

## 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 sent out in advance.  
Voting: 26 agreed, 3 against and no abstentions.
- b. **Board Annual Report**
- c. **Board Financial Report by ECPC Treasurer, Ingrid Kossler**

Ingrid Kossler looked through the documents presented to the AGM.

- Question: Kathi Apostolidis inquired about point d)
- Question from Kathy Oliver: what is the income from others?
- Ingrid Kossler replied: selling the furniture in the old office, bank interest, honoraria, etc.
- Question from Kathi Apostolidis: What is the Board cost?
- Answer from Ingrid Kossler: Travelling for Board meetings, etc.
- Question from Kathy Oliver: What about expenses for personal meetings?
- Francesco de Lorenzo: Money for starting project



- Question from Kathi Apostolidis: What is the cost for M-ICAB?
- Answer from Erik Briers: Money for meetings within M-ICAB project, printed information. Erik Briers also gave more explanation of M-ICAB and EAPM projects that evolved into their own movements now.
- Question: How many ECPC staff?
- Ingrid Kossler: 2 persons now, N. Colson and D. Horgan in 2012 (+ 3-4 interns)

Voting of the Financial report 2012: 25 members in favor, none against and 4 abstentions.  
Result: Financial report 2012 was approved by the AGM.

#### **d. Report of the auditor**

There was no Audit Committee. The report was made by an independent external auditor. The summary of the report was made in English, the official report was in Dutch. Erik Briers explained the legal requirements of the Belgian Auditor.

- Question: What has Belgian law to do with it?
- Answer from Erik Briers: Dutch law requires Dutch documents. Activity center of ECPC is in Brussels.
- Tom Hudson: Further explanation will be provided after the AGM.
- Question: Should the AGM vote on further discussion on this?
- Kathy Oliver: What is the purpose? What do we achieve?
- Comment: European Association under the law of the Netherlands. English translation is not legally valid. Non-official and temporary documents were posted on ECPC website.
- Erik Briers: The statute is in Dutch, if there is a legal dispute, only the Dutch version is valid.

Nobody wished to continue the discussion.

Back to the Auditor report.

- Kathi Apostolidis: Is the full report available?
- Francesco de Lorenzo: We need to talk about future. Things need to be approved. New Board will prepare AGM well in time and will work so that AGM is a platform for debate.
- Ingrid Kossler: Nobody sent the request prior to AGM although the document was sent out in advance.

Voting on the report of auditor: 22 in favour, 2 against and 5 abstentions.

Result: the report of auditor was approved.

#### **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 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).

- Question: what are the consultancy fees, other fees, translation and video?
- Answer from Erik Briers: EAPM project and other projects
- Comments from Kathi Apostolidis: Project costs became increased.
- Comments: on M-ICAB and EAPM initiatives, whether these initiatives bring added value to ECPC.

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

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

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

Francesco de Lorenzo: Fee is needed in ECPC statutes. Suggestion of membership survey.

ECPC leverage: 1-20, 20-50, etc. Why spend time and money for survey? Change the statutes?

- Comment from Shajjad Rizvi: Supporting ECPC by paying
- Kathy Oliver: Active contribution is also valuable. Suggest voluntary donations. Adding another dimension to the funding stream.
- Tom Hudson: Other resources besides the Pharma industry funding should be looked for.
- Tom van der Wal: ENAN trips to different countries bring better outcome than survey.

**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.



- Question: What is working group?
- Erik Briers: Continuation of Young People Project
- Question: Substantial part of the budget is potential. We cannot dedicate 1/3 to Core costs.
- Ingrid Kossler: Understand the concerns but one cannot make projects without staff.
- Shajjad Rizvi: Need diversification of funding?
- Erik Briers: Creating a new basis and trust in ECPC. Continuation of ECPC will result in sustaining partners' support.
- Vlad: Where are we now in the plan?
- Ingrid Kossler: 40.000 EUR received, 40.000 EUR of two sustaining partners confirmed by email for ongoing projects, 26.000 EUR received contract signed last year. Expense until now: estimated half of what stated, reserves: 265.000 EUR.

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

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

Voting in favour 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.

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 even before the elections. 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 of ECPC registration in Belgium and new statutes: ECPC needs new statutes and move the registration to Belgium. The new Board will work on this.
  - Question: In the Netherlands non-profit organizations do not pay tax, is it the same in Belgium?



- Answer: Yes

Voting for transfer of ECPC to Belgium with changing statutes: 27 in favour, 1 against and 1 abstentions.

- Question: reason for certificate of good behavior?
- Answer by Erik Briers: Contracts with European Commission.

- Any other business: 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.*