

## Newsletter: February 2017

*In 2017 we celebrate our 10<sup>th</sup> year of advocacy, involvement, awareness-raising and information sharing.*

A warm 'Hello' to all our members! My name is Chris Christensen and I have been elected Chair of Cancer Voices SA (CVSA) for 2017. It is with some apprehension that I take over the role from Julie Marker who has devoted so many years to being an amazing advocate for people affected by cancer in South Australia.

I aim to continue the advocacy work that Julie and Ashleigh Moore have so successfully embedded in the health system in our state. Our purpose is to raise a voice for all South Australians affected by cancer so that we can all be assured that our cancer diagnosis, treatment, care and survivorship are the result of good systems, not just good luck!



As the new year begins, the CVSA Executive Team is already focusing on our key directions for 2017 in alignment with our Strategic Plan 2015-2020

[http://www.cancervoicessa.org.au/assets/documents/Position\\_Papers/cancer\\_voices\\_sa-strategic\\_plan\\_and\\_priorities-2015-2020.pdf](http://www.cancervoicessa.org.au/assets/documents/Position_Papers/cancer_voices_sa-strategic_plan_and_priorities-2015-2020.pdf) .

Your thoughts and ideas about the focus for our advocacy in 2017 are important for us to hear. **What do you think our focus should be?** Some of our ideas include:

- Safety and Quality of Cancer Care
- Implementation of the South Australian Cancer Survivorship Framework
- Improving Palliative Care Services
- Consumers Priorities for Cancer Research
- 10 years of Cancer Voices in South Australia – lessons and achievements

Please email [info@cancervoicessa.org.au](mailto:info@cancervoicessa.org.au) with your thoughts and ideas by 6 March 2017.

### Recent Events

#### **Survivorship Conference 2-3 February 2017, in Adelaide**

The Survivorship Conference brought together a diverse group of clinicians, researchers, policy makers and consumers from Australia and beyond. The theme of the 2017 conference was “*Cancer Survivorship: Pathways to better policy and practice*”. The conference focused our thinking on how we can translate the growing evidence in this area into day to day applications to make a difference for cancer survivors.

Diverse perspectives were explored from Australia, the UK and the USA, with the goal of identifying how together we can progress best practice by learning and sharing with each other about what constitutes survivorship quality of life.

CVSA members Julie, Tony, Karen, Chris and Monique were all invited speakers at the conference and wowed the audience with their consumer perspective on topics such as healthy living following a cancer diagnosis, when cancer can't be cured, and cancer - the things we don't talk about.

The Ashleigh Moore Oration was followed by a brief tribute from Julie on the ground breaking work undertaken by Ashleigh Moore OAM in establishing and building the excellent reputation of CVSA as an advocacy group. This was on 3<sup>rd</sup> Feb, 3 years to the day of Ashleigh's passing. His legacy lives on.

During the Survivorship Conference our CVSA television stars! Julie and Karen were interviewed by the ABC, with UniSA Prof Marion Eckert, and did a great job of articulating some quality of life issues for survivors. The interview can be viewed at the following link: <http://www.abc.net.au/news/2017-02-04/research-into-quality-of-life-issues-identified-by/8241754>

Further information and photos of the Survivorship conference can be found on the CVSA facebook page: <https://www.facebook.com/CancerVoicesSA/>

Key messages from the conference collated from Twitter feeds can be found at: <https://storify.com/hagsie/survivorship-conference-2017>

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## **Looking Ahead**

### **Transforming Health and Cancer Services**

We will continue to monitor the implementation of Transforming Health with a focus on cancer services. In 2016 we wrote to and had a meeting with the Health Minister about the inclusion of clinical trials at the new Royal Adelaide Hospital. We will continue to monitor this and other services provided to patients.

### **South Australian Cancer Services (SACS)**

We will continue to represent people affected by cancer on the South Australian Cancer Services (SACS) strategy committee, whose principal goal is to advise on the development of patient centred, evidenced based, sustainable and effective clinical services across the continuum of care, based on population need, as outlined in the SA Health Care Plan and the Statewide Cancer Control Plan.

As per our purpose we will continue to advocate for person-centred care which is safe, accessible, equitable, effective and efficient. We will also continue to advocate for multi-disciplinary, multi-sectoral and comprehensive care, evidence based treatment and care and data driven service provision supported by effective technology.

### **South Australian Cancer Survivorship Framework**

CVSA representatives have been working in collaboration with SACS, government and non-government health professionals and organisations, and researchers to develop a statewide Cancer Survivorship Framework. We look forward to supporting the implementation of the framework during 2017 so that all South Australians diagnosed with cancer can be assured of receiving a cancer treatment summary, needs assessment and a survivorship care plan based on their identified needs.

The project was funded for 2 years by the National Cancer Expert Reference Group (NCERG) as an initiative of the National Cancer Work Plan.

The key objectives of the framework are to:

1. Develop concise, standardised templates for a cancer treatment summary, survivorship care plan and cancer needs assessment tool
2. Identify and address cancer survivor needs
3. Enable well-coordinated, best-practice care for cancer survivorship
4. Monitor and continuously improve care for cancer survivorship
5. Engage, inform and collaborate with key stakeholders.

It has been a very positive experience for CVSA to be part of this project working together in a co-design environment on things we care about. Chris Christensen, Julie Marker and Karen Van Gorp made significant contributions to the development of the framework.

## **Senate Select Committee into Funding for Research into Cancers with Low Survival Rates**

On 29 November 2016 the Senate established a select committee to inquire and report on the impact of health research funding models on the availability of funding for research into cancers with low survival rates. CVSA will be writing a submission to this inquiry. Any comments or thoughts you have would be most welcome and can be forwarded by Monday 6 March 2017 to: [info@cancervoicessa.org.au](mailto:info@cancervoicessa.org.au)

Terms of Reference for the inquiry include:

- the current National Health and Medical Research Council funding model, which favours funding for types of cancer that attract more non-government funding, and the need to ensure the funding model enables the provision of funding research into brain cancers and other low survival rate cancers.
- The obstacles to running clinical trials for brain cancers and other cancers with relatively lower rates of incidence with regard to:
  - funding models that could better support much-needed trials, and funding support for campaigns designed to raise awareness of the need for further research including clinical trials
  - the low survival rate for brain cancers, lack of significant improvement in survival rates, and strategies that could be implemented to improve survival rates; and other relevant matters.

Further information about the inquiry can be found at:

[http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Funding\\_for\\_Research\\_into\\_Cancers/FundingResearchCancers](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Funding_for_Research_into_Cancers/FundingResearchCancers)

### **Survivors as Teachers**

We can all use our lived experience to support health professionals to learn about the experience of consumers and what contributes to a safe and quality cancer experience. A summary of this Cancer Voices SA program was presented at the 2015 Survivorship Conference *[“More than just telling my story” when cancer survivors become teachers.](#)*

### **Survivors as Teachers – Adelaide University Medical Student tutorials**

We will again be running a series of 14 tutorials with third year university medical students at Adelaide University. Sessions will run from March to September. Contact Julie at [info@cancervoicessa.org.au](mailto:info@cancervoicessa.org.au) for the dates & further details if you would be willing to participate in these tutorials.

### **Difficult conversations: UniSA nursing student workshops**

On Saturday 11 February CVSA members Maxine, Lesley, Chris and Julie presented to a group of about 100 third year nursing students from the University of South Australia. Maxine and Lesley spoke from the carer perspective of 'Difficult conversations' and end-of-life care, generously sharing their experience of their husbands diagnosis of Mesothelioma. The stories of the lived experience of cancer are powerful and it was evident that the students were moved by what they heard.

### **Professional Certificate in Health Consumers Engagement**

Julie and Chris are assisting Professor Karen Grimmer at the UniSA International Centre for Allied Health Evidence in the presentation of a new [Professional Certificate in Health Consumer Engagement](#). Julie participated in a pilot of this course during 2015 and has contributed feedback to the revised course design. Health Consumers Alliance SA and CVSA hope to bring the consumer experience to the course, and also participate in teaching in an interactive session.



## **CVSA New Year Resolutions!**

To continue to raise an independent voice to influence the achievement of better outcomes for South Australians affected by cancer, through advocacy, involvement, awareness and information so that all those diagnosed with cancer in South Australia:

- have access to high quality information, well coordinated, multi-disciplinary and integrated best practice cancer treatment and care
- have holistic care that takes into account the mental and social effects of cancer not just the physical symptoms by including psychosocial, complementary therapies and other support needs
- can be assured that their treatment and care will be safe and of high quality
- can be assured of an efficient and meaningful communication flow within and between services involved in their treatment and care
- are treated equally regardless of geographical location, social or economic status, age, ethnicity, sexuality, gender, state or type of cancer.

### **CVSA will achieve our resolutions through:**

#### **Engagement and Influence**

- promoting quality, safety, access and equity in treatment and care by representing and reflecting the views and diversity of people affected by cancer in appropriate forums, reviews and inquiries at the local, state, national and international levels
- identifying and building relationships with key individuals, organisations, policy makers, researchers, people affected by cancer and their carers.

#### **Programs and Projects<sup>4</sup>**

- sustaining and enhancing our core programs of “Survivors as Teachers”, cycling, and walking
- proactively engaging and collaborating in projects that support the achievement of our goals by using our members cancer experience and knowledge.

#### **Effective Strategy and Operations**

- managing our operations through a collaborative and transparent approach
- building strong working relationships with people affected by cancer, Cancer Voices Australia, local, state and federal governments, community organisations, not for profit organisations, private organisations and researchers.

So, we are off to a constructive, solution focused year of involvement. There is much to be done and we will keep you up to date via our website and newsletters. We sincerely your support by providing your insights, experiences and/or gift of donations.

### **Our very best wishes to all our members**

*Chris Christensen*

On behalf of the Executive Team, Cancer Voices SA