



Chair's Report Annual General Meeting 30 November 2011

Cancer Voices SA is **'raising a voice for those affected by cancer'** through **advocacy, involvement, awareness and information.**

Our focus is on wellness and not just illness.

Having cancer is not a pre-requisite for joining up.

Membership is free and open to all South Australians eg cancer patients, their partner, carers, family, friends, neighbours, colleagues and supporters because **'Cancer doesn't affect one person, it affects the entire community around them'**

We are an independent, not-for-profit, 100% volunteer organisation, formed in 2007. We cover all types& stage of cancers across all ages, social circumstances, gender and locality.

The Cancer Voices SA membership continues to grow and has now reached about 800. The organisation is led by a 10 member Executive Team. Additional Supporters advise the Executive on specific topics including multicultural, Aboriginal and eHealth issues.

We aim to be representative, responsive and respectful of the diversity of our grassroots members background and experiences, and we try hard to hear those views. We have regular engagement and interaction via our websites (www.cancervoicessa.org.au and www.cvsacyclingteam.org.au), social media ([@CancerVoicesSA](https://twitter.com/CancerVoicesSA), [Facebook](#) – CancerVoicesSA, YouTube) and physical activity initiatives.

Our key priorities for action in 2011 have been

Advocacy

- Representing 'people affected by cancer' on key cancer forums and committees at the state and national level
- Presenting the 'patient experience' to oncology staff, students, researchers and community groups
- In research, being involved in design, progress advice and as participants in studies or promoting clinical trials and focus group participation
- Advocacy and action on issues of concern

Involvement & Awareness

- Growing our grassroots army, with engagement and interaction online (via our website, FaceBook, Twitter, YouTube), through Cancer Conversations and sporting initiatives
- 2 way communication to consult and engage with the community
- Reviewing and reflecting on feedback to identify and implement additional activities
- Completing 4 'commitments to action' pledged as part of the Global Cancer Campaign – cycling for cancer awareness, cancer conversations in Aboriginal communities, online 2 way system for advocacy, Australian cancer patients charter

Information

- Providing updates and access to quality cancer-related information

Organisational Resilience

- Building Organisational capacity through our Business Planning process, and with the Plan being incorporated into all aspects of our operation., procedures, reporting and financial accountability.
- Develop individual capacity through training & mentoring opportunities

Two major Cancer Australia grant funded projects are nearing completion:

- an online advocacy tool for 2-way communication, integrated into our new website,
- piloting Cancer Conversations in Aboriginal Communities.

Cancer Voices SA believe it is important that the 'lived experience' of people affected by cancer is captured and presented in a variety of ways. We have sought innovative approaches including Cancer Conversations, sharing information via opportunities such as the LIFESUPPORT magazine, involving people in research, priority setting, design of services, and via the creativity of individuals like poet Geoff Goodfellow (Waltzing with Jack Dancer), photographer Randy Larcome and Mike Riddle with his poetry and children's books.

Presentations to oncology nursing students and other forums have been well received, and we have ongoing involvement in research, particularly in the developing area of psycho-oncology.

Contributing to the design of the new Flinders Centre for Innovation in Cancer has been another opportunity for consumer feedback to 'make a big difference'.

We've raised cancer awareness with a stall at the Disability and Aging Expo, and at other events.

CVSA are gradually setting in place a variety of important but time consuming tasks to build our organisational capacity. A thorough Strategic Planning exercise has been undertaken and is being incorporated into all aspects of our operation.

Cycling continues to be a major mechanism for raising awareness of cancer and also motivating, inspiring and promoting an active lifestyle with regular physical activity for survivors and supporters. We recently [conducted our own community even that attracted 300 riders which was captured in photos, a brief video, and media interest. Cancer Voices SA cycling team members also featured in a national TV 7.30 Report.](#)

The impact of illness will always be an issue for Cancer Voices. Serious health problems affect others in the Executive Team. Despite this, we've achieved a huge amount for a 100% volunteer group!

Thank you to all Cancer Voices SA members for your support and involvement.



Chair, Cancer Voices SA

See attached a list of the [main activities](#) undertaken by Cancer Voices SA in 2011.

Achievements for CancerVoices SA in 2011

Presentations

- To FMC Oncology Nurses on patients view of treatment (Mar 11)
Radiotherapy Conference – treatment from the patients view (Apr 11)
RAH Postgrad Oncology nurses (Aug 11)
SA PoCoG – consumer issues (Sep 11)

Events organized by CVSA

- [Pre-Twitter ride](#) with Lance Armstrong (Jan 11)
- LIVESTRONG Day [ride](#) (Oct 11)
- Exercise and Cancer Forum (Nov 11)
- Cancer Conversations in Aboriginal Communities – Pt Lincoln Sept 11, Port Adelaide Nov 11

Forums/Meetings/Workshops attended:

- Clinical Oncology Society Australia [Annual Conference](#) COSA (Nov 11)
- Cancer - Exercise & Nutrition Workshop [FCIC](#) (Nov 11)
- [Festival of Ideas](#) – ‘Waltzing with Jack Dancer’ & ‘Tell me the truth-difficult conversations about cancer’.
- Display stall CanLink Networking forum [CanTeen](#)/CYWHS – (Sep 11)
- Health Consumers Alliance ([HCA](#)) Advocacy training (Sep 11)
- National Health Reform briefing (Sep 11)
- Prioritising Gaps in Colorectal Cancer Clinical Trials –consensus meeting (Aug 11)
- Display stall at Disability and Ageing Expo (Aug 11)
- Radiation Oncology RORIC – [Beyond Bricks and Mortar](#) Conference (Aug 11)
- [Centre for Men’s Health Research](#) –Update forum (July 11)
- Forum: [Stigma and Nihilism in lung cancer](#) (Jun 11)
- [Health Services Complaints Commissioner](#) – Safer Conversations Training (Jun 11)
- [PoCoG/ PC4 JCAG](#) training day (Apr 11 & Sep 11)
- Health Consumers Alliance ([HCA](#)) Conference: Patient Centred Care (Apr 11)
- [CCSA](#) Planning Forum (Apr 11)
- Cancer Australia Strategic Planning with Consumers (Apr 11)
- Launch of book – Waltzing with Jack Dancer (Mar 11)
- [CCSA](#) Student’s Research Forum (March 11)
- Cancer Clinical Network [Expo](#), (Feb 11)
- Launch of [CanTeen Youth Networks Program](#), (Jan 11)

Media:

LIVESTRONG Day Ride [video](#) (Oct 11)
5AAA Amanda Blair radio interviews – (Aug 11)
[LifeSupport Magazine](#) – members stories contributed (Aug 11)
CVSA's [Ashleigh Moore interviews Chris Brewer](#) (26 Jan 2011)
LIVESTRONG's Chris Brewer interviews Ashleigh Moore (21 Jan 2011) [LIVESTRONG Blog](#)
[Lance's legacy](#) in SA, as a cyclist and cancer survivor (20 Jan 2011) [ABC TV 7.30 Report](#)

Representation on:

- [SA Cancer Clinical Network](#) (CCN) Steering committee and subcommittees/working groups:
 - Head and Neck Cancer Pathway working group*
 - Complementary Therapies working group (chaired by CVSA Exec)*
- [Flinders Centre for Innovation in Cancer](#) - Consumer input to design
- SA eHealth Consumer Reference Group
- Consumers eHealth Alliance (CEHA) Australia
- [Cancer Voices Australia](#) (CVA) Board.
- [Cancer Australia](#) - National Consumer Advisory Committee.
- Cancer Australia Consumer Engagement Framework – Consumer Reference Group
- Cancer Australia Lung Cancer –Models of Care Steering Committee
- MultiDisciplinary Team Care Project Advisory Group
- [CareSearch](#) - Palliative Care National Advisory Group
- [PoCoG/PC4](#) National Joint Consumer Advisory Group

[AIHW](#) Cancer Data Monitoring Advisory Group
SA Cancer Research Collaborative
SA Psycho-oncology Research Group
CCNSW National [Cancer Directory](#) Advisory Group

Newsletters (&additional ebulletins)

[eBulletin - October 2011](#)

[Raising a Voice - June 11](#)

Key Projects

Cancer Conversations in Aboriginal Communities (Cancer Australia Consumer Networks grant)
Online 2way communication for cancer advocacy – (Cancer Australia Consumer Networks grant)
CVSA Business Plan

Cycling team

Monthly training rides and weekly group rides

Cyclosporitif – 3 teams in this series Nov11

Participation in Tour Down Under, Ride Like Crazy, Coast-to-Coast, Amy's Ride, Grand Slam Series

Twitter ride with Lance Armstrong Jan 11

Livestrong Day Ride – 2Oct11

Interactive website www.cvsacyclingteam.org.au