



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

**Strengthen  
Inspire  
Deliver**



## 2018 Patient Group Pavilion – Preliminary Programme

5 September 2018

**Tuesday 2 October: Organisational framework**

Presenters name and organisation	Presentation Title	Presentation Summary
<b>Session 1</b>		
<b>Chaired by Ms Amanda Pomery, Director, Support &amp; Community Outreach, Prostate Cancer Foundation Australia</b>		
9:30-9:40 Mrs Mona Knotek-Roggenbauer, Vice President & President, Europa Donna, Austria	The metastatic advocacy training course project	Participants will hear more a project to develop and implement an intensive MBC Advocacy Training Course that will enable cancer advocates in Europe to develop and carry out tailored programmes to best address MBC issues and help patients in their own countries
9:40-9:50 Mr Moses Osani, Associate Information Officer, Communication Division, UN Environment, Kenya	Voices of Cure	Participants 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>		

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10:30-10:45 Break		
<b>Session 2</b>		
<b>Chaired by Mrs Maria Fatima Garcia Lorenzo, CEO, Kythe Foundation, Philippines</b>		
10:45-10:55 Dr Mazanah Muhamad, President, 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>		
<b>Chaired by Mrs Mary Wong, Chairman, Global Chinese Breast Cancer Organisations Alliance, Hong Kong/China</b>		
13:30-13:40 Dr Rajesh Bhalla, Medical Advisor, Indian Cancer Society Delhi, India UICC Member	Utilisation and reporting of breast screening via tele-radiology	Participants will gain understanding of how a breast screening process conducted as an out-reach programme closer to the 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 has empowered and supported 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	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>		

**Session 4****Chaired by Mrs Ranjit Kaur Pritam Singh, President Breast Cancer Welfare Association & Board Member, Reach to Recovery International, Malaysia**

14:30-14:40 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
14:40-14:50 Mr Pietro Presti, Director General, Fondazione Tempia & Member, European Cancer Patient Coalition, 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

**15:00-15:30 Q&A with the chair and the three presenters**

15:30-15:45 Break

**Session 5****Chaired by Mrs Gautami Tadimalla, CEO, Life Again Foundation, India**

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 Mohammed, 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 Mrs Firuza Abdullaeva, Chairman, Avesto, Tajikistan, UICC Member	Raising patient voices in Tajikistan	Participants will learn how the project ' Raising patient voices in Tajikistan' aims to empower Tajik women living with advanced breast cancer to lead productive lives with a higher quality of life at the patient level, the local level, and the system level.
<b>16:15-16:45 Q&amp;A with the chair and the three presenters</b>		
<b>Session 6</b>		
<b>Chaired by Ms Leonie Young, Peer Support Coordinator, The Wesley Hospital Choices Cancer Support Centre, Australia</b>		
16:45-16:55 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
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 7</b>		
<b>Chaired by Mrs Anna Cabanes, Director, Global Programmes, Susan G. Komen, US</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 Mrs Tarishi Desai Legal Research Officer 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	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 8</b>		
<b>Chaired by Hon Madame Yuthar Al Rawahi, Founder &amp; President, Oman Cancer Association</b>		
10:15-10:25 Ms Ana Laura Platas de la Mora, Alianza Mexcana contra el Cancer	Integrative oncology techniques for young women with advanced breast cancer	Participants will be given insights into methods of support for young women with metastatic breast cancer (MBC) in Mexico, including occupational therapy, expressive creative techniques, mind-body interventions and acupuncture
10:25-10:35 Dr Hadi Abu Rasheed, Head of Health Education, Qatar Cancer Society, 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 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 9</b>		
<b>Chaired by Mr Paul Ebusu, Executive Director, Uganda Cancer Society</b>		
11:15-11:25 Mr Anselme 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	Fostering a sense of belonging	Participants will become familiar with new initiatives to debunk cancer

Ms Demetria Lubinga, Chairperson, Breakthrough Cancer Trust, Zambia UICC Member		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 10</b>		
<b>Chaired by Mr Richard Vines, CEO, Rare Cancers Australia</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, Peer Support Coordinator, The Wesley Hospital Choices Cancer Support Centre, 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 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
<b>14:15-14:45 Q&amp;A with the chair and the three presenters</b>		
<b>Session 11</b>		
<b>Chaired by Mr Ng Yong Hao, Medical Social Worker, National Cancer Centre Singapore</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 UICC Member	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 12</b>		
<b>Chaired by Mr Diwakar Rajkarnikar, Past President and Advisor, Nepal Cancer Relief Society (NCRS)</b>		
16:00-16:10 Prof. Loh Siew Yim, 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 Chairman Puan Sri Azrene Abdullah, 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: *Patients voices*

Presenters name and organisation	Presentation Title	Presentation Summary
<b>Session 13</b>		
<b>Chaired by Mrs Vandana Gupta, Founder, V Care Foundation, India</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 14</b>		
<b>Chaired by Ms Demetria Lubinga, Chairperson, Breakthrough Cancer Trust, Zambia</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>		
11:00-11:15 Break		
<b>Session 15</b>		
<b>Chaired by Mrs Erin Schwartz, VP of Global Strategy, The Max Foundation, US</b>		
11:15-11:25 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
11:25-11:35 Ms Leonie Young, Peer Support Coordinator, The Wesley Hospital Choices Cancer Support Centre, 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
11:45-11:55 Ms Sondra Davoren, Senior Legal Policy Advisor, McCabe Centre for Law and Cancer, Australia	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>12:00-12:30 Q&amp;A with the chair and the three presenters</b>		