European Cancer Patient Coalition

# European Cancer Patient Coalition

# **Extraordinary General Assembly**

# **20 July 2022**

Minutes

# Table of Contents

1. Opening and Attendance....3
2. Welcome address....3
3. Action Plan and Budget 2023....3
4. External Statutory Auditor (2022-2024)....7
5. Closing remarks....8

Annexes....9

# 1. Opening and Attendance

The virtual General Assembly starts at 15:00
The meeting is chaired by the President of the ECPC, Francesco de Lorenzo
The Secretary is George Kapetanakis – ECPC Secretary

The meeting was held virtually with members of the Board and the Secretariat joining from ECPC's offices. The ECPC President Francesco de Lorenzo chaired the meeting, assisted by the ECPC Secretary, George Kapetanakis.

In total, 33 Full members and one Associate member participated at the Extraordinary AGM. The participants' list is attached to the Minutes (Annex 1).

# 2. Welcome address

ECPC President, Francesco de Lorenzo, welcomed all attendees and encouraged them, be it members or staff, to contact him should they need support and/or to get involved in research projects. De Lorenzo introduced ECPC Director, Charis Girvalaki, who welcomed all participants and upon her request, ECPC staff introduced themselves. Following this, Director Girvalaki explained the procedures on how to vote and how to ask questions. Director of ECPC, Charis Girvalaki, opened the meeting with the agenda of the AGM. As a reminder, the items in the Extraordinary Annual General Meeting Agenda are:

1) Approval of the Board's Action Plan and Budget for 2023

2) Nomination and vote on an external Statutory Auditor for the financial years 2022-2024.

# 3. Action Plan and Budget 2023

The ECPC Director started by introducing the Action Plan and Budget for 2023 and briefly referred to the sections of *Policy and Advocacy*, *Health and Research*, *Education and Capacity Building*, *Communication and Governance*, as well as ECPC's finalized, ongoing and future projects, as well as to ECPC's partnerships.

President De Lorenzo informed the AGM about the ECPC's participation at the Conference of Oncology, hosted by the Czech Presidency of the Council of the European Union, in July in Brno, pointing out that ECPC was the only invited European patient organisation. In addition, De Lorenzo updated the AGM about the discussions with the Czech Health Minister and oncology experts regarding lung and prostate cancer screening. Considering that there, have been big delays for the adoption of the EU Council Recommendations on cancer screening and that currently the new EU Guidelines for Breast Cancer are available through the ECIBC[1]-European Commission Initiative on

[1] ECIBC https://healthcare-quality.jrc.ec.europa.eu/

Breast Cancer and the new ECICC-European Commission Initiative on Colorectal Cancer will start in September, the President invited ECPC members to advocate to their Ministries of Health to activate the screening Guidelines for breast cancer, and the screening recommendations for colon, and uterus cancer, as well as for the vaccination for HPV. Moreover, as ECPC participates in the ECIBC, represented by Past President Kathi Apostolidis, ECPC members can ask Kathi for advice and support in their breast cancer screening advocacy activities. President De Lorenzo noted the importance of involving patients in cancer research, to have their say in developing treatments that patients need and to use the unique opportunities available now through the EU Commission policy and research initiatives to improve cancer care in all EU Member States. He proceeded to explain the key reasons guiding researchers to engage with patients and patients' organisations at every stage of the research process.

Referring to HTA, President De Lorenzo, highlighted the need for patient organizations to be prepared for the Joint Clinical Assessment implementation by 2030. He reminded the AGM of the significant impact that the ECPC had on shaping the new HTA Regulation that will be effective in 2025. ECPC is proud to have created momentum on the European Union cooperation on HTA during the process of amending the Regulation 726/2004[2], voted by the European Parliament in 2016. The Regulation 726/2004 gives the European Medicines Agency (EMA) responsibility for the centralised authorisation procedure for human and veterinary medicines in all EU/EEA countries. In 2015, the European Commission proposed to update the veterinary part, and to create a separate regulation for the veterinary products. In the process, ECPC has strongly advocated the European Parliament to take this chance to update also the rules for human use products (medicines). ECPC collaborated closely with the European Parliament and was successful in having its proposed amendments adopted. They would require the Commission to establish a European relative effectiveness evaluation for medicines for human use, valid for all EU/EEA countries[3].

A call for the European Commission to develop a proposal for EU cooperation on HTA followed. In early 2019, ECPC launched an online educational module on HTA for cancer patients, which helped to increase the knowledge and confidence of ECPC members for participation in HTA bodies at national level, and advocate for their right to participate, in member states where there are no established frameworks for patient involvement in HTA. In 2020, ECPC developed a toolkit[4] for patients and patient organizations on how cancer patients can be involved in the HTA process. The President added that it is worth noting that ECPC's impact on shaping the HTA Regulation led to harmonising prices and facilitating reimbursements all over Europe. The challenge though remains in the implementation. ECPC will continue to closely monitor the progress in 2023 and to bring its added value in the policy debate at the EU level as a relevant stakeholder.

---

[2] REGULATION (EC) No 726/2004 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 31 March 2004 laying down Community procedures for the authorisation and supervision of medicinal products for human and veterinary use and establishing a European Medicines Agency https://health.ec.europa.eu/system/files/2016-11/reg_2004_726_en_0.pdf

[3] The European Parliament is committed to facilitate access to life-saving medicines https://ecpc.org/news-events/the-european-parliament-is-committed-to-facilitate-access-to-life-saving-medicines/

[4] Health Technology Assessment E-Module https://ecpc.org/tool-box/health-technology-assessment-e-module/

De Lorenzo gave the floor to the Past President and current Chair of the Scientific Committee, Kathi Apostolidis, who acknowledged the importance of ECPC, as the largest European umbrella organization important organisation for cancer patients in Europe, thanks to its members and staff. Apostolidis thanked the President for his overview of ECPC work on HTA and encouraged ECPC members to ask the support of the Board and the Secretariat in their advocacy activities on HTA or any other cancer policy matter. Referring to the patient involvement in cancer research K. Apostolidis clarified that ECPC efforts in research are closely linked to policy, stating that new medicines and new treatments cannot be achieved without research.

Apostolidis referred to the recent launch of the platform on Cancer Inequalities in Europe and mentioned that ECPC carried out a survey in 2019, on socio-economic disparities in cancer, covering social insurance benefits for disease, early pension, return to work, equal pay. Although this survey was completed in 2019, the breakout of the COVID-19 pandemic has delayed the publication of its results and the report is currently updated. Apostolidis informed the attendees that they will receive a questionnaire from ECPC Senior EU Affairs Officer, Adela Maghear, to check if any change occured in the responses they had made in 2019. Finally, the Chair of the Scientific Committee added that the results of the survey will be presented in a White Paper on socio-economic disparities in cancer that will be published later this year.

President De Lorenzo noted the presence of several breast cancer patient organisations in the Extraordinary AGM and used the opportunity to introduce ECPC Board Member and Treasurer, Evgenia Aleksandrova, who will start a Working Group for Breast Cancer patients for sharing information about early detection, care and rehabilitation. De Lorenzo informed the AGM about another new Working Group dedicated to haematological malignancies, which will be led by ECPC Vice President, Jana Pelouchova, and Italy's Associazione Italiana Contro le Leucemi, Linfomi e Mieloma (AIL) CML Patients Group member, Felice Bombaci. President De Lorenzo mentioned "Radu" Vasile Ianovici, ECPC Audit Committee member and a former Board member, who led the Onco-Haematology Working Group in the previous years, and asked him to assist ECPC Vice President, J. Pelouchova and F. Bombaci, for increasing the working groups' productivity. Furthermore, the President addressed the need to reactivate the working group on social disparities and mentioned interest in pursuing the creation of a Working Group on innovation.

The Chair of the Scientific Committee, Kathi Apostolidis, added that the Rare Cancer Working Group is active and all members are welcome to participate and to inform their members with rare cancers to join. Evgenia Aleksandrova stressed the importance of collaboration and encouraged attendees to join efforts in the Breast Cancer Working Group (BCWG) and to work closely with each Member States' health policy authorities and institutions.

Vasile Ianovici, introduced himself and noted the good work of the last three years in the Rare Cancer Group; he publicly thanked ECPC Senior EU Affairs Officer, Adela Maghear, for her assistance with the activities of the RCWG. Ianovici added that he will gladly collaborate in the Haemato-Oncology Working Group, being a CML patient himself. Furthermore, he casted his approval of the Action Plan 2023, as he had to exit the call due to a meeting overlap.

Myeloma Euronet Romania´s Representative, Viorica Cursaru, thanked ECPC President for his presentation and stated that she was disappointed, for the absence of a committee or working group, that would tackle inequalities and disparities on access to treatments and medication. Cursaru added that, unless a committee is established to tackle the disparities of access to treatment and medication, the situation will remain unchanged. She also referred to Apostolidis' mention of social inequalities and that this issue has already been tackled by the Commission with the introduction of the Social Pillar two years ago.

President De Lorenzo addressed Cursaru's concerns mentioning that ECPC has a working group on inequalities, which is the former Legal Network Working Group, renamed Working Group on Social Disparities in Cancer at the meeting of the working group during the Annual Congress 2018. The European Cancer Inequalities Registry is a flagship initiative of Europe's Beating Cancer Plan. It provides sound and reliable data on cancer prevention and care to identify trends, disparities and inequalities between Member States and region.

The President asked the Director Charis Girvalaki to get in touch with Viorica Cursaru to discuss the problems faced by patients in her country and to examine the possibility to start a working group on access to cancer treatment. Codice Viola's representative, Piero Rivizzigno, shared his concerns about the role of ECPC in drug development processes. President De Lorenzo responded that ECPC for the last 12 years is represented in the EMA Patient and Consumers Working Party, and has two representatives, one being the Chair of the Scientific Committee, Kathi Apostolidis and that he represents ECPC in the Board of the CDDF – Cancer Drug Development Forum.

Chair Apostolidis commented that, whenever there is a new medicine for approval, the EMA's Scientific Committee wants to hear from patients, what it means to live with a disease and its treatments. ECPC collaborates with EMA and several cancer patients during the last 9years have been invited to present at the EMA. Regarding the role of cancer patients in the cancer drug development and approval she noted that at national level, member states seek to hear from registered bodies, thus, the role of cancer patient organisations cannot be substituted by the role of individuals.

ECPC Director Charis Girvalaki presented the Budget 2023 estimates for the expected revenues and costs. She explained that the main sources of income are the projects funded by industry and the EU funded projects, described in the Action Plan 2023.

Pauline Evers, of the Dutch Federation of Cancer Patients Organisations, asked if ECPC receives funding from the pharmaceutical industry. Charis Girvalaki answered that the projects of the Action Plan are mostly funded by pharma and non-pharma companies and P. Evers asked how this is reflected in the budget. ECPC Director explained that the foreseen costs for the projects of the Action Plan come from pharma and non-pharma companies and are reflected in the budget.

ECPC President took the floor and explained that, initially, ECPC was mainly funded by pharma companies, but now, funding has shifted more to receiving funds from the European Commission. He added that ECPC's budget is communicated to the EMA. K. Apostolidis complemented De Lorenzo's explanation by stating that ECPC, together with other organisations, formally presented to the EC the

need to fund patients' organisations that, otherwise, would have to call to pharmaceutical companies for funding.

Peter Lakwijk, Treasurer of the Thyroid Federation International, stated that he missed what volunteers contribute to the organisation. He added that the European Commission should be informed that volunteers are paying for their organisations, as another mean of funding, besides the support of the industry. ECPC President responded to P. Lakwijk, that what he states is true and, in fact, many volunteers are taking part in research projects and that joint action in this direction is needed.

Peggy Karampatou, Executive Representative and Project Coordinator for the Association of Cancer Patients KEFI of Athens asked if there is a module or program at ECPC offering cancer information to patients to understand their disease. K. Apostolidis responded that ECPC is working considerably in that field and that ECPC has several resources for the information of patients. She underscored the importance of the events, campaigns, brochures, white papers and other resources, which she briefly described.

At this stage, ECPC Director asked attendees to vote for the Action Plan and Budget 2023 and reiterated the procedure.

The voting results of the Action Plan and Budget 2023 were 26 in favour , 3 against and 0 abstentions. As a result, the Action Plan and Budget 2023 were approved.

ECPC President asked those who did not vote the Action Plan and Budget 2022 to express the reasons why they voted against, in order to help the organisation grow and provide better results.

Pauline Evers took the floor. She linked her disapproval to the question she raised before, about the sources of ECPC income. She stated she did not see in the budget the detail of how much of ECPC's activities are funded by pharmaceutical companies or by the European Commission. To her, it was still unclear how ECPC is funded. ECPC Secretary, George Kapetanakis, explained that the budget of 2023 is a forecast, based on the experience of the previous years thus, we cannot know now the percentage of industry funding. F. de Lorenzo added that ECPC's budget in the previous years was mainly supported by the pharmaceutical industry and that ECPC is working to steadily increase the percentage of funding by non-pharma industry and foundations, so that there is a better balance between the support received from the private sector and that received from EU funded projects.

## 4. External Statutory Auditor (2022-2024)

ECPC Director proposed to move on to the second item on the Agenda, the voting of an External Statutory Auditor for the financial years 2022-2024. Charis Girvalaki explained that ECPC invited ten External Statutory Auditors to send their offers. She went on to present the firms which sent their offers and how each one met the selection criteria. The ranking of the offers received was conducted by ECPC Finance and HR Manager, Anna Bruma. Charis Girvalaki informed the AGM that the Board

proposed L&S Registered Auditors, represented by Saskia Luteijn. The decision was made since this firm met all the criteria, and it was the most affordable, charging €5.250 per year, excluding VAT.

The Representative for the Association of Cancer Patients in Finland, Riikka-Leena Manninen, asked why a new auditor would be selected and if there was something wrong with the previous one. The President responded that nothing was wrong, however, the contract was only for one year, since the statutory audit should be decided by the AGM as well as the auditor. Therefore, ECPC has invited offers from several and also from the previous auditor and now the AGM has to approve the statutory audit for three years and appoint an auditor based on the offers received. He asked ECPC Finance and HR Manager, Anna Bruma, to provide further information. Anna Bruma explained that among the received offers,the one from Saskia Luteijn had the clearest strategy and the lowest price. De Lorenzo mentioned that all the offers are available to the AGM participants for consultation.

Referring to the voting procedure of the Extraordinary AGM, P. Lakwijk remarked that the voting should be anonymous, to be democratic. ECPC Director and Secretary Kapetanakis reminded attendees that, even before the pandemic, during in-person AGMs, the voting was conducted by raising hands and the procedure remained democratic. Last but not least, Director Girvalaki highlighted that using other voting platforms would increase the costs for ECPC.

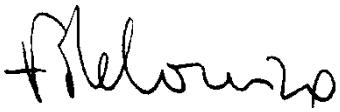
The Director conducted the final voting on the External Statutory Auditor: the results were 27 votes in favour, 3 votes for disapproval and 1 abstention. Therefore, the decision was approved.

“The extraordinary general assembly decides to nominate the L&S Registered Auditors , located in Kortemansstraat 2, 1731 Asse and represented by Saskia Luteijn, as statutory auditor for the legal period of 3 years, more specifically the year ending the 31st of December 2022, the 31st of December 2023 and the 31st of December 2024. The annual fee of the statutory auditor’s mandate amounts to € 5.250 per year, excluding VAT.”

## 5. Closing remarks

In his closing remarks, President De Lorenzo invited the member organisations to read carefully the Action Plan and to get more involved in ECPC’s activities in actions meeting their interests. He considers the research projects as very stimulating and that there will likely be a webinar at the beginning of 2023 to better explain what ECPC is doing for each research project. De Lorenzo also mentioned that ECPC is working on Next-Generation Sequencing and biomarkers, which is highly important for personalized medicine in cancer. Finally, he took the opportunity to praise the members of the ECPC Scientific Committee and raised the importance of the Right to be Forgotten project, led by Scientific Committee member, Dr. Francoise Meunier.

De Francesco expressed his hope that each member will find a way to come closer to ECPC and added that ECPC’s voice represents the voices of its members, and that the organisation is stronger if more members become more active. Finally, he reminded all attendees that a members’ survey will be conducted to get to know each one better.



Francesco de Lorenzo
President

George Kapetanakis
Secretary to the Board

## Annexes

I. **The list of ECPC full and associate members present at the AGM 2022**

II. **Action Plan and Budget 2023**

III. **Appointment of the Statutory Auditor Proposal**