORT

A printed copy of the Financial Report was distributed among the Members (Annex 5).

ECPC Director Mihaela Militaru (MM) introduces the financial report on behalf of the ECPC Treasurer and Vice President Vlad Voiculescu (VV), who was not present. MM delivers a presentation to the audience, in which she describes the main points of the financial report (Annex 6).

MM explained the total result in 2015 increased by more than 125% (an additional amount of 205.912 euro) in comparison with 2014. This was thanks to the continued efforts of rebuilding the positive reputation of ECPC and reinstating the trust of our sustaining partners by implementing successful projects and by policy initiatives toward the European institutions. 4 new companies joined the group of sustaining partners of ECPC in 2015.

| Description | EUR |
|--------------|---------------|
| Total costs | 505.173 EUR |
| Total income | 682.912 EUR |
| Result | + 163.831 EUR |

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 (75.18%), but ECPC has also increased the funding from non-industry sources (24%), in particular by winning a grant from the Waldesian church, which will allow to provide 8 ECPC members with much needed IT equipment.

Furthermore, MM underlined that ECPC has been also working more closely with its Members willing to increase their outreach to the European Union. In particular, the Brain Tumour Charity has sponsored the project “The Brain Tumour Charity’s engagement in Europe and with the European Union”, while another ECPC Member, Lung Cancer Europe, contributed to the organisation of the event “The future of the fight against lung cancer”. Both initiatives increased the overall percentage of non-industry funding collected by ECPC in 2015.

MM also commented on ECPC’s participation in EU funded projects. MM explained that ECPC is continuously being contacted to participate to EU funded consortia. Thanks to the work of Kalliopi Christoforidi (KC), ECPC has been able to react better and faster to these collaborations’ proposals and MM expects that some of the proposals submitted to the Commission will eventually be funded.

MM discussed also the prospective budget for 2016, reporting that to date, 636.634 EUR have been committed by ECPC sustaining partners for the activities of 2016. MM reports also that ECPC will enjoy the pro bono services of the Brussels’ consultancy Hannover to create a three-year strategy, which will further increase the chances of further consolidating ECPC’s credibility, and therefore increase the total budget of the organisation.

As per the production of the Financial Report document, MM underlined that the comments shared by the ECPC Members during the 2015 AGM have been duly taken into consideration, and the 2016 report has been designed specifically to satisfy such comments.

MM concluded by reporting that ECPC produced an independent audit for the first time, in addition to the internal Audit Committee Report, in line with the requirements of Belgian Law. This greatly increases the transparency and accountability of ECPC towards its Members and third parties.

Ken Mastris (KM) asked if ECPC has any plan to increase the reserves of the organisation, for example by investing them. MM reported that this was done in the past, but for the moment there are no concrete investment plans for the reserves.

Audit Committee Member Pietro Presti (PP) took the floor to summarise the ECPC Audit Committee report on 2015 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 2015 financial report.

FdL suggested not to impose membership fee for 2016.

VOTE ON THE 2014 FINANCIAL REPORT

47 votes in favour.

0 votes against.

0 abstentions.

The General Assembly approved the 2014 Financial Report.

VOTE ON 2015 MEMBERSHIP FEES FOR THE PERIOD 2015-2016

0 votes in favour

47 votes against.

0 abstentions.

The General Assembly decides not to impose membership fees for the period 2015-2016.

ITEM 4: RESULTS OF THE ECPC ELECTIONS 2016

In line with article 7.8 of the ECPC Statute, the 2013-2016 Board of ECPC is discharged of its duties and responsibilities.

The General Assembly asked FdL to keep chairing the General Assembly Meeting, supported by JP for the minute-taking.

ECPC Public Affairs Coordinator Francesco Florindi (FF) presented the results of the elections to the audience (Annex 7 and 7bis). In line with the Guide to Elections (Annex 4), the scrutiny of the votes received for the 2016 elections were counted at the presence of an independent Notary, Ms Gillardin from the notary studio Actalys, on the 23rd May 2016. The results of the scrutiny were communicated confidentially to the elected candidates for them to produce the necessary documents for the confirmation of eligibility, in line with article 7.7 of the Statute (so called “Art. 7.7 documents”). FF produced originals of the minutes of the scrutiny signed by the notary (Annex 7) together with all the annexes to the minutes, including the original envelopes and voting forms received for elections (Annex 7bis). The original documents of the elections 2016 were made available during the AGM for all Members to check.

FF presented a summary of the votes received:

| Board Membership | |
|------------------|-----|
| Valid votes | 110 |
| Non valid votes | 3 |
| Total | 113 |

| Audit Committee Membership | |
|----------------------------|-----|
| Valid votes | 107 |
| Non valid votes | 5 |
| Total | 112 |

FF explained that three envelopes were submitted after the deadline of the 11th May, set by the Guide to Elections document (Annex 4) and communicated to all ECPC Members. For the Audit Committee elections, 2 votes were considered invalid because they presented more than the allowed number of preferences (three). Furthermore, FF explained that one of the envelopes presented only one voting form for the Board elections, which justifies the difference of one vote between the Audit Committee elections and the Board elections.

FF then presented the results of the scrutiny:

| n | Board Membership election results | n votes | % |
|---|-----------------------------------|------------|----------------|
| 1 | De Lorenzo | 88 | 15.97% |
| 2 | Apostolidis | 72 | 13.07% |
| 3 | Winterbottom | 66 | 11.98% |
| 4 | Chrostowski | 61 | 11.07% |
| 5 | Pelouchova | 60 | 10.89% |
| 6 | Cimpoeru | 59 | 10.71% |
| 7 | Bolanos | 47 | 8.53% |
| | Jarvinen | 18 | 3.27% |
| | Mastris | 15 | 2.72% |
| | Anderson | 14 | 2.54% |
| | Dimitrova Alexandrova | 11 | 2.00% |
| | Voiculescu | 11 | 2.00% |
| | Cavallero | 10 | 1.81% |
| | Schiavon | 8 | 1.45% |
| | Cursaru | 7 | 1.27% |
| | Canzanella | 4 | 0.73% |
| | | 551 | 100.00% |

| n | Audit Committee election results | n votes | % |
|---|----------------------------------|------------|----------------|
| 1 | Presti | 72 | 26.67% |
| 2 | Philippou | 61 | 22.59% |
| 3 | Balogh | 56 | 20.74% |
| | Voiculescu | 20 | 7.41% |
| | Deniel Ihlen | 16 | 5.93% |
| | Necchi | 12 | 4.44% |
| | Santangelo | 10 | 3.70% |
| | Canzanella | 9 | 3.33% |
| | Ikalovic | 7 | 2.59% |
| | Dodeva Hristovska | 7 | 2.59% |
| | | 270 | 100.00% |

The names in green are cancer survivors or patients.

The names in red correspond to candidatures that have been withdrawn.

In line with the ECPC statute, article 7, and with the decision of the ECPC AGM 2015 (Annex 3), the ECPC Board for the mandate 2016 – 2019 will be composed of 7(seven) Members. The following candidates have been elected to the position of Board Members:

- Francesco De Lorenzo
- Kathi Apostolidis
- Andrew Winterbottom
- Szymon Chrostowski
- Jana Pelouchova
- Dan Cimpoeu
- Natacha Bolanos

In line with the ECPC Statute, article 10.4, the Audit Committee is composed of 3 (three) Members. The following candidates have been elected to the position of Audit Committee Member:

- Pietro Presti
- Nicolas Philippou
- Istvan Balogh

The ad hoc Committee for the confirmation of eligibility presented its report, after having checked the documents provided by each elected candidates, in line with article 7.7 of the ECPC statute. The Committee reported its finding to the AGM (Annex 8) together with the original documents submitted by each elected candidate (so called “Article 7.7 documents”, Annex 9). The Committee confirmed that all elected candidates have provided the requested documents, and that all elected candidates fulfil the eligibility criterion. Therefore, the Committee recommended the AGM to confirm the result of the Election.

Each elected candidate took the floor to introduce him/herself to the ECPC Members. FdL stressed on the importance to better connect ECPC with its Members, to better implement ECPC initiatives at the national level. He also addressed the future objective to further increase public funding for ECPC, particularly from the participations to EU funded projects, for which the creation of the Scientific Committee will be instrumental.

Kathi Apostolidis (KA) underlined the importance to consolidate existing partnership with ECPC stakeholders like OEI, UICC, ESMO and ECCO. KA also underlined the need to provide more and better capacity building tools to ECPC Members. Finally, KA reminded the importance to represent ECPC within the EMA, which will be secured by herself with the support of former ECPC Board Member Rafal Swierzewski (RS).

FdL suggested KA and RS to produce monthly reports on their engagement within the EMA, to ensure that both the Secretariat and the ECPC Membership are aware of the work done by ECPC within the EMA. In relation to this point, RS reported that during his mandate, ECPC was involved into several EMA projects, namely:

- A subgroup of the Consumers’ and Patients’ Working Party on paediatric. ECPC is co-chairing the initiative, which has still to kick off;
- ECPC is member of the working group on the monitoring of side effects of medicines;
- ECPC has been involved in the discussion on possible new legislations on vaccines.

Jana Pelouchova (JP) outlined her activity in ECCO PAC in preparation of the Patient Track of ECC2017 congress. She also commented on patients' role within the EMA SAG. Finally, JP reported over her work within the RARE CANCERS EUROPE platform, which is currently focusing on clinical trial methodology for rare cancers, randomisation of trials, and therefore it remains very relevant for the work of ECPC on rare cancers.

KA informed the audience that ECPC is a member of the ESMO Patient Advocates Working Group (PAWG) whose main activity is the program development of the Patient Advocacy Track in the ESMO Congress. It should be noted that the PAWG succeeded in integrating the Patient Advocacy Track into the Scientific Program and had its first capacity building workshop in February this year on patients involvement in research.

Natacha Bolanos (NB) took the floor to show her pride in having been elected to the new ECPC Board. She went on confirming that her mission for the mandate will be to better involve the ECPC Membership in the initiatives of ECPC, particularly in the field of survivorship, drawing from her experience within GEPAC.

Dan Cimpoeru (DC) thanked the ECPC Membership for having trusted him with a position within the new Board. As a lawyer, DC will put to service his expertise, in particular in the field of access to treatments. He called for a reinforced collaboration with the Secretariat to enlarge the ECPC initiatives on new fields of interest for cancer patients (for example, in competition law) where ECPC can have a crucial impact.

Andrew Winterbottom (AW) addressed the audience stressing that ECPC can be a great starting point for many ECPC Members to step up their advocacy and policy initiatives. He reported the success of the ECPC White Paper on Bladder Cancer as an example of how our ECPC Members can be at the centre of the policy and advocacy initiatives of ECPC. He underlined the importance to collaborate to ensure that change is implemented at the national level.

Louis Denis (LD) took the floor to compliment the old Board of the excellent transparent management of ECPC. LD in particular praised the work of the ECPC President and its guidance, particularly by better involving Eastern European organisations within ECPC. LD reported that Europa Uomo will take inspiration from such approach and will open a chapter in Krakow soon, kindly requesting ECPC's support on this matter.

Giorgios Kapetanakis (GK) thanked ECPC for the great role in empowering the Members with scientifically validated and useful information. He called for more bridges to be built between the Board and the Membership. JP replied by reporting already successful examples of new connections between the Board and the Members, particularly with ECPC Members from Eastern and Southern Europe.

Hans Henrik (HH) takes the floor to mention that ECPC could get involved in the field of alternative therapies. FdL replies that the ESMO Congress in Copenhagen in October 2016 will be a great opportunity to meet with the ECPC Danish associations and discuss the topic in detail.

Seda Kansu (SK) reminds the audience that for the ECPC initiatives to truly have an impact at national level, they should be translated in local languages. She confirmed her willingness to translate ECPC works in Turkish.

Beata Ambroziewicz (BA) reports to the audience the gratitude of the elected candidate Szymon Chrostowski (SC) who was excused for not attending the AGM due to health reasons.

Furthermore, the newly elected Board informed the audience that it held an informal Board meeting before the AGM to agree on the division of roles within the Board, in line with article 7.3 of the ECPC statute. The Board reports the following:

- FdL will hold the position of President
- KA will hold the position of Vice President
- JP will hold the position of Secretary
- AW will hold the position of Treasurer

The decisions taken during the informal Board Meeting shall be ratified during the first formal Board Meeting, to be held in September 2016

VOTE ON THE CONFIRMATION OF ELIGIBILITY OF THE ELECTED CANDIDATES FOR THE ECPC ELECTIONS 2016

47 votes in favour.

0 vote against.

0 abstentions.

The General Assembly confirmed that all elected candidates fulfil the requirements of the eligibility criteria. The new ECPC Board and Audit Committee for the mandate 2016-2019 were officially installed.

ACTION POINTS

- KA and RS shall produce monthly reports on the relationship with EMA.

ITEM 5: COMMITTEE ON RARE CANCERS

In line with article 10.2 of the ECPC Statute, the General Assembly submits a proposal to the Board to establish a committee. The committee shall be called “Working Group on Rare Cancers” and should be composed of:

- Jana Pelouchova on behalf of Diajnoza CML
- Andy Winterbottom on behalf of Fight Bladder Cancer
- Simone Silenzi on behalf of Italia Glioblastome Multiforme – Cancro al Cervello
- Constantinos Chrysaphinis on behalf of Brain Tumour Charity
- Barbara Tamagni on behalf of Associazione Italian GIST
- Maria Silyanovska on behalf of VIOM
- Stamen Menova on behalf of Bulgarian Association for Patients Defence
- Lia Le Roy on behalf of Study Group Brain Tumours
- Athanasia Samara on behalf of KEFI

The objective of the Working Group is to coordinate ECPC’s position and initiatives in the field of rare cancers. The Working Group will enjoy the support of the ECPC Secretariat for the organisation of its meetings and for the fulfilment of its mission. The members of the Working Group agreed to produce a programmatic document

to explain in detail the mission, rational and functioning of the group. Such document shall be made public on the ECPC website within a dedicated webpage.

Each ECPC Member, Full or Associate, is welcome to join the Working Group. The General Assembly requested the Board to ask all ECPC Members, via the ECPC newsletter, to express their interest in joining the Working Group.

VOTE ON THE ESTABLISHMENT OF THE WORKING GROUP ON RARE CANCERS

47 votes in favour.

0 vote against.

0 abstentions.

The General Assembly establishes the Committee “Working Group on Rare Cancers”.

The meeting ended at 12.00.

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

ANNEXES

ANNEX 1: LIST OF PARTICIPANTS

ANNEX 2: PROXY

ANNEX 3: MINUTES OF THE 2015 AGM

ANNEX 3BIS: ANNEXES TO THE MINUTES OF THE 2015 AGM

ANNEX 4: GUIDE TO THE ELECTIONS

ANNEX 5: FINANCIAL REPORT, INCLUDING AUDIT COMMITTEE REPORT

ANNEX 6: PRESENTATION OF MIHAELA MILITARU ON FINANCIAL REPORT

ANNEX 7: MINUTES OF THE SCRUTINY OF THE ECPC ELECTIONS 2016

ANNEX 7BIS: ANNEXES TO THE MINUTES OF THE SCRUTINY OF THE ECPC ELECTIONS 2016

ANNEX 8: REPORT OF THE AD HOC COMMITTEE ON THE CONFIRMATION OF ELIGIBILITY

ANNEX 9: ORIGINALS OF THE ARTICLE 7.7 DOCUMENTS PROVIDED BY ELECTED CANDIDATES