



ECPC AGM, 19th November 2011 – Minutes

Session I: Progress Report; Statutes Revision

- Members noted the passing of Board member Arthur Masny with sadness, and paid tribute to his contribution to this field.
- The appointments of **co-opted Board members** Jana Pelouchová and Ingrid Kössler were ratified unanimously.
- ECPC Board and staff reported on **recent activities**, especially of the Forum Against Cancer Europe in the European Parliament.
- It was noted that all would like ECPC to become more closely involved with **professional medical groups**, and were pleased to hear about the collaboration with EHA on a workshop in August.
- ECPC will continue to lobby on the issue of **how the Commission funds patient organisations** who also receive funding from pharmaceutical companies.
- There was consensus among the membership that ECPC is the main voice for patients in Europe, as well as a request for ECPC to **formalise its relationships** with other key stakeholders such as Europa Donna through a Memorandum of Understanding.
- The proposed **statutes** were presented to the membership, who approved them by a strong majority. However, it was proposed and unanimously agreed that the statutes would be distributed to all full members, who would be given four weeks to respond with a positive or negative vote, or comments. Any comments received will be presented to the Board, who may choose to edit the text accordingly and then resend the statutes for a second round of voting.

Session II: ECPC Accounts

- The **financial report** was presented. Members requested that for future AGMs, a brief overview (like the one provided for the statutes) is distributed, and the full report made available in advance. Explanations were provided about changes made to ECPC's internal administration, as well as further anticipated changes over the next year. The members agreed that great progress was being made in growing ECPC into a strong and sustainable organisation.
- The financial report was approved unanimously by the members, with all Board members abstaining from this vote.
- The **membership fee** was discussed. Members were in favour of introducing at least a nominal fee as a means of indicating commitment to the organisation. The possibility of

ECPC Board: I Kössler • F de Lorenzo • S Ene • T Hudson • S Narbutas • J Pelouchova • H Van daele • T van der Wal

ECPC Office: ECPC, 26 rue de la Loi/ Wetstraat 26, 1040 Brussels – Belgium
Tel: +32 (0)2 8888 943, E-Mail: info@ecpc-online.org, Web: www.ecpc-online.org, www.forumagainstcancer.eu
ECPC is registered in Utrecht (The Netherlands), Reg.-Nr. 30211815

different levels of fee – for organisations of different sizes and resources – was discussed. It was agreed that this item should be on the agenda of the next AGM.

- For the 2012 AGM, it was requested that the **financial reports** should be circulated in advance and that they should include more columns to enable members to compare current with previous years.
- Office staff indicated that they would be recruiting more **interns** as a cost-effective way of building manpower in the office. Members welcomed the idea that member organisations might be able to send an intern to volunteer in the office, and a recommendation was made to investigate the possible use of mobility grants for this.
- It was requested that a short biography and job description of each **staff member** should be made available via the website.

Session III: Feedback from Members

- **Little People Association Romania** representative Shajjad spoke about an issue that had arisen over recent work there. Young cancer patients had been featured in a fundraising video for hospitals, and their images had been treated inappropriately. Make up had been used on the children's faces to make them appear more ill, and they were filmed making statements such as 'I don't want to die.' Little People Association had raised this with the local producers and funders of this video, with no success, but had had a more positive reaction from the UK head office of company funding the video. They had apparently believed the children were paid actors, not real cancer patients, and were unhappy about this discovery. The members discussed this issue at length, and agreed that **the proper use of images and video footage of cancer patients for fundraising and media** was an important and sensitive issue. It was agreed that ECPC would work together with corporate donors, European lawyers and media/PR sources to develop a **Code of Ethical Conduct** which could be launched in the European Parliament and could be used by corporate donors as leverage for good practice. In drafting this, members and other organisations would be invited to share stories and thoughts via the ECPC website. This will be a project for 2012.
- The difficulty in getting **responses from members via surveys** was reported and discussed. The ECPC Board and Office are very keen to be able to investigate and report on the views and priorities of the member organisations. It was suggested that by keeping surveys to a minimum, and wording questions well, we could gradually improve feedback.
- There were some comments regarding the **ECPC newsletter**. It was confirmed that the newsletter is open to all who wish to access it. It was also agreed that there would be no more than 10 newsletters a year to avoid overloading members with emails. There was also a recommendation to add additional news stories to our **website**, and to look into the possibilities of automatic website translation.
- Members will also be invited to submit an **annual report of activity**, to provide a regular opportunity to update their contact details and to inform ECPC about their projects.
- It was suggested that in each country, we would identify an **active member** to assist the office in updating our database and identifying active organisations to invite to join ECPC and/or participate in our activities.

ECPC Board: I Kössler • F de Lorenzo • S Ene • T Hudson • S Narbutas • J Pelouchova • H Van daele • T van der Wal

ECPC Office: ECPC, 26 rue de la Loi/ Wetstraat 26, 1040 Brussels – Belgium

Tel: +32 (0)2 8888 943, E-Mail: info@ecpc-online.org, Web: www.ecpc-online.org, www.forumagainstcancer.eu

ECPC is registered in Utrecht (The Netherlands), Reg.-Nr. 30211815