



EUROPEAN
CANCER
PATIENT
COALITION

ECPC GENERAL ASSEMBLY
BUCHAREST, 20TH -22ND JUNE 2014

SPEAKERS' BIONOTES



PRAKIS

Maria Moudatsou

Maria Moudatsou is a Forensic Psychologist and the Director of Institutional and Vertical Fundraising at NGO Praksis, where she works since 2005. Previously, she held the post of Director of Communications & Fundraising. She has an extensive and diversified experience of EU Funded Projects & co-funded projects, mainly related to social vulnerable groups, research, social intervention and lobbying. (such as Equal, ERF, FP7, Progress, Leonardo, ERF Community Actions, EIF, ERT, EACEA, ERF, ISEC, Daphne, NSRF, PPVT etc.) for intervention programs for social vulnerable groups, research and advocacy on issues such as asylum seeker/ refugee policy, migration, health services, criminal justice system, trafficking, drugs etc.

Mrs Moudatsou is also active in advocacy, taking part in several meetings with Greek and / or EU representatives and/ or Governmental representatives of Ministries of Member States and/ or EU and International Organizations. She has extensive experience in fundraising and NGO sustainability, strategic planning interventions and strategic alliance building.

Her academic interests and experience relate to migration policy, asylum procedures and penal policy. She has teaching experience in adult education (Criminological Psychology, empowerment teams, migration/refugees, trafficking, establishing associations, networking, strategic policy of civil society, fundraising and sustainability, capacity building). She has studied in the UK, at Middlesex University (BSc) and Manchester Metropolitan University (MSc). At the moment, she is working at her PhD thesis on trafficking.

She has participated in many conferences as a member of the organizing and scientific committee as well as a speaker and trainer / expert in workshops at Greece and other Member States; such as at the European Patients' Forum as an expert in fundraising and strategic planning; training representatives from patients organizations from Greece, Italy, Spain and Portugal.



*Former ECPC President
and co-founder*

Lynn Faulds Wood

Lynn is the founding President of European Cancer Patient Coalition and a cancer survivor (colon & skin cancers). She is an award-winning BBC TV presenter & investigative journalist. Thanks to her successful career, she has involved major celebrities in the UK and Europe in campaigns to raise awareness of colon/bowel cancer.

When the EURO CARE data showed that the UK had poorer survival from cancer than most of Europe, Lynn helped to set up the European Cancer Patient Coalition to bring together patients across Europe. She ran ECPC for eight years as its first Chair/President. She also helped to develop screening guidelines for colon cancer in Europe with IARC (International Agency for Research on Cancer) and to launch awareness and screening campaigns in many European countries.

In the UK she helped to produce the world's first evidence-based symptoms of colon cancer and pioneered formal training & accreditation centres for colonoscopy. She has also opened many colon cancer centres and endoscopy units in UK hospitals.

Dorel Săndesc



*State Secretary
Romanian Ministry of
Health*

Prof. Dr. Săndesc is one of the most renowned Romanian physicians, currently President of the Romanian Society of Anaesthesia and Intensive Care.

Prof. Dr. Săndesc studied at the University of Medicine and Pharmacy, Cluj-Napoca, Romania. He received further training in Anaesthesia and Intensive Care at the "V. Babes" University of Medicine and Pharmacy, Timisoara, Romania. Awarded with several fellowships to enhance his specialisation in anaesthesia and intensive care (England, Holland, France), he obtained a Diploma of In-Depth Specialisation in Anaesthesia and Intensive Care from the Academy of Lyon, France.

As an affirmed physician, Prof Săndesc is member of several medical associations, including the European Society of Intensive Care Medicine, the World Federation of Societies of Anaesthesiologists (as •Member of the Executive Committee). He is Head of the Surgery Department within the "V. Babes" University of Medicine and Pharmacology, Timisoara, and also Head of the Anaesthesia and Intensive Care Department, County Emergency Hospital, Timisoara, Romania

Prof. Dr. Săndesc published more than 80 scientific papers, articles and monographies, both in Romanian journals and international ones. This reflects his research activity: he was awarded with 7 national research grants and he holds the position of principal Investigator in 22 International Clinical Trials.



Project Lead, European Cancer Concord (ECC)

Mark Lawler

Prof Mark Lawler is Chair in Translational Cancer Genomics and Associate Director of Postgraduate Studies, Centre for Cancer Research and Cell Biology, Queen's University Belfast. He is a member of the European Alliance for Personalised Medicine (EAPM) and is leading their development of a Research Roadmap for Personalised Medicine in Europe. In addition to his focus on translating research discoveries for patient benefit, Mark also has a keen interest in both research and cancer care policy. He sits on a number of European Commission/European Research Council Committees in Brussels.

He has been to the forefront of a number of patient focussed cancer healthcare initiatives at the national and EU level. Over the last two years, he was project lead for the European Cancer Concord (ECC), a pan European initiative involving equal partnership between patients and their advocates and health care professionals, which aims to remove inequalities and improve cancer care for the citizens of Europe. The efforts of the ECC came to fruition with the launch of the European Cancer Patient's Bill of Rights on World Cancer Day, 4th February 2014 in the European Parliament in Strasbourg.



Member of the European Parliament

Cristian Busoi

Cristian Busoi, at the second term as an MEP, is very familiar with the issues affecting the health sector, both at national and EU level. He graduated the Faculty of Medicine, University of Medicine and Pharmacy 'Carol Davila', Bucharest and has a Ph.D. in Public Health and Health Management from the University of Medicine and Pharmacy in Timisoara. Before joining the European Parliament, Mr. Busoi was a member of the Romanian Parliament, where he was part of the Health Committee. In June 2013, he was named head of Romania's National Health Insurance Fund, subsequently resigning from the European Parliament. Cristian Busoi is co-author of the book "EU Health Policies".



Journalist

Vlad Mixich

Vlad Mixich is senior editor for HotNews.ro and editorial coordinator for "Viata Medicala", a weekly medical newspaper. He is Eisenhower Fellow for Innovation in 2014 and has won several awards for his work, including the Milan Kundera Prize for his first book. He holds a degree in Medicine and Psychotherapy and was a fellow of the German Marshall Fund of the United States and of The Carter Centre, USA.



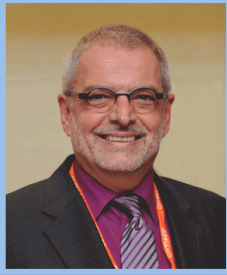
Stakeholder & Communication Division, EMA

Nathalie Bere

Nathalie has been working at the European Medicines Agency (EMA) for over 16 years and is currently responsible for the interaction and involvement of patients and consumers in EMA activities. The EMA is the EU regulatory Agency responsible for the scientific evaluation and supervision of medicines developed for use in the European Union.

Since January 2009, Nathalie has been dedicated to supporting the Agency's engagement with patients and consumers via a network of over 37 European patients and consumers organisations, including management of the Agency's "Patients and Consumers Working Party" (PCWP). Her work involves not only the daily interactions with patients, but also developing and monitoring the scope of involvement of these stakeholders within the various Agency activities, such as participation in scientific advisory groups, committee consultations and the review of medicines information for patients.

During the past few years there has been a significant increase in patient participation and Nathalie is committed to further strengthening this involvement, with particular emphasis on ensuring adequate training and support is given to those who participate.



*Leader of WP10
'Biobanking'
Eurocanplatform*

Peter Riegman

Peter Riegman is Molecular Biologist and head of the Erasmus MC Tissue Research Support Unit including the Erasmus MC Tissue Bank.

Peter has a vast experience within EU funded research project. He is currently involved in 3 European projects, EurocanPlatform, EEC and BIOPOOL. Previously, he contributed to SPIDIA, BBMRI, EuroBoNeT, ENCCA and coordinated TuBaFrost.

Peter is also active within major cancer-related associations. He served as OECI-WG biobanks chair 2006-2010, he held the presidency of ISBER in 2010, followed the next year by his mandate as ESBB president (2011).

He is now member of the Biopreserv. Biobank. Editorial board, BBMRI-LPC SEAC, P3G ISC and Dutch PSI UMC coordinator for Erasmus MC.



*President
Independent Cancer
Patients' Voice*

Maggie Wilcox

Maggie worked as a Health visitor with Geographic and a GP practice case load plus experience as specialist within a social services team and with elderly in the community. Afterwards, she worked as a CNS in Palliative Care – mostly as Nurse Director of a large community team providing 24hr cover but also as hospital Macmillan Nurse before retiring after breast cancer diagnosis.

She was treated in 1997 with surgery and radiotherapy followed by mastectomy in 1998, due to post-radiotherapy problems. She undergone an endocrine therapy with Tamoxifen as well, followed by Letrozole. So far the situation seems to have been normalised.

Maggie gathered most of her advocacy experience in relation to breast cancer research. Her deep interest in Biobanking started before her cancer diagnosis.

Maggie is the president of Independent Cancer Patients Voice and association keen to raise public awareness on the need for tissue donation. Member of CCB, HTA Stakeholder Group, Local Cancer Partnership Group, several TMGs, the UK Breast Intergroup and the SLOANE Group.



*Amethyst Radiotherapy
Clinic*

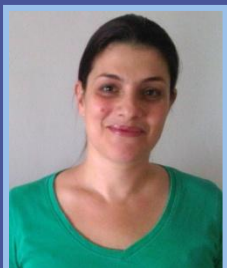
Ion-Christian Chiricuța

Prof. Dr. Ion-Christian Chiricuța is internationally renowned in radiotherapy having devoted his career to treating cancer patients.

Between 1965 and 1980 he studied Atomic and Nuclear Physics at the Faculty of Physics (University of Cluj Napoca) as well as General Medicine at the Medico-Pharmaceutical Institute in Cluj Napoca. Prof. Dr. Chiricuța obtained in 1978 a Ph.D. in Physics from the Babes-Bolyai University and the title of medical doctor at the Institute of Medicine and Pharmacy in Cluj. From 1988 to 1995 Prof. Dr. Chiricuța worked in the Radiotherapy Clinic of Wuerzburg University and since 1991 he is a specialist doctor in radiation therapy.

In 1996 Prof. Dr. Chiricuța was appointed chief physician and director of the Institute of Radiation Oncology at the Hospital St. Vincenz Limburg, where he was active until 2010. In the same year, Dr. Chiricuța obtained a Ph.D. in Medicine at Wuerzburg University and in 2002 he received the title of professor at the University of Wuerzburg.

Currently Prof. Dr. Chiricuța teaches with the University of Medicine and Pharmacy Carol Davila. He is the author of three books on oncology and radiotherapy, co-author of 4 other books and authored over 40 articles in various publications.



*Assistant Professor of
Dermatology
University of Medicine
and Pharmacy Bucharest*

Ana-Maria Forsea

Dr. Forsea acquired her dermatology specialty training in Bucharest, Romania and in Berlin, Germany, and her PhD degree at the Free University of Berlin, Germany. She completed her education with the Visiting Fellowship of the American Academy of Dermatology at Memorial Sloan-Kettering Cancer Centre, New York, USA and pursued her post-doctoral research as Visiting Scientist at Harvard School of Public Health, Boston, USA.

Her main fields of interest are skin cancer prevention and education programs, skin cancer registration, melanoma early detection and screening strategies, dermoscopy and imaging technologies for the in vivo diagnosis of skin diseases, and medical and public education for skin diseases prevention



*President, European
Development Platform*

Nela Pavaloiu

Nela Păvăloiu, President of the Human Values Foundation, has been active in the NGO sector for more than 15 years and developed important cultural and social projects for young people and children across Europe.

In 2010, Mrs. Pavaloiu has founded the European Development Platform in Brussels and Bucharest, a platform for dialogue based on generating debates and meetings between local and European groups in order to initiate and contribute to an interactive dialogue on current issues, aiming to provide economic smart solutions, to support the implementation of economic and social projects.

Among other projects, the European Development Platform has been running since last year the national campaign "Choose Personalised Medicine", a programme aimed to improve the access of Romanian patients to innovative treatments and equality of chances.



*Ph.D. - International Law
at the University of
Naples II*

Andrea Saccucci

PhD in Human Rights at the University of Palermo in 2002; Associate Professor of International Law at the Seconda Università di Napoli; Professor of Migration Law at the LUMSA of Rome; Professor of International Protection of Human Rights at the ASERI and the Università Cattolica of Milan; Visiting Scholar at the Law School of the Columbia University of New York in 2006; Practicing lawyer specialized in litigating individual and collective cases before the European Court of Human Rights; Expert of the Council of Europe, EU and OSCE in the framework of training activities and fieldwork for lawyers, judges, prosecutors and ombudsman throughout Europe; Author of many books and articles in international law and human rights.

ECPC SPEAKERS AND FACILITATORS



President

Francesco De Lorenzo

Francesco is a colon cancer survivor, medical doctor and professor of biochemistry – University Federico II Naples. He has a rich experience in cancer advocacy being the co-founder, former Vice President and Board member of ECPC. He is also the founder and president of the Italian Associations of Cancer Patients (AIMaC), Italy's first Cancer Information Service (CIS), and of the Italian Federation of Cancer Patients Organisations (FAVO). Francesco is also active in Italy's governmental network of cancer Institutes (ACC), Italy's National Cancer Plan Committee and National Volunteer Observatory of the Italian Welfare Ministry. Francesco engaged in Italian politics as Member of the Parliament, holding several ministerial mandates (Ministry of Health, 1989-1993). At the EU and international level, Francesco is member of the ESMO Patient Advisory Group, works in the EPAAC WP9, participates to the European collaborative Group on Cancer Survivorship (ECGCS) where he serves as a member, and he is also a Founding Member of the Elite Oncology Roundtable, created under the auspices of the Society for Translational Oncology – STO, from which the European Cancer Patients Bill of Right originated.



Vice President

Kathi Apostolidis

Kathi is a Public Affairs Consultant with extensive experience in regulatory affairs, marketing and communications. Twice breast cancer survivor, she was involved since 1995 in cancer patient rights advocacy. She is Chair of the Intergroup Committee for Cancer Patient Rights Advocacy/Greece (DEDIDIKA) and member of other Greek & international breast cancer associations. She is involved in e-health and m-health integration in healthcare policy, in social media in healthcare and is a member of the Strategic Committee for DigitalGreece2020, co-founder of #opnhealth, a frequent invited speaker at medical conferences, a member of the Advisory Board of «Doctors2.0 & You» and of «Patients in Power» conferences, of the Society for Participatory Medicine, and a Salzburg Global Seminar Fellow.



*Vice President
Treasurer*

Vlad Voiculescu

Vlad is a Romanian economist based in Vienna. In 2009, moved by the experience of a friend fighting cancer Vlad embarked on a journey that changed his priorities, his career and ultimately his life. Vlad's main objective is to ensure equal access to treatment to all cancer patients in Europe. He is also a long-time volunteer and founding member of the several organizations in Romania. Among his main engagements, Vlad administers an information platform for patients and doctors (www.medicinainternationala.ro) and an information platform raising awareness about shortages of cancer drugs in Romania (www.medicamente-lipsa.ro). Vlad is an Aspen Institute fellow.



Secretary

Jana Pelouchova

Jana is a patient, founder and chairperson of Diagnoza CML patient society in Czech Republic (chronic myeloid leukaemia - CML). As a co-founder of the CML Advocates Network and president of the Leukaemia Patient Advocates Foundation she is active in the international CML patient community. Jana is an ECPC Board Member and Secretary since 2011 and ECPC representative in the Rare Cancers Europe and ECCO Patient Advisory Committee.



Board Member

Elena Caruso

Elena is an IT Engineer with expertise in communications currently working at Toyota Company based in Brussels. Elena is a cancer carer, having taken care of her father when he was diagnosed with a Non-Hodgkin (LNH) stomach lymphoma. Seven years later he was diagnosed with acute leukaemia which caused his death. Elena is a Board Member of Associazione Bianco Airone Pazienti Onlus (ABAPO), an Italian cancer patients group supporting cancer patients and families to improve quality of life, for which she is in charge of international relations.



Board Member

Sarah Lindsell

Sarah has 20+ years experience in NGO's joining The Brain Tumour Charity in April 2011 from The Challenge Network where she was Director of External Affairs and Fundraising. Prior to this, she held the role of UK Services Director for The Duke of Edinburgh's Award a federated structure. Sarah previously held the roles of: CEO for Caritas, a lobbying federation that addresses poverty and injustice, part of the umbrella body Caritas Internationalis; and CEO for a grass-roots charity helping those living in poverty. She maintains an active commitment to supporting health and social justice issues, has undertaken research in family support and voluntary sector management, has a Masters degree in Voluntary Sector Management and First Class degree in Social Policy. Sarah was involved at European level with Caritas Europa and lobbied on health and social care issues on behalf of member organizations and their patient/user groups.



Board Member

Rafal Swierzewski

Rafal is a scientist and a cancer survivor of fibrosarcoma. He works at the Foundation for Children with Cancer Diseases "Krwinka" - Poland. He earned his PhD in 2006 from the Institute of Physical Chemistry of the Polish Academy of Sciences and was a trainee at the Istituto per lo Studio delle Macromolecole, Consiglio Nazionale delle Ricerche, Genova, Italy.

His scientific work covers physico-chemical properties of biologically active compounds, drugs used in cancer chemotherapies and model substances properties in intercellular environment. Rafal is a member of the Polish Society of Thermal Analysis and Calorimetry, he has served as member of numerous Scientific Conference Organizing Committees and he is a graduate of the HTA/PatientAcademy/LSE.



Director

Mihaela Militaru

Mihaela Militaru joined ECPC in August 2013 as Director. Prior to this she had worked in EU affairs for 12 years, first as a liaison officer of the Senate of Romania with the European Parliament and subsequently as a policy adviser within the European Parliament (8 years). Her activity in the European Parliament focused in the last years on healthcare policy and the measures needed at EU-level for fighting diseases such as cancer, multiple sclerosis, autism and fibromyalgia. Mihaela holds a Masters' Degree in International Relations and European Affairs from the National School for Political and Administrative Studies in Bucharest as well as a Masters' Degree in Conference Interpreting from the University of Bucharest, Faculty of Foreign Languages. Mihaela speaks Romanian, English, French and Bulgarian and has basic knowledge of Spanish and Italian.