



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

**Strengthen  
Inspire  
Deliver**



## 2018 Patient Group Pavilion – Preliminary Programme

1 May 2018

### Tuesday 2 October: *Organisational framework*

Presenters name and organisation	Presentation Title	Presentation Summary
<b>Session 1</b>		
9:30-9:40 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
9:40-9:50 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
9:50-10:00 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 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
<b>10:00-10:30 Q&amp;A with the chair and the three presenters</b>		
10:30-10:45 Break		

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<b>Session 2</b>		
10:45-10:55 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
10:55-11:05 Mrs Lilian Sackey, Perioperative nurse, Komfo Anokye Teaching Hospital, Ghana	Cancer and the gods: effects of traditional beliefs on cancer patients	Participants will hear more about the positive and negative effects of traditional beliefs on cancer patients and ways to overcome them
11:05-11:15 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)
<b>11:15-11:45 Q&amp;A with the chair and the three presenters</b>		
12:00-13:30 Lunch break		
<b>Session 3</b>		
13:30-13:40 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
13:40-13:50 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
13:50-14:00 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
<b>14:00-14:30 Q&amp;A with the chair and the three presenters</b>		
<b>Session 4</b>		
14:30-14:40	Learning to cope with eventualities	Participants will hear about an initiative that brings together the

Dr Syed Humayun Jafri, Head, Public Relations Department and International Patient Advisor, Tata Memorial Hospital, India UICC Member		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
14:40-14:50 Mr Pietro Presti, Director General, Fondazione Tempia, Italy 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
14:50-15:00 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
<b>15:00-15:30 Q&amp;A with the chair and the three presenters</b>		
15:30-15:45 Break		
<b>Session 5</b>		
15:45-15:55 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
15:55-16:05 Dr Suraiya Mansur, Chief Operating Officer, Medicaid Cancer Foundation, Nigeria UICC Member	Kick Out Cancer Campaign	Participants will hear how to raise awareness about and funding for cancer through football games
16:05-16:15 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
<b>16:15-16:45 Q&amp;A with the chair and the three presenters</b>		
<b>Session 6</b>		
16:45-16:55 Ms Geraldine McDonald, Director	Patient Navigation in Cancer Care: Is	Participants will hear examples of best practice for patient navigation and the critical success factors for an effective patient navigation

Wellbeing, Peter MacCallum Cancer Centre, Australia UICC Member	it worth the investment?	programme
16:55-17:05 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
17:05-17:15 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
<b>17:15-17:45 Q&amp;A with the chair and the three presenters</b>		

### Wednesday 3 October: *Navigating cancer care*

<b>Presenters name and organisation</b>	<b>Presentation Title</b>	<b>Presentation Summary</b>
<b>Session 1</b>		
9:00-9:10 Ms Sondra Davoren, Senior Legal Policy Advisor, McCabe Centre for Law and Cancer, Australia UICC Member	Informed financial consent – what does it mean and how can it benefit patients and clinicians?	Participants will take away a strong understanding the concept of informed financial consent, and their rights as patients to know about the potential costs of cancer treatment
9:10-9:20 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
9:20-09:30 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
<b>09:30-10:00 Q&amp;A with the chair and the three presenters</b>		
10:00-10:15 Break		
<b>Session 2</b>		
10:15-10:25	Taking cancer education and	Participants will be given insights into a learning curriculum and

Ms Emily Ochieng, Programme Officer, Kenya Cancer Association, Kenya UICC Member	awareness to the workplace	methods of forming organisational peer support groups to advocate for inclusion of cancer in human resources policies
10:25-10:35 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
10:35-10:45 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 in view of implement an effective consumer driven advocacy project
<b>10:45-11:15 Q&amp;A with the chair and the three presenters</b>		
<b>Session 3</b>		
11:15-11:25 Mr Anselme Mubeneshayi Kananga, Coordinator, 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
11:25-11:35 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
11:35-11:45 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
<b>11:45-12:15 Q&amp;A with the chair and the three presenters</b>		
12:15-13.45 Lunch break		
<b>Session 4</b>		
13:45-13:55 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
13:55-14:05 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
14:05-14:15 Dr Jennifer King, Director, Science & Research, Lung Cancer Alliance, US	Patient navigation through clinical trials and molecular testing: understanding and addressing	Participants will hear the lessons learned about identified barriers to both clinical trial enrolment and molecular testing

UICC Member	barriers	
<b>14:15-14:45 Q&amp;A with the chair and the three presenters</b>		
<b>Session 5</b>		
14:45-14:55 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
14:55-15:05 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
15:05-15:15 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
<b>15:15-15:45 Q&amp;A with the chair and the three presenters</b>		
15:45-16:00 Break		
<b>Session 6</b>		
16:00-16:10 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
16:10-16:20 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
16:20-16:30 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
<b>16:30-17:00 Q&amp;A with the chair and the three presenters</b>		

## Thursday 4 October: *Patient voices*

Presenters name and organisation	Presentation Title	Presentation Summary
<b>Session 1</b>		
9:00-9:10 Dr Jennifer King, Director, Science & Research, 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
9:10-9:20 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
9:20-9:30 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'
<b>9:30-10:00 Q&amp;A with the chair and the three presenters</b>		
<b>Session 2</b>		
10:00-10:10 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 show that there is room for improvement in the way providers, policy makers and MBC patients communicate and ultimately reduce MBC stigma and patients groups meetings
10:10-10:20 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
10:20-10:30 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 about the experience of organisations such as LALEC and how they have contributed to transform the care model for cancer patients
<b>10:30-11:00 Q&amp;A with the chair and the three presenters</b>		
<b>11:00-11:15 Break</b>		
<b>Session 3</b>		
11:15-11:25	Educational needs and training	Participants will hear about the importance of providing volunteers with a cancer

Ms Ranjit Kaur Pritam Singh, Member, Board of Directors & Past President, Reach to Recovery International, Malaysia UICC Member	opportunities in the provision of peer support	overview, communication skills, an understanding of the emotional impact of cancer, and the do's and don'ts for visiting with and supporting patients
11:25-11:35 Ms Leonie Young, IMPACT Consumer Coordinator, Breast Cancer Trials, Australia	Mere Survival or Meaningful Survivorship	Participants will discuss various aspects of meaningful survivorship in the context of patients diagnosed with metastatic cancer
11:35-11:45 Dr Ashwin Hurribunce, Board Member, PinkDrive, South Africa UICC Member	The relationship between HIV AIDS and cancer/NCDs	Participants will hear how both diseases relate and about the best possible methods of screening and awareness campaigns for global implementation
11:45-11:50 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
<b>11:50-12:20 Q&amp;A with the chair and the three presenters</b>		