

ECPC GENERAL ASSEMBLY
FRIDAY 3 – SUNDAY 5 JUNE 2016
BRUSSELS, HOTEL RENAISSANCE
ADVANCING THE RIGHTS OF CANCER SURVIVORS



Event organised under the high patronage of
EU Commissioner for Health and Food Safety, Vytenis Andriukaitis

We invite the participants to the AGM to communicate the event, sharing their impressions on social media. Our accounts on:

 Twitter: @cancereu, please use the AGM hashtag #ECPC16 in all your tweets, so that your readers find all content about ECPC AGM in one place;

 Facebook: <https://www.facebook.com/ECPCfb>

**1st
DAY** **FRIDAY 3 JUNE**
OPENING CEREMONY

16.20 – 16.30	WELCOME MESSAGE by Mihaela Militaru, Director of ECPC
16.30 – 16.40	MESSAGE FROM THE EUROPEAN COMMISSION Martin Seychell, Deputy General Director of DG SANTE
16.40 – 17.00	ECPC 2013 – 2016: WHAT HAVE WE ACHIEVED IN THE PAST THREE YEARS? ECPC President, Board Members and ECPC Secretariat will present the work done by ECPC over the past three years
17.00 – 17.30	MACMILLAN – INFORMATION FOR PATIENTS AT ITS BEST Prof Jane Maher, MacMillan's Chief Medical Officer, will present best practices on information to cancer patients
17.30 – 17.40	Discussion
17.40 – 17.55	PRESENTATION OF MY SURVIVAL STORY PROJECT Martin Inderbitzin, initiator of "My Survival Story" Project
17.55 – 18.30	SCHOLARSHIPS AWARD CEREMONY Six young cancer survivors from different EU countries will be awarded the ECPC scholarship Group photo
20.00 – 22.00	GALA DINNER WITH LIVE CONCERT Featuring Rebecca Anouche (cancer survivor) performing her "Song of the decades" accompanied by Michael Merkus

**2nd
DAY** **SATURDAY 4 JUNE**
SESSIONS

SESSION 1: HONOURING CANCER SURVIVORS

09.00 – 11.30 Co-chairs: Prof. Francesco De Lorenzo, President of ECPC and Rafal Swierzewski, PhD, ECPC Board Member

PANEL I – A EUROPEAN CANCER SURVIVORSHIP PLAN

Introduction by the chair - 10 min

09.10 – 09.30 CanCon WP 8 Survivorship and Rehabilitation

Speaker: Dr Cludia Ferrari, CanCon WP 8 leader

09.30 – 09.45 ECPC-ESMO collaboration on the update of the Patients' Guide

Speaker: Prof Francesco De Lorenzo, President of ECPC

09.45 – 10.05 Discussion

PANEL II – CANCER AND WORK – BEST PRACTICES AT NATIONAL LEVEL

10.05 – 10.20 Isabelle Lebrocqy, Cancer Survivor, Patient Advocate and Social Entrepreneur (Opuce), the Netherlands

10.20 – 10.30 Seda Kansu, Founder of Pembe Hanim Cancer Patient Organization, Turkey

10.30 – 11.00 COFFEE BREAK

PANEL III – YOUNG CANCER SURVIVORS – UNDERESTIMATED AND NEGLECTED POTENTIAL

Introduction by the chair – 10 min

11.10 – 11.20 The PanCare Network and its EU related projects

Speaker: Dr Lars Hjorth, Project Coordinator

11.20 – 11.30 Discussion

SESSION 2: UNDERSTANDING HEALTH TECHNOLOGY ASSESSMENT (HTA)

11.30 – 13.00 HTAs are at the centre of the debate regarding pricing and reimbursement of cancer drugs. ECPC will open a discussion on the current role of patients in HTA decision-making process, and how cancer patients can understand (and influence) HTA decisions.

Chair: Prof Isabelle Durand-Zaleski, Professor of Medicine, University of Paris XII and Director of the Evaluation for the Haute Autorite de Sante

Introduction by the chair: 10 min

11.40 – 11.55 What is HTA and why patients should be involved ?

Speaker: Prof Bruno Flamion, Head of the Laboratory of Physiology and Pharmacology, Molecular Physiology Research Unit, University of Namur

11.55 – 12.10 How can patients improve HTA decision making

Speaker: Karen Facey, PhD, Honorary Research Fellow, Usher Institute of Population Health Sciences and Informatics, University of Edinburgh and health policy consultant

12.10 – 12.25 European Network for Health Technology Assessment (EUnetHTA): is a centralised HTA procedure for Europe feasible?

Speaker: Wim Goettsch, Leader of EUnetHTA Joint Action 3

12.25 – 12.35 ECPC triggering change: our contribution to the revision of Regulation 726/2004

Speaker: Francesco de Lorenzo, President of ECPC

12.35 - 13.00 Open discussion moderated by Prof. Isabelle Durand-Zaleski

13.00 - 14.30 LUNCH

SESSION 3: JOINT ACTION ON RARE CANCERS

14.30 - 15.10

Chair: Jana Pelouchova, ECPC Secretary

The Joint Action on Rare Cancers (JARC) and the European Reference Networks (ERNs) are crucial game-changers for rare cancer patients in Europe. ECPC will represent the patient perspective within the Joint Action. JARC provides an unique platform to bring together different EU stakeholders with a view to setting up a European and national agenda for rare cancers. ECPC will involve its members in different tasks of this Joint Action.

Speaker: Dr. Annalisa Trama, Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Member of JARC Coordinating team

15.00 – 15.10 Q&A

SESSION 4: VALUE OF INNOVATION IN ONCOLOGY

15.10 - 15.40

Moderator: Francesco Florindi, ECPC Public Affairs Coordinator

What are the most important features of a new cancer treatment, from the patients' perspective? On which issues should research focus its efforts to improve the life of cancer patients? ECPC will present a draft policy document on the value of innovation in oncology trying to answer these questions.

Interactive session with input from all ECPC Members

SESSION 5: ECPC-OECI JOINT DECLARATION

15.40 - 16.10

Chair: Francesco de Lorenzo, President of ECPC

In September 2015, ECPC and the Organisation of European Cancer Institutes (OECI), signed a Memorandum of Understanding (MoU) with the aim to consolidate and expand their collaboration. A first result of this MoU was the drafting of a Joint Declaration which will help patients and cancer institutes to consolidate their relationship.

Speakers: Patrick Miqueu, PhD, Project Manager, Institut Jules Bordet, Brussels
Francesco Florindi, ECPC Public Affairs Coordinator

Interactive session with input from all ECPC Members

16.10 – 16.30 COFFEE BREAK

SESSION 6: M-HEALTH AND E-HEALTH: UNDERSTANDING THE FUTURE OF CANCER CARE

16.30 – 17.00

Chair: Kathi Apostolidis, ECPC Vice-President

mHealth and eHealth are becoming a reality in the cancer patients' pathways. Much of their potential, however, remains unknown to patients and under-exploited by healthcare professionals. ECPC will present a few success stories to showcase how mHealth and eHealth can contribute to improve patients' outcomes.

Speakers:

Dave de Bronkart, the famous @epatientDave leader of the participatory medicine movement
Dee O'Sullivan, Managing Director of myhealthapps.net

17.00 – 18.00 MEETING OF RARE CANCERS PATIENT ORGANISATIONS

During the meeting, ECPC Members and non-Members representing the rare cancers patients community will meet with Dr Trama to discuss about their collaboration within the Joint Action.

19.30 DINNER

3rd DAY **SUNDAY 5 JUNE**
ANNUAL MEETING OF THE ECPC GENERAL ASSEMBLY

09.00 – 09.10 APPROVAL OF THE MINUTES FROM THE LAST AGM

09.10 – 09.40 2015 ANNUAL REPORT

Presentation of the 2015 annual report

09.40 – 09.50 Questions from members on the activity report

09.50 – 10.20 2015 FINANCIAL REPORT

Presentation of the 2015 financial report and the budget for 2016 by ECPC Director Mihaela Militaru

Presentation of the Audit Report

10.20 – 10.30 VOTE ON ANNUAL AND FINANCIAL REPORTS

10.30 – 10.40 PRESENTATION BY THE “CONFIRMATION OF ELIGIBILITY COMMITTEE”

**10.40 – 11.20 PRESENTATION OF THE NEW ECPC BOARD MEMBERS:
VIEWS AND STRATEGY**

11.20 – 11.30 PRESENTATION OF THE NEW AUDIT COMMITTEE

11.30 – 12.00 COFFEE BREAK

12.00 – 12.30 OTHER BUSINESS

Any other business or topics not yet discussed during the AGM

Closing remarks



This event is organised with the support of:

abbvie

AMGEN

AstraZeneca 

 Boehringer
Ingelheim


Bristol-Myers Squibb

 Celgene

Genomic Health™

 **IPSEN**
Innovation for patient care

Johnson & Johnson

Lilly

 **MSD**

 Pfizer

 Roche