#### **AGM MINUTES 2013**

8 June 2013, Brussels, Belgium

Voting members present: 23

Proxy votes: 6

Total votes: 29

Opening words of Tom Hudson:

- History commemoration of Kathy Redmond and Alberto Costa and other founding members;
- Thanks to Arthur Masny and Heide Preuß who deceased;
- Tribute to Tom van der Wal and Sandy Craine;
- Review of Jan Geissler's contribution to building up ECPC;
- Introduction of Erik Briers, Executive Director;
- Thanks to the current Board: Francesco de Lorenzo, Henk Van daele, Ingrid Kossler, Simona Ene, Sarunas Narbutas, Jana Pelouchova;
- Highlighting Young Cancer Patient Networking.

Kathy Oliver proposed introduction of AGM participants (name and country). Introduction followed.

Adopting new AGM Agenda: The new AGM agenda was approved and adopted.

### a. Adopting minutes of previous AGM:

The Minutes were read and approved with 26 votes in favour, 3 against and no abstentions.

#### b. Board Annual Report

## c. Board Financial Report by ECPC Treasurer, Ingrid Kossler

The Treasurer, Ingrid Kossler, presented the Financial Report for 2012 and answered questions of the participants. She explained that the Financial Report is not exactly comparable to that of 2011 due to the fact that the organization adopted the international accounting system only midyear in 2012. In the discussion that followed, the audience raised questions on the cost of projects, board and staff expenses, income sources, which the Treasurer answered. Following the discussion, the Financial report 2012 was approved by the AGM with 25 votes in favor, none against and 4 abstentions.

#### d. Report of the auditor

Erik Briers, Office Director, presented to the AGM the report of the Auditor, which was made by an independent external auditor, as previously there was no Audit Committee. The report is written in Dutch, which is the official language of ECPC, as an organization registered in the Netherlands, with a summary translation in English. Further, the Office Director, explained that as ECPC has its offices in Belgium, which is a bilingual, Dutch and French, country, the Auditor Report in Dutch satisfied also the requirements of the Belgian legislation governing operation of non-profit organizations.

Following the discussion, the Report of the Auditor for 2012 was approved by the AGM with 22 votes in favor, 2 against and 5 abstentions.

#### e. Adoption of Balance Sheet and Statement of income and expenditure

Ingrid Kossler was asked to take over the position of Treasurer in February 2012. She explicitly declared no responsibility for Finances prior February 2012, which included Finances 2011.

Ingrid Kossler gave explanations on income, result and budget for 2012. ECPC moved in September 2012 to a new office in Rue Montoyer. The cost of moving and repair of the new office was of about 25.000 EUR. There was difference in Board cost in budget and expenditure because originally 30% of the Office Manager's salary was allocated to this column (the work of the Office Manager was related to the Board, Nickie acting as personal secretary to the President).

Voting on Balance Sheet and Statement of income and expenditure: **22 in favor, none against, 7 abstentions.** 

# f& g. Membership fee and contributions from the associate and expert members and any other contributions:

Francesco de Lorenzo suggested that a fee is needed in ECPC statutes and there is also need of a membership survey.

- Shajjad Rizvi was in favor of supporting ECPC by paying;
- Kathy Oliver commented that active contribution is also valuable. She suggested voluntary donations;
- Tom Hudson suggested that other resources besides the Pharma industry funding should be looked for.

Voting on imposed membership fee: 1 in favor, 27 against, no abstentions.

#### h. Adoption of the budget for the year 2013

Ingrid Kossler gave an overview of expenditure for 2013: about 344.000 EUR; 80.000 EUR committed from Pharma/ sustaining partners.

Potential funding: on hold (depending on election results).

Total from sustaining partners: 226.000 EUR New: eSmart project for 4 years of 119.399 EUR.

Other income: bank interest, etc. Total planned income: 343.000 EUR.

Need of substantial reserves.

Voting on budget 2013: 24 in favor, 2 against, 5 abstentions.

#### i. The granting of discharge to the Board members

Voting in favor of giving discharge:

- 1- Discharge to all Board members
- 2- Discharge to individual Board members
- Francesco de Lorenzo: Responsibility of Board doesn't go to AGM.
- Erik Briers: Giving discharge is a legal requirement. For 2013 the new Board takes responsibility.

Voting: 25 in favour, none against, 6 abstentions.

## j. 3 members Committee of AGM was formed to evaluate documents of newly elected Board members.

The vote counting process took place in the office on 7 May with participation of 3 witnesses including Francesco de Lorenzo.

Three members of the AGM were asked to evaluate the documents of the newly elected Board members (Max Lippuner, Maude Andersson and Paula E Bowen). Report of the 3 members Committee was presented.

Received legal documents of 6 candidates out of 7 candidates. Kathi Apostolidis did not provide legal documents. For other 2 candidates Jana Pelouchova and Francesco de Lorenzo, there was no translation into English of the documents.

It was agreed that Sarah Lindsell and Kathi Apostolidis must submit the documents of good behavior until 30 September 2013. Kathi Apostolidis answered that she had emailed all requested documents to the attention of the Chair, Tom Hudson and as she had the original set with her she handed it to the Chair of the AGM.

Erik Briers: Article 19 of the statute under 6 on the power of the Board to decide.

Tom Hudson announced the successful candidates who will form the new Board: Francesco de Lorenzo, Kathi Apostolidis, Vlad Vasile Voiculescu, Elena Caruso, Rafal Swierzewski, Jana Pelouchova and Sarah Lindsell.

Tom Hudson announced the successful candidates of the Audit Committee: Pietro Presti, Istvan Balogh and Hannu Tavio.

Francesco de Lorenzo (FdL) gave some words on the new Board: election promises came true, there are 4 new Board members who are very young. The new Board represents new know-how and new energy. FdL then emphasized that for the first time the Board had fully and unanimously agreed on the **Key Points** for the next years <u>even before the elections</u>. Francesco de Lorenzo expressed his confidence that the visible team spirit of the new Board will show results in the near future and will improve the work of ECPC.

#### **Key points for ECPC:**

- Putting particular attention to the organization members;
- Improving access to treatment;
- Minimum standard to care;
- Create working groups dealing with partners' subject;
- Well-organized office;
- Rare cancer focus (at least 3 people dedicated);
- Social problems: return to work, recognition of disability;
- Most important is not asking for new laws, we will base on existing decisions and implement them;
- EU action plan on cancer, EPAAC;
- National Coordinators (bring back the ECPC membership to activity network with ECPC);
- More funding, independent from industry;
- Network of organizations to work with research and industry (IMI meetings);
- Explore the possibility of sharing the premises of ECPC with another European umbrella organization;
- Collaboration with research organizations;
- WHO document.

## k. Any other business:

- Discussion on the need of registering ECPC in Belgium and drafting new statutes.

## Voting: 27 in favor, 1 against and 1 abstentions.

- Kathy Oliver gave information on ECCO Congress 2013 for patient involvement opportunities for patient organizations.
- Erik Briers acknowledged the work of ECPC Ex-President, Tom Hudson. Tom Hudson expressed appreciation to ECPC team for the work performed.

Closing remarks and best wishes.

AGM finished at 16.28.

Minutes were taken by Jana Pelouchova.