



**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:***

**European Parliament**

**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.*

## FRIDAY 8 JUNE PRE-MEETINGS OF THE WORKING GROUPS (CONTINUED)

### 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 Thessaloniki
4. Greece: SYKAFIAR
5. Greece and Turkey: Karkinaki and Pembe Hanim



6. Latvia: Viroterapy Foundation
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 – 10:20 The report of the Association's Audit Committee**

Pietro Presti, Chair of the ECPC Audit Committee

**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 – 11:00 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 modifications to the 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**