



**Cancer Voices South Australia
Annual Report
22 November 2015**

It is with great pleasure, as Chair of Cancer Voices SA (CVSA) that I present to you the CVSA Annual Report for 2015.

Cancer Voices is a 100% volunteer organisation, sharing our experiences and knowledge gained from cancer to improve the path for others. Our work is underpinned by advocacy, involvement, awareness and information. We want good systems not just 'good luck'; everyone should receive good quality cancer treatment and care. Our focus is also on wellness and not just on illness.

No group functions effectively without having a clear strategy, policies and efficient operations. The Executive team spent considerable time this year developing a CVSA Strategic Plan for the period 2015 – 2020. The plan outlines our values, vision, purpose and key relationships. It also highlights our approach to achieving our purpose and vision through engagement and influence, programs and projects, and effective strategy and operations. (Thank you Chris Christensen, Deputy Chair for expert guidance through this planning process).

This year has once again seen us raise an independent voice for people affected by cancer in a broad range of areas. Many members have represented CVSA on the numerous groups, programs and projects we are currently involved with around treatment, systems, research, information and survivorship, and promoting quality, safety and equity in treatment and care. This work continues to build positive relationships with key individuals, organisations, policy makers, researchers and people affected by cancer. We have engaged and influenced in these areas while at the same time are maintaining and improving our core programs and embedding the consumer perspective in a number of new projects.

Key achievements

The following highlights the key programs and projects in which we have been involved during 2015:

- **Survivors as Teachers** have been a core CVSA program for the past 4 years. During 2015 the program has grown and received much interest, particularly following the presentation describing the program at the 2015 National Cancer Survivorship Conference held in Adelaide. This year CVSA members have presented 'Survivors as Teachers' tutorials to the following groups:
 - University of South Australia, Palliative and Supportive Care Nursing Forum
 - Adelaide University Medical School series of 13 x 1 hour tutorials with 150 third year medical students
 - Flinders University School of Nursing series of 11 x 1 hour tutorials for 250 first year nursing students

Thank you to all the members who have participated in our 'Survivors as teachers' initiative as speakers, facilitators and supporters. Feedback shows your impact is amazing.

- **CVSA Cycling Group** continues (since commencing in late 2008) to actively engage people in the community as well as cancer survivors through our regular rides, Annual Cancer Voices Challenge ride, and other events.

Thank you Con Nakos for your tireless efforts supporting the cycling group; thank you to all who regularly ride wearing our jersey, and also in CycloSportif and other events. Thank you Brendon Harslett for your initiative, generosity and effort to organise the successful 'Pantani' film night fundraiser with proceeds to Cancer Voices

- **CVSA Walking Group** was established in June 2015 to encourage those affected by cancer to be active. The walks take place in Belair National Park and while group numbers vary week to week there is a small core of enthusiasts. Thank you Chris Christensen for starting this.
- The **2015 national cancer Survivorship Conference** convened by Flinders Centre for Innovation in Cancer, was strongly supported by CVSA, with CVSA Chair on the planning committee. We were delighted to hear the **inaugural Ashleigh Moore Oration** presented to more than 250 health professionals and delegates by **Sally Crossing AM, Chair of Cancer Voices NSW and convenor of Cancer Voices Australia**. CVSA members presented at the conference on the following topics:
 - More than just telling my story – when cancer survivors become teachers
 - Why aren't we measuring what matters to cancer survivors in Australia
 - Working together to ensure structured exercise is safe and more accessible for cancer survivors
 - Research on cancer survivorship in Australia: current status, gaps and needs
 - Supporting Return to Employment After Cancer in Disadvantaged Communities
 - Strengthening Cancer Survivor's Roles in cancer trials advisory groups
- CVSA is an active partner in the **South Australian Statewide Survivorship Framework Project** with Executive team members on the Steering Committee. The project is funded by the National Cancer Expert Reference Group (NCERG). The framework will develop templates and processes to support delivery of a minimum agreed standard of care to all patients treated with curative intent irrespective of tumor type or age (paediatric through to adults, young and old) in the public and private health sector.
- CVSA is an active partner in the **Return to Work After Cancer Project** in partnership with Flinders Centre for Innovation in Cancer. As active members of the Steering Committee CVSA representatives have been involved in designing the project, and conducting focus groups and forums to hear the experiences and determine the gaps in services and support for people returning to work with or after cancer, particularly for those living with disadvantage. A key outcome of the project will be an online portal with information and resources for cancer patients and their family, employers, workplaces, health professionals and others.

In addition to our core activities, we have been active with other significant areas of advocacy, engagement and influence during 2015:

- In response to media revelations of **chemotherapy dosing errors** and concerns about safety and quality systems, CVSA Executive Team forwarded a letter of concern to the South Australian Minister for Health about this incident, and partnered with Health Consumers Alliance SA to follow up through various avenues around safety, quality and medicines policy. Subsequently the CVSA Chair was appointed as a member of the independent review panel. We await release of the review findings.

There is still much to be done to ensure that people affected by cancer can rely on good systems and not just good luck.

- **Consumer Engagement in Research**- has been pursued through a range of activities eg Cancer research proposals were presented at the University of South Australia Workshop by CVSA Executive team member Dr Agnes Vitry , CVSA Chair gave presentations at the Primary Health Care Research pre-conference workshop, and Flinders University PhD students' Knowledge Exchange Workshop; through involvement in the Reducing the Gap between Research, Policy and Practice Initiative, a shared initiative of Primary Health Care Research and Information Service (PHCRIS), Health Services Research Association Australia and New Zealand (HSRAANZ), Cancer Voices SA, South Australian Health and Medical Research Institute (SAHMRI), Flinders University and Adelaide University; CVSA representatives are active participants in the SA PsychoOncology Research Group.

We also actively promote opportunities for anyone affected by cancer to participate in research studies and surveys via our online Community NoticeBoard

<http://www.cancervoicessa.org.au/awareness/community-noticeboard>

- **SA Oncofertility Registry:** CVSA representatives, Monique, Jon and Liam participated in a meeting to establish a South Australian chapter of the Australasian Oncofertility Registry which was launched by Randwick Hospitals Campus and the University of New South Wales. It will collect data from participating cancer and fertility centres about referrals and uptake of fertility preservation as well as collecting data on the fertility outcomes after cancer treatments.
Twelve CVSA survivors participated in a **GP-oncology shared care for survivorship** workshop organised by the Primary Care Collaborative Cancer Clinical Trials Group (PC4).
- A **Gastro-Intestinal (GI) cancer Community Forum** was held in Gawler in October to engage with communities and raise awareness of GI cancers. The CVSA Chair is a member of the GI Cancer Institute/Australasian Gastro-Intestinal Trials Group Consumer Advisory Panel, and along with several other CVSA members led the local organising committee of this event.
- "Yarning About Cancer" was a presentation delivered by the CVSA Chair at the SA Cancer Services planning day for the 2016-2020 Cancer Control Plan, Aboriginal Companion Document.
- **Transforming Health** - CVSA submitted responses to public consultations on Transforming Health, and Executive members represented CVSA at consumer workshops convened by Health Consumers Alliance, so issues of concern to those affected by cancer were raised.
- A Men's Health Forum and a Prostate Cancer Symposium were attended by CVSA representatives
- **Re Biobank consent forms:** CVSA collected feedback on consumer views about certain BioBanking consent forms and presented this to the Royal Adelaide Hospital Ethics Committee.

CVSA representatives are also involved at the national level eg.

- National Advisory Group of the CareSearch Palliative Care Knowledge Network,
- Australian Institute of Health and Welfare Cancer Data Monitoring Advisory Group
- **Medical Benefits Scheme Review** consultation held in Adelaide was attended by CVSA Deputy Chair, providing CVSA views on a range of items under review.

This is just a sample of the activities Cancer Voices South Australia has been involved in during 2014-2015. We work very hard.

We seek to be collaborative and transparent in our approach while building our public profile and the capability of our members.

I sincerely thank all members of CVSA for their ongoing investment of time and input into the many and varied aspects of our work. As a completely volunteer, independent and not for profit organisation we continue to rely on your valuable contributions, particularly as our reputation and connections grow and demand for our input increases.

I think CVSA founder Ashleigh Moore would be very proud to see how his legacy lives on.

Finally, I wish to acknowledge the outstanding contributions of the CVSA Executive Team – especially Deputy Chair Chris Christensen, and in alphabetical order: Agnes, Con, Eric, Louise, Mariann, Pam, Steph. Almost every day, these guys are responding to emails, providing advice, making suggestions or representing Cancer Voices in some way in activities and events.

Pam Sandys – our Secretary since CVSA formed in 2007, is retiring from the Exec Team, and we sincerely thank you Pam for her wisdom, steadfast support and contributions over 9 years.

It's been an incredibly busy year, a rewarding year, yet so much more still needs to be done.

Warmest regards

A handwritten signature in cursive script that reads "Julie Marker". The signature is written in dark ink on a light-colored background.

Julie Marker, Chair, Cancer Voices SA 22 November 2015