European Cancer Patient Coalition

2019 General Assembly

Minutes

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1 Opening of Meeting and Attendance

Date: Sunday 10 June 2018
Venue: Brussels, Belgium Hotel Renaissance, Rue du Parnasse 19, 1050 Brussels

Total Number of attendants: 70
Of which are Full Members with voting rights: 64

Speakers list:
Francesco de Lorenzo (Chair)
Kathi Apostolidis (KA)
Antonella Cardone (AC)
James Caldwell (JC)
Pietro Presti (PP)
Kristina Dorthe Liff Helbrink – Tidsledeme (KDLH)
Roberto De Miro (RDM)
Beata Ambroziewicz (BA)
Jacqueline Daly (JD)
Maude Andersson (MA)
Robert Greene (RG)
Jana Pelouchova (JP)

The General Assembly starts at 11:00

The meeting is chaired by the President of the ECPC Francesco de Lorenzo

The secretary is Jana Pelouchova.

The following GA members volunteer for the electoral committee:

(1): George Kapetanakis, (2): Jelena Burianova, (3): Roberto de Miro

The electoral committee is elected by acclamation and established by the chairperson.

1.1 Adoption of the Agenda for the General Assembly

Agenda for the General Assembly

1. Opening of Meeting and Attendance

1.1 Adoption of the agenda for the General Assembly meeting
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9 Conclusions and closing of the GA
9.1 Introduction to the new Board

Voting on adopting the Agenda (64 members voting)

The agenda is adopted unanimously

1.2 Adoption of the minutes of the previous General Assembly

A vote is held on the minutes of the previous General Assembly, henceforth referred to as the ‘*GA’* which have been distributed to all the participants previously

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Voting on adopting the minutes (64 members voting)

The minutes are adopted unanimously

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2 Introduction to the new Director and Activity Report

The new Director introduces the secretariat and each staff member presents itself
[See Annex III]

Antonella Cardone, *Director*

Christopher Thomas Everton Russ, *Administrative Assistant*

Jiska Bolhuis, *Head of Finance and Human Resources*

Clémence Morinière, *Partnerships & Communication Manager*
Paulína Gono, *Partnerships & Communications Assistant*
Lenna Morris, *Partnerships and Communications Assistant*

Alex Filicevas, *Head of EU Affairs*
Matias Olsen, *EU Policy Assistant*

Isabelle Ellen Manneh, *Head of Health & Research Programme*
Max Schravendeel, *Health & Research Officer*

The Chair proposes moving up the agenda item of saying goodbye to the old board as some board members are leaving early.

Voting on changing the agenda to say goodbye to current board members now rather than later (64 members voting)

The proposed change to the agenda is adopted unanimously

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7 Release of responsibility of the current Board

AC thanks on behalf of the ECPC the previous Board members and especially the President for their contributions to the organisation.

Chair: ''ECPC is now the most representative voice for cancer patients. I hope everyone feels that I did what you asked of me. We must ensure that we maintain the strong momentum and aim for even more ambitious results. I am sure that, Kathi, the new ECPC President will do a great job. For you there is the possibility to keep this going even after Kathi. We need to ensure the continuity of the organisation, so that the work of ECPC will go on after us. The future of the organisation belongs to you, the younger generations. We need new energy and to ensure that the work we are doing is not lost because we fail to recruit good people. One thing to especially keep in mind in the future is that ECPC represents the patients voice from all points of view. See you next year.''.

JP: ''Dear colleagues, for me it's a goodbye after nine years and three election periods. But it is not a final goodbye because I will continue my activities in the rare cancers area. I am a leukemia patient and our organization in Czechia is expanding so in the working group on rare cancers in ECPC I am sure we will be seeing each other again. The communication with our members has always been my favorite job. I have visited many of the Eastern European organisations to highlight the connectivity with the European umbrella organisation and I hope this has helped your organisations at national level. I will continue my work on ELBA and in the patient advisory committee of ECCO. Thank you for your collaboration and I am looking forward to further work.''.

AC lists the outgoing Audit Committee members; Pietro Presti, Nicolas Philippou, Istvan Balogh and thanks them for their contribution.

9.1 Introduction to the new Board

The Chair introduces the new Board Members highlighting that only Kathi and Maude are from the previous board. Pietro was chairing the Audit Committee and now he is in the Board.

The new elected board members are:

(1) President – Kathi Apostolidis,
(2) Vice President – Pietro Presti,
(3) Secretary - Jacqueline Daly,
(4) Treasurer - Beata Ambroziwicz,
(5) Board Member - Robert Greene
(6) Board Member - Vasile Ianovici,
(7) Board Member - Maude Andersson.

KA: ''First of all, I would like to thank you for your confidence in electing me. Together we will get to work on the new fronts that have opened up over the last two years. Ahead of us is the big project of the Mission on Cancer, which was initiated by our previous President, we will continue with cancer survivorship and access to treatment. I hope for your collaboration and active search of new topics and I urge all of you to closely collaborate with our office. I urge you to send us information on what happens with regards to policy at the national level so we can use it in our work, and to use our policy work in your country. If you need assistance with translation, we are here to help you.''

9.2 Introduction to the new Audit Committee

The Chair thanks the previous Audit Committee members and introduces the new Audit Committee:

(1): James Caldwell,
(2): Constantine Nicolaides,
(3): Roberto Persio

2 Introduction to the new Director and Activity Report Cont.

2.1 Communication Activities of ECPC

CM presents the Communication Activities of ECPC
[See Annex IV]

3 Activity Report

[See Annex V]

AC presents the highlights of the Activity report
[See Annex VI]

3.1 Discussion on the Activity Report

JC: With all this great work you do, how will ECPC be able to manage the workload?

AC: These are already ongoing or completed activities. As for staff capacity, we have three new staff members as interns and one new full-time long-term employee. If the EU projects are funded, we would have to hire more people to work on these projects. These projects require specific expertise from a scientific/research point of view. We would have to examine how the scientific committee can support the secretariat. We are aware we would need more people if we receive these funds.

Chair: I would like to say a few words since I will take care of the research in my role in the Scientific Committee. Do you think this is one of the most important things ECPC can be doing? To empower patients to be co-researchers, research should not only be limited to the board. If you agree with me, please show your hands.

[Hands are raised]

Raise your hand if you do not think this is important

[No hands raised]

Good. I want to involve our members in this kind of work. I am very much looking forward to seeing which one of you would be interested to work directly with us.

Voting on 2018 Activity Report (64 members voting)

The activity report is unanimously approved

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4 Adoption of the 2018 Financial Report

[See Annex VII]

AC presents the highlights of the 2018 Financial Report

[See Annex VIII]

AC presents the projected revenue for 2019 totalling 1.294.000 of which 77 percent is already secured. The revenue sources are then presented, and it is noted that we are not dependent on any one company but receive funding from many different ones for each project. A comparison with 2018 is given and differences explained.

4.1 The report of the Association's Audit Committee

[See Annex IX]

PP presents highlights of the Audit committee’s report and recommends that the financial statement be approved.

4.2 Discussion of the Financial Report

AC: In 2018 there was € 1.204.132 revenue. Running costs, human resources, operational costs and implementation of projects during 2018 came to a total of € 1.026.327. This year we had a negative result of € -2.196.

PP: The number is not correct. The revenue is not 1.204.132, but 1.024.132 in 2018.

AC: Yes. Sorry. That's obviously a typo.

Chair: As you know ECPC is a member of EMA, so our budget is also checked by them. Every year EMA checks the budget. The requirement is that over 20 percent of our revenue cannot come from a single organisation. Our philosophy is therefore to have as many sponsor organisations as possible so that we avoid that one of them could condition our behaviour.

GA Participant: The last line, the 20.000 for election. What is this exactly?

AC: A lot of money was spent on printing and sending by post the voting envelops for the election. We also had a lawyer supporting us in the election procedure of the board. This is an exceptional cost that we have every three years. So therefore, there was no cost associated with it in 2018.

GA Participant: I just want to ask if it is not possible to vote for the board electronically?

AC: Electronic email was discussed, but in the end it was decided via post. Next time the new Board election will probably go through electronic email.

GA Participant: How much money is in the bank?

AC: On 1st of January it was € 163.000 (the detail was provided on the spot by Jiska Bolhuis, Head of Finance and Human Resources)

Chair: About the voting, we discussed this. We do not have a formal way to identify who is voting, unless we have the feedback directly from the organizations to ensure we have the right email address. So, we couldn't decide to use an electronic solution. By post we know that the envelope arrives and is handled by the correct person, and then the counting of the votes was checked by a lawyer.

Voting on adopting the financial report (64 members voting)

The financial report is unanimously adopted

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5 The 2019 Budget

[See Annex VII]

AC presents the 2019 foreseen expenditures.

Voting on the 2019 budget (64 members voting)

The 2019 budget is unanimously adopted

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6 The 2019 Action Plan

[See Annex X]

AC presents 2019 Action Plan highlights
[See Annex XI]

6.1 Discussion of the 2019 Action Plan

GA Participant: Hi I am from Switzerland and I have been thinking on this idea now for two, three years. I now share it with you: The idea is to make a database for all cancer diseases in English so that the patients have a place to find all the information they need. It should be medical information but also such information as how to cope with the disease, procedures, etc.

AC: Perhaps our Danish friends would like to have a word, because they mentioned during an informal conversation how it would be good to be aware of where in Europe the disease can be treated.

KDLH: For example for prostate cancer you currently have many different treatment options for the same condition across Europe but what is available in Germany is not in Denmark. We should therefore inform about different treatment options for each specific cancer. Again, for prostate cancer you can have surgery, nanoknife, chemotherapy, etc. This information should be available to patients.

Chair: We already have some ongoing projects that provide this information for rare cancers.

KA: We have a list of all rare cancers so that if you have a diagnosis of a rare cancer you can look at the rare cancer network (rarecarenet.eu) and see if your diagnosis is listed. Then you have to consult with your local medical team for referral to a European centre of excellence. There are then national centres of excellence as a national counterpart.

Chair: I agree that we still can do more. For now, in the JARC, we have a list published, we can now give all the indications, but it is not yet really functioning as a network and telemedicine is not yet activated in the ERNs. For each rare cancer we provide the information on where to seek treatment. It only gives guidelines or recommendations, so our work now together with you will be to focus on implementation. That depends on the member state, the guidelines will be implemented in a book from September, and the Working Group on Rare Cancers is currently engaged with this work.

GA Participant: I just wanted to say that for rare cancers all the information is already available on orpha.net. The definitions are also available.

RDM: We would like to add targets for the project, e.g. informed consent forms. ECPC cannot now give advice on treatment, we are providing information online, but every patient must seek advice from his healthcare provider. If we look at the relationship doctor-patient and patient-carer, I see that information consent forms are drafted as if they have opposed interests, while we should work towards developing an alliance between the health care provider and the patient. This should be in trials but also during regular treatment, as they all are working together against the disease. This would be an interesting field to investigate further.

AC: On a different topic, but in relation to enhance collaboration among our members, having spoken with some of your colleagues from Turkey, they are very well experienced with the Erasmus+ program when it comes to organising exchange programs with other patient organisations. I believe that ECPC can facilitate this, if you are interested in projects with young people, then you could be involved in fundraising for these projects. Of course, this would be for the year 2020. It will require some administrative work but will give you visibility at the EU and national level.

Voting on the 2019 Action Plan (63 members voting) *One member left the GA early*

The 2019 Action Plan is unanimously approved

8 The Granting of Discharge to the Board Members

The Chair introduces the topic, as a voting by the GA is required.

Voting on Granting Discharge to the Board Members (63 members voting) *One member left the GA early*

Discharge is granted unanimously

9 Conclusions and closing of the GA

9.1 Introduction to the new Board Members

Kathi Apostolidis – President

Kathi is the President of the European Cancer Patient Coalition and the President of the Executive Committee of ELL.O.K., the Hellenic Cancer Federation/Greece. She is a Public Affairs Consultant with broad and diversified experience in regulatory and public affairs, diplomacy, strategy, marketing and communications with international companies and public service. Jointly with the President, she is responsible for strategy, strategic alliances, relations with the European Commission and other EU and national high-level cancer stakeholders. Surviving breast cancer twice, she was involved in breast cancer, survivorship and cancer patient rights advocacy for the last 25 years. Her advocacy covers issues of access to cancer care, informed shared decision making in cancer care, patient involvement in cancer research, health and cancer care policy and economics, cancer care delivery, patient safety, health technology assessment, and digital technology in cancer care. At national level she serves as Board Member at KEFI Association of Cancer Patients, Volunteers and Physicians in Greece and as Director/Member of other Greek cancer patient associations.

Pietro Presti - Vice President

Born in Turin, Italy, Pietro Presti is a dynamic and goal-oriented manager with a broad experience in the healthcare sector, especially in oncology, including prevention, screening, advocacy, cancer control and research. With a master's degree in law and MBA, he is currently General Secretary at "Fondo Edo Tempia", an Italian private association primarily involved in cancer prevention and advocacy, palliative care, psycho-oncology and support to the public health-care system. He is also Managing Director at "Edo ed Elvo Tempia Foundation", a private foundation operating in the field of oncological prevention, diagnosis and research. He possesses an excellent track record of managing and scaling complex and innovative projects and public-private partnerships. As a volunteer, he serves as board member at international and national associations and organisations in cancer advocacy, education and research. He has spoken at several international and national conferences, lectures at Master's level at the University of Turin, is a team member of the European BenchCan project (www.oeci.eu/Benchcan/), and has participated in a Solitary Everest Base Camp Trek for Philanthropic Fundraising Challenge to donate a DigniCap device to the hospital of Biella.

Jacqueline Daly – Secretary

Jacqueline is the Director of Services at East Galway and Midlands Cancer Support Centre in Ballinasloe, Co. Galway, Ireland, co-founded in 2012. She is a contributor to ECPC and has worked on their publication 'Living Well During Cancer Treatment' and has written the Structured Education Programme to Support Men with Prostate Cancer (STEP). Married to Mike, with one son Seamus, she herself is a Cancer Survivor and Complimentary Therapist.

Beata Ambroziewicz - Treasurer

Beata is the President of the Polish Union of Patient Organisations "Citizens for Health", Board Member of Polish Cancer Patient Coalition, President of Let's Win Health Foundation, Member of National Development Council & National Health Council in Poland, Deputy Editor-in-Chief of Cancer Patient Voice Magazine and Member of the Steering Committee for Coordination of EFSI intervention in the health sector. She graduated from the University of Warsaw and for over 10 years has represented patient organisations. Actively cooperating with non-governmental organizations, PAGs, she has represented health-related institutions, Ministry of Health, National Health Found, Patient Rights Ombudsman and many others. She coordinates the implementation of nationwide projects financed from EU and Norwegian funds such as: "Citizens for Health", "Civil Agreement for Oncology" or "Social monitoring of implementation of oncology package by Ministry of Health. Beata organises and participates in many national and international conferences, symposia, and trainings on health and patient empowerment. She promotes the constitutional principles of subsidiarity, social dialogue and cooperation, openness, solidarity and mutual support for unions, associations, federations, foundations and other patient organisations.

Maude Andersson - Board Member

Maude is a board member of the European Cancer Patient coalition and the Vice-President of Gynsam (Swedish Gynaecological Cancer Patients National Coalition). Her first personal encounter with cancer was in 1984, when a lump was discovered in her left breast and removed. In 1999 she was diagnosed with ovarian cancer and had surgery, radiation and had brachytherapy. She previously worked as an engineer for Ericsson and at the Department of Physics and Electrical Engineering at the University of Karlstad. She is currently a patient representative in the Regional Cancer Centers in Sweden – the Gynecological Cancer Group, the Palliative Group, the Contact Nurse Group, Patient and Associate Group, and the Rehabilitation Group. She is also a member of the Disability Board in the County Council in Värmland, Editor of Gynsamposten (the journal of the Swedish Gynaecological Cancer Patients National Coalition) and President of GCF Musslan (a patient association for women with gynaecological cancer living in the west of middle Sweden). She works to ensure that all people have access to the latest and best care available, preventive measures such as health checks and screening are implemented, and all patients are offered rehabilitation. In Sweden, she has launched a network for young women with a cancer diagnosis, coordinated a project to support immigrant women with cancer, and lobbied the national government for better health care and HPV vaccination. As a board member of the European Cancer Patient Coalition, she is working on rare cancer issues, HPV vaccination for boys, writing a book about cancer side-effects, as well as continuing to work with Nordic Sister Organisations.

Robert Greene - Board Member

Robert Greene is the Founder and President of HungerNdThirst Foundation, a foundation which focuses on the management of dysgeusia through awareness, research, education and product development. He is a Patient Advocate for Inspire2Live, an Ambassador for Imerman Angels and ‘professional patient’. Former healthcare professional he was diagnosed and treated for colon cancer in 2012 and diagnosed and treated for prostate cancer in 2018. He advocates for a more patient centered and patient centric approach in clinical trials. Dedicated to creating awareness for taste alteration caused by cancer treatment and its impact on quality of life, he believes that the nutritional status of patients should be a focus point upon receiving a cancer diagnosis, and that health care professionals should never lose sight of the emotional and social aspect of food. A strong believer that collaboration is key when addressing issues faced by patients diagnosed with cancer.

Vasile Ianovici - Board Member

Vasile is a patient diagnosed with chronic myelogenous leukemia about 15 years ago, at this time in molecular remission and still under treatment with imatinib. After diagnosis he started fighting the disease and managed to cope with all the challenges in his life; he continued to work in the company where he was employed for over 20 years, having previously been a naval mechanic for 8 years. With vast management, marketing, and public relations experience, he decided to get involved and try to do more for the patients like himself, diagnosed with oncological diseases. Thus, in 2013 he was co-opted in the board of Suceava Cancer Patients Association and censor of the Romanian Federation of Cancer Associations. From 2015 he became a co-founder and vice-president of the Association of Patients with Myeloproliferative Neoplasies MIELOPRO, which is a full member association of Romanian Federation of Cancer Associations, of CML Advocates and ECPC. In parallel daily work at his job, he has contributed to the organisation and deployment of many support, promotional and educational activities for cancer patients within the MIELOPRO Association.

KA thanks everyone for their attendance and wishes everyone safe travels.

GA closes at 12:54

Annexes

I. **Election of the Board – Record of Votes**

II. **List of Full Member Delegates**

III. **Introduction of the secretariat staff**

IV. **Communication Activities of ECPC**

V. **2018 Annual Report**

VI. **Highlights of the 2018 Annual Report**

VII. **2018 Financial Report**

VIII. **Highlights of the 2018 Financial Report**

IX. **The 2018 Report of the Association's Audit Committee**

X. **The 2019 Action Plan**

XI. **Highlights of the 2019 Action Plan**