



**World Cancer Congress**  
Kuala Lumpur, Malaysia  
1–4 Oct 2018

**Strengthen  
Inspire  
Deliver**



## 2018 Patient Group Pavilion – Preliminary Programme

15 January 2018

### Congress Day 1: *Organisational framework*

Presenters name and organisation	Presentation Title	Presentation Summary
Mrs Norsidawati Abdul Gani, Program Manager, KanWork Cancer Society, Malaysia	The Development of Culturally Appropriate “My Story”	Participants will gain understanding of how the development of cancer patient stories may help others undergoing similar challenge, and how it should be culturally and contextually adapted
Dr Rajesh Bhalla, Medical Adviser, Indian Cancer Society (Delhi Chapter), India UICC Member	Utilization and reporting of breast screening via tele-radiology	Participants will gain understanding of how breast screening process conducted as an out-reach programme closer to women’s home environment, could reduce mortality/morbidity
Prof. Dan Cimpoeru, Board Member, European Cancer Patient Coalition, Belgium UICC Member	How Europeans can defend their legal rights for access to care	Participants will gain understanding of successful legal campaigns for better cancer care, with practical examples. The presentation will promote best practice sharing in order to drive change
Prof. Francesco De Lorenzo, President, European Cancer Patient Coalition, Belgium UICC Member	Supporting Europeans caring for someone with cancer	Participants will gain understanding of the societal importance of informal care giving, and practical examples of national and European policies to support families that contain someone affected by cancer
Ms Ibtisam Ghrayeb, Head nurse, Pediatric intensive care unit, Al Makassed Hospital East Jerusalem, Palestine	Music therapy help build a bridge among all people	Participants will learn how music therapy as a new mean can help patients and their families to face cancer and other diseases

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Mrs Vandana Gupta, Founder, V Care Foundation, India UICC Member	Navigating Cancer Care	Participants will learn more about the journey of cancer patients and their challenges in the Asian region from pre-symptoms-access care-financial considerations including health insurance cancers-quality cancer care-life after cancer to palliative care
Dr Syed Humayun Jafri, Head, Public Relations Department and International Patient Advisor, Tata Memorial Hospital, India UICC Member	Learning to cope with eventualities	Participants will hear about an initiative that brings together the parents of pediatric cancer patients in an environment where they learn how to cope with issues related with the treatment which ultimately reduces the number of children patient's treatment drop-outs in the long run and in turn will increase patient survival rate
Ms Katherine Lane, Nurse Manager - Cancer Council 13 11 20, Cancer Council Victoria, Australia UICC Member	Use of simulated patients in the induction and training of oncology health professionals & volunteers	Participants will gain learn about innovative approaches to health professional and volunteer induction and training, relevant to their work environment, and ways to identify the different communication skills that are required when providing support via different mediums to people affected by cancer
Dr Lydia Malakoff, Director, European Cancer Patient Coalition, Belgium UICC Member	Realising the global voice of people with bladder cancer	Participants will be able to take away and apply strategies for motivating volunteers, coordinating digital online collaboration platforms, translating early detection awareness campaigns into multiple languages and cultures, mapping and identifying assets, and forming a coalition between geographically and culturally diverse organisations
Ms Nor Aida Maskor, Cancer Awareness Program Manager, KanWork Cancer Society, Malaysia	Strategic Collaborative Cancer Awareness Campaign at Mosque	Participants will hear about ways to promote healthy lifestyle and cancer early detection in community's religious centers (ie: a mosque)
Ms Geraldine McDonald, Director Wellbeing, Peter MacCallum Cancer Centre, Australia UICC Member	Patient Navigation in Cancer Care: Is it worth the investment?	Participants will hear examples of best practice for patient navigation and the critical success factors for an effective patient navigation programme
Dr Stephanie Michaud, President & CEO, BioCanRx, Canada	From Muridae to Homo: Patient-researcher engagement in the research translation continuum	Participants will learn how to provide opportunities to support the knowledge exchange between patients and researchers, and how to facilitate networking efforts to create and enable patient leaders and academic scholars to work together on translational projects.
Ms Jillian Mills, Practical Support Manager, Cancer Council NSW, Australia UICC Member	Webinars for Chinese Migrants with Cancer: Findings from a Systematic Review and Focus Groups	Participants will learn how using innovative webinar technology to empower and support Chinese migrants' affected by cancer

Dr Suraiya Mohammed, Chief Operating Officer, Medicaid Cancer Foundation, Nigeria UICC Member	Kick Out Cancer Campaign	Participants will hear how to create awareness and raise funds for cancer through the game of football
Dr Mazanah Muhamad, President, KanWork Cancer Society, Malaysia	Bereaved Loved Ones Peer to Peer Support	Participants will be able to gain insight into Peer to Peer Support provided to bereaved families and parents
Dr Vitalis Okwor, Radiation Oncologist, University of Nigeria Teaching Hospital (UNTH) Enugu, Nigeria UICC Member	Impact of Support Group Intervention on quality of life of patient with advanced breast cancer	Participants will learn about how support group interventions helped patients with advanced breast cancer to improve their quality of life
Mr Moses Osani, Communications Officer, Kenya Cancer Association , Kenya UICC Member	Voices of Cure	Participant will hear about emergent advocacy issues relevant to cancer healthcare systems, including models and guidelines for effective advocacy campaigns and actions by patients for better outcomes
Mrs Renuka Prasad, Hony Secretary, Indian Cancer Society Delhi, India UICC Member	Rise against cancer	Participants will learn about innovative ideas to raise funds through an impactful awareness campaign

## Congress Day 2: Navigating cancer care

<b>Presenters name and organisation</b>	<b>Presentation Title</b>	<b>Presentation Summary</b>
Mrs Azuwa Abdullah, CEO, Breast Cancer Foundation, Malaysia	Fundraising the fun way : Bond With Pride	Participants will learn new unusual ways to fundraise: Bond With Pride is where individual women donors are paired with breast cancer survivors to bond together for a beauty therapy session at sponsored venues which helps them to develop understanding and companionship
Dr Hadi Abu Rasheed, Head of Health Education, Qatar Cancer Society, Qatar UICC Member	Empowerment platform in a cultural melting pot	Participants will gain understanding of innovative methods to establish cross sectors and cross regions capacity building programmes
Ms Annette Beattie, Peer Support Programmes Manager, Cancer Council NSW, Australia UICC Member	The power of peer support enabled beyond borders	Participants' takeaways will include research and evidence base related to the development of peer support programmes, implementation methods with case studies representing the cancer continuum and evaluation techniques applied and outcomes
Ms Sondra Davoren, Senior Legal Policy Advisor, McCabe Centre for Law and	Informed financial consent – what does it mean and how can it benefit	Participants will take away a strong understanding the concept of informed financial consent, and their rights as patients to know about

Cancer, Australia UICC Member	patients and clinicians?	the potential costs of cancer treatment
Ms Regina Fernandez, Health Psychologist, Universidad Rafael Landivar, Guatemala	Myths about cancer	Participants will be presented with the myths and beliefs surrounding this disease in Guatemala and a study that aims to help combat these myths through the creation of a guide for health workers
Dr Jennifer King, Director, Science & Research, Lung Cancer Alliance, US UICC Member	Patient navigation through clinical trials and molecular testing: understanding and addressing barriers	Participants will hear the lessons learned about identified barriers to both clinical trial enrolment and molecular testing
Dr Deborah Lawson, Legal policy advisor, McCabe Centre for Law and Cancer, Australia UICC Member	Getting back to work: legal protections for people with cancer	Participants will take away a strong understanding of their rights in the workplace, including a range of diverse examples of the types of reasonable adjustments that should be made for people affected by cancer in the workplace
Ms Demetria Lubinga, Chairperson, Breakthrough Cancer Trust, Zambia UICC Member	Fostering a sense of belonging	Participants will become familiar with new initiatives to debunk cancer myths and cultural stigma, including the use of technology to create successful survivor forums
Mr Thomas-Albert Ndayisaba, Livelihood Programme Manager, Partners In Health-Inshuti Mu Buzima, Rwanda UICC Member	The effects of breast cancer support groups on breast cancer knowledge and quality of life at Butaro Cancer Centre of Excellence	Participants will be presented a study that shows the positive effect of breast cancer support groups implemented at the Butaro Cancer Centre of Excellence (BCCOE) in northern Rwanda
Ms Emily Ochieng, Programme Officer, Kenya Cancer Association, Kenya UICC Member	Taking cancer education and awareness to the workplace	Participants will be given insights into a learning curriculum and methods of forming organisational peer support groups to advocate for inclusion of cancer in human resources policies
Ms Debora Olwal, Executive Director, Kenya Cancer Association, Kenya UICC Member	A community based approach to cancer care in resource limited settings	Participants will learn how a community based approach in resource limited settings can help increase community engagement in cancer risk reduction factors, reduce stigma and improve access to cancer screening and care
Ms Kirsten Pilatti, General Manager - Strategic Projects, Breast Cancer Network Australia, Australia UICC Member	The State of the Nation - Australia	Participants will be given the example of a framework to follow to gather, analyse and implement an effective consumer driven advocacy project
Prof. Loh Siewyim, Assoc Prof Dr, Keepable cancer community, Malaysia	Patient self management for chronic phase of survivorship	Participants will be given a 'socio ecological model' drawing as a trigger for them to start thinking of the various level of determinants to be consider in planning a community group
Ms Danielle Spence, Director of Policy and Advocacy, Breast Cancer Network Australia, Australia UICC Member	Lost in the sea of pink	Participants will hear how to use the power of the patient story as an advocacy tool that can to influence change
Mr Richard Vines, CEO, Rare Cancers Australia, Australia	Managing Conflicts of Interest	Participants will hear real world examples and pose hypothetical challenges of how conflicts occur and how to deal with them. The presentation will have a focus on both financial conflicts and patient

		care conflicts.
Mrs Budiastuti Wening, Vice Chairperson, Indonesia Breast Cancer Foundation, Indonesia UICC Member	Improving Breast Cancer Care, Leveraging Patient Voices	Participants will learn how dealing with data evidence and the burden in an archipelagic country such as Indonesia is a big challenge and how to overcome it
Mr Ng Yong Hao, Medical Social Worker, National Cancer Centre Singapore, Singapore	Empowering Cancer Survivors as Volunteer Leaders in Support Groups & Programmes	Participants will be able to take away a framework that outlines major considerations in engaging survivors as volunteer leaders
Ms Leonie Young, IMPACT Consumer Coordinator, Breast Cancer Trials, Australia	Consumers having an IMPACT in clinical trials research	Participants will hear more about the importance of women's contributions to clinical trials research, including effective strategies for advocates

### Congress Day 3: *Patient voices*

<b>Presenters name and organisation</b>	<b>Presentation Title</b>	<b>Presentation Summary</b>
Ms Maira Caleffi, President, FEMAMA, Brazil and UICC Board Member	Coping with Metastatic Breast Cancer: the patients' perspective in a Brazilian Cancer Centre	Participants will hear about the findings of the survey on metastatic breast cancer (MBC) that was carried out in a Brazilian Cancer Centre. The results suggest there is room for improvement on communication between providers, policy makers and MBC patients, potentially reducing MBC stigma and patients groups meetings
Mr Chris Curtis, Chairman, World Cancer Ambassador, Chris Curtis Consultancy LTD, UK	From Cancer to the Palace in 6 years	Participants will gain understanding of how one patients voice can help health professionals and key opinion leaders make changes in the cancer pathway and how to develop and maintain a successful Head & Neck Patient Support Group
Ms Emily Eyres, Chief Operating Officer, Lung Cancer Alliance, US	Patient Decision Making for Lung Cancer Screening and Treatment	Participants will be provided with a blueprint of what was done in the United States to promote lung cancer screening and patient-provider communication around decision-making that they can take back to their communities to support education, advocacy, and policy development
Mrs Indra Jasuja, Joint Secretary, Indian Cancer Society Delhi, India UICC Member	Life on a Roll	Participants will hear more about the benefits of training cancer patients and care givers to enhance quality of life and detoxifying the word 'death'
Mrs Noelen Kotschan, CEO, PinkDrive, South Africa UICC Member	The relationship between HIV AIDS cancer and NCD	Participants will hear how both diseases relate and about the best possible methods of screening and awareness campaigns for global implementation
Dr Deborah Lawson, Legal policy advisor, McCabe Centre for Law and Cancer, Australia UICC Member	Miracle cancer cure claims and the law	Participants will gain an understanding of the importance of developing evidence-based, resources for people affected by cancer on how to safely access complementary therapies, and how to navigate legal frameworks for health complaints as well as the use of real-life case studies in law reform

		submissions to demonstrate the need for legislative or policy change
Prof. Nur Aishah Mohd Taib, University Malaya Medical Centre, Malaysia	YouTube in your Language: Breast Cancer Treatment Literacy	Participants will hear about a new initiative to improve care for newly diagnosed breast cancer patients through the development of audio-visual educational tools on multimodal treatments, side effects and navigating admission, discharge and follow-ups in Malay, Mandarin and English languages
Mr Ansleme Mubeneshayi Kananga , Coordiantor, Palliafamilli, Congo (Kinshasa) UICC Member	Integration of social care for palliative patients: a public health problem Case of RD Congo	Participants will hear more about the issues related to social care for patients of sub-Saharan African origins and the important role of the social assistant in accompanying during the bereavement
Mr Philip Odiyo Ouma, Patient Support Manager, Faraja Cancer Support Trust, Kenya UICC Member	Improving cancer care in low resource setting through complimentary therapies: the Faraja Experience	Participants will hear about the successful partnerships established by Faraja Cancer Support Trust which enable the centre to offer psychosocial care services across Kenya through complimentary therapies
Mr Diego Paonessa, CEO, Liga Argentina de Lucha Contra el Cáncer (LALCEC), Argentina UICC Member	CONCIERGE SERVICE - We are going to become the guardian angel of our patients	Participants will hear more about the experiences of organisations such as LALEC in contributing to transform the care model of cancer patients
Ms Ranjit Kaur Pritam Singh, Member, Board of Directors & Past President, Reach to Recovery International, Malaysia UICC Member	Educational needs and training opportunities in the provision of peer support	Participants will hear about the importance of providing volunteers with a cancer overview, communication skills, an understanding of the emotional impact of cancer, and the do's and don'ts for visiting with and supporting patients
Ms Maureen Rigney, Director of Support Initiatives, Lung Cancer Alliance, US	Assessment to programming: responding to the needs of the lung cancer community	Participants will learn how the results of a community needs assessment survey can be translated into a cost-effective method of meeting identified needs, especially for lung cancer patients