

ECPC ANNUAL CONGRESS

FRIDAY 8 – SATURDAY 9 JUNE 2018

&

ECPC GENERAL ASSEMBLY

SUNDAY 10 JUNE 2018

VENUE:

RENAISSANCE BRUSSELS HOTEL, RUE DU PARNASSE 19, 1050 BRUXELLES

EVENT ORGANISED UNDER THE HIGH PATRONAGE OF:

EU Commissioner for Health and Food Safety, Vytenis Andriukaitis

AND

Her Royal Highness Princess Astrid, Belgium

FRIDAY 8 JUNE
PRE-MEETINGS OF THE WORKING GROUPS

9:30 – 11:30 ECPC Board meeting

Venue: Renaissance Hotel, Copenhagen Room

12:00 – 16:00 ECPC Working Group on Rare Cancers meeting

Chair: Jana Pelouchova

Venue: Renaissance Brussels Hotel, Madrid Room

ECPC is one of the patient organisations representing the needs, rights and hopes of rare cancer patients in the Joint Action on Rare Cancers (JARC). In 2016, ECPC established a Working Group on Rare Cancers, in order to guarantee that a large number of rare cancer patient organisations, representing different European countries and rare cancers, can contribute to JARC.

Through this Group, ECPC is working on prioritising rare cancers in the agenda of the EU and Member States, with a view to national cancer plans and quality of healthcare, harmonisation of clinical practice, innovation through promotion of clinical and translational research, developing innovative and shared solutions, mainly to be implemented through the European Reference Networks on rare cancers, in the areas of quality of care, research, education and state-of-the-art definition on prevention, diagnosis and treatment of rare cancers.

On 8 June 2018, Annalisa Trama from the Istituto Nazionale dei Tumori di Milano, will be presenting to the Working Group the priorities of the Joint Action on Rare Cancers for 2018 and 2019. The meeting will specifically focus on identifying the needs for educational tools and learning programmes of the rare cancer patient communities which will enable them to participate in the design of clinical trials, in research projects, in scientific and /or regulatory, ethics committees.

12:00 – 16:00 ECPC Working Group on Bladder Cancer meeting

Chair: Andrew Winterbottom

Venue: Renaissance Hotel, Warsaw Room

In order to better represent the bladder cancer patient community, ECPC counts on the expertise and collaboration of bladder cancer patient organisations all over Europe. The Working Group on Bladder Cancer will share best practices from the 2018 bladder cancer awareness campaign in May and review the results of the international bladder cancer patient experience survey of over 1,000 people with bladder cancer and their carers. This meeting will also include presentations on best practices from Bladder Cancer Canada and the Bladder Cancer Advocacy Network USA.

12:00 – 14:00 ECPC Legal Network for Cancer Patients meeting

Co-Chair: Roberto de Miro

Venue: Renaissance Hotel, Copenhagen Room

The ECPC Legal Network for Cancer Patients brings together a solid base of legal practitioners to share their legal competences on a volunteer basis in order to benefit people with cancer. Many people with cancer and their carers face substantial social challenges related to employment and work-life balance. These social barriers are often linked to legal solutions that can be addressed at both the European and national level. Thus, the ECPC Legal Network for Cancer Patients will examine issues such as the European Commission's Proposal for a "Work-Life Balance for Parents and Carers Directive", which clearly outlines the recognition of the definition of carers and protection of their right to paid leave for the carers to care for their loved ones. They will also discuss the European Parliament own-initiative report on "Pathways for the reintegration of workers recovering from injury and illness into quality employment", and the Dying to Work MEP Focus Group, of which ECPC is a joint secretariat along with the office of MEP Rory Palmer.

FRIDAY 8 JUNE
OPENING CEREMONY OF THE ANNUAL CONGRESS

RENAISSANCE HOTEL, BALLROOM

15:30 – 16:30 Registration

16:30 – 16:40 Welcome

Lydia Makaroff, ECPC Director

16:40 – 17:00 Introductions

ECPC Board and Staff

17:00 – 17:35 ECPC's achievements in the past year

Francesco De Lorenzo, ECPC President

17:35 – 17:40 Video message from the EU Commissioner for Health and Food Safety, Vytenis Andriukaitis

Discussion with ECPC Members

17:40 – 18:40 Communicating with People affected by Cancer (Chair: Andrew Winterbottom)

John F Smyth

Discussion with ECPC Members

18:40 – 19:00 Group photo

20:00 – 22:00 Dinner

Venue: Renaissance Hotel, Ballroom

SATURDAY 9 JUNE
ANNUAL CONGRESS

RENAISSANCE HOTEL, BALLROOM

09:00-09:30 Sign-in

09:30-09:40 Summary of the agenda for the day

Lydia Makaroff, ECPC Director

09:40-11:00 Health Technology Assessment (HTA) (Chair: Kathi Apostolidis)

ECPC's achievements in HTA advocacy

Francesco De Lorenzo, ECPC President

HTA online education module

Katie Hamilton (Costello Medical)

Overall aims

Presentation of the animation

Introduction to the purpose of the session

Module Content Overview

Module structure, functionality and supporting booklet

"Guided Tour" of each chapter of the module

Feedback from ECPC Members about the HTA module.

Independent, structured feedback forms will be provided to the Members during the session.

After a feedback session, HTA experts will make short presentations and open the debate with the audience on HTA and reimbursement, the recent Commission proposal on HTA and how patient organizations can create a win-win situation with their national HTA agencies.

HTA and reimbursement

Irina Cleemput (Belgian HealthCare Knowledge Institute)

Overview of the European Commission's HTA proposal

Ioana Siska (European Commission, DG SANTE)

How to create a win-win solution

Ivana Cattaneo (Vice-Chair Efpia Oncology Platform)

Panel discussion on HTA aspects.

11:00-11:20 Members Market Place and Coffee Break

11:20-12:30 Immuno-oncology therapies & molecular testing (Chair: Andrew Winterbottom)

The basics of tumour immunology

Leif Hakansson

Molecular testing in the era of personalised medicine

Nicola Normanno

Discussion with ECPC Members

12:30 – 13:30 Lunch buffet

13:30-14:50 Cancer Carers (Chair: Maude Andersson)

Opening remarks

Maude Andersson

ECPC White Paper on Cancer Carers

Francesco De Lorenzo, ECPC President

Personal testimonies from cancer carers

Tim Brown, Fight Bladder Cancer UK

Roberto de Miro, Italian Federation of Volunteer-based Cancer Organizations

Eurocarers Cancer Carers Toolkit, produced in collaboration with ECPC

Claire Champeix, Policy Officer at Eurocarers

Discussion with ECPC Members

14:50-15:20 ESMO-ECPC Survivorship Guide (Chair: Jana Pelouchova)

Kathi Apostolidis, ECPC Vice-President

Francoise Meunier, European Organisation for Research and Treatment of Cancer

Discussion with ECPC Members

15:20 – 15:40 Coffee break

15:40 – 16:10 Guided self-care relaxation and mindfulness workshop

16:10 – 18:10 ECPC Members share their best practices, successes and challenges (Chair: Maude Andersson)

1. *Czech Republic: Mamma Help*
2. *Finland: PROPO*
3. *Greece: Alma Zois Athens*
4. *Greece: SYKAFIAR*
5. *Greece and Turkey: Karkinaki and Pembe Hanim*
6. *Latvia*
7. *Poland: Polish Cancer Patient Coalition*
8. *Romania: Romanian Association for Services and Communication in Oncology (APSCO)*
9. *Spain: Spanish Organisation Against Cancer (AECC)*
10. *Turkey: Hope and Life Association*

Discussion with ECPC Members

19:30 – 22:00 Dinner

Venue: *Parnasse, Hotel Restaurant*

SUNDAY 10 JUNE
ECPC GENERAL ASSEMBLY

RENAISSANCE HOTEL, BALLROOM

08:30 – 08:45 Sign in

08:45 – 08:50 Summary of the agenda for the day

Lydia Makaroff, ECPC Director

08:50 – 08:55 Adoption of the minutes of the previous General Assembly Meeting

08:55 – 09:00 Formal introduction of ECPC Board to the General Assembly

09:00 – 09:50 The Board's Annual and Financial Reports

Presentation of the 2017 Annual Report

Francesco De Lorenzo, ECPC President

Adoption of the clear image on ECPC assets and statement of income and expenditure for the past financial year

Adoption of the budget for the next financial year

Andrew Winterbottom, ECPC Treasurer

Discussion

09:50 – 10:00 The report of the Association's Audit Committee

Pietro Presti, Chair of the ECPC Audit Committee

10:00 – 10:20 Position of the Romanian member association regarding the ECPC activity

10:20 – 10:30 Number of the Board members to be elected in 2019

Presentation of the number of the Board members to be elected in 2019

Voting on the number of the Board members to be elected in 2019

10:30 – 10:50 Modifications to the ECPC Statute

Special power for ECPC Director to appear in front of Notary in order to communicate the modifications in the ECPC Statute approved by the General Assembly.

Presentation of the Modifications to the Statute

10:50 – 11:00 Position of the Romanian member associations regarding the proposal to modify the ECPC

Statute Voting on Modifications to the Statute. Modifications to the Statute are decided upon by a two thirds voting majority of the members present or represented at the General Assembly.

Annex of modification of Article 4 – Members

Annex of modification of Article 6 – Termination of Membership

Annex of modification of Article 10 – Experts and Committees

Annex of modification of Article 13 – General Assembly

Annex of modification of Article 14 – Agenda

11:00 – 11:10 ECPC General Regulations

Presentation of the General Regulations

Voting on the General Regulations. The General Regulations must be adopted and amended by a regular majority of the members present or represented at the General Assembly

11:10 – 11:20 Closing remarks

Francesco De Lorenzo, ECPC President

11:20 – 11:30 Any other business or topics not yet discussed during the General Assembly**11:30 – Farewell coffee and departures**

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