



Cancer Voices SA

Raising a Voice for People Affected by Cancer

Annual Report 2017



www.cancervoicessa.org.au
info@cancervoicessa.org.au
PO Box 588, Kensington Park SA 5068

2017 IN SUMMARY

2017 has been a year of challenges, opportunities and continued advocacy for Cancer Voices SA. All of our efforts are focused on achieving better outcomes for people affected by cancer. We want all people affected by cancer to be central to their treatment and ongoing care, with good systems and information underpinning their experiences and outcomes.

We are, I believe, a small but influential group in the area of cancer health, actively pursuing and responding to matters of quality, safety, access and equity in the treatment and care of people affected by cancer, at the local, state and national levels. It is through our relationships with people affected by cancer, with key individuals, organisations, policy makers and researchers working in the field of cancer health. These relationships have strengthened during 2017, particularly with universities, researchers and policy makers.

Our core programs, Survivors as Teachers, Cycling Team and Walking Group continue to promote our focus on wellness, both physical and psychological and have involved many of our members during the year. Their commitment, particularly to sharing their lived experience continues to be the foundation upon which our advocacy work is built.

Being a small, 100% volunteer, not for profit organisation we do struggle at times with managing the governance arrangements and financial necessities required to maintain our organisation. We need more people with skills in finance, web development and maintenance, and policy, to commit to supporting the management of the organisation so that we can continue to grow our organisation and build our capacity as an advocacy group.

That said, we are resolute in our directions and I look forward to working with the Executive Team and members to continue our important work into 2018.

CVSA Strategic Directions 2015-2020

Values	Vision	Purpose
<ul style="list-style-type: none"> • Advocacy • Involvement • Awareness • Information 	That all people affected by cancer are central to their treatment and ongoing care, with good systems and information underpinning their experiences and outcomes.	To raise an independent voice to influence the achievement of better outcomes for South Australians affected by cancer.
<i>We deliver our values, vision and purpose through:</i>		
Engagement and Influence		
<ul style="list-style-type: none"> • 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 and people affected by cancer. 		
Programs and Projects		
<ul style="list-style-type: none"> • Sustaining and enhancing our core programs through continuous and active involvement with our stakeholders. • Proactively engaging and collaborating in projects that support the achievement of our values, vision and purpose, using our cancer experience and knowledge. 		
Effective Strategy and Operations		
<ul style="list-style-type: none"> • Effectively managing our operations through a collaborative and transparent approach. • Improving the public profile and capability of Cancer Voices SA and its membership. • Developing Cancer Voices SA policy and position statements, in collaboration with Cancer Voices Australia, to underpin our values, vision and purpose. 		
<i>We achieve our values, vision and purpose by building relationships with:</i>		
<ul style="list-style-type: none"> • People affected by cancer • Local, State and Federal Governments • Community Organisations • Not for Profit Organisations • Private Organisations • Research Organisations 		

Engagement and Influence

Meetings

As consumer representatives we use the lived experience of our members to raise a voice to influence the cancer agenda and to advocate for matters across the cancer continuum - prevention, diagnosis, treatment, follow-up, palliative care, which are important for people affected by cancer. Cancer Voices SA has a consumer representative on the following groups and/or was invited to attend a meeting as a consumer representative, as a one-off forum participant or ongoing engagement roles on the following groups:

- Health Consumers Alliance – South Australian Health and Medical Research Institute (SAHMRI) “Consumers in Research” Group
- South Australian Cancer Services Strategy Group
- Australasian Gastro-Intestinal Trials Group, (AGITG) – AGITG Consumer Advisory Panel and Scientific Meetings
- Consumer and Community Space at the newRAH
- Consumer Health Forum Ministerial Roundtable
- SAHMRI Bowel Cancer Research Interest Group
- SA Pathology Safety and Quality Committee
- PC4 Concept Development Workshop
- Consumer Health Forum – Medicinal Cannabis Forum
- Primary Care Collaborative Cancer Clinical Trials Group (PC4), Consumer Advisory Panel, Concept Development Workshops and Scientific Symposium
- Psycho Oncology Co-operative Research Group (PoCOG)
- University of South Australia Cancer Care Research Symposium

Presentations

Cancer Voices SA members advocated for people affected by cancer in a number of forums during 2017 including:

- The Survivorship Conference 2017 where members, Tony Hamdorf, Julie Marker, Karen Van Gorp, Monique Bareham and Chris Christensen presented the survivor 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. Julie Marker and Karen Van Gorp were interviewed by the ABC alongside University of South Australia Professor Marion Eckert, discussing quality of life issues for cancer survivors and the need for patient reported outcomes to be monitored.
- The Australian Institute of Health Innovation (AIHI) Symposium - an invitational symposium was held to discuss research in the future of the health system and the new research proposals of the AIHI. Steph Newell, Julie Marker, Eric Browne and myself provided consumer input into the discussions through panel and table group discussions and influencing research and design in areas such as preventing patient harm from new digital technology applications, consumer contributions to safe and high-quality test result management and safety in emergency departments.



- The Adelaide/Mitcham Prostate Cancer Group presentation on the role of Cancer Voices SA.
- University of South Australia Cancer Care Research Symposium.
- Health Care - Safety and Quality presentation with Flinders University Masters in Health students, highlighting safety and quality from the perspective of consumers collective lived experience.
- Cancer Nurses Society of Australia Annual Congress
- University of South Australia Consumer Engagement in Health Care Presentation to Professional Certificate Students



Submissions and Applications

An important part of our advocacy is the writing of submissions and applications to government. This year we have been involved in the following:

- Cancer Voices Australia submission to the Senate Inquiry on funding for research into cancers with low survival rates and subsequent invitation to speak to the Inquiry.
- Application to Mitcham Council seeking funds for our Walking for Wellness program, which was successful in receiving \$500 towards publicity and to grow the benefit with team branded protective clothing.
- Submission of a letter to the Federal Minister for Health, the Hon. Greg Hunt following the Consumer Health Forum Ministerial Roundtable, highlighting the key elements that would make a difference for cancer consumers – holistic integrated healthcare using cancer nurses to support continuity and communication; connected data in the form of health care plans for all people diagnosed with cancer; and cancer research that includes consumers in governance arrangements and the setting of priorities.
- Contribution to updating the Clinical Practice Guidelines for the Prevention, Early Detection and Management of Colorectal Cancer.

Publications

- Contribution to the SA Cancer Control Plan – Case Studies provided by Jackie Bateau, Tony Hamdorf and Chris Christensen
- Lived Experience Case Study of Chris Christensen in *Clinical Nursing Skills An Australian Perspective*, Bloomfield et al, Cambridge University Press, 2017

Programs and Projects

Survivors as Teachers

Our flagship program – *Survivors as Teachers* has continued again during 2017 and I thank all members who

have volunteered their time to talk with medical, nursing and allied health students this year.

In particular I would like to recognise the *Survivors as Teachers* program that has been organised by Julie Marker at the University of Adelaide for the past six years, providing approximately 150 third year medical students per year with tutorials lead by our volunteers. In small groups of 8-12 students, our volunteers describe their diverse, unique circumstances, experiences, consequences of their cancer diagnosis, treatment, encounters with clinicians and the health system. Evaluation consistently provides evidence that the tutorials can have a profound impact on students, assisting them to understand patients as people, not just a case to solve.

Thank you to the more than 30 Cancer Voices members who have volunteered for this program during 2017 with special thanks to Julie Marker and Cath Caon for their commitment to the coordination and facilitation of the tutorials.

The *Survivors as Teachers* program also saw Cancer Voices members presenting at the University of South Australia and Flinders University.

Maxine Williams, Lesley Shears, Julie Marker and Chris Christensen presented about *Difficult Conversations in Nursing: End of Life Care* to University of South Australia third year nursing students alongside their Lecturer Dr Kevin O'Shaughnessy, for the fourth consecutive year.



Paul Macchia and Chris Christensen presented on the topic of *Living with Cancer* to Flinders University Allied Health Students for the third year on the topic of Living with Cancer.

The stories of the lived experience of cancer are powerful indeed and Cancer Voices SA is indebted to all who share their story with us, thus enabling us to build strong evidence of the challenges and opportunities for improvement where our advocacy can make a difference.

CVSA Cycling Team

Cancer Voices SA like to focus on wellness, not just illness and our cycling team and walking group are testament to our commitment to this end.

Every Sunday Cancer Voices riders wearing our jersey can be seen riding through the Adelaide Hills. Thanks to Con Nakos for his ongoing leadership of the Cancer Voices SA Cycling program, which has been ongoing since December 2008.

In October our 7th annual Cancer Voices SA Challenge Ride saw approximately 100 riders set off from Kensington Reserve on a 67 Or 35 kilometre ride up Norton Summit, through Picadilly and Aldgate Valley, Verdun and Ashton Hills.

Thanks also to all the volunteers who make this event possible: Con Nakos, Julie Marker and Eric Browne, Bill Nash, Chris Mayer and Kay Sutton.

CVSA Walking Group

Every Tuesday Cancer Voices SA walkers can be seen walking in Belair National Park. It is a group that benefits not only from the exercise but also from the discussions had during the walk.

Our new yellow T-shirts with the distinctive Cancer



Voices branding are the result of the grant received from Mitcham Council. Many thanks to Julie Marker and Di Creaney who have lead the group walks when Chris Christensen has not been available.

Research

Members of CVSA are increasingly in demand and involved in raising the voice of cancer survivors in research. Some of the research activity our members have been involved in during 2017 include:

- Bowel Cancer Research Interest Group – South Australian Health and Medical Research Institute
- Associate Researcher – Identifying information needs post-diagnosis for oesophageal and gastric cancer survivors, and their main supporters: An exploratory survey study which was accepted as an oral presentation at the 19th World Congress of Psycho-Oncology and Psychosocial Academy in Berlin
- Consumer Co-Supervisor for PhD thesis titled “Patient Reported Outcomes”
- Placement of survivors in research application processes

We welcome anyone interested to become involved in any of these activities to contact us at:

info@cancervoices.org.au

Strategy and Operations

This is the 10th year of Cancer Voices SA as a 100% volunteer organisation. This is a remarkable achievement given the volunteer nature of the group. What it demonstrates is the passion and persistence of people affected by cancer to raise their voice and to influence and advocate for good systems and not to just rely on good luck when it comes to surviving a cancer diagnosis.

It takes good people with commitment to make such an organisation work and we have a core group of people who help to achieve our purpose and vision.

Alliances

During 2017 Cancer Voices SA has worked with a number of key groups with a view to strengthening our areas of joint work and building effective working relationships. Key alliances during 2017 include:

- Cancer Voices New South Wales and Cancer Voices Australia where we have worked together on policy issues such as the future of Australian health care, Radiotherapy and the matching of cancer survivors with researchers and research projects
- Australian Institute of Health Innovation where we were invited to provide input into and discussions on the Institutes research projects and focus
- Health Consumer Alliance South Australia who provide us with space to host meetings, involve us in policy discussions and liaise with us on all matters pertaining to cancer.
- Consumer Health Forum where we were invited to a roundtable with the federal Minister for Health, the Hon Greg Hunt and provided advice on national health policy
- Adelaide University, Flinders University and the University of South Australia where we continue to grow our Survivors as Teachers program and be involved in a range of cancer research projects.

Information Sharing

For the past 10 years Cancer Voices SA has been sharing information via our Newsletters, our Email groups, our website www.cancervoicessa.org.au, Facebook, Twitter, Flickr and our cycling website www.cvsacyclingteam.org.au

These media are essential to our work and maintain our profile in the public arena.

Finance

It is clear that funding the important work of Cancer Voices SA is not easy. We are currently reliant on the kind and very much appreciated donations we receive across the year, but need to consider other sources of income in order to sustain our activities. The main purpose of Cancer Voices is to raise a voice for people affected by cancer, in order to improve outcomes, not to fund raise.

Unfortunately to achieve our purpose we need to have sufficient funds to host our own events, to support members attendance and participation in meetings where the critical discussions about cancer are being held, and to attend and present at conferences so that we can hear and be heard.

I thank all who made our film night a success, raising \$1400 and thank you to all those people who have donated to Cancer Voices SA during 2017. I urge all members to use their networks to source funds for Cancer Voices SA into 2018.



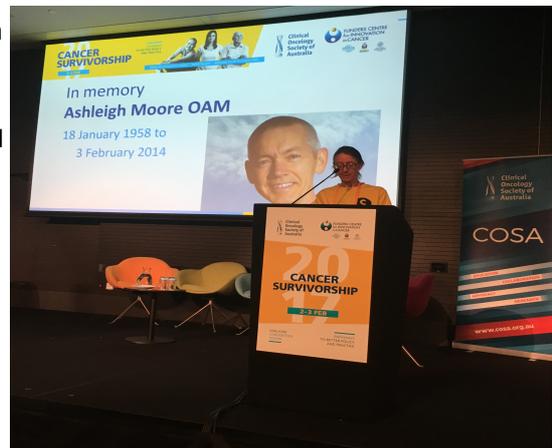
Executive Team

Last but most importantly I thank the Executive Team for the work they do and the support they give to making Cancer Voices SA a well respected volunteer organisation. It is not easy to respond to all the matters that are raised with us in the course of a year, while at the same time pursue our own organisational purpose and goals. We do need more people to help manage the load of requests we receive and the policy matters in which it is important for us to be involved.

I believe the purpose and vision initiated by Ashleigh Moore (Cancer Voices SA founding Chair) in 2007 is as important today as it was 10 years ago. It was with great feeling that Julie Marker reminded all participants at the 2017 Survivorship Conference of his legacy. We have much to thank Ashleigh for and whilst we have achieved much during 2017, there is much more to do.

I particularly want to give my deep thanks and appreciation to the Executive Team, Julie Marker, Eric Browne, Steph Newell, Con Nakos and Agnes Vitry, who continue to provide sound advice and ongoing support. Thank you all. I would especially like to mention Julie Marker who is the backbone and corporate memory of Cancer Voices SA. Julie is one of the founding members of Cancer Voices SA from 2007 and we have begun work on documenting our past 10 years of advocacy. The ongoing work and reputation

of Cancer Voices SA is predicated on the work, achievements and passion Ashleigh, Julie and others have brought to raising a voice for people affected by cancer in order to improve outcomes.



I urge you to continue to support us in whatever way you can and look forward to growing our membership and advocacy work in 2018.

Chris Christensen
Chair Cancer Voices SA
3 December 2017