



Board Meeting
October 3rd, 2005 – 10:00 – 17:00
Jan's & Michi's Home, Ottobrunn (Munich)

MINUTES

Present

Lynn Faulds Wood (LFW) - Chair
Harm Jan Roelants (HJR)
Kees van Bezooijen (KB)
Heide Preuss (HP)
Tom Hudson (TH)
Jan Geissler (JG)
Hildrun Sundseth (HS)
Pan Mallis (PM)
Michi Geissler (MG)
Elisabetta Iannelli (EI)
Roberto de Miro

Not attending

Kathy Redmond (KR)
Jesme Baird (JB)

1. Introduction and welcome of new board members

LFW welcomed all to the first ECPC Board Meeting. A short introduction round followed with a special welcome to our new board members Elisabetta Iannelli, Pan Mallis and Kees van Bezooijen.

The applications of all board members with background information can be found in the eRoom at https://eroom.eds.de/eRoom/001/ECPC/0_81a79

2. Chairman's report

LFW handed out the latest lists of full and associate members. You can find the latest member lists also in the eRoom at https://eroom.eds.de/eRoom/001/ECPC/0_5d09e
(File ECPC > ECPC member organisations > member lists)

Any feedback and corrections about the member organizations is highly appreciated. Please forward it to Lynn's Office (email: ecpc@bowelcancer.tv)

LFW introduced the Patient Summit of Central and Eastern Europe Patient Organisations in Warsaw at 26./27.11.2005. All board members are welcome to join the Summit. ECPC (Hildrun and Jesme) is involved in defining the agenda of the summit.

ECPC thanked Kathy Redmond for her invaluable support and experience to ECPC in the past and the ECPC Board would like to invite Kathy Redmond to be a special advisor to ECPC in the future.

The chairman's report can be found attached (attachment 1).

3. Constitution

HJR reported about the latest update regarding the ECPC constitution and the further procedure to finish the registration of ECPC as soon as possible, expected November 2005. The actual costs re. the development of the constitution and the registering process are 2.500.- EUR, the estimated costs are ca. 5.000.- EUR.

ECPC is very grateful to Roberto, Elisabetta's husband, who joined the meeting for his valuable remarks and suggestions regarding the ECPC constitution. The constitution was talked through, with special attention to articles about the Board of Directors, the voting mechanisms and the General Assembly.

The following amendments have been approved by the board:

- Inclusion of a "Consideration" at the beginning of the constitution to state why the establishment of ECPC is so important
- In general: "Council" shall be replaced by "General Assembly"
- *Article 1 (Name and seat):* "place of registration" instead of "seat"
- *Article 2 (Purpose):* the non profit aspect should be included as well as the networking aspect. The quality of life of cancer patients should also include social and psychosocial aspects
→ Roberto is going to redraft the Article 2
- *Article 6 (Patrons):* This section is going to be removed and an explanation is drafted for the by-laws
→ Roberto is going to draft a new article
- *Article 8 (Board of Directors):*
 - Para. 1.:
 - President, president-elect and past-president is replaced by president and vice president.
 - The board consists at least of five (not four, to have an uneven number) individuals (not natural persons)
 - Para. 3: Shall be deleted.
 - Para. 4:
 - Cross out "other" (at "The other board members)
 - In addition: "The period of the presidency is not part of the six years".
 - Para. 8: "Each full member can propose one candidate." (instead of: "Each full member can propose a candidate per vacant seat.")
 - Para. 10: It has to be checked if according to Dutch law the majority voting mechanism can be changed to a "simple majority" or "most of the votes".
- *Article 9:*
 - Para. 2: It has to be checked with the Dutch notary, if e.g. a donation of a villa is acceptable.
 - Para. 3: The established ECPC committees should be included.

- *Article 10:*
Para. 2: It has to be checked if according to Dutch law if the representative authority can be the president or the vice president together with the secretary or the treasurer.
- *Article 12:*
Para. 2: Roberto will redraft the paragraph.
- *Article 13:*
Para. 1: past-president has to be replaced by vice-president
- *Article 14:*
Para. 1: Change: ... "except where this period has been extended by the board.." (not the council)
- *Article 15:*
Para. 3: The written notification has to be explained in the by-law. This mean e.g. per email, fax or a note at the ECPC website.
- *Article 17:*
Para. 2: Change: "The funds should be donated to another body with similar objects, but not to a full member."

ACTION POINTS

- **Roberto:** To redraft the noted articles of the ECPC Constitution and forward the redraft to HJR
- **HJR:** To incorporate the amendments into the constitution and to check open questions with the notary and report back to the ECPC Board

4. Election of ECPC Officers

The following ECPC Officers have been nominated and appointed by the board of directors:

President: Lynn Faulds Wood

Vice Presidents: Tom Hudson and Jan Geissler

Treasurer: Pan Mallis

Secretariat: Elisabetta Iannelli

ACTION POINTS

- **MG:** Update ECPC Website

5. Strategic Plan

LFW presented ECPC's "Five Guiding Strategic Goals" and the "ECPC Objectives".

The following amendments have been agreed by the board:

- Introduction
 - o Launched in 2003 (instead of established)
 - o Best outcome → treatment and care
 - o Add aspect of quality of life (social and psychosocial aspects)

- ECPC five Guiding Strategic Goals
 - o Advocating and influencing change in legislative... (instead of "Effecting change")
 - o Add "supporting cancer control plan"
- ECPC Objectives 2005 – 2010
 - o Objective 1:
 - Recruit member organizations and partner organizations...
 - Major cancers (instead of big)
 - Add breast cancer
 - Add "to form a network of members"

ACTION POINTS

- **MG:** Update ECPC's "Five Strategic Goals" and the "ECPC Objectives"
- **All board members:** Send further comments/feedback to MG

6. ECPC Work Plan 2005/2006

LFW and MG presented the draft work plan 2005/2006. The Work Plan can be found in the attachments.

The following ECPC committees have been appointed:

Financial Committee (FiCo)

Jesme (Chair), pending JB's acceptance as she was not present
 Pan
 Michi (ECPC Office)

Membership and Governance Committee (MGCo)

Harm Jan (Chair)
 Elisabetta
 Clare/Michi (ECPC Office)

Policy and Communication Committee (PoCo)

Hildrun (Chair)
 Lynn
 Heide
 Jan
 Kees
 Tom
 Michi (ECPC Office)

Funding Committee (FundCo)

Tom (Chair)
 Hildrun
 Harm Jan
 Kees
 Michi (ECPC Office)

The temporary ECPC Executive Team (Lynn, Hildrun and Kathy) ceases, the whole board is in charge of the ECPC activities now. The new executive power of ECPC is the President (Lynn), Vice President (Tom and Jan) and the secretary (Elisabetta).

It was agreed by the board that the Utrecht office will be closed down and ECPC will be run by a "virtual office" with MG. HJR will try to retrieve all necessary information about ECPC's position, obligations (ECPC office contract/office equipment, Danielle's contract) and options in Utrecht to proceed in a neat way.

ACTION POINTS

- **MG:** Support to establish the Committees
- **MG + each committee:** Develop plan to implement the action points of the Work Plan 2005/2006
- **HJR/LFW/MG:** Retrieval of information and further processing with Utrecht closure.

7. ECPC Finances

MG presented a financial overview (including Sustaining Partners) and the actual/estimated budget for 2005 as well as the planned budget for 2006. The figures can be found in the attachments.

The board agreed to the following points:

- Budget of 25.000.- EUR for the MAC project 2006
- Need to find non-pharma sponsors for ECPC to maintain credibility of a pharma-independent organisation
- MGs invoices are paid including VAT (according to her letter of agreement)
- HS will work out concept for "uniquely informed patients initiative" to apply for further commission funding

ACTION POINTS

- **KB:** To liaise with MB about existing contacts in Holland to potential ECPC sponsors
- **HS:** To work out concept for "uniquely informed patient initiative"

8. Masterclass 2006

Hildrun and Jesme are the coordinators of the Masterclass 2006. Goal for 2006 is a more practical approach to the advocacy issues. As soon as there is a first draft for the agenda available a telco is scheduled with the board to discuss the agenda.

ACTION POINTS

- **HS/JB:** Draft first agenda of Masterclass
- **MG:** Schedule telco with ECPC Board

9. Any other Business

MG would highly appreciate a more frequent use of the eRoom, e.g. for discussing certain topics, sharing dates in the calendar, storing and sharing documents at a central place.

ACTION POINTS

- **MG:** Prepare User Manual for eRoom
- **MG:** Schedule tele-teaching for use of eRoom if requested

10. Agenda points for next Board Meeting

- ECPC Membership Fee (proposal for General Assembly in May 06)
- ECPC in the context of EU and European Union
- Executive Director
- ECPC Patrons

11. Next Board Meetings

The next two board meetings will be scheduled at

- Monday, 6th of February 2006 (the place has to be defined)
- Friday, 12th of May in Milan (before our Masterclass 2006).

MG/05.10.2005