



EUROPEAN
CANCER
PATIENT
COALITION

ECPC GENERAL ASSEMBLY

ENSURING THE RIGHTS OF CANCER PATIENTS IN EUROPE


HOTEL NOVOTEL
BUCHAREST ROMANIA

June 20-22, 2014

**ECPC GENERAL ASSEMBLY
ENSURING THE RIGHTS OF CANCER PATIENTS IN EUROPE**

HOTEL NOVOTEL

Friday, 20 June

	Registration desk opens at 15.00 p.m.
17:00–18:00	Informal meeting with the Board
18:00–19:00	Sustainability of patient organizations in difficult times <i>A hands-on workshop on fundraising and advocacy matters</i> <i>Maria Moudatsou, PRAKSIS, Greece (PARIS RIVE GAUCHE ROOM)</i>
19:00–20:00	Presenting the work in progress of the movie “The Network” – a documentary film on the missing cancer drugs and their smuggling to Romania (A production Parada Film/Wearebasca) (Director: Claudiu Mitcu) <i>* followed by a debate in the presence of the film Director</i>
21:00–22:00	Cocktail

Saturday, 21 June



OPENING

09:00–09:30

Coordinator: Mihaela Militaru, *Director ECPC*

Building on our 10-year legacy

Francesco de Lorenzo - President of ECPC

The principles on which ECPC was established

Lynn Faulds Wood – former ECPC President and co-founder

09:30–11:00

1st Session: Patients ask policy makers: can all Europeans access cancer care?

Coordinator: *Kathi Apostolidis, Vice-President of ECPC*

1.1. Romania's plan to reduce inequalities in cancer care

Prof. dr. Dorel Săndesc, Secretary of State, Romanian Ministry of Health

1.2. A catalyst for change:

The European Cancer Patient's Bill of Rights

Prof. Mark Lawler, Project Lead, European Cancer Concord (ECC)

1.3. How MEPs can highlight and advocate against healthcare inequalities in Europe

Cristian Busoi - MEP Romania

1.4. The Commissions' perspective on tackling inequalities in cancer care in Europe

Mr. Antoni Montserrat, Policy Officer for cancer and rare diseases, Directorate of Public Health, European Commission

1.5. Healthcare journalism and its role

Vlad Mixich, 2014 Eisenhower Fellow for Innovation, Journalist

Discussion

11:00–11:30

Coffee Break – Press statements

11:30–12:30

2nd Session: Patient empowerment starts with knowledge

Coordinator: Rafal Swierzewski, *ECPC Board Member*

2.1. Patient involvement in medicines evaluation within the European Medicines Agency

Nathalie Bere, Stakeholder & Communication Division, EMA

	<p>2.2 The importance of Biobanking in Cancer- patient's perspective <i>Peter Riegman - Leader of WP10 'Biobanking' of Eurocanplatform</i> <i>Maggie Wilcox - Independent Cancer Patients' Voice</i></p> <p>Discussion</p>
12:30–12:45	Coffee Break
12:45-13:25	<p>3rd Session: Access to cancer care Coordinator: Francesco De Lorenzo, President</p> <p>3.1. The importance of access to radiotherapy <i>Prof. Dr. Ion-Christian Chiricuta, Amethyst Radiotherapy Clinic (Romania)</i></p> <p>3.2. The importance of evidence: Cancer registration <i>Ana-Maria Forsea, MD, PhD, Assistant Professor of Dermatology, Carol Davila University of Medicine and Pharmacy Bucharest</i></p> <p>3.3. Equal chances : access of Romanian patients to innovative and personalised treatments <i>Nela Păvăloiu, President, European Development Platform</i></p> <p>Discussion</p>
13:25–14:25	Lunch
14:25-15:15	<p>4th Session: Cancer patient rights: tools for advocacy Coordinator: Jana Pelouchova – Secretary of ECPC</p> <p>4.1. The Cross-border Healthcare Directive – A myth or a fallacy ? <i>Kathi Apostolidis, Vice-President ECPC</i></p> <p>4.2 Defending your rights as cancer patients to the European Courts <i>Prof. Andrea Saccucci, Ph.D. - International Law at the University of Naples II</i></p> <p>Discussion</p>
15:15-15:30	Coffee Break
15:30-16:50	<p>ECPC Members take the floor 7 patient organizations present their best practices</p>

16:50-17:05

Break

17:05–18:35

Assessing members' needs, contributions and potential for collaboration, Introduction by Francesco de Lorenzo

"What can ECPC do for me?"

"How can I contribute as a member for this to happen?"

ECPC Members will reunite in Working Groups. Each Working Group will have a facilitator that will collect the priorities, suggestions for actions needed on the most relevant action areas (e.g. National CancerPlans, Access to Medicines, Access to Employment and Social Benefits, etc.)

ECPC WGs and facilitators:

- *Access to employment and social benefits – Kathi Apostolidis*
- *Access to integrated cancer care (Medicines, Radiotherapy, Rehabilitative Care) - Vlad Voiculescu*
- *Paediatric Oncology – Rafal Swierzewski*
- *Rare Cancers – Kalliopi Christoforidi and Jana Pelouchova*
- *Head and Neck Cancers – Mihaela Militaru*
- *Lung Cancer - Francesco de Lorenzo*

18:35-18:45

Conclusions – Francesco de Lorenzo, President


20:00-22:00

Gala Dinner at CASA DOINA

(www.casadoina.ro)

Sunday, 22 June

Formal Annual General Meeting of ECPC

	
09:00	ECPC President announces the opening of Annual General Meeting 2014 Nomination of the AGM Secretary Approval of 2013 AGM Minutes Annual Report of ECPC <i>Francesco de Lorenzo - President and Kathi Apostolidis - Vice-President</i>
10:00	Treasurer Report and Audit Committee Report <i>Vlad Voiculescu, Vice President & Treasurer</i> <i>Hannu Tavio-Audit Committee</i>
11:00–11:15	Voting of the Treasurer's Report and Approval of the budget
11:15	Transfer of ECPC seat from the Netherlands to Belgium <i>Francesco de Lorenzo, ECPC President</i>
12:00	Presentation of the conclusions and closing of the AGM by ECPC President

ECPC gratefully acknowledges the support of:

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www.ecpc.org

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