



Minutes of the 36th Annual General Assembly

30 October 2016

Paris, France

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1. Opening and Adoption of Agenda

Sakari Karjalainen (SK) opened the General Assembly and welcome all the participants. He mentioned the GA will end up at 18:30 instead of 19:00. He thanked Jacqueline Godet (JG), President of the French Cancer League, for hosting the meeting. SK first year as ECL President has been very busy. He mentioned the new Task Force on Accessible Cancer Medicines' meeting which was held before the GA. A task force is more flexible than a working group and can be easily set up in case of emergency. Quick outcomes will hopefully arise and prevent the task force to become a permanent structure. This will allow ECL to work more efficiently on emergency issues.

2. Approval of Minutes from last General Assembly 2015

The minutes were approved.

3. Reports from Working Groups and Other Themed Activities

Tobacco Control

Philip Morris is a powerful enemy: it was the biggest spender on EU lobby activities in Brussels in 2013 (5 million €) and it has engaged 161 persons to lobby against the Tobacco Products Directive (TPD). After many discussions and meetings, the Commission decided on 6th July 2016 not to renew its agreement with PMI

Elizabeth Hjorth (EH) mentioned that in Denmark and in Norway, there have been discussions on insurance and pension funds to diversify their investments and not in tobacco industries. This could be a topic to discuss within the ECL members. LJ said there is a UICC statement on this subject; this is a new area and we can try to collect more data.

SK closed the discussion by saying that the ECToH congress next year in Portugal will be very interesting with regards to the current issues.

Patient Support Working Group

The group has been working since 2007. The PSWG Vice-Chair, Liz Atkinson from Cancer Focus Northern Ireland will take over the role of PSWG Chair on a temporary basis from Lucia Budacova of League against Cancer, Slovakia. The group has met once in 2016, kindly hosted by the Catalan Federation of Entities against Cancer (FECEC) in Barcelona, Spain, on June 21st-22nd. The main items of discussion were rehabilitation, access to medicines and family caregivers.

Results of a survey on rehabilitation programmes in Europe will be collected in a rehabilitation atlas which will be available to the leagues before Christmas 2016; it will also be available on the ECL website. The PSWG will continue to meet twice per year in 2017, with Secretarial support from ECL. The main themes for 2017 will be communications, family caregivers, rehabilitation and palliative care. The group will also work on updates of the governing 'terms of reference' document and update existing guidelines for interacting with the pharmaceutical industry.

Some abstracts were accepted at the World Cancer Congress in Paris and the PSWG was strongly represented (Patient track).



European Code Against Cancer (ECAC)

David Ritchie (DR), ECL senior cancer control officer, reminded the participants about the background to the European Code Against Cancer. The dissemination of the ECAC is done by national cancer leagues, supported by ECL at the European level. Available in 23 official EU languages, it is translated into non-official EU languages e.g. Luxembourgish, Catalan, Turkish, etc.

2016 was a busy year promoting the Code with various activities including:

- the commissioning of an animated video about the European Code Against Cancer;
- the launch of a pilot “train the trainers” workshop (held in Bucharest, Romania) to educate stakeholders about the ECAC;
- two workshops for ECL members on the dissemination of the European Code Against Cancer;
- the 2nd annual ECL youth ambassadors for ECAC workshop;
- the launch of ECL microgrants to encourage member leagues to apply for a grant for the promotion of the European Code Against Cancer (8 applications were successfully funded);
- the European Week Against Cancer Youth Competition to design an infographic for ECAC.

JG asked how to measure the impact of those activities. DR replied that the main objective is to disseminate the ECAC by working in close collaboration with ECL members and stakeholders. Therefore, the most feasible evaluation of these activities relates to the processes involved and the uptake of best practice guidance by ECL members and other stakeholders. Measuring the impact is a very tough challenge, but will become the focus of ECL action in 2017 through close cooperation with the International Agency for Research on Cancer (IARC).

Marc Michils (MM) said more emotion and more actions are necessary to make people change; words on paper are not enough. Wendy Yared (WY) said that ECL organized workshops where ECL members can share their experience. Hans Storm (HS) said that those activities are fine because they are agreed upon under the terms of the grant agreement with ECL and the European Commission; a positive point is that it is the fourth edition of the Code and it is done in an easier way to better reach a wide audience. ECL members should use this tool to lobby MEPS and politicians at national level to put the power behind the Code into action: this action would be first a political one, changing the attitude and behaviors in European countries. SK added that the Code has a strong link with the National Cancer Plan and it could form a strong evidence-based content for prevention. The Code has been very useful.

No comment on the following topics:

EU Multi-stakeholder platform on Diet, Physical Activity and Health

EU Joint Action on Cancer Control (Cancon)

MEPs Against Cancer (MAC) Parliamentary Group

3. Reports of ECL Board and Secretariat Activities 2016

HS said how impressive the secretariat activities are but was wondering what the ECL members were getting from it? What is the role the ECL leagues are playing? How can they help the secretariat? More information on attended meetings should be shared. WY replied that information can be found in the monthly ECL Newsletter; via MAC, ECL has a direct connection with MEPS so ECL members should take this opportunity for any issue raised in their country. ECL now has a strong visibility at the European Parliament. SK believed that ECL has a very good strategy, communication could be improved nevertheless. Joan Kelly (JK) asked if ECL is happy with its members’ responses. Participation from leagues can be very little. WY said that ECL doesn’t get enough responses so ECL



has made lists for secondary contacts as well as contact in prevention, tobacco, skin cancer and PSWG. ECL needs more feedback.

4. Task Force on Equal Access to Cancer Drugs

Michel Rudolphie (MR) presented himself as having worked for 14 years in the pharmaceutical industry and said that people leagues have been talking to have no influence on setting the price of a drug. It is a huge complexity. Governments are now not able nor capable to pay the price (report issued in the Netherlands in 2014). Articles and discussion in 2015 at the national level. However, if we want to change something, it is only possible at the European level. This issue was put on the European agenda during the Dutch Presidency. ECL was able to also embrace that issue very quickly and to set up a specific Task Force.

Evelyn Scheres (ES) presented the Task Force. Some countries are paying 50% more than others for the same medicine. Actions need to be taken. During the World Cancer Congress, leaflets and a presence will be there. The Task Force made a Declaration of Intent (goals are stated on it), 14 NGOs signed it + Romania. It will be on the ECL website. On December 7th, in Lisbon, there will be a round table with industries and ministers of Health and ES will share a Manifesto. Ongoing discussions in the Netherlands between industries and the Dutch Cancer Society.

SK asked what would be the current worse problem. ES replied that it is the lack of transparency on pricing from pharmaceutical industries. LJ said that from his own experience, it is almost impossible to get transparency from industries. ES said that solution is at hand but it is the way to reach it which is still the problem. Johannes Bruns (JB) said that an important issue is access to drugs, not only the price which is a too focused issue. MM congratulated ES for the Task Force and asked if ECL could use the power of patients/the power of people into this debate? WJ said that ECL will look into collaborating with some Patients organisations but, for example, the umbrella ECPC is totally funded by pharma. SK said we have to be aware that their interests are not necessarily the same as ECL's. EH said that the Danish Cancer Society also appreciate this Task Force initiative

5. Implementation Plan 2017

2017 will be the last year of the 3 year Operating Grant. A new call should be launched in March 2017.

6. Finances

Rosin Foster (RF) thanked Martina Chen, ECL Finance Officer, for her help and her good work. The Operating Grant has been well used and is a very important part of the budget. Not much changed in expenditures except for staff pension for ECL employees.

HS asked what will happen if ECL does not get another OG? RF said ECL activities will go back to what they were before; most of the activities are around the dissemination of the Code so ECL would have to stop them.

No new member this year.



7. European Conference on Tobacco or Health (ECToH) 22-25 March 2017, Oporto

Vitor Veloso presented the next Conference. Many abstracts have been received. He encouraged ECL members to join this big important event.

SK said that the next ECToH will take place in 2020.

8. Board Elections / Re-Election

SK was due for reelection and was reelected as President.

9. ECL Annual Meetings 2017

The next ECL GA and Annual Conference will take place in Denmark, 26-29 September, in Copenhagen.

10. Any Other Business

IARC would like to seek financial and other support from ECL members for some cancer prevention projects. More information will be provided via the ECL secretariat.

WY mentioned the World Cancer Congress Master Courses 2016, one being led by ECL and invited ECL members to attend the session.

11. Closing

SK thanked JG for offering a gift to the participants and thanked the participants for attending and closed the meeting.

12. Annexes

- Participants List
- ECL Source of Income



Co-funded by
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ECL General Assembly, Participants List

October 30, Paris, France

Belgium	Kom Op tegen Kanker	Mr	Marc	Michils
Cyprus	The Cyprus Anti-Cancer Society	Ms	Maria	Ioannidou
Denmark	Danish Cancer Society	Ms.	Elizabeth	Hjorth
Denmark	Danish Cancer Society	Mr	Hans	Storm
Faroese Islands	The Faroese Cancer Society	Ms	Durita	Tausen
Finland	Cancer Society of Finland	Mr.	Sakari	Karjalainen
France	French league against cancer	Ms	Jacqueline	Godet
Germany	German Cancer Society	Mr	Johannes	Bruns
Germany	German Cancer Society	Mr	Olaf	Ortmann
Germany	German Cancer Society	Mrs	Ulrike	Heibig
Iceland	Icelandic Cancer Society	Ms	Ragnheiður	Haraldsdóttir
Ireland	Irish Cancer Society	Mrs.	Joan	Kelly
Luxemburg	Fondation Cancer Luxemburg	Mrs	Lucienne	Thommes
The Netherlands	Dutch Cancer Society	Mr	Michel	Rudolphie
The Netherlands	Dutch Cancer Society	Mrs	Eveline	Scheres
The Netherlands	Dutch Cancer Society	Mr	Guy	Muller
Poland	Polish Cancer League	Ms	Magdalena	Zmyslowska
Portugal	Portugal Cancer League	Mr	Vitor	Veloso
Romania	Romanian Cancer Society	Ms	Adriana	Melinic
Slovakia	League Against Cancer Slovakia	Mr	Cestmir	Altaner
Switzerland	Swiss Cancer League	Ms	Ursula	Koch
United Kingdom	Cancer Focus Northern Ireland	Mrs	Róisín	Foster
United Kingdom	Cancer Focus Northern Ireland	Mrs	Liz	Atkinson
Belgium	ECL	Mrs	Wendy	Yared
Belgium	ECL	Mrs	Ghislaine	Gerbler
Belgium	ECL	Mrs	Kate	O'Regan
Belgium	ECL	Mr	Luk	Joossens
Belgium	ECL	Mr	David	Ritchie
Belgium	ECL	Mrs	Martina	Chen

