

**In this issue:** Update of CVSA activity; National update from Cancer Voices Australia

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## Update of Cancer Voices SA (CVSA) activity

Dear Cancer Voices SA members,  
There has been a lot happening this year, and a busy, exciting time is scheduled for the next few months.

Cancer Voices SA have gone 'Global' by contributing Commitments to the LIVESTRONG Global Cancer Campaign, and also by conducting Cancer Conversations as part of the international 'Go Public' Campaign to Control Cancer.

### Global Cancer Campaign

Lance Armstrong launched the **Global Cancer Campaign** during the 2009 Tour Down Under in Adelaide on 19 January. This Campaign is being promoted by the LIVESTRONG - Lance Armstrong Foundation (<http://www.livestrong.org/>) and taken world-wide through Lance's comeback to cycling.

The Global Cancer Campaign aims to:

1. **Raise awareness of cancer** (a third of cancers could be cured if detected early and treated adequately)
2. **End the stigma of cancer** (turn cancer victims into cancer survivors)

3. **Reduce the global burden of cancer** through collaboration and personal, organisational and government (local, state and national) commitments to 'make a difference'. "Cancer doesn't affect just one person; it affects the entire community around them".

Cancer Voices SA met with the LIVESTRONG CEO, **Doug Ulman** to discuss opportunities for collaboration with LIVESTRONG and the Global Cancer Campaign in Australia. The LIVESTRONG-Lance Armstrong Foundation is a world leader in cancer advocacy. (Ashleigh Moore, right, with Doug Ulman, left, at the Global Cancer Campaign launch).



LIVESTRONG urged world leaders, leading cancer organizations and cancer survivors to join together by making commitments to take action in their communities to reduce the burden of cancer.

In June, Cancer Voices SA submitted 4 commitments aligned with the aims of the Global Cancer Campaign, and activities that we wish to pursue over the next 12 months.

These commitments are:

1. **Cycle for Cancer – Community ride**  
Cancer Voices SA aims to establishing a cycling event with cancer awareness as a key objective, to focus on altering the public attitude and stigma about cancer, increasing community involvement in physical activity for cancer prevention and supporting patients during their cancer journey, as well as raising awareness of the many types of cancer.
2. **Australian aboriginal cancer conversations**  
Cancer Voices SA will conduct cancer conversations with aboriginal Australians to understand their perspectives, cultural and other concerns and hear suggested solutions for their communities 'cancer outcomes' gap.
3. **Australian Cancer Consumers Charter**  
Cancer Voices SA is a partner with Cancer Voices Australia to develop and publish a National Cancer Consumers Charter, in collaboration with other national cancer groups.
4. **On-line cancer advocacy in Australia**  
Communication is vital if Cancer Voices is to represent and respond to issues and concerns of 'those affected by cancer', to seek feedback and share information. Cancer Voices SA aim to trial a variety of online 2-way communications for cancer advocacy in South Australia.

**LIVESTRONG** has invited 4 Cancer Voices representatives to attend the Global Cancer Summit in Dublin in August, where we will get the opportunity to connect with other advocates, network, gain media exposure and access tools and resources to help achieve our commitments and mobilize local cancer activities.

For more information about the Global Cancer Campaign, see our website at [http://www.cancervoicessa.org.au/Global\\_Cancer\\_Campaign.asp](http://www.cancervoicessa.org.au/Global_Cancer_Campaign.asp)

### Cancer Voices SA Cycling Team

In January, Cancer Voices SA rallied a team of 123 cyclists to 'raise awareness' of cancer and Cancer Voices by wearing the team name on their jersey for the 155km **Tour Down Under Mutual Community Challenge Ride**. Many team members were cancer survivors,

others were the family, friends, or supporters of someone with cancer, and everyone knew about Lance Armstrong's response to his battle with cancer ie. just 7 times a winner of the Tour de France! Also riding in the Cancer Voices SA team was Michael Milton, the gold medallist paralympian who lost his leg to cancer when he was 9 years old, and 18 months ago was diagnosed with oesophageal cancer. A final highlight was having Lance accept a jersey signed by all the team members. See more about this on the Cancer Voices cycling page

<http://www.cancervoicessa.org.au/cycling.asp> .



Lance Armstrong accepts Cancer Voices SA jersey, signed by the 123 team members. (Jan 2009)

An enthusiastic group of around 70 cycling team members continues to train and participate in events. Evidence shows that a healthy lifestyle is important for cancer prevention as well as assisting recovery and resisting relapse of cancer. We've seen positive ongoing engagement with cancer consumers and the community through the cycling team initiative.

**Join the Cancer Voices Cycling Team and get ready for the 2010 Tour Down Under Community ride.** Early bird registration ends 31<sup>st</sup> July. Find more information at <http://www.cancervoicessa.org.au/cycling.asp>

## 'Go Public' Community Cancer Conversations

'Go Public' is another international initiative that Cancer Voices SA is participating in. This initiative is jointly run by the Canadian 'Campaign to Control Cancer', the International Union Against Cancer (UICC), and LIVESTRONG.

Go Public called for volunteers to engage in Community Conversations on Cancer Control. Cancer Voices SA conducted 10 'Cancer Conversations', involving more than 60 people. A summary from each Cancer Conversation was submitted. A final report of Cancer Conversations from around the world will be released in September at a **Global Leadership Forum for Cancer Control**, in Canada. This Forum is an international conference that will share best practices in public engagement for cancer control, including the ideas gleaned from Cancer Conversations submitted around the world.

*Cancer touches the lives of everyone, everywhere. The more people talk about this disease, the more it cannot be ignored. By spreading the word publicly, you will help dispel misconceptions, reduce stigma and increase awareness about cancer.*

*We thank you for sharing your story.*

**LIVESTRONG**  
LANCE ARMSTRONG FOUNDATION

Several conversations with the aboriginal community encouraged us to commit to continuing to hold further Cancer Conversations. Sandy Miller is assisting and providing leadership.

Thank you to all the Cancer Voices members and friends who participated in these Conversations. Your thoughts and suggestions are important to us, and will assist us in local action on the issues raised. See more information on the Cancer Voices website at [http://www.cancervoicessa.org.au/cancer\\_conversations.asp](http://www.cancervoicessa.org.au/cancer_conversations.asp)

## Cancer Advocacy Training

The first Advocacy Training course was run by the Cancer Council SA (CCSA) and Cancer Voices SA in March, with 13 graduates of the 2 day course. 'Many Thanks' to Caroline Grenville from the Public Interest Advocacy Centre for expert facilitation, Dr Vikki Knott (CCSA), and assistance from the Cancer Council NSW. The course will run again in November. Phone 8291 4343 or email [info@cancervoicessa.org.au](mailto:info@cancervoicessa.org.au) if you wish to register. More details can be found at [http://www.cancervoicessa.org.au/Advocacy\\_Training.asp](http://www.cancervoicessa.org.au/Advocacy_Training.asp).

## Cancer patients and SuperBugs

Cancer Voices SA were concerned by the closure of cancer wards in April, due to the number of patients infected with vancomycin-resistant enterococcus (VRE). Through ongoing representation on the Safety and Quality in Health Care Consumer and Community Advisory Group, Cancer Voices was able to present a draft Position Statement with some suggestions for action on this issue. We suggest consideration of the Victorian system with transparent reporting of performance indicators and benchmarks relating to cleaning standards, hand hygiene, infection surveillance; with surveillance extended to oncology inpatient and out-patient areas, and involving oncology area staff, patients and their visitors in infection control. Find our Position draft 'Infection Control in Oncology Patients' at <http://www.cancervoicessa.org.au/newsletters+documents.asp>

## New faces on the Executive Team

We wish to introduce new members on our Executive Team. Welcome to Maria Adamczak, Vince Riviere, Jim Vlahakis and 'welcome back' to Liam Hunt and Cholly Winter. Find more about 'the Team' at <http://www.cancervoicessa.org.au/executive-team.asp>

A big **'Thank You'** to David Chapman and Louise Murada for their contributions to Cancer Voices SA. Very best wishes and good health, for you and your families. Louise and David have very busy lives and needed to step back from the Executive Team.

## National Update Cancer Voices Australia

### Federal Budget 2009-2010 - \$2b Cancer Funding

The Australian Government will invest a record \$2 billion to build a world-class cancer care system. This includes

- Cancer infrastructure: \$100 million to new Lifehouse Sydney Cancer Centre at the Royal Prince Alfred Hospital in Sydney; \$426.1 million to Parkville Comprehensive Cancer Centre in Melbourne; \$70 million to expand the Garvan St Vincent's Cancer Centre in Sydney to enhance its world-class research capacity.
- \$560 million to build a network of up to ten best-practice regional cancer centres with accommodation centres, to help close the gap in outcomes for cancer patients in rural and regional Australia.
- \$120 million to replace BreastScreen Australia's 205 outdated analogue machines with state-of-the-art digital mammography equipment.
- \$600 million over the next five years for cancer medicines: Avastin for metastatic colorectal cancer, Sutent®, for people with renal cell carcinoma, Herceptin® for metastatic breast cancer.
- \$2.6 million for the Building Cancer Support Networks Program to fund up to 24 new support groups for people with cancer in the first year;
- \$15.1 million to support clinicians, consumers and health organisations across Australia to collaborate more closely on cancer care, building on the successful Cancer Services Network National Demonstration Program;
- \$6.8 million to improve lung cancer care through identifying research and clinical priorities, provide more consistent data and target health professionals to deliver best practice for this deadly cancer; and
- \$4.2 million in a national cancer monitoring centre so health professionals and service planners better understand national trends and patterns in cancer including risk factors, diagnoses, health service use and health outcomes.

Cancer Voices Australia lobbied for a number of these initiatives and will be further involved in the roll-out of several initiatives.

## Intravenous Chemotherapy Supply Program

The Intravenous Chemotherapy Supply Program could impose substantial financial burden on many cancer patients. It is a complex issue which we briefly outline: The Federal Government's new Intravenous Chemotherapy Supply Program is a cost cutting measure, due for introduction in the next couple of months, and causing considerable worry for both cancer patients and pharmacists.

At the moment the chemotherapy drugs come in a vial, with the dose measured out for a particular patient and any remaining drug is then discarded.

The problem is, these drugs are very expensive (eg. sometimes more than \$500 per vial) and the government is saying that pharmacists should reuse the left-over cancer drug to prepare the dose for another patient. Pharmacists argue that left-overs of unstable drug cannot possibly be used again days down the track and that the government's proposal to only pay pharmacists for the amount needed for a treatment (rather than the whole cost of a vial itself) means that patients would have to pay for the discarded amount. (Adapted from <http://blogs.abc.net.au/queensland/2009/05/worry-over-chem.html> )

We are very grateful for the expert input of Dr Ian Roos from Cancer Voices Victoria, Mariann McNamara from Cancer Voices SA, and others who are negotiating with the Government on this issue. The cost, availability and safety for patients receiving these drugs, and risks for pharmacists who are dispensing these cytotoxic drugs every day, are amongst the factors that need to be worked through before this Program proceeds.

### To contact us

CVSA Exec welcome feedback on any of the items and issues raised in this newsletter.

Contact us at [info@cancervoicessa.org.au](mailto:info@cancervoicessa.org.au) , phone 08 8291 4343, or [www.cancervoicessa.org.au/](http://www.cancervoicessa.org.au/)

*Ashleigh Moore,  
Executive Chair, Cancer Voices SA.*