

Minutes of the ECPC General Assembly 2017

Financial report

Following the presentation, Mr. Andrew Winterbottom presented the financial report. He began his presentation with the overall accounts, continued by the industry funds and concluded to the non-industry revenue.

He underlined that the expenses by type may be misleading and vary because the figures do not represent the real expenses in different projects: many of the costs were included in the human resources, and that manpower is devoted to the other endeavors.

As for the office running costs, some of the figures usually go up and down each year depending on the tweaks on costs as well.

The projected revenue for the 2017 was 885,879€ - a major increase in comparison with the previous years. These were the resources that had already been negotiated.

Mr. Ken Mastris asked whether the mentioned figures appear on ECPC website. He also inquired if ECPC followed EMA guidance on finance.

Mr Andrew Winterbottom replied positively to both inquires.

Then vote for the report took place with no votes against.

Professor Francesco de Lorenzo thanked Mr. Winterbottom, Mrs. Makaroff and Mrs. Bolhuis for their efforts in conducting the financial report.

Audit Committee report

Mr. Philippou presented and read the audit report.

On behalf of the Audit Committee, he said that the financial report gives a fair view of the financial situation, and their comments were minimal and already incorporated in the final financial report that had been distributed.

Audit Committee's comments were also submitted to the Board and direction for the strategic plan 2017-2019.

He mentioned that it is very important for the Committee to have job satisfaction and they will monitor that very closely during the upcoming years.

They also requested to review the expense and manual, employee expenses, managing accounts (including knowing the cash flow) and be given all the board minutes that are relating to the audit committee functions in order to discuss them afterwards. Mr. Philippou declared that they are looking forward to work for the next two years of mandate.

Mr. Andrew Winterbottom made it clear that all the suggestions have been accepted by the Board and will incorporate them in their procedures.

Mrs. Lydia Makaroff thanked the previous Director for the smooth handover, the secretariat and, Mrs. Bolhuis for managing the financial operations. She declared that ECPC has a vision to move away from industry to more non-industry funding and create a greater focus on capacity building, so we need to

listen to European cancer patients. She encouraged everyone to do not hesitate to contact the Office and share their visions mentioning that we still have working groups and many projects open for input and she finished her speech by thanking the audit committee for their devotion to ECPC goals.

Mrs. Jana Pelouchova highlighted that the working group on Rare Cancers is a very important piece of work of ECPC and thanked the co-chairs of the group for preparing everything, and the project manager Mrs. Manneh-Vangramberen who announced that we had new group members that joined that weekend as well.

Mrs. Natacha Bolaños said that the first year in ECPC, she was working with a very professional team and it was a great learning process which was facilitated due to the daily work and efforts of the staff on daily basis. She also mentioned that the project on Bladder cancer, which comes in line with all the other work of ECPC on pancreatic cancers, aims to engage with our members and incorporate your knowledge and that ECPC needs to create more workstreams like these to work together.

Mr. Pietro Presti expressed that he was happy about the audit committee work. The forecast of the revenues for the recent years had been a very important step forward and this represents the sustainable development that every NGO should have.

Mrs. Manneh-Vangramberen said that this year we also had the Prefer project. We had Isabelle Huys the other day speaking on the project itself. She mentioned that she is currently leading the patient advisory group and makes sure that all patients voice is heard. She also said that she has other projects ongoing such as one on prostate and another on blood and that ECP is trying to bring the patient perspective on them.

She reminded that 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 and that we are still waiting for the final results.

Professor Francesco De Lorenzo pointed that 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.

Then he requested from Mr. Francesco Florindi to tell the Members how we do the lobbying work in the Parliament and the importance of mHealth and eHealth.

Mr. Francesco Florindi started his speech by telling that mHealth is an untapped potential. He mentioned that he had spoken at the eHealth Week this year in Malta. It was an initiative to show that mHealth is possible but two major challenges we need to deal with are economics and data protection and that it was a pity that at these meetings, himself and just a few others were the patient advocates who are present. So, mHealth is not a revolution, but an evolution.

He continued his speech by saying that on the lobbying efforts we managed to lobby the Parliament about the price of medicines by going himself with Mr. Domingo physically to the European Parliament and knock the MEPs doors. But he declared that the most effective way is to engage personally with the MEPs and also through the Members. Professor De Lorenzo also opened the channel with some Italian MEPs so he made clear that the more connections you help us make, the better work they will do. We have some country connections, Irish MEPs, German, Spanish, Czech but still we can connect so much better.

Professor Francesco De Lorenzo also requested from Mr. Florindi to talk about how we succeeded on getting amendments included emphasizing that 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 and that there is no way they can come with those ideas themselves.

Mr. Francesco Florindi pointed that Professor de Lorenzo said that this is how it should be done.

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.

Mrs. Jana Dusper from Croatia claimed that 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 and that she has a suggestion to ECPC, since we are a partners in the Joint Action and hopefully in the next one, of 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. She also requested 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).

Professor replied that he thinks that in the next joint action we might try to tell exactly how each country is taking part in the joint action, and then she can go to her countries' institutions. We can also try to get some people to be involved in some working group in the joint actions but first we have to know each other better and that we shall now go through the Annual Report. Last year ECPC Board 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, Mrs. 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

Mrs. Lydia Makaroff marked that ECPC works very closely with pancreatic cancer Europe as she is actually a board member. Every November we have a world pancreatic cancer day. and asked everyone to let her know if they want to join the organisation, since they will be having an event in the European Parliament at the end of this year.

Ms. Natacha Bolanos said that she is also member and they 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. She also confirmed that they actually had the opportunity to analyse every point of view, and that is the model we should always follow since we can really make an impact through this work. She said that they are working on awareness, research, cooperation and collaboration with every country and also with industry, because they 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 they are working with.

Professor de Lorenzo highlighted that 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 the member states would like to be more involved in any of this work please let us know. We also

have the Make Sense and Head and Neck cancer initiatives so it would be appreciated if there are any comments or suggestions regarding the above for the annual report.

Mr. Andrew Winterbottom clarified that 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 and requested if anyone needs any help on these issues to ask for it. He also mentioned that we have highlighted a couple of initiatives, but it is not just about that, it is anything we could do about these goals so feel free to let us know. Voting for the annual report took place with no votes against so Annual Report 2016 was approved.

After that Professor de Lorenzo kindly asked the Assembly to approve another issue. When Brexit happened, ECPC 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 and he asked the Assembly to confirm the decision by the Board that we will keep UK organisations on board. Everyone agreed.

Mr. Winterbottom added that as a Board, following our statutes, ECPC 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.

Questions and answers were followed. Mr. Thomas Halpin asked to clarify if ECPC wants to include all members in these groups.

Ms. Natacha Bolanos asked whether pancreatic cancer is not considered rare. Mrs. Isabelle Manneh-Vangramberen: gave an explanation on joint actions.

Mr. Francesco Florindi also replied that he thinks 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.

Mrs. Jana Dusper from Croatia said that we have a good collaboration at national level with the organisation that deals with it. But they cannot include them formally and requested ECPC to ask the coordination to include national members.

Mr. Francesco Florindi replied that explanation on the next joint action will be given on cancer control. It will be more complicated for patient organisations to collaborate and that new rules are going to be difficult on this matter.

Professor de Lorenzo claimed that once we know the program of the new joint action, if we can realise that ECPC will be involved (since Mr. Tit Albrecht 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 and we even wrote a letter to the Commissioner about this. They will probably make subcontracting with us, and Professor de Lorenzo thinks ECPC will be there. After that, we 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, it will be a similar structure to the group of rare cancers but for the joint action.

He also suggested to discuss how we can better communicate with Mrs Dusper and that ECPC has been doing a direct communication with all members but once we send any communication we would like to hear from her. He also proposed whether the newsletter is a good tool or if she would want to have another type of communications.

Mrs. Nancy Anderson informed that she had been calling all UK organisations since we do not feel they are as active as they could be. They could benefit from all the rest organisations and that we will keep talking with them and will keep them involved.

Mrs. Anna Rek said that for now, we have been approaching our members since she 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 in which we have more than 600 subscribers. She also requested to send her an e-mail providing her with more addresses for those who would like to receive the newsletter at since it is difficult to keep all the addresses updated. She also mentioned that another channel is social media, which most of our members have been using constantly and that she would be more than happy to conduct a tailored training for you about social media if you need so to find out the best way to communicate with all Members remaining open to any ideas or suggestions.

Questions and answers were followed: A representative from Israel wanted to talk about one subject that was not heard in any of the lectures: medical cannabis. He/she mentioned that the situation of ECPC is understandable because of 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. The day before we discussed about nutrition, and he/she think that medical cannabis can help many cancer patients for appetite. Israel is in the front of this and would be glad to help and give information to everyone in ECPC if we will decide to handle this subject.

Mrs. Jana Pelouchova said that she can only second that. She mentioned 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.

A representative from GBM Italia said that in her group they deal with this topic. She also wished if it would be possible to have it as a topic in the next Annual Congress. Facebook is important, we are important, and she said she wishes to see Zuckerberg here and the responsible for Google Europe. It is a need to have the most important people on communications here.

Professor de Lorenzo suggested that each one has 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.

Ms. Natacha Bolanos commented that in Spain they do have options but there is a lot of controversy. It would be good to know what the situation around Europe is and we 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.

A representative from Israel added that they have the green book by the Ministry of Health. And everything on this topic is in the book and is ready to send this book to ECPC.

Professor de Lorenzo thanked for the offer and said that ECPC will work on this and he would like to go back to the point on improving communications. As it is known, ECPC has started the Policy Newsletter. For instance, we already communicated you the recent approval of the WHO cancer resolution and wondered if this information was useful.

Mrs. Anna Rek said that the first Policy Newsletter was sent in May and asked to reach out to her in case anyone wants to add more e-mail addresses to the mailing list.

Mrs. Jana Dusper from Croatia said that the newsletter is a very good way to communicate. Now they have the Policy one and the activities which it is very good. She also made a small suggestion: perhaps to connect lots of organisations through Facebook.

Mrs. Anna Rek suggested to create a Facebook group strictly for ECPC so you can join from personal accounts or organisation accounts. She has been thinking a lot on creating a proper platform to upload files for our members, chat etc. and asked if that would be useful with everyone replying positively.

Mr. Andrew Winterbottom recommended to embrace social media. From his own experience, ECPC has grown quite a lot thanks to it. He suggested using tools like SurveyMonkey to ask our members for their preferences and to contact him at any point for any ideas.

Mrs. Anna Rek communicated that that every comment that comes from Mr. Winterbottom, she always take them into account. After last Annual Congress, ECPC received many forms of evaluation, and we were gathering all the comments to improve for this year.

Mr. George Kapetanakis said that this is the third year he is in the Annual Congress, and he feels part of it and that every year is getting better. Last year he already thought that better communication is better to engage with each other. The communication now is better but there is still space to improve. He also suggested doing experiments for communication.

Mr. Robert Greene announced that he is conducting research on the taste alteration with Wageningen University.

Professor de Lorenzo thanked him for his comments and asked to keep giving him feedback.

Mr. Andrew Winterbottom said that the day before he had the session of our members' presentations which he liked very much and everyone agreed that it was very good but requested to have more time for presentations.

Professor made an announcement that Simon resigned from the board. He resigned from his umbrella organisation and from ECPC board because he thinks 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 and therefore 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.

The representative from Finland said that he is humbled to become member of the Board. He is also lymphoma patient and has a lot to learn but he is ready to study and willing to listen to the members.

Professor de Lorenzo finishes the General Assembly by thanking everyone who contributed to the success of the Annual Congress.