

### **'What matters more: my genes, my age, my cancer, my choices?'**

This is the provocative title of the Consumer Forum at the Clinical Oncology Society of Australia 2013 Conference in Adelaide on Sunday 10<sup>th</sup> November, 1-4pm.

Consumers, carers, along with local and international health professional speakers pondered this question through short sessions on **'Cancer and your genes'**, **'Looking after older people with cancer'** and **'Exercise and cancer'**.

The Consumer Forum is now a standard feature of each COSA Annual Scientific Meeting. COSA EO Marie Malica works with local consumer advocacy groups and Cancer Council to develop the event. Cancer Voices SA (CVSA) took a leading role in planning and presenting the 2013 Consumer Forum, with help from Cancer Council SA and Stephanie Miller, Executive Director of Health Consumers Alliance of South Australia.

COSA President Sandro Porceddu opened the event with acknowledgement to the traditional owners of the Adelaide area, the Kaurna people. He welcomed all visitors from near and far (about 50 attendees), and noted the importance of consumers' engagement in cancer care.

Julie Marker, co-facilitator and Deputy Chair of Cancer Voices SA, thanked Dr Porceddu and COSA for the opportunity the Consumer Forum provides for information to be heard directly from worldwide cancer experts. Julie went on to describe the important and diverse roles of consumers in advocating for better cancer treatment and care with examples from Cancer Voices SA activities. 'Good systems not Good Luck!', 'patients can help' and 'get active' were key messages. Tribute was paid to the leadership of Ashleigh Moore OAM since CVSA was launched at the COSA Forum in 2007 in Adelaide.

### **Cancer and your genes**

Community interest in cancer risk and genes has been sparked by media around Angelina Jolie and her decision to have a radical double mastectomy to reduce her cancer risk, based on her family history and genetic test results.

Local genetics expert Dr Nicola Poplawski explained how genetic spelling errors or faults can accrue with age, like 'genetic rust'.

This analogy and 'basic genetics 101' set the scene for Dr Vanessa Blair to detail a type of hereditary cancer (Hereditary Diffuse Gastric Cancer) found in New Zealand.

Chris Christensen described her personal journey of discovering she had a rare peritoneal cancer (a silent cancer she wants to make noisier); then new implications and uncertainties for herself and her family after finding she has a BRCA1 genetic mutation.

Speakers were asked for 2-3 'take home 'tips' (key points for action, information or practical advice) for the audience to take away. Tips from this session:

- Cancer risk increases with age
- Family genetic risk accounts for only about 5% of cancers
- Patients want good information to make informed choices

### **Looking after older people with cancer**

Doctors tend not to use age alone to define an 'older person', said Dr Nimit Singhal, local cancer specialist and this COSA Conference convenor. 'Functional age' is

highly individualised, including age in years eg 60, 65, 70+yrs but also considering other significant medical conditions, social networks supporting a patient, goals of cancer treatment and the toxicity of treatment options.

Tips for anyone with cancer aged 70+ were:

- Ask for a cancer coordinator
- Tell your Drs your treatment goals, preferences and wishes
- Be aware that finances and family are the most common causes of distress

A 'carers perspective' was provided by Melissa Cadzow, who looked after her widowed dad for 2 yrs after he was diagnosed with lung cancer in his 70s. Melissa juggled competing priorities with 2 small children and work. As a carer she felt stressed about 'doing the right thing' and challenges of finding information and sorting problems. Not realising consequences of referrals and specialist practicing rights at different locations proved to be a major barrier to 'patient centred' continuity of care for someone with existing comorbidities.

An interview with an older person about their experience and insights of cancer diagnosed in their later years unfortunately had to be cancelled as 2 speakers and 2 back-up speakers for this session were not able to attend 'on the day'.

### **Exercise and cancer**

Dr Lee Jones presented compelling research evidence of benefits from exercise for enhancing recovery after cancer. Think of exercise as a treatment for cancer. While more studies are needed to work out the correct 'dose' and type of exercise treatment, current adult physical activity recommendations are safe and suitable before, during and after cancer treatment.

Animal studies have shown that tumours grew 30% slower in mice that were exercising

Exercise can also mitigate against the loss in fitness caused by cancer treatments. Lung cancer patients who were physically fitter had less treatment complications. This was shown from an exercise program for 70+yr olds in the 4wks prior to surgery, which resulted in 20% improvement in fitness.

Loss in fitness during 12 weeks of chemotherapy is equivalent to the decline usually seen from 10yrs of ageing! A study of sedentary women after breast cancer treatment found a double whammy if starting off unfit with the impact of therapy, leaving them of similar fitness to women 20 yrs older.

Take away tips:

- Your exercise prescription: 3 days/wk of moderate (brisk walking) continuously for 20mins or accumulating 30 mins/day 5 days/wk
- Mostly it's 'excuses' not 'barriers' eg no one to walk with, too cold/too hot.

It was clear that there is no simple answer to our question 'What matters more: genes, age, cancer, choices?' They all matter, they all have an impact, and information is needed to make informed choices.

The value of the COSA Consumer Forum for people affected by cancer was confirmed by the positive feedback from the audience.

Julie Marker  
Cancer Voices SA

**Forum speaker biographies and introductions.  
COSA Consumer Forum 10 Nov 2013**

Welcome to everyone, to 'locals' and all those who have travelled quite far.

A special welcome to our guest speakers today, who include local and international clinical experts, cancer survivors and carer.

This is 'our event', for the community to take advantage of the visitors, expertise and topic themes being featured in the Clinical Oncology Society Australia's Annual Conference being held during the coming week, and this year in Adelaide for the first time since 2007. Knowledge is Power, and we hope you can be proactive participants in your own health care, and empowered/ inspired to achieve holistic patient-centred care for yourself and others. Everyone has something they can contribute, and today's speakers will be touch on ways that can happen.

This Community Forum has been convened by the Clinical Oncology Society Australia, in collaboration with the Cancer Council SA and Cancer Voices SA. Thank you COSA, Thank you Cancer Council, Thank You Cancer Voices members who contributed to the planning of this event.

**AIMS for today's Forum**

**-Information**

**-encourage/ inspire you to get Involved**

**-stimulate you to advocacy and action**

I'd now like to introduce Stephanie Miller, Executive Director of Health Consumers Alliance of SA who will be co-facilitating this afternoon's Forum with me. This is symbolic, not only because the Health Consumers Alliance is the peak consumer organisation in SA and part of the national Consumers Health Forum of Australia, but also because HCA assisted Cancer Voices SA to become established, and we were officially 'launched' at the COSA Consumer Forum in Nov 2007, the last time this event was held in Adelaide. Our partnership with HCA is still strong. Volunteer consumer organisations need to work together.

**1.05-1.20pm Consumer involvement and Cancer Voices SA**

**Julie Marker**

Julie is the Deputy Chair of Cancer Voices SA. She was a fit, active 45yr old clinical trial co-ordinator when she was first diagnosed with colon cancer in 2001. There was no family history or risk factors ... but now a 3 times metastatic colon cancer survivor ... Julie devotes a huge amount of time & effort to 'give back', using her experiences of cancer and helping others to do the same. Julie also enjoys riding her bike up steep hills with the Cancer Voices cycling group.

**1.20 Cancer and Your Genes**

Strong community debate has been sparked following the relatively recent media around Angelina Jolie, and her decision to have radical double mastectomy surgery, based on her family history genetic test results, in order to reduce her cancer risk. At that same time in Australia and in the US, the courts were reviewing whether patents could be awarded over these naturally occurring human cancer genes, in the case of Myriad Genetics. The BRCA1 and BRCA2 Breast cancer genes are well known, but our next speakers are here to enlighten us more broadly with facts and issues around 'cancer and your genes'.

**1.20 -1.40 The Genetic Staircase to cancer  
Nicola Poplawski**



Dr Poplawski works as a Clinical Geneticist in the Adult Genetics Unit of the South Australian Clinical Genetics Service, located at the Women's and Children's Hospital in Adelaide, Australia.

Dr Nicola Poplawski is a Paediatrician and Clinical Geneticist who trained in New Zealand (the University of Otago), Australia (the Women's and Children's Hospital in Adelaide) and Canada (the Hospital for Sick Children, Toronto). She is interested and has experience in genetic education for the public, for families

and for health care professionals. Her research focuses on clinical aspects of inherited diseases, including inherited cardiac and endocrine disorders, and familial cancer.

**1.40-2.10 Beating Hereditary Stomach Cancer: Science, Scopes & Surgery  
Vanessa Blair**



**Whangarei Hospital and University of Auckland, New Zealand**

Dr Vanessa Blair, FRACS, PhD. General, Breast, Endocrine and Skin Cancer Surgeon, Whangarei Hospital, New Zealand. Lecturer in Surgery, University of Auckland.

Vanessa trained in General Surgery in New Zealand (NZ) and was made a Fellow (RACS) in 2009. At Auckland University she received the Rotary Club of Auckland Prize, awarded to the most

distinguished graduate in medicine. During surgical training she did a PhD in Hereditary Diffuse Gastric Cancer (HDGC), about which she has written several papers and book chapters and been involved in publication of NZ and international guidelines. Vanessa has been involved in the family education meetings with NZ HDGC families.

She is on the NZ National Tumour Board for Melanoma, convened in 2012 to formulate national standards of care.

After completing a fellowship in breast, endocrine and melanoma surgery, in 2011 she returned to her home province in far north NZ to take up a consultant post at Whangarei Base Hospital, which covers a population that is 32% Maori and includes rural and remote areas.

Her interests centre on her 2 young sons, the small farm her husband is developing and all things culinary.

**2.10-2.20 My Cancer, My Gene  
Chris Christensen**



Chris Christensen is a daughter, sister, mother, wife, friend, colleague, public servant, systems thinker, information junkie, photographer, traveller, avid reader, music lover, volkswagen fan and general lover of life. Chris is living with cancer and is interested in learning all she can about her cancer in particular and cancers in general. As a patient/consumer/client Chris is passionate about having access to data and information about cancer; being central to cancer treatment decisions and

process; having open and ongoing communication with the medical community; being involved in supporting others living with cancer; supporting quality improvement in the treatment process; and being a contributor to research. Chris is a member of Cancer Voices SA and is an Ambassador for the Cancer Council in South Australia.

### Looking after older people with cancer

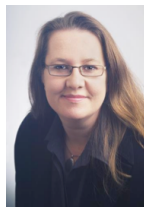
Getting older is arguably the biggest risk factor for cancer, with 1:3 people affected by cancer to the age of 75yrs, but 1:2 by the age of 85yrs. As the proportion of 'older' people increases in Australia, more of us are likely to become cancer patients or carers of an older person with cancer. What do we need to know, or take into account? What difference might those extra years make- for patients, carers and care providers?

### 2.40- 2.55 Looking after older people with cancer – an oncologists perspective Nimit Singhal



**\*NB Nimit is the COSA ASM 2013 Convenor  
Medical Oncologist at the Royal Adelaide Hospital**

Dr Nimit Singhal completed his oncology training at Royal Adelaide Hospital in 2006 and has subsequently joined the faculty as a staff specialist. His main areas of interest include Clinical trials and cancer in elderly. He has been instrumental in setting up the Geriatric Oncology program at Royal Adelaide Hospital. He is a principal investigator in many clinical trials, including several investigator initiated studies. He is actively involved in teaching and supervising both undergraduate and postgraduate students, and is a member of various professional bodies.



### 3.15-- 3.30 Carer's perspective - Melissa Cadzow Melissa Cadzow

*Melissa is an active health consumer advocate. Melissa's interests are cancer, palliative care, children's health, eHealth and consumer health issues in general. As her dad's carer she shared many special moments and much laughter with him during his last two years, she has two gorgeous young children and her IT business with her husband is their other baby. She enjoys serving on advisory boards in the areas of business, information technology and health.*

### 3.30-3.50 Exercising for Recovery after Cancer

Implement what we know works and research what we don't know. If we implemented what we currently know works, cancer outcomes could be improved by 30%. Exercise is one of those things that we now know works to help prevent a whole heap of health issues, including cancer – but getting people to do it routinely at the recommended dose, well that is going to take some research to figure out how! Are cancer patients able to be motivated to exercise for recovery after cancer? Can we raise expectations for people to be even fitter after cancer than in their life before cancer? Has advice in the past been 'killing us with kindness' when advised to 'take it easy, don't push yourself too hard?' How active do you need to be for best recovery after cancer treatment? Dr Lee Jones will tell us.

### Lee Jones



### Duke Cancer Institute, North Carolina, USA

Dr Lee W Jones, PhD I am Associate Professor and Scientific Director of the Duke Center for Cancer Survivorship in the Department of Radiation Oncology within the Duke Cancer Institute. I was born in Stoke-on-Trent, England and completed my Bachelor's of Science (Hons) in Sport and Exercise Science at the University of Brighton (Eastbourne, East Sussex, England). Following a year of employment as a lifestyle consultant, I moved to Canada to complete my Masters of Science in Kinesiology at Lakehead University (Thunder Bay, Ontario, Canada). From there I moved to Edmonton, Alberta to complete my PhD in Exercise Oncology research at the University of Alberta. I also completed my Postdoctoral Fellowship in Exercise Oncology research at the University of Alberta. I joined DUMC in January 2005 in the Program of Cancer Prevention, Detection, and Control. In July 2009, I was made Director of Cancer Survivorship Research and the Duke Exercise-Oncology Program within the Duke University Health System and Duke Cancer Institute.

I live in Durham with my wife, Nicole. I am an avid exerciser and have completed the New York Marathon twice on both occasions to raise money for the Tug McGraw Foundation that supports brain tumor research.

Closing

**What matters more: my genes, my age, my cancer, my choices? They all matter, they all have an impact.**



L-R: Dr Vanessa Blair, Dr Nicola Poplawski, Melissa Cadzow, Dr Nimit Singhal, Stephanie Miller, Dr Lee Jones, Chris Christensen.