Minutes General Assembly 2017 – draft notes by AD

Financial report (Andrew Winterbottom)

Following the presentation, Winterbottom presents the financial report. Begins by presenting the overall accounts. Then, industry funds, by company. Then, non-industry revenue.

The expenses by type are misleading because the figures do not represent the real expenses in different projects: many of the costs are included in the human resources, and that manpower is devoted to the other endeavours.

Office running costs, some of the figures will go up and down each year depending on the tweaks on costs.

The projected revenue for the 2017 is 885,879€, a major increase from past years. This is money that has already been negotiated. We do not do things at risk.

Q&A:

Kyriakos Mastris: Do you put these figures on the website? Do you accept EMA guidance on money?

Andrew Winterbottom: Yes and yes.

VOTE for the report: No votes against.

FDL: Thanks Andrew, Lydia and Jiska.

Audit Committee report (Nicolas Philippou):

Presents and reads the audit report.

In our opinion, the financial report gives a fair view of the financial situation, our comments were minimal and were already incorporated in the final financial report that has been distributed.

Our comments were also submitted to the Board and direction for the strategic plan 2017-2019.

For the office, it is very important for us to have job satisfaction and we will monitor it very closely during the next years.

The audit committee would like to see expense and ___ manual, employee expenses, managing accounts (including knowing the cash flow). We should be given all the board minutes that are relating to the audit committee functions. And we would like to be able to discuss these things.

We are looking forward to work for the next two years of mandate.

Winterbottom: All these suggestions have been accepted by the Board and will incorporate them in our procedures.

Lydia Makaroff: Thank to previous Director for the smooth handover and Jiska for the financial operations. We have a vision to move away from industry to more non-industry funding. Thank the secretariat. Would like to have much greater focus on capacity building, we need to listen to

European cancer patients. Do not hesitate to contact the Office and share your visions. We have working groups and many projects open for input. Thank the audit committee.

Jana Pelouchova: The working group on Rare Cancers is a very important piece of work of ECPC. Thank the co-chairs of the group for preparing everything, and the project manager Isabelle. We have new group members that have joined this weekend.

Natacha Bolaños: First year in ECPC, very professional team, learning process. It is very easy to work on a daily basis thanks to the work of the staff. I want also to mention the project on Bladder cancer, which comes in line with all the other work of ECPC on pancreatic cancers, with the aim to engage with our members and incorporate your knowledge. We need to create more workstreams like these to work together.

Pietro Presti: Very happy about the audit committee work. The forecast of the revenues for the recent years have been a very important step forward. This represents the sustainable development that every NGO should have.

Isabelle Manneh: We have the Prefer project. We had Isabelle Huys the other day speaking on the project itself. At the moment I am leading the patient advisory group, I make sure that all patients voice is heard. We also have other projects, one on prostate, other on blood. We are also trying to bring the patient perspective on them.

eSMART is an ongoing project, to use a special application in different clinics around Europe that patients can use to get reminders for appointments, prescriptions, doses… We are still waiting for the final results.

Francesco De Lorenzo: eSMART project is very important for our focus on eHealth and mHealth. This project allows the patient to directly get in touch with the hospital. And also to save money.

Ask FF to tell the Members how we do the lobbying work in the Parliament and the importance of mHealth and eHealth.

Francesco Florindi: mHealth is an untapped potential. I spoke at the eHealth Week this year in Malta. It is an initiative to show that mHealth is possible. Two major challenges are economics and data protection. The pity is that at these meetings, myself and just a few others are the patient advocates who are present. So, mHealth is not a revolution, but an evolution.

On the lobbying efforts ….. we managed to lobby the Parliament about the price of medicines. Alberto and myself go physically to the European Parliament and knock the MEPs doors. But the most effective way is to engage personally with the MEPs and also through the Members. Prof. De Lorenzo also opened the channel with some Italian MEPs. So the more connections you help us

make, the better work we will do. We have some country connections, Irish MEPs, German, Spanish, Czech… But we can connect so much better.

Francesco De Lorenzo: Please also talk about how we succeed on getting amendments included. We have to get the timings right, and we have to read and do a lot of work giving the MEPs concrete proposals so that they can include it in the report, there is no way they can come with those ideas themselves.

Francesco Florindi: You said it all, that is how it is done.

Francesco De Lorenzo: For example, we tried some MEPs to connect with other MEPs to have signatures for our ____. The other work we are doing is with the Commission, we have a lot of exchange of ideas. We are having a very good feedback from the work we are doing in the European Parliament. The EPP asked us to be part of their working group to give suggestions on what to improve on cancer policies for the next years, and we went to present some ideas and sent some in written.

Q&A:

Jana Dusper (Croatia): In some countries, patient advocacy groups work really well with the focal points of joint actions for the country but in others not so well. I have a suggestion to ECPC, since we are a partner in the Joint Action and hopefully in the next one, whether it is possible to make a committee of patients representatives to be included in the Joint Action, so that the voice of the patients can be heard when doing the cancer control plans. It should not be a big problem.

Asks for the creation of a policy working group, composed of ECPC members, to facilitate the collaboration between ECPC Members and the next Joint Action on cancer (iPAAC).

FDL: I think in the next joint action we might try to tell you exactly how each country is taking part in the joint action, and then you can go to your countries' institutions. We can also try to get some of you to be involved in some working group in the joint actions, we have to know each other better. We might now go through the Annual Report. Last year we decided to create Bladder cancer and rare cancer working groups. Now we are also thinking to create a urological cancers working group. Also on breast cancer, Kathi Apostolidis is part of the international commissions on this. If you want us to do more on this direction, we could open a working group on breast cancers, but we need to know who could run it beforehand. Organisations involved in the working groups can therefore become more involved in the work of ECPC.

Annual Report 2016:

Lydia: We work very closely with pancreatic cancer Europe, I am actually a board member. Every November we have a world pancreatic cancer day. Let me know if you want to join the organisation, we will be having an event in the European Parliament at the end of this year.

Natacha: I am also member and we are doing a lot of things in Spain. That platform puts together oncologists, and people working on the creation of registries, which is basic to have data about the reality of patients and clinical trials. We have there the opportunity to analyse every point of view, and that is the model we should always follow. We can really make an impact through this work. We work on awareness, research, cooperation and collaboration with every country and also with industry, because we want them to understand that there is a need to put in practice the incorporation of patients' voice, including in the design of the clinical trials. In pancreatic cancer, the

quality of life is really compromised, so to have the patients' voice since the beginning is very important to change the framework we are working with.

FDL: Starting from the white paper on bladder cancer that we were developing, we tried to transfer to the member states the ideas of the white paper and adapt them. So, if any of you from the member states would like to be more involved in any of this work please tell us. We also have the Make Sense and Head and Neck cancer initiatives. I would appreciate if you have any comments or suggestions for the annual report.

Andrew Winterbottom: The report is a record of what we did last year and a springboard of what we'll do in 2017. The bottom line of our work is to make sure that there is equal access to treatments and to make sure that disparities between countries and cancer types cease to exist. Please, if you need any help on these issues, ask us. We have highlighted a couple of initiatives, but it is not just about that, it is anything we could do about these goals. If you think any other initiative needs to be sorted out, please tell us.

Voting annual report: No one against. Approved.

FDL: I would like the Assembly to approve another issue. When Brexit happened, we decided to write to all our UK organisations that we will not do a 'Brexit' in ECPC. It is quite a hard job to get in touch with all UK organisations because they are a lot. I would like to ask you to confirm the decision by the Board that we will keep UK organisations on board. (All agree).

Andrew: As a Board, following our statutes, we will make sure that the relationship between members of the EU and non-members is more inclusive and we could review our statutes to make that happen.

Q&A:

Thomas Halpin: Just to clarify, do you want to include all members in these groups? \...\ ??????

Natacha: Pancreatic cancer is not considered rare… ??????

Isabelle Manneh: Explanation on joint actions ???????

Francesco Florindi: I think there is an interest of the membership to get more involved in the joint action. Similar group as in rare cancers but for the next joint action.

Jana Dusper (Croatia): We have a good collaboration at national level with the organisation that deals with it. But they cannot include us formally. I ask ECPC to ask the coordination to include national members.

Francesco Florindi: Explanation on the next joint action on cancer control. It will be more complicated for patient organisations to collaborate. The new rules are going to be difficult on this matter.

FDL: Once we know the program of the new joint action, if we can realise that ECPC will be involved (yesterday Tit Albreht told us that the Commission asked them to take care of the patients organisations, now it seems that they will at least accept our request to not to be involved without proper funding, we even wrote a letter to the Commissioner about this). They will probably make subcontracting with us, I think ECPC will be there. And then, ECPC will decide where to go in each work package, and once we know this, we will communicate through a newsletter and ask you to contribute to an internal group of ECPC to bring suggestions and ideas to the joint actions. Basically a similar structure to the group of rare cancers but for the joint action.

I would also like to discuss with you how we can better communicate with you. We have been doing a direct communication with all members. But once we send any communication we would like to hear from you. I wonder if the newsletter is a good tool or if you would want to have another type of communications.

Nancy: I have been ringing all UK organisations, we do not feel they are as active as they could be. They could benefit from all the rest organisations. We will keep talking with them and will keep them involved.

Anna: For now, we have been approaching our members since I joined ECPC. The main communication channels are our website (the new sections on news and ECPC projects and members projects), our newsletter for our members, we have more than 600 subscribers. Please send me an e-mail telling me more addresses that you would like to receive the newsletter at. It is difficult to keep all the addresses updated. Another channel is social media, which most of our members have been using constantly. I am more than happy to conduct a tailored training for you about social media if you need so. I would really love to know what way you find the best to communicate with you. If you have any ideas, suggestions.

Q&A:

From Israel: I want to talk about one subject that I did not hear in any of the lectures: medical cannabis. I understand the situation of ECPC because the funding from industry, but ECPC cannot ignore the medical cannabis because it solved many problems specially for cancer patients. In Israel, for example, there is a new unit in the Ministry of health that deals with this, and they chose six oncologists that are entitled to give direct license to cancer patients for medical cannabis prescriptions. Yesterday we talked about nutrition, I think that medical cannabis can help many cancer patients for appetite. Israel is in the front of this. I would be glad to help and give information to everyone in ECPC if you will decide to handle this subject.

Jana Pelouchova: I can only second that. Just last week in Czech Republic we had a meeting with the regulator who gave an overview on the problem. In our country there are certain clinicians and oncologists who are entitled to prescribe medical cannabis under special indications. Our country has been pioneering in growing and harvesting it by the government (with tenders) for medical purposes. There is a clear methodology on how to do it scientifically.

GBM Italia: In our group we deal with this topic. I wish if it would be possible to have it as a topic in the next AGM. Facebook is important, we are important, I wish to see Zuckerberg here. And the responsible for Google Europe. It is a need to have the most important people on communications here.

FDL: I suggest that each one of you, maybe we can have a picture of how the situation is around Europe, and we can see how we can do at the European level. But naturally this topic is not an easy one so we should know what and how to do.

Natacha: Yes, in Spain we do have options but there is a lot of controversy. It would be good to know what is the situation around Europe. We would need to find those Key opinion leaders to try to write guidelines on that. In brain tumours, for example, it is recommended as part of the palliative care.

Israel: In Israel we have the green book by the Ministry of health. And everything on this topic is in the book, I am ready to send this book to ECPC.

FDL: Thank you, we will work on this. Now, I would like to go back to the point on improving communications. Also, we started the Policy Newsletter. For instance, we already communicated you the recent approval of the WHO cancer resolution. Is this information useful?

Anna: The first Policy Newsletter was sent in May, please reach out to me if you want to add more e-mail addresses to it.

Jana Dusper (Croatia): The newsletter is a very good way to communicate. Now we have the Policy one and the activities, it is very good. One small suggestion: perhaps we can connect lots of organisations through Facebook.

Anna: We can also create a Facebook group strictly for ECPC, and you can join from personal accounts or organisation accounts. I have been thinking a lot on creating a proper platform to upload files for our members, chat, etc… (an internal communications platform). Would you find it useful? \people say yes\.

Andrew Winterbottom: We should embrace social media. In my own experience, we have grown quite a lot thanks to it. I suggest using tools like surveymonkey to ask our members for their preferences. If you get any idea at any point, please contact us.

Anna: I want to add that every comment that comes from you, I always take them into account. After last AGM, we received many forms of evaluation, and we were gathering all the comments to improve for this year.

George Kapetanakis: This is the third year I am in the AGM, and I feel part of it and every year is getting better. Last year I already thought that better communication is better to engage with each other. The communication now is better but there is still space to improve. I suggest doing experiments for communication.

Robert Greene (NL): On cannabis and nutrition, we are conducting research on the taste alteration with Wageningen University.

FDL: Thank you for your comments, please keep giving us feedback.

Andrew: Yesterday we had the session of our members' presentations. I liked it very much. \people agree it was very good but request to have more time for presentations\.

AOB:

FDL: Simon resigned from the board. He resigned from his umbrella organisation and also from ECPC board, the reason is because I think he is changing his work. We got in touch with the umbrella organisation in Poland, it looks like also they agree that maybe Simon now will have some conflict of interest, he cannot stay anymore in ECPC board. The Board accepted his resignation, and the Statutes say that the replacement will go to the next one on the list of votes. We asked our member from Finland who was the next one on the list.

Finnish: I am humbled to become member of the Board. I am lymphoma patient. I have to learn a lot now but I am ready to study. I am willing to listen to the members.

FDL: Thank you for contributing to the success of the AGM.