Cancer Voices SA
Raising a Voice for People Affected by Cancer
Annual Report 2018

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CANCER VOICES SA 2018 - KEY ACHIEVEMENTS AND HIGHLIGHTS

CVSA AREAS of ENGAGEMENT and INFLUENCE

Safety and Quality in Cancer Services
S.A. Chemotherapy Standards Working Group Member
State Election Health Policy – meetings with MPs and Minister Wade
Conference proceedings – presentations and posters
Melanoma Patients Australia Board Member
Melanoma Guidelines Group Member
Member - Unicorn Consumer Advisory Group
Member - Care Search Palliative Care Knowledge Network
Consumer Advisory Panel Member – Australasian Gastro Intestinal Trials Group
Joint Community Advisory Group Psycho-Oncology Trials Group Member
Primary Care Collaborative Cancer Clinical Trials Group Member
Australian Institute of Health and Welfare Cancer Data Monitoring Advisory Group Member
S.A. Bowel Cancer Consumers Research Interest Group Member
Australian Society of Medical Imaging and Radiation Therapy Member
Australian Council on Health Care Standards Accreditation Surveyor
Health Consumer Alliance Member
Cancer Australia Consumer Network Member
Australian Digital Health Agency Board Director
Contribution to National Inquiries
SA Local Health Networks

CVSA PROGRAMS and SPEAKING ENGAGEMENTS

Weekly Cycling Group
Weekly Walking Group
Adelaide University Survivors as Teachers Medical Student Program
Flinders University Allied Health Students Living with Cancer Forum
Flinders University Health Masters Students – Healthcare Safety and Quality Workshop
University of South Australia Oncology Nurses Living with Cancer Forum
Graduate Oncology Nurses Workshop
Coast FM Interview – The Work of Cancer Voices SA
ABC Science Friction Clinical Trials Podcast
Wynn Vale Community Centre Cancer Group Discussion
Consumer Co-Design in Research Workshop – Diabetes Research Foundation
Consumers in Research Workshop – Flinders Centre for Innovation in Cancer
Victorian Cancer Centre Conference – Poster Presentation
Australian Clinical Trials Alliance Summit
Consumer Engagement in Healthcare Workshop
Ovarian Cancer Forum – Living with Cancer

Find out more by visiting: www.cancervoicessa.org.au
CVSA RESEARCH PROJECT INVOLVEMENT

Digital Health
SA Clinical Trials Network
Advanced Care Planning in Vulnerable Populations
Care for People with Multimorbidities
Return to Work after Cancer
Cancer Survivorship
Scientific Correlates of a Triple Immuno-oncology Combination in Metastatic Melanoma Patients
Cancer Australia Collaborative Cancer Research Scheme Reviews
Reviewing Grants for Cancer Australia
Australian Clinical Trials Alliance
Patient Reported Outcomes
Staging, Treatment and Recurrence (STaR) Project

CVSA OPERATIONS

100% independent and led by volunteers
Monitoring of Strategic Plan
Governance and Financial Management
Responding to public queries
Supporting the work of Cancer Voices Australia and the National Cancer Consumers Network

We are most grateful for all donations from CVSA members and the public in 2018
We are seeking donations for CVSA to remain viable in 2019 – please dig deep.
Membership is free!


Find out more by visiting: www.cancervoicessa.org.au
2018 has seen a year of continued cancer advocacy by Cancer Voices SA (CVSA). Requests for our participation in research initiatives is increasing with CVSA members being involved in research projects as reviewers, participants, consumer representatives and/or associate researchers. This I believe has been the result of many years of successful consumer advocacy, in South Australia and nationally, by CVSA, an organisation whose purpose is to influence the achievement of better outcomes for South Australians affected by cancer. One important way of doing this is our involvement in research. We have continued to build relationships with, people affected by cancer at the local, state and national levels; key cancer organisations; policy makers; and researchers, pursuing issues related to quality, safety, access, equity, prevention, diagnosis, treatment, follow up care and palliative care.

In 2018 we wrote to and met with Members of Parliament prior to the State Election, providing them with an overview of the work of CVSA and seeking their commitment to CVSA proposals for improvement in South Australia’s cancer services. It is pleasing to see that government health policy reflects a number of our proposals.

Our core programs, Survivors as Teachers, Cycling Team and Walking Group continue to promote our focus on education and wellness, both physical and psychological, and are well supported by our members. Their commitment to a healthy lifestyle and the discussions had during these programs about their lived experience, current research and cancer services, continues to be the foundation upon which our cancer advocacy work is built.

Being a small, 100% volunteer, not for profit organisation we do well to manage the governance arrangements and financial necessities required to maintain our organisation. Support from members in the areas of financial management, web development and maintenance and fundraising would assist us to continue to grow and further build our capacity as a cancer advocacy group.

This year we have been totally reliant on donations to remain financial and are indebted to those people who have given so generously. Without you we could not continue our work. Looking to 2019 we will be encouraging donations and fundraising events in order to remain viable. Any assistance from members in these endeavours would be much appreciated.

That said, we are resolute in our continued commitment to raising a voice for South Australians affected by cancer and I look forward to working with the Executive Team, CVSA members and others supportive of our work, to continue our critical cancer advocacy work into 2019 when we will be considering strategic directions for 2020 – 2025.

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**CVSA Strategic Directions 2015-2020**

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<th>Values</th>
<th>Vision</th>
<th>Purpose</th>
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<td>Advocacy</td>
<td>That all people affected by cancer are central to their treatment and ongoing care, with good systems and information underpinning their experiences and outcomes.</td>
<td>To raise an independent voice to influence the achievement of better outcomes for South Australians affected by cancer.</td>
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**We deliver our values, vision and purpose 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 and people affected by cancer.

**Programs and Projects**
- 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**
- 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.

**We achieve our purpose and vision by working with cancer survivors, carers and stakeholders.**
CVSA Areas of Engagement and Influence

As consumer representatives CVSA members engage and influence by using their lived experience and the collective knowledge and experience of our members to raise a voice to influence the cancer agenda and to advocate for matters across the cancer continuum - prevention, diagnosis, survivorship, treatment, follow-up care and palliative care. CVSA engaged and influenced through consumer representation on a broad range of groups during 2018 where members are appointed as consumer representatives, invited representatives or forum participants. A full list of the groups CVSA members are involved in is listed on page two of this report. Further information about a number of areas of engagement and influence are highlighted below.

State Election

The South Australian Election was held in March 2018. Prior to the election CVSA members were asked for feedback on what mattered to them about Cancer Services in South Australia. In collating the information five key areas for action were identified:

1. Variation in access to specialist cancer treatment services
2. Lack of coordinated, person centred cancer treatment and care from the time a person is diagnosed with cancer and throughout their survivorship period through to end of life care
3. Consumer involvement in cancer research and access to research trials as a treatment option
4. Palliative care services
5. Data and information

A letter was forwarded to key Members of Parliament outlining the work of CVSA, highlighting our areas for action and seeking a meeting to discuss these matters. We met with a representative of the Minister, the Opposition Health spokesperson, now Minister for Health, and SA Best. Discussions were fruitful and we were pleased to see a number of our key areas for action included as policy proposals by the various parties. A subsequent letter was sent to the new Minister for Health and Ageing, Mr Stephen Wade, congratulating him and offering the knowledge and experience of CVSA members in progressing the state’s health agenda as it relates to people affected by cancer. We were particularly pleased to see the commitment to doubling the level of chemotherapy delivered in regional South Australia and to an increase in focus and funding for palliative care services.

Chemotherapy Standards

2018 saw S.A. Health establish a group to ensure that updates to the Standards for Chemotherapy Services in South Australia (the Standards) are informed by clinical expertise and are contemporary, with consideration of best, evidence-based clinical practice in the provision of cancer services, for cancer patients receiving chemotherapy treatment within the South Australian context. CVSA’s consumer representative on the group, Chris Christensen has provided advice and recommendations throughout the review process to ensure that the updated Standards incorporate a consumer perspective, are patient centred and articulate best practice approaches in the delivery of chemotherapy services for cancer patients. It is anticipated that the Standards will be finalised early in 2019 following further consultation.

Australasian Gastro-Intestinal Cancer Trials Group

The Australasian Gastro-Intestinal Cancer Trials Group (AGITG) is a multi-disciplinary collaborative group of medical and research professionals who conduct trials and research to improve treatments for gastro-intestinal (GI) cancers. Julie Marker has been involved in this group for a number of years and assists with review of research proposals and drafting of feedback for government submissions. The group has played an important role in research which has changed international treatment practice for Colorectal, Gastro-Intestinal Stroma Tumour and Oesophageal cancer patients. Julie attended the 2018
AGITG Annual Scientific Meeting which is known throughout Australasia as the premier meeting in the gastro-intestinal cancer space where she engaged in discussions about research, current challenges and innovations, as well as hearing about the latest in research and treatments from international and local leaders.

**Primary Care Collaborative Cancer Clinical Trials Group, the Psycho-Oncology Cooperative Research Group and the Joint Community Community Advisory Group**

The Primary Care Collaborative Cancer Clinical Trials Group (PC4) and the Psycho-Oncology Co-operative Research Group (PoCoG) seek to improve the emotional support and psychological care of people affected by cancer. The Joint Community Advisory Group (JCAG) is a joint initiative between PC4 and PoCoG to promote and increase community participation in the activities of both groups. JCAG provide advice on research directions and priorities from a consumer perspective. CVSA has two of our members on this group, Julie Marker and Don Piro. They contribute in a range of ways including by providing input on research activities and priorities for PC4 and PoCoG: reviewing research concepts and protocols; participating in working groups; facilitating links with the cancer community and consumer groups; raising awareness and advocating for priorities; and advocating consumer participation in research and clinical trials.

**Stage Treatment and Recurrence Project**

Cancer Australia is working on methodologies for collecting, collating and reporting data relating to cancer stage, treatments, and recurrence of cancer at the national level through the Stage, Treatment and Recurrence (StaR) program. CVSA member Agnes Vitry is a member of the project group which is building understanding of the variability in cancer stage at diagnosis across tumour types, population groups and geographical locations, considering treatments received compared to best-practice care recommendations and patterns of cancer recurrence. It is anticipated that over time, this will improve the availability of information on national trends and patterns of cancer care, health service utilisation and cancer outcomes as well as contributing to better policy and practice in cancer control and improved outcomes for Australians affected by cancer.

**CVSA Programs and Speaking Engagements**

**Programs**

CVSA has three core programs – Survivors as Teachers, CVSA Cycling Group and CVSA Walking Group. We would like to enlarge our education program but are currently restrained by our financial capacity. That said, our Survivors as Teachers Program has gone from strength to strength and our cycling and walking programs support our focus on wellness and quality of life. Further information about these programs and a number of 2018 speaking engagements is highlighted below.

**Survivors as Teachers Program**

Our flagship program – Survivors as Teachers has continued again during 2018 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 and Jo Thomas at the University of Adelaide for the past seven years, providing approximately 150 third year medical students per year with tutorials lead by our volunteers. In small groups of 8-12 students,
our volunteer speakers 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 2018 with special thanks to Julie Marker and Cath Caon for their commitment to the coordination and facilitation of the tutorials.

Our leadership of this program has resulted in an invitation to contribute to the development of the new curriculum for medical students at the University of Adelaide and to continue to develop our Survivors as Teachers program with online materials. This is an exciting new step.

Under the banner of the Survivors as Teachers program Cancer Voices members were also invited to present at the University of South Australia and Flinders University on topics such as Living with Cancer, Consumer Co-Design in Research, and Consumer Engagement in Healthcare.

It is the collective lived experience of cancer that CVSA members share which enables us to advocate across the cancer continuum from prevention, to diagnosis, treatment, survivorship, palliative and end of life care and we thank all those who support the program by so generously speaking about their lived experience. You are making an important contribution to educating students about living with a cancer diagnosis.

**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 and commitment to the Cancer Voices SA Cycling program, which has been ongoing since December 2008.

In October our 8th annual Cancer Voices SA Challenge Ride saw approximately 80 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.

Special thanks to all the volunteers who make this event possible, in particular Julie Marker, Eric Browne, Bill Nash and Con Nakos.

**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.

We are getting to know the park, its flora and fauna, rather well and enjoy the many and varied conversations and learning that occurs as we walk and talk, followed by coffee. Many thanks to Julie Marker and Di Creaney who have lead the group walks when Chris Christensen has not been available.
Speaking Engagements

Cancer Voices SA members are regularly asked to speak about a range of topics relating to people affected by cancer. Highlights are outlined below.

**Victorian Cancer Survivorship Conference**

The 2nd Victorian Cancer Survivorship Conference hosted by the Victorian Comprehensive Cancer Centre and Peter MacCallum Cancer Centre was attended by Julie Marker and Chris Christensen. The theme of the conference was “The Survivorship Equation. Evidence + Best Practice = Better outcomes” and Julie and Chris were invited to give a poster presentation at the conference, the title of which was, *Survivors in the Survivorship Equation: Survivor evidence + survivors views of best practice = better outcomes*. The conference had a variety of speakers – both national and international, while also featuring personal survivor stories. Conference delegates were from a variety of disciplines, including medical, nursing, psychology and research, providing an opportunity to discuss the topic of cancer survivorship in depth. CVSA attendance at these conferences is critically important for presenting the work of CVSA as well as hearing from and networking with other survivors and health professionals.

**ABC Podcast on Clinical Trials**

CVSA Executive Team members Karen Van Gorp and Chris Christensen were invited to participate in an ABC Science Friction program hosted by Natasha Mitchell. The topic *Selling hope: the trials and tribulations of experimental drug trials* was important to Karen and Chris who have both been involved as participants in clinical trials. Their input into the program provided deep insights into the lived experience of being a clinical trial participant. Professor Ian Olver, Director of the Sansom Institute for Health Research, Medical Oncologist, Cancer Researcher and Bioethicist from the University of South Australia and Rod Burrows, a clinical trial participant from Western Australia were also interviewed for the program. The podcast can be downloaded through the following link: [https://www.abc.net.au/radionational/programs/sciencefriction/trials-and-tribulations/9919970](https://www.abc.net.au/radionational/programs/sciencefriction/trials-and-tribulations/9919970)

**Coast FM Interview**

CVSA was invited to talk about our work in an interview with Dave Hearn of Coast FM during 2018. This was a great opportunity to profile the work of CVSA, its vision, purpose and current areas of advocacy. We were also able to promote our website, providing links to our membership and donation pages. Dave had cared for his wife during her illness and asked Julie Marker and Chris Christensen, who attended the interview, insightful questions about the cancer experience.

**Ovarian Council Australia Adelaide Forum**

Chris Christensen was invited to present at the *Research, Hope and Understanding Forum* hosted jointly by Ovarian Cancer Australia and Cancer Council S.A. The purpose of the forum was to provide an opportunity for women living with Ovarian Cancer, their families and friends to hear the latest ovarian cancer research and to meet with other South Australians with Ovarian Cancer. Speakers included a Medical Oncologist, Geneticist and Chris, who shared her experience of living with Primary Peritoneal and Ovarian Cancer. In particular Chris highlighted the ongoing nature of her cancer, having had five recurrences in eight years, as well as the need for good information upon which to make decisions.
CVSA Research Project Involvement

Members of CVSA are increasingly in demand and involved as knowledgeable consumers in research applications and projects. CVSA is indebted to all who share their lived experience with us, thus enabling us to build strong evidence of the challenges and opportunities for improvement, which we can bring to all phases of the research cycle. CVSA members are involved in reviewing applications, proposing topics for research, participating in research projects and communicating the findings. The following provide two examples of the work in which we are involved.

Strategies for the inclusion of vulnerable populations in developing complex and sensitive public policy: A case study in Advance Care Planning

To provide people at the end of life with choice and dignity in their care, advance care planning has become an increasingly important issue, yet many patients’ end of life preferences are not known. This project, funded by the National Health and Medical Research Council, Partnership Projects, brings together key stakeholders from government, professions, non-government organisations and consumers to determine how people from different cultural backgrounds (with specific engagement with Aboriginal and Torres Strait Islander peoples), and those requiring specialist health services to meet their health needs, can appropriately be included in policy development on issues that affect them. While various policies and practices have been developed to help Australians document their end of life preferences the policies and practices are designed in the main to suit the majority of the population and do not always meet the needs of vulnerable Australians. CVSA members Liz Shears and Chris Christensen were invited to be consumer members of this 4 year multi-discipline and multi-institutional project looking at the inclusion of vulnerable populations in Advance Care Planning.

The South Australian Cancer Trials Network

Clinical trials provide the evidence to inform best practice, offer people affected by cancer opportunities to benefit from the latest medical research and provide legitimate alternative therapy options. The aim of this project is to establish a South Australian cancer clinical trials network (SACTN) across all sites providing cancer treatment and care. Cancer Voices SA is a consumer partner organisation and represented on the group by Julie Marker, Karen Van Goorp and Chris Christensen. The primary objective of the project is to establish the necessary infrastructure, personnel support and business model required to effectively and sustainably operate a state-wide cancer trials network. Stakeholders, including consumers will be engaged throughout the project to ensure acceptability, feasibility and long-term sustainability of the system design.

CVSA Operations

This is the 11th year of CVSA. These eleven years reflect the passion and continued engagement of people affected by cancer to use their experiences 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 us achieve our purpose and vision.

The relationships built over the past 11 years strengthens us as an organisation as well as providing a significant contribution to the outcomes of our joint work particularly with organisations such as:

- Cancer Voices Australia and Cancer Voices New South Wales, with whom we work on policy
matters, national inquiries and reviews, matching cancer survivors with researchers and research projects and responding to groups seeking the Consumers Included logo for their events

• Adelaide University, Flinders University and the University of South Australia where we continue to grow our Survivors as Teachers program and are currently involved in a range of cancer research projects

• Health Consumer Alliance South Australia who provide us with space to host meetings, involve us in policy discussions and liaise with us on matters pertaining to cancer

• Consumer Health Forum (CHF) where we were invited to attend a forum to discuss the consumer perspective on national health policy for the next Federal Election.

**Finance**

The continued viability of CVSA is dependent on our ability to generate funds. We are currently reliant on the kind and very much appreciated donations we receive across the year, but need other sources of income in order to sustain our activities. In order to achieve our purpose we need to have sufficient funds to host our own events, to support the Survivors as Teachers program, to continue to offer free membership, 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 engage and influence.

I urge all members to use their networks to source donations or funds, or to organise some fundraising events for CVSA in 2019.

**Executive Team**

The Executive Team are all volunteers with no business premises from which to manage the respected work of CVSA. The team receive no payment from CVSA and work from their homes. I cannot thank them enough for the work that they have done this year and the support they have given to me as the Chair - Julie Marker, Eric Browne, Steph Newell, Con Nakos, Agnes Vitry, Jackie Bareau, Karen Van Gorp and Courtney Oakes. Thank you all. My special thanks to Julie Marker who continues to take a key leadership role in managing the organisations day to day finances, responding to a broad range of queries, contributing to submissions, managing membership communications, representing CVSA on a number of state and national groups and leading the Survivors as Teachers program.

I believe the purpose and vision initiated by Ashleigh Moore (Cancer Voices SA founding Chair) in 2007 is as important today as it was 11 years ago. It is not easy as a volunteer group to respond to all the matters that are raised with us in the course of a year, particularly with the research community realising the value of engaging consumers in their work. We do what we can, and more, to contribute to those things which will help us to achieve our purpose and vision, raising a voice for people affected by cancer in order to improve their experience and outcomes.

I look forward to your continued support for the advocacy work of CVSA in 2019.

Chris Christensen
Chair Cancer Voices SA
2 December 2018