Speaker Background Briefing

Oncology Collaboration: Patient Group Summit

15-16 September 2017

Vienna

Summit overview

The summit will be a structured but relaxed forum which aims to inform, empower and equip patient groups so that are better able to address the challenges they face. The meeting will also encourage relationship building and the strengthening of peer-to-peer networks between groups and countries.

Logistics

Title: Oncology Collaboration: Patient Group Summit
Location: The Hilton Garden Inn, Vienna, Austria
Date: 15-16 September 2017
Contact information: oncologycollaboration@portland-communications.com

Summit objectives

- **Bring together** the cancer patient community to encourage sharing of experiences and ideas

- **Facilitate dialogue** and learning about capacity building, communications and effective cancer policy campaigning

- **Inform** the community about relevant developments in cancer and global standards

- **Empower** patient advocates to take on old challenges with new insight

- **Equip** organisation with new skills and knowledge to be more effective

Speakers

Name	Affiliation
Professor Tit Albreht	Ljubljana Medical Faculty, Slovenia
Professor Mark Lawler	Queen's University Belfast, UK
Professor Vahit Ozmen	Istanbul University, Turkey
Mr Bartosz Polinski	Alivia Foundation, Poland and UK
Mr Kawaldip Sehmi	The International Alliance of Patients' Organizations (IAPO)
Ms Maja Juznic Sotlar	VIVA Magazine, Slovenia
Professor Richard Sullivan	Institute of Cancer Policy, King's College, London, UK

Tit Albreht, Associate Professor of Public Health at the Department of Public Health, Medical Faculty in Ljubljana, Slovenia

Professor Albreht received his PhD from the University of Amsterdam in Health Services Research in 2011. He has been a consultant to the WHO for the past 12 years and a health services and health system researcher with interests in developing modern patient-oriented and equitable health systems. He dedicates his research to the exploration of the health services nationally and internationally. He has interests in the performance of health systems, evidence based health policy, health workforce planning and mobility and the development of more efficient healthcare.

Since 2006, Professor Albreht has been actively involved in the development of cancer policies at the European level, in particular during the Slovenian presidency to the Council of the EU. He co-ordinated the Joint Action Cancer Control (CanCon), dedicated to the development of health policy support and advice to cancer control policies at the level of the EU and of the Member States.

Mark Lawler, Chair in Translational Cancer Genomics at Queen's University Belfast

Mark Lawler is a Professor with over 20 years' experience in cancer research. He is Associate Professor in Experimental Haematology/ Oncology, TCD, Chief Molecular Geneticist at St James's Hospital, Honorary Associate Professor in Oncogenetics, Smurfit Institute of Genetics, TCD and visiting Professor in Medical Genetics and Molecular Medicine, University of Chieti, Italy. He has published over 100 articles in international peer review journals and has been honoured with numerous awards including the Vander Molen Prize for Leukaemia Research, the Ely Lilly Prize, the Ulster Cancer Foundation Prize.

Mark is also President of the Irish Association for Cancer Research and has recently been appointed as Chair of the Scholar Exchange Group. Professor Lawler was recently Director of Post-graduate Teaching and Learning in the School of Medicine, Trinity College Dublin and has a significant commitment to scholar exchange. Mark has a long history of working with patient representatives; in partnership with other authorities in oncology and ECPC, Mark published a position paper in 2015 on inequalities in cancer care called Challenging the Europe of Disparities in cancer'.

Professor Vahit Ozmen, Istanbul Medical Facility, Turkey

Vahit Ozmen is Professor of Surgery at the Istanbul Medical Faculty of Istanbul University.

He is also a founder member and Secretary General of the World Breast Health Association, and has published several books on Breast Cancer in Turkey. Professor Ozmen is also a founding member of the Turkish medical societies for surgery, kidney transplantation, laparoscopic and endoscopic surgery and breast health.

Bartosz Polinski, CEO, Alivia Foundation, Poland. Chairman, Alivia Foundation UK

Bartosz is the founder and CEO of the Alivia Foundation, Poland. The Alivia Foundation runs a number of programmes aimed at helping young people seek the right cancer care. The organisation aims to improve awareness of cancer and also represent oncology patients in public debate. The organisation was set up in 2010 after Bartosz found it difficult to get the oncology care his sister needed after being diagnosed at the age of 28. Since then, the Alivia Foundation has helped other families to navigate the health system and assists financially where the national health fund cannot.

Kawaldip Sehmi, CEO of IAPO

Kawaldip is the CEO of IAPO (the International Alliance of Patients' Organizations) which is a unique global alliance representing patients of all nations across all disease areas. IAPO works with its member organizations to get patients' voices heard by everyone involved in healthcare.

IAPO works to promote patient-centred healthcare around the world. Currently, IAPO has 276 member organizations from 71 countries representing 50 disease areas. The IAPO vision is to see patients placed at the centre of healthcare. The mission of IAPO is to help build patient-centred healthcare worldwide.

Kawaldip oversees the strategy and direction of IAPO. He has extensive public health experience, previously having held leadership positions at Richmond Psychosocial Foundation International, Coram Children's Legal Centre, the Global Health Inequalities Programme and the European Network of Quitlines. Kawaldip's qualifications include an MSc in the Public Health International Programme from the London School of Hygiene and Tropical Medicine, an MBA in Business Administration from the London Business School and Open University, and an LLB (Hons) from the London College of Law.

Maja Juznic Sotlar, Editor of special editions on health, VIVA

Maja has been a journalist covering health matters for 20 years. Maja currently works as a staff member for the Viva magazine, one of the leading health care magazines in Slovenia. Maja has a special interest in oncology. Maja frequently writes articles on different aspects of oncology, organises press conferences and other media events, symposia for professional audiences and health care campaigns. As a founding member of EuropaColon Slovenia, Maja is very active in raising awareness in the field of colorectal cancer and also edits the organisation's newsletter Koloskop.

Richard Sullivan, Director, Institute of Cancer Policy, King's College, London

Richard Sullivan is Professor of Cancer and Global Health at Kings College London and a Director at the Institute of Cancer Policy and Co-Director of King's Conflict & Health Research Group. He serves on the executive boards of King's Health Partners Comprehensive Cancer Centre, the King's Centre for Global Health and the Union for International Cancer Control. Richard qualified in medicine, and trained in surgery (urology) gaining his PhD in cell signalling from University College London. He was clinical director of Cancer Research UK between 1999 and 2008. Following a period at the London School of Economics working on complex healthcare systems he moved to Kings College London in 2011. Richard's research programmes focus on global cancer policy and conflict & health.

Invited Patient Groups

Country	Patient Groups
Belarus	In the name of Life
Bulgaria	National Patients Organisation of Bulgaria
Croatia	Coalition of Associations in Healthcare
Czech Republic	League Against Cancer, Prague
Czech Republic	Onko Unie
Estonia	Estonian Cancer Society
Hungary	Recovering Together
Israel	Flute of Life
Israel	Israel Cancer Association
Kazakhstan	Together against cancer
Latvia	Latvian Cancer Society/Tree of Life
Lithuania	Association of Oncology
Poland	Alivia
Poland	Polish Cancer Patients' Coalition
Romania	The Romanian Cancer Society (Member of FABC)
Russia	Zdravstvuy
Russia	All Russian Society of Haematological Diseases
Serbia	NORBS
Slovakia	Association for the Protection of Patient's Rights
Slovenia	Onko-Net
Turkey	Pink Lady
Turkey	Memeder
Ukraine	Equal Right to Life

Agenda overview

Day One - Friday 15 September

Session one: Opportunities and barriers in patient advocacy

09.00	Introduction, objectives and Pfizer's role in patient advocacy	Pfizer
09.30	Icebreaker: Experience sharing	Portland
09.55	European patient groups in cancer care	R Sullivan
10.10	No decision about the patient without the patient	M Lawler
10:45	**Coffee**	
11.00	How to tell your story	Portland
11.20	Workshop: your message and ensuring it is understood	Portland
12.30	**Lunch**	

Session two: Patient groups in policy decisions

13.20	The role of National Cancer Control Plans/policy	T Albreht
14:05	A Turkish case study by Dr Vahit Ozmen	V Ozmen
14.25	Introduction: Engaging with policy makers	Portland
14.35	Workshop: Engaging with policy makers	Portland
15.30	**Coffee**	

Session three: Partnerships and campaigning for change

15:45	A Polish case study from Alivia Foundation	B Polinski
15:55	Introduction: media strategy, digital and pitching stories	Portland
16:15	Workshop: media strategy, digital and pitching stories	Portland
17.15	Working with the Media - Expert Panel: (Albreht, Lawler, Polinski, Sotlar, Sullivan)	
18.15	Recap	Portland
19.00	**Dinner**	

Day Two - Saturday 16 September

Session four: The power of patient groups

09.00	Recap and overview	Pfizer/Portland
09.30	The importance of the patient group and the network	K Sehmi
10:15	Introduction: Overcoming common challenges	Portland
10.35	Workshop: Overcoming common challenges	Portland
11.35	**Coffee**	
11.50	Round-up session	Delegates
12:30	Summary and close	Pfizer/Portland
13:00	**Lunch**	